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LONG-TERM BEHAVIORAL HEALTH CARE UNBUNDLED:
THE IMPACT OF COMORBIDITY AND AGGRESSION ON CAREGIVER STRAIN
AND SERVICE COSTS FOR INDIVIDUALS WITH INTELLECTUAL
DISABILITIES

by

Kristine Tevis

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Major: Psychology
(Social Psychology)

Under Supervision of Professors Mario Scalora and Sarah Gervais

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University of Nebraska, 2020

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Individuals with intellectual disabilities represent a unique population with an array of needs. High rates of comorbid mental and physical health conditions as well as the presence of disruptive behaviors pose significant challenges to service providers and funding entities. Existing cost models may underestimate these specialized needs and limit access to required services. Through secondary analysis of archival health data from individuals with intellectual disabilities at one agency in Nebraska ($N=73$), the current study examines how individual characteristics and aggression influence cost and caregiver strain from a systems theory perspective. Bivariate comparisons revealed that more severe aggression and more frequent aggressive behaviors (including verbal aggression, aggression against others, aggression against self, and aggression against property) relate to higher levels of caregiver strain and higher costs. Correlation and regression analyses revealed that existing rate models used to set service rates overlook significant factors when predicting actual costs. Individuals with comorbid physical and mental health conditions, especially those with serious and persistent mental illnesses, who also exhibit aggressive behaviors (measured by frequency and severity),

significantly predict higher direct costs better than models that only account for levels of functioning. Despite consistent acuity based on similar behavioral severity ratings, IQ, and adaptive functioning scores, individuals served in extended family home settings displayed fewer aggressive behaviors and induced less strain on their caregivers, while receiving services at over \$10,000 per month cost savings compared to their counterparts served in group home settings. Examination of emerging setting effects offers a progressive interpretation of the results with practical implications for developing rate-setting methodologies and public policy considerations.

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CHAPTER 1

INTRODUCTION

While national health care costs reached \$3.3 trillion in 2016 (Centers for Medicare & Medicaid Services [CMS], 2017), mental disorders emerged as the most costly condition in the United States and Canada (de Oliveira et al., 2016; Roehrig, 2016;). Strategies to better manage health care costs while preserving or improving the quality of care have become a significant focus of national policy. Fundamental aspects of national healthcare reform center around notions to replace historic fee-for-service models of service reimbursement to value-based options to improve quality of care. Health care funders assume the burden for managing health services and devising models to most efficiently accommodate all service recipients regardless of condition.

Jointly funded by federal and state government, Medicaid provides health coverage to the elderly, persons with disabilities, and low-income individuals. Medicaid spending grew almost 4% in 2016, reaching \$565.5 billion, nearly 20% of all national health expenditures (CMS, 2017). With exponentially rising healthcare costs, states (including Nebraska) began introducing managed care arrangements where states hire companies to manage Medicaid dollars in an attempt to control the costs, access, and utilization of care. Arguably, one of the most vulnerable populations under this umbrella of care includes those with intellectual or developmental disabilities (IDD).

In 2013, national estimates identified 6.2 million people live with an IDD; and 1,134,193 of those individuals receive long-term support and services through their state IDD agency funded by Medicaid (Larson et al., 2016). Individuals in this population often receive long-term support services (LTSS) ranging from institutional care, nursing

home care, community-based support, and in-home assistance. LTSS expenditures funded through Nebraska Medicaid--the largest payer of LTSS in the state and has an annual budget over \$2.1 billion--reached \$849,854,429 in the 2018 fiscal year (Nebraska Department of Health & Human Services [NDHHS], 2018). Expenditures for blind and disabled Medicaid enrollees accounted for \$942,790,854 of the 2018 budget. Although elderly and disabled individuals represented 22% of all Medicaid enrollees, this group accounted for 64.9% of all expenditures in 2017-2018 (NDHHS, 2018).

As a result of the growing expenditures associated with caring for individuals with IDD across the world, the World Report on Disability (World Health Organization, 2011) called for “progress in . . . disability cost estimates and better data” (p. 42). To complicate the situation further, in addition to LTSS Medicaid funds, multiple funding streams cover physical and mental health services for this population (e.g., Home & Community Based Services waiver, Aged & Disabled waiver, state/local dollars, state plan services), introducing unique obstacles for those studying service utilization and health care costs that ultimately inform policymakers. In other words, since multiple sources fund services, cost data becomes difficult to aggregate accurately.

The complexity associated with multiple funders and multiple funding sources, continued poor access to needed care, and uncertain quality outcomes prompted an aggressive Medicaid reform and redesign of LTSS in Nebraska. Starting January 1, 2017, Nebraska implemented a managed care system to administer physical, behavioral health, and pharmacy coverage called Heritage Health (NDHHS, 2017), further supporting a national trend to coordinate health management services. Although LTSS remains excluded from managed care initiatives in Nebraska, State officials continue to

work on implementing a solution where managed care directs all services in the state to control costs through anticipated technology and expertise.

The remainder of this paper will focus on the extraordinarily complex issues surrounding individuals with IDD and the system of care charged with providing necessary mental and physical health care. I will identify characteristics of the population and challenges for caregivers, review existing literature on service utilization and health care costs, and critically examine the economic impact of the existing service structure and reimbursement system through a secondary data analysis. This study will enhance existing research by examining the specific factors driving costs associated with care for individuals with IDD and the psychological demands of caring for this population. In particular, how much does it cost to serve individuals with IDD in non-institutional settings, and what characteristics or behaviors (e.g., comorbidity and challenging behaviors such as physical aggression) are associated with high cost care for individuals with IDD that place the most demands on those who care for these individuals?

A better understanding of the population will allow researchers and policymakers to better forecast the economic impact of recent reform efforts in order to allocate future resources in a rational, equitable, and cost-effective manner as they move toward alternative reimbursement systems, such as risk-based or pay-for-performance contracting. In addition, examining characteristics of the highest cost individuals will provide valuable information aimed at identifying the core competencies for caregivers and professionals who serve this population. Improved understanding will ultimately enhance the quality of care and potentially reduce the psychological strain on caregivers.

CHAPTER 2

IMPORTANT TERMS & REVIEW OF THE LITERATURE

Defining IDD

Formerly referred to as mental retardation, a societal shift towards using the term intellectual disability better aligns with current professional practices and international terminology and reduces the negative associations reflected in historic terminology (Schalock et al., 2007). Although clinicians and researchers typically concur with respect to eliminating the use of terms such as mental retardation, ongoing definitions of intellectual disability vary slightly depending on the source. According to the American Association on Intellectual and Developmental Disabilities (AAIDD) (n.d.), intellectual disability is “characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical demands” (Definition of Intellectual Disability section, para. 1). Consequently, due to these impairments, many believe these individuals require lifelong support in order to function in society. Although commonly accepted by the field, this definition captures only the general nature of cognitive limitations among those diagnosed, but fails to address the types of limitations or range of severity of individual deficits that may impact an individual diagnosed with IDD.

Researchers commonly define intellectual disability as a complex condition implying impairments of cognitive and personal functions that are “difficult to precisely define, such as intelligence, learning, adaptive behavior, and skills, with onset in early life, and that tend to persist life-long” (Hemmings & Bouras, 2016, p. 15). Although very similar to the AAIDD’s definition, this second definition is more conceptually sensitive,

and promotes a more worldwide framework for research. Nonetheless, many researchers utilize pre-existing groups already diagnosed with IDD. Therefore, researchers often need to examine the clinical criteria used for diagnosing individuals with intellectual disabilities. Clinicians and applied researchers typically utilize the DSM5 for diagnosing and classifying individuals with mental disorders in the United States. The diagnostic criteria for Intellectual Developmental Disorder (IDD) includes the following (American Psychiatric Association, 2013):

- A. Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgement, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing.
- B. Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work, and community.
- C. Onset of intellectual and adaptive deficits during the developmental period (p. 33).

The DSM5 further classifies individuals diagnosed with IDD into mild, moderate, severe, and profound levels of severity. Although traditionally measured by IQ, psychological scientists have recognized significant limitations in IQ measures especially at the lower end of the scale. Therefore, introduction of the DSM5 urged clinicians to

develop severity classifications predominantly relying on adaptive functioning level. However, practitioners still commonly rely on the use of IQ scores as a baseline indicator of intellectual impairment severity. For instance, in the DSM-IV (1994), the diagnostic manual used from 1994-2013, mild mental retardation¹ ranged from IQ level 50-55 to approximately 70, moderate mental retardation ranged from 35-40 to 50-55, severe mental retardation ranged from 20-25 to 35-40, and profound mental retardation referred to IQ scores below 20 or 25. Some clinicians argue that without an objective measure such as IQ testing, classification in severity categories may become more subjective, leading to its continued use.

Regardless of the heterogeneity in functioning among these individuals, some researchers neglect to acknowledge these operational differences, despite their profound effects on study results. The Nebraska Department of Health and Human Services, Division of Developmental Disabilities, utilizes IQ scores and the Inventory for Client and Agency Planning (ICAP) to measure an individual's needs and functioning level. IQ scores serve as an intellectual functioning measure while the ICAP measures adaptive functioning. The state relies on this combination of evaluation criteria to concretize impairment severity of consumers and determine reimbursement rates for services.

Despite similarities in the aforementioned definitions, many entities continue to use terminology such as mental retardation and developmental disability to represent or classify individuals with intellectual disability. A careful analysis of the transition towards a consensual acceptance in terminology indicates that the terms have changed over time but the definition has remained relatively stable over the past 50 years, offering

¹ The DSM-IV used the term mental retardation to refer to what is now considered intellectual disability.

the following three essential components of intellectual disability: limitations in intellectual functioning, behavioral limitations in adaptation behavior, and early onset (Schalock et al., 2007). Therefore, it appears important to examine all three elements when investigating characteristics of the population as a whole or when comparing this population to other non-disabled groups. Unfortunately, when examining the literature on individuals with IDD, significant variability remains, such that some studies differentiate between levels of intellectual and adaptive functioning while the majority of studies categorize all individuals with IDD into one group despite clear heterogeneity.

Serious & Persistent Mental Illness (SPMI)

According to the Substance Abuse and Mental Health Services Administration (SAMHSA, 2017), serious mental illness (SMI) refers to “individuals 18 or older, who currently or at any time during the past year have had a diagnosable mental, behavioral, or emotional disorder of sufficient duration, meeting diagnostic criteria specified in the diagnostic manual of the American Psychiatric Association and that has resulted in functional impairment, that substantially interferes with or limits one or more major life activities” (p. 11). Major life activities range from difficulties in daily or instrumental living skills to restricted functioning in social, family or vocational/educational environments. Although sometimes used interchangeably, conditions considered to be SPMI are those that become severe and persistent, or chronic. In Nebraska, SPMI refers to an individual who:

1. Is age 19 or older;
2. Has a primary diagnosis of schizophrenia, major affective disorder, or other major mental illness under the current edition of the Diagnostic and Statistical

Manual of Mental Disorders published by the American Psychiatric Association. Developmental Disorders or Psychoactive Substance Use Disorders may be included if they co-occur with the primary mental illnesses listed above;

3. Is a significant risk of continuing in a pattern of either institutionalization or living in a severely dysfunctional way if needed mental health services are not provided, and this pattern has existed for 12 months or longer or is likely to endure for 12 months or longer; and
4. Has a degree of limitation that seriously interferes with the individual's ability to function independently in an appropriate and effective manner, as demonstrated by functional impairments which substantially interferes with or limits at least two of three areas: vocational/education, social skills, or activities of daily living (206 NAC 2-000; 471 NAC 35-001.01).

Diagnoses typically considered meeting the criteria for SPMI include schizophrenia, psychotic disorders, major depressive disorders, bipolar disorder, and borderline personality disorder. The literature reports a range of negative outcomes for individuals diagnosed with SPMI. These individuals experience higher rates of physical conditions such as obesity (Daumit et al., 2003), more severe symptoms of mental illness, more hospitalizations, poorer course of illness, and increased rates of suicide, homelessness, and violence (Bennett & Barnett, 2003; Dixon, 1999).

In addition to heightened severity of symptomology and poorer outcomes, the notion of chronicity distinguishes SPMI from other forms of mental illness and somewhat parallels the chronic disease model in physical health care. Although commonly

considered a lifelong condition, some SPMI definitions quantify chronic as lasting at least 2 years or more (Ruggeri et al., 2000; Parabiagli et al., 2006). The prolonged aspect of SPMI introduces a litany of complications for treatment and service reimbursement. With the increasing trends to incorporate managed care technologies, including a heavily reliance on medically necessary care and brief, solution-focused treatments, SPMI populations pose a substantial challenge. Long-term treatment and care with varying levels of acuity within each condition typically remain excluded from managed care plans or only achieve authorization for treatment when the condition becomes acute. Furthermore, the definition is conceptually indistinguishable from key components of the IDD definition, which further blurs the line of healthcare coverage definitions and becomes difficult to manage within funding sources, especially when multiple funding streams cover different types of care. In addition to definitional challenges, further examination of the literature shows that the clinical picture becomes complicated very quickly when considering how SPMI and IDD diagnoses interact.

Complexity & Comorbidity

In addition to the range of functional impairments, individuals with IDD suffer from high rates of mental and physical illness. For example, in a study comparing individuals with and without IDD, those with IDD experience higher rates of mental and physical illnesses, more mental and physical conditions, and comorbidity occurs at an earlier age than the general public (Cooper et al., 2015). Research examining the prevalence of mental illnesses in people with IDD ranges from 13.2-74%, depending on the sampling methodology, participant selection criteria, diagnostic classification system, measurement tools, and methods used to define IDD and mental illness in the study

(Hemmings & Bouras, 2016). A recent meta-analysis examined studies from 1985 to 2018 and found a pooled prevalence rate of 33.6% of individuals with IDD who also experienced mental health conditions (Mazza et al., 2019). When examining within-group differences, the prevalence of mental illness decreases as the severity of IDD increases. More specifically, Holden and Gitlesen (2004) found higher rates of anxiety, depression, and psychosis among individuals with moderate IDD when compared to those with severe or profound IDD. However, the authors also recognized the difficulty in differentially diagnosing individuals with more severe forms of IDD. Reduced levels of intellectual functioning pose significant obstacles for researchers, caregivers, and clinicians due to communication difficulties and reliance on secondary informants.

Individuals with IDD also experience high rates of medical conditions (Jauhari et al., 2012). A recent international meta-analysis exploring comorbid health issues revealed a significant prevalence of comorbidity with epilepsy (70%), pulmonary/respiratory problems (21%), hearing problems (21%), dysphagia (30%), reflux disease (16%), and vision problems (56%) among individuals with severe or profound IDD and motor disabilities that impede their ability to move independently (van Timmeren, Schans, et al., 2017). Other studies examining individuals with IDD found high rates of comorbidity with obesity and hypertension (de Winter et al., 2011), pulmonary/respiratory problems (Poppes et al., 2010), gastrointestinal problems (Van der Heide et al., 2009), and low bone mineral density (Lohiya et al., 2004).

The literature is quite clear that comorbidity and even multimorbidity, the presence of two or more illnesses, seems more prevalent among individuals with IDD than other populations. A recent study found that 65% of individuals with IDD in their

sample incurred more than two diagnoses, which increased to 85% among participants with more severe IDD (Lehotkay et al., 2009). In older adults with IDD, defined as 50-years old or older, multimorbidity appeared prevalent in 79.8% of the sample, and 46.8% of the participants experienced four or more conditions (Hermans & Evenhuis, 2014). A study in Scotland examining a large healthcare database revealed similar results. Individuals with IDD exhibited more physical conditions (61.5%), mental health conditions (26.7%), and higher rates of comorbidity (40.6%), whereas individuals without IDD suffered from fewer physical conditions (43.6%), mental conditions (15%), and lower rates of comorbidity (27.1%). Schizophrenia, bipolar, anxiety, depression, and alcohol misuse also appeared more frequently among individuals with IDD (Cooper et al., 2015). Not only are comorbid conditions more prevalent with individuals IDD, rates are higher for those with more severe forms of IDD and those who are older.

Unfortunately, multimorbidity has been associated with an array of consequences such as poorer clinical outcomes, higher health care costs (Barnett et al., 2012; Lehnert et al., 2015) and even higher rates of death among those with IDD (Schoufour et al., 2018). Considering the difficulties diagnosing individuals with IDD and mental illness, comorbidity and multimorbidity estimates may underestimate the actual prevalence of multiple disorders in this population especially in individuals with more severe forms of IDD. Together, this research indicates that these individuals exhibit a wide range of complex social, emotional, mental, cognitive, and intellectual needs, a significant obstacle for researchers and clinicians, especially those examining and treating comorbid and multi-morbid conditions.

Further complicating the interpretation of comorbidity literature, researchers typically utilize a broad conceptualization of comorbid conditions, simply understood as the presence of two or more conditions, typically physical conditions. Scientists have only begun to explore the relationship of physical-psychiatric comorbidity, the presence of both physical and mental conditions, prevalent in approximately 17% of the U.S. population (Druss & Walker, 2011). Few studies examine the impact of multiple types of conditions such as multiple mental health or multiple physical conditions. Although researchers identify a high prevalence of mental illness and physical illness among this population, the effects of physical-psychiatric comorbidity among individuals with IDD remains relatively unknown. Logical next steps suggest examining the full complexity of this population by considering multimorbidity across disciplines, specifically those with IDD, mental health, and complex or chronic medical conditions, and sometimes multiple mental health illnesses and more than one medical condition. It would be reasonable to assume that as a person's clinical presentation becomes more complicated, the needs associated with the care of that individual become more complicated, leading to higher health care and service costs, which may or may not be in a linear relationship.

One aspect of this population that has received substantial research attention is the effects of challenging and aggressive behavior among individuals with IDD. According to Benson and Brooks (2008), challenging behavior can range from "verbal and physical aggression, property damage, self-injury, disruptive behavior, temper tantrums, stereotypy, socially inappropriate behavior, and noncompliance" (p. 454). Although the prevalence of challenging behavior varies between studies based on inclusion criteria and operational definition of aggression, some studies report the occurrence of aggressive

behaviors as high as 51.8% among individuals with IDD (Crocker et al., 2006). A survey of 926 community staff members who support individuals with IDD in Ontario, Canada, revealed that nearly all (92%) staff members reported exposure to client aggression in the past six months (Hensel et al., 2012). The survey also revealed that 25% of staff reported daily aggression exposure, and 20% of staff experienced a physical injury from client aggression towards themselves.

Although the majority of research examines aggression as a singular category, some researchers have begun exploring various types of aggression displayed by individuals with IDD. Heavily relying on existing literature on overt aggression, Crocker, Mercier, Allaire, and Roy (2007) developed aggression profiles through a cross-sectional study of adults with mild and moderate IDD. The researchers identified five types of aggression including verbal aggression, aggression against property, self-aggression, physical aggression, and sexual aggression and then developed profiles based on the presence of each type of aggression. In a more recent literature review, Crotty, Doody, and Lyons (2014) examined the research and prevalence of each type of aggression in studies with individuals with IDD. The authors concluded that research is limited for a few types of aggression, but pursuing a consistent typology across future studies will advance the care of such individuals. Studies including other populations, such as those with mental illness, also use similar typologies to develop their methodology (e.g. see Varghese et al., 2016).

A few studies have explored the relationship between the level of IDD severity and the prevalence of various types of challenging behavior. Poppes, van der Putten, and Vlaskamp (2010) conducted a study in the Netherlands examining 181 individuals with

profound IDD and multiple disabilities. Telephone interviews with psychologists caring for the individuals revealed that 82% of participants displayed self-injurious behaviors while 45% exhibited aggressive and destructive behavior. Furthermore, individuals with visual impairments, tactile impairments, and psychiatric issues demonstrated higher rates of challenging behaviors. In another study comparing individuals with mild and severe autism, the individuals with more severe forms of autism exhibited higher rates of aggression, property destruction, disruptive behavior, and self-injury compared to individuals with mild impairments (Matson & Rivet, 2008). Examination of other international samples revealed that psychiatric conditions and symptomology such as restlessness, irritability, sadness, poor concentration, and fear/panic were also associated with challenging behaviors (Holden & Gitlesen, 2003; Holden & Gitlesen, 2009).

In addition to the relationship with mental health conditions, researchers have also explored the association of physical conditions and challenging behaviors. A cross-sectional study of individuals with mild and moderate IDD living in the community receiving IDD services revealed that individuals with mental and physical conditions displayed more aggressive behaviors when compared to individuals with fewer and less severe conditions (Crocker et al., 2014). Logistic regression analysis also demonstrated a significant association with physical aggression and level of intellectual impairment. Individuals with moderate IDD displayed physical aggression almost twice as much as those with mild IDD. Individuals with mental health disorders also exhibited higher rates of verbal aggression and property destruction. When examining specific disorders, physical aggression appeared highest among individuals with speech disorders (Crocker et al., 2014).

In summary, individuals with IDD suffer from a range of impairments; some function well in non-institutional settings with little to no assistance, while others experience a range of problems requiring considerable support and specialized treatment. High rates of mental and physical illnesses combined with challenging behaviors such as physical aggression, expose a complicated picture of clinical needs. As scientists reveal the prevalence of various comorbid and multimorbid combinations, economists have begun unraveling the financial impact of diagnosed conditions and individual behaviors obscuring healthcare treatment. Contemporary economic literature suggests that individuals with IDD and mental illness represent the population with highest healthcare costs, specialized service use, and unmet health needs (Salvador-Carulla & Symonds, 2016). Considering the latest knowledge in healthcare utilization and rising costs, researchers have begun to examine and identify the factors influencing healthcare costs and service use.

Economic Impact

A cross-sectional study of 919 individuals with intellectual disabilities in the United Kingdom explored the economic impact of intellectual disability severity and challenging behaviors. The study indicated higher service costs for individuals with more severe intellectual disabilities who also displayed high levels of challenging behaviors (Knapp et al., 2005). Unfortunately, the researcher's model only accounted for 1/3 of the cost variation, leading to the conclusion that additional factors contribute to cost. Other international studies found similar results where individuals who exhibit challenging behaviors accounted for the highest service costs (Einfeld et al., 2010; McGill & Poynter, 2012). A sample comprised of all the individuals with IDD in

California revealed that individuals with more severe levels of intellectual disability, dual diagnosis (i.e., comorbidity), special behavior, behavior modifying drugs, and who were older accounted for the highest cost of services in the state according to Medicaid claims data (Harrington & Kang, 2016).

A few studies explore how comorbid physical conditions with intellectual disability influence healthcare and service costs. A comparison of children with IDD and cerebral palsy found that those with both disorders averaged almost three times more medical expenses than those with only one or the other condition (Kancherla et al., 2012). Another study found that intellectual severity, hearing impairment, physical disorder, and mental illness also significantly contributed to higher costs (Strydom et al., 2010). Finally, a study utilizing administrative health insurance claims data from Illinois, New York, and Texas Medicaid programs discovered not only high rates of comorbidity with mental illness (81%) and medical conditions (40%), such as schizophrenia (17%), epilepsy (22%), metabolic disorders (5%) infections (22%), and skin disorders (21%), but the presence of comorbid mental illness and medical disorders increased total annual expenditures by \$4,952-\$5,084 when compared to individuals without IDD (Vohra et al., 2017). Further analysis also uncovered high prescription drug use claims potentially indicating greater healthcare needs compared to a matched control group. Unfortunately, the study only looked at overall medical expenditures, so the economic impact of comorbidity remains incomplete for support services or the effects on mental health treatment costs.

As previously discussed, this population represents a heterogeneous group of individuals with an array of impediments. Although scientists have identified this

population as exhibiting high rates of comorbidity, challenging or disruptive behavior, and physical and mental illnesses, we know little about what is driving service costs or the combined effects of all of these factors. Existing literature examining the economic impact of caring for individuals with IDD either involves aggregated healthcare costs or mental health treatment costs of the IDD population as a whole (e.g., see Kancherla et al., 2012; Unwin et al., 2017; Zane et al., 2008), which excludes the impact of unique population characteristics or expenditures related to allied health efforts. For instance, most economic impact estimates ignore public health expenditures such as legal costs and police contact used to assist in the management of challenging behaviors.

Although research examining police contact remains sparse, a recent survey of police officers in Australia reported contact with people with IDD an average of 2.89 times per week and as high as 13 times per week for some officers (Henshaw & Thomas, 2012). In addition, an international literature review revealed that on average 7-10% of the prison population consists of individuals with IDD (Hellenbach et al., 2017). However, some studies in the review disclosed rates as high as 69.6% and very high comorbidity rates with mental health disorders and physical health disorders among those with IDD. Therefore, exclusion of the prison population in existing research likely underestimates overall prevalence rates of both comorbidity and overt aggressive behaviors as well as the economic impact of those contacts.

Despite the aforementioned unique characteristics of this population subset, individuals with IDD present other unique challenges to healthcare networks. Current funding models, like value-based contracts, are designed to capture the needs of most individuals yet do not differentiate between various population characteristics when

designing rate structures and outcome expectations. For example, individuals with IDD, challenging behavior, and mental illness display a range of communication difficulties and interaction styles that may require longer office visits to achieve comparable outcomes of their nondisabled peers. Moreover, most individuals with IDD lack proficient health literacy (Chinn, 2014; Chinn, 2017), even basic/functional literacy, required to recognize physical health symptoms or the interaction between many physical and mental health symptoms. Furthermore, health professionals lack knowledge of IDD (Hemm et al., 2015) and fail to make reasonable adjustments that would support these individuals when engaging in health-related decision making (Alborz et al., 2005).

Considering the high rates of comorbidity, aggression or challenging behavior, communication difficulties, and other compounding factors unique to this population, examining costs through an ecological, systems theory, and service utilization lens offers a more comprehensive and holistic approach to cost modeling. From a service utilization perspective, individuals who seek or receive services essentially drive total costs. Closer examination of service utilization patterns will therefore reveal determinants of cost. In more detail, the original Behavioral Model of Health Services Use posits that healthcare utilization can be explained by predisposing, enabling, and need components of a family (Anderson, 1968). Although primarily driven from a family decision-making perspective, Andersen (1995) revised his theory to shift principal decision making towards the individual. For individuals with IDD and mental health conditions, most health-utilization decisions occur through multi-disciplinary teams of direct care providers, advocates, and the guardian. The model suggests that individual, predisposing characteristics (e.g., demographic factors, health beliefs and knowledge), combined with

enabling resources (e.g., resources available and funded in the specified community) influence the perceived need to utilize health services. The model assumes that individuals with higher service needs utilize services at higher rates if resources are available. However, researchers have primarily examined this relationship from the perspective that needs predict utilization. Preliminary studies show that individuals with IDD experience poorer well-being, which relates to higher service utilization and cost (Cronin & Bourke, 2017).

While maintaining a holistic, systemic approach, utilization should be considered across all the systems that interact with the individual. Systems theory suggests that the sum is greater than the individual parts of the systems (Bertalanffy, 1968). However, systems interact and change with the environment (Valentinow, 2012) and across social contexts (Hoff & Stiglitz, 2016). For individuals with IDD, care crosses multiple systems beyond healthcare and LTSS service systems. Although research clearly shows significant healthcare costs, non-medical factors may influence costs of care in other systems, for instance the legal system. Interactions with police officers aimed to control challenging or aggressive behavior, represent costs to the public not reflected in healthcare costs but clearly impact the total cost of care. However, changes to the healthcare system or LTSS service system resulting in poorly managed mental health symptoms could result in cost shifting to other systems serving individuals with IDD. Although some studies identify challenging behavior as a contributing variable to higher costs, few studies identify the specific behaviors that contribute most to higher service cost or consider costs to other systems that interact with this population.

Citizens with complex clinical presentations including IDD with serious mental illnesses and physical illnesses cost more than other comorbid populations without IDD and mental health illnesses. Behaviors associated with impulse control, aggression, and other executive functions add both management and clinical treatment complications beyond those of customary psychological and physical treatment. Caring for individuals with complex issues also places additional strain on caregivers. In other words, these folks demand more resources and require professionals with expertise beyond the typical treatment population, creating psychological consequences for those caregivers.

Caregiver Strain

Caregiver strain refers to the strain or burden experienced by caregivers due to the additional demands, responsibilities, and difficulties associated with caring for an individual with emotional or behavioral disorders (Bickman et al., 2010). Although research suggests caregiver strain remains high for parents and families supporting individuals with IDD (Al-Krenawi et al., 2011; Kenny & McGilloway, 2007; Lecavalier et al., 2006), other caregivers such as direct service workers also experience strain associated with supporting individuals with IDD.

Several large studies show that approximately one-third of staff working in IDD services experience stress at levels indicative of the presence of a mental health problem derived from poorer self-reported health and greater self-reported stress and work pressure (Hatton, Rivers, Emerson et al., 1999; Hatton, Emerson et al., 1999). Common stressors include clients' challenging behavior, poor client skills (e.g., poor communication skills, mobility, slow or no habilitation progress), lack of staff support, lack of organizational resources (e.g., undesirable physical working conditions, lack of

sufficient staff, high workload), low-status jobs (e.g., low income, lack of job security, lack of promotion or training opportunities), bureaucracy (e.g., paperwork, organizational rules and regulations, ambiguity of job role and tasks), and work-home conflict (e.g., extensive work hours or lack of external support) (Hatton, Rivers, Mason et al., 1999; Robertson et al., 2005). However, client characteristics such as challenging behaviors posed the highest source of strain for staff; whereas, sources such as having a low-status job and lack of staff support were associated with lower work satisfaction and intention to leave their jobs. A survey of residential staff working with individuals with IDD revealed that the fear of assault mediated the relationships between challenging behaviors and strain, specifically through emotional exhaustion (Rose et al., 2013). In other words, staff exposed to challenging behaviors such as physical aggression and assault experienced emotional exhaustion, which translated into more overall strain.

Studies show negative outcomes for staff experiencing high levels of strain. For instance, stress from caring for individuals exhibiting challenging behavior can damage staff well-being (Hastings, 2002), negatively impact service quality through reduced positive interactions and helping behavior (Lawson & O'Brien, 1994; Rose et al., 1998), and indirectly damage service quality through increased turnover, absenteeism (Rose, 1995), burnout (Chung & Harding, 2009), and increased vacancy rates (Hewitt & Larson, 2007; Test et al., 2003). In the U.S., turnover rates range from 50-75% in private agencies serving individuals with IDD (Hewitt et al., 2008; Larson et al., 2002). Considering the workforce implications, agencies supporting individuals with IDD face an array of challenges recruiting, hiring, retaining, and training quality direct care

workers, in addition to the financial impact of managing these chronic issues, which may directly or indirectly increase agency operating costs.

Costs of direct care likely relate to many factors including client complexity and available resources. For instance, workforce issues and professionals who lack the necessary training or knowledge to treat and care for individuals with complicated clinical populations may influence costs (e.g., require more staff or specialized staff for certain clinical presentations). Furthermore, examining cost components helps researchers and health professionals understand why some individuals are more costly in order to determine how treatment providers can efficiently manage and treat individuals with more complex clinical presentations. However, the first step in unraveling this problem and before any informed decision can be suggested to improve this situation, one must begin to identify the costs of care. This study attempts to understand the economic impact of existing service structures and explore the factors contributing to service utilization patterns and relative costs. The study aims to (1) examine the prevalence rates of specific types of comorbidities (psychiatric and non-psychiatric) in a Midwest sample, (2) describe the patterns of behavior and individual characteristics among high-cost community service utilizers, (3) examine the degree to which certain characteristics of users predict cost variations in community services, (4) investigate the association of specific types of challenging or aggressive behaviors, mental and physical comorbidities, and estimated service utilization costs among individuals with IDD receiving non-institutional services, and (5) examine the applicability of the Behavioral Model of Health Services Use by evaluating if participants with higher needs, those with more

frequent and more severe symptomology, receive higher levels of service through relative cost estimates.

Hypotheses

Hypothesis 1: A range of bivariate relationships with average monthly service expenditures is predicted to appear in the sample.

- a. Individuals with lower IQs will be associated with significantly higher monthly service expenditures.
- b. Individuals with lower adaptive functioning indicated by lower scores on the ICAP will be associated with significantly higher monthly service expenditures.
- c. Higher caregiver/staff strain, measured by the Caregiver Strain Questionnaire, will be associated with significantly higher monthly service expenditures.
- d. Individuals with more severe behaviors, measured by higher full scale scores on the Developmental Behaviour Checklist (total score), will be associated with significantly higher monthly service expenditures.
- e. Individuals with higher rates of challenging behavior (aggregated frequency of all incidents including self-injurious behaviors, suicide, property destruction, altercations, assaults, theft/larcenies, behavioral outbursts, threatening behavior, false allegations, substance abuse, elopement, and fire setting) will be associated with significantly higher monthly service expenditures.

Hypothesis 2: Individuals who suffer from comorbid mental and physical health conditions will be associated with significantly higher average monthly service expenditures compared to those with only one or the other type of condition.

Hypothesis 3: Individuals with more severe forms of IDD (moderate, severe, and profound), as noted in the diagnosis or IQ scores, and comorbid physical health and serious mental illness will be associated with significantly higher average monthly service expenditures than those with less severe forms of IDD.

Hypothesis 4: Individuals who display higher rates of aggression against others (rates of behavioral incidents including assault, altercations, and behavioral outbursts) will be positively associated with an array of behavioral response outcomes.

- a. Individuals with higher rates of aggression against others will be associated with significantly higher rates of emergency safety physical interventions.
- b. Individuals with higher rates of aggression against others will be associated with significantly higher rates of police contacts.
- c. Individuals with higher rates of aggression against others will be associated with significantly higher rates of incarcerations.
- d. Individuals with higher rates of aggression against others will be associated with significantly higher rates of ER visits.
- e. Individuals with higher rates of aggression against others will be associated with significantly higher rates of psychiatric hospitalizations.

Hypothesis 5: Disruptive subscale scores on the Developmental Behaviour Checklist (DBC), will significantly predict higher average monthly service expenditures than full scale scores.

Hypothesis 6: A range of bivariate relationships with caregiver strain, measured by the Caregiver Strain Questionnaire (CGSQ), is predicted to appear in the sample, including the following:

- a. Caring for individuals with more severe forms of IDD will be associated with significantly higher caregiver strain when compared to individuals with less severe forms of IDD.
- b. Higher rates of mental health and physical health comorbidity will be associated with significantly higher caregiver strain when compared to those with no mental or physical health comorbidity and one or the other condition.
- c. Higher rates of aggression against others (rate of assaults, altercations, and behavioral outbursts) will be associated with significantly higher caregiver strain.
- d. Higher rates of aggression against self (rate of self-injurious behaviors and substance abuse) will be associated with significantly higher caregiver strain.
- e. Higher rates of verbal aggression (rate of threatening behavior and false allegations) will be associated with significantly higher caregiver strain.

- f. Higher rates of aggression against property (rate of theft/larceny, property destruction, and fire setting) will be associated with significantly higher caregiver strain.
- g. More severe behaviors, measured by higher scores on the DBC, will be associated with significantly higher caregiver strain.

Hypothesis 7: The frequency of aggressive behaviors including verbal aggression, aggression against others, aggression against self, and aggression against property will significantly predict average monthly service expenditures, with aggression against others achieving the highest predictive value in the model.

Hypothesis 8: Aggression against others, verbal aggression, aggression against self, aggression against property, IQ, behavior severity (DBC total score), caregiver strain (CGSQ score), and adaptive functioning (ICAP score) will significantly predict average monthly service expenditures better than existing rate structures that only include adaptive functioning and IQ.

Hypothesis 9: Aggression against others and aggression against property will directly predict average monthly service expenditures, but will also indirectly influence service expenditures by significantly increasing caregiver strain.

CHAPTER 3

METHODS

For the purpose of this study, secondary analyses of archival data from medical records, care plans, clinical records (van Timmeren, Waninge, et al., 2017), and physical health screens were examined from an agency providing non-institutional, community services to individuals with IDD from January 1, 2016, to August 31, 2019, for at least 100 days. Sources of documentation included clinical care files, incident reports (General Event Records-GERs), facility maintenance and repair logs, billing documents, staff schedules/timesheets, and other relevant agency documents. The clinical care file contains detailed documentation of medication consumption, treatment episodes, health appointments, police contacts, property destruction, aggressive acts, disruptive and challenging behavior occurrences, acute hospitalizations, and all other critical incidents. Data collection, obtained from behavioral reports, occurred from an incidence-based approach to measure the frequency of a variety of disruptive behaviors in addition to periodic scored assessments. Total cumulative incident and treatment costs for the year were calculated and compared to individual characteristics based on reimbursement and billing records, incident estimates, and actual expenditures.

Site & Sample

Participants met the following criteria for inclusion in the study: (1) verified as having an intellectual or developmental disability by the Nebraska Department of Health and Human Services (NDHHS), Developmental Disability Division, and (2) received community-based residential services through OMNI Behavioral Health d/b/a Omni Inventive Care (Omni) from January 1, 2016, to August 31, 2019. Participants received

either extended family home (EFH) or group home care, both considered residential services, and presented with a variety of intellectual limitations and presenting issues. Created in 1993, Omni serves individuals in community settings despite clinical presentation, disability, or condition severity. In response to local needs and national efforts towards community integration, Omni began providing community-based services for individuals with IDD in addition to their existing innovative mental health services starting in 2009.

Measures and Coding

Using a codebook (see Appendix 1), a single reviewer examined participant treatment files and billing documents to extract study data and code all research variables. Coding was used strictly for data analysis, so no subjective interpretation was required during the data collection process. Variable information was extracted from existing assessment scores, billing records, and incident tracking reports (GER) for each participant. Therefore, additional reviewers or reliability safeguards were not necessary.

Service Program. OMNI offers two primary residential services based on setting for individuals with IDD—group homes and extended family homes (EFH). Determined by clinical presentation, referral requests, availability of a willing home, clinical need, and supervision and monitoring requirements of other individuals in the group home or EFH home, individuals are admitted into either a community-based group home or an EFH. Each group home houses 1-3 individuals diagnosed with similar disabilities in a single-family home in Omaha, NE. The home is located in a neighborhood and staffed 24 hours per day, 7 days a week, by awake, behaviorally trained employees. An EFH home offers similar living arrangements (1-3 residents in a single-family dwelling) but is

more like adult foster care for individuals with IDD. The consumers live with an identified family in their home and may or may not receive additional supportive services during the day².

Comorbidity. The researcher collected the number of comorbid conditions by examining current and past clinical records for the presence of IDD, mental health disorders, and medical conditions. Mental health diagnoses were determined by the presence of a DSM-5 diagnosis from a mental health or medical professional. For the purposes of operationalizing comorbidity categories, IDD diagnoses were not considered mental health conditions. Medical conditions were obtained from past medical records and data derived from a comprehensive health screen completed during the participant's intake into Omni services. An intellectual/development disability diagnosis was verified through either the NDHHS or Special Education documentation, which was a condition of participation in the study.

The researcher coded each participant based on either the presence or absence (0=diagnosis not present, 1=diagnosis present) of a mental health diagnosis, medical condition, and IDD diagnosis. Then all three diagnostic variables were combined to create a latent variable of comorbidity. Values for the new variable ranged from 1-3 to capture the degree of comorbidity (1 being the presence of only an IDD diagnosis, and 3 being the presence of all three types of diagnoses). Specific participant mental and physical diagnoses were recorded individually for descriptive and prevalence analyses. The same process occurred for SPMI Comorbidity. Conditions considered as SPMI

² More information available at www.Omniic.com.

diagnoses included Major Depression, Schizophrenia, Bipolar, and Borderline Personality Disorder.

Since one hundred percent of the sample possessed an intellectual disability diagnosis and a mental health diagnosis, coding was later converted to high and low comorbidity categories (0=low--those with only an IDD and mental health condition; 1=high--individuals with IDD, mental health, and physical health conditions). Consistent categorizations were developed for SPMI comorbidity.

Intellectual Functioning. Participant IQ and IDD diagnostic severity served as two measures of intellectual functioning. Diagnostic reports in the client's file revealed IDD severity levels. If diagnostic reports excluded specific severity levels, IQ scores determined the IDD severity level based on DSM-IV criteria.

Adaptive Functioning. In order to further differentiate participants beyond intellectual disability severity, which typically only captures intellectual functioning, all subjects were assessed for adaptive functioning prior to admission into Omni services and periodically throughout their long-term care. During the objective assessment process with NDHHS, state officials complete an Inventory for Client and Agency Planning (ICAP) assessment on all service recipients. The ICAP measures adaptive functioning and service needs by examining motor skills, social and communication skills, personal living skills, community living skills, and problem behaviors (Bruininks et al., 1986). The adaptive functioning section of the assessment includes 77 tasks rated on a 4-point scale (0=never or rarely; 1=does, but not well; 2=does fairly well; 3=does very well). The problem behavior section covers eight broad categories, and measures frequency and

severity of each category. When combined, the assessment offers a summary score intended to represent overall level of functioning and ongoing service needs.

The combined summary scores range from 0 to 100. Lower scores indicate lower functioning and require a higher level of personal care and supervision, whereas higher scores represent higher functioning and require limited to no assistance or supervision. As part of the assessment process, the assessor reviews relevant clinical documentation and interviews at least two individuals who have known the participant for at least three months and interact with him/her daily.

Since the ICAP assessment informs state personnel of client needs, it also serves as the primary assessment for rate setting in Nebraska. However, service providers recently criticized state officials for perceived inconsistent administration practices (e.g., some individuals assessed every two years while others lack reassessment over 10 years) and poor adherence to administrative protocols (e.g., inconsistent use of informants, eliminating questions, etc.), which introduced doubt on the reliability of ICAP administration from NDHHS personnel. Amidst increasing conflict, some caseworkers rejected requests for ICAP scores on a few clients. As a result, Omni staff attended training to administer the ICAP and began completing the assessment on clients admitted to their programs. Scores were then compared to ICAP results from NDHHS to compare accuracy and reliability as well as use for initial scores when ICAP results from NDHHS were unavailable.

For this study, the ICAP summary scores from either NDHHS administration or Omni staff were used for analysis comparisons. If both scores appeared in the clinical record, the average score was collected. Cronbach's alpha analysis between NDHHS and

Omni administrations showed adequate reliability ($\alpha=.832$) to justify the use of Omni administered ICAP scores for those individuals without a NDHHS administered ICAP.

Staff/Caregiver Strain. Individuals with higher needs and more complex issues impact caregivers. The workforce caring for individuals with IDD experience a number of challenges resulting in increased burnout, high rates of turnover, and high vacancy rates. Staff member completion of the Caregiver Strain Questionnaire-revised short form (CGSQ; Bickman et al., 2010) was collected for each client served during the study period. The CGSQ measures the demands, responsibilities, difficulties, and negative psychological consequences associated with caring for individuals with emotional or behavioral disorders. The questionnaire includes ten items rated on a 1-5 scale (1=not at all, 5=very much) averaged to generate a global scale score along with objective and subjective sub-scores, each ranging from 1-5. Unfortunately, subscale scores were unavailable to the researcher; so hereafter, reference to the CGSQ will represent the global caregiver strain score.

Psychometric analysis of the revised short form revealed a global scale internal reliability (α) of .91 (Brannan, Athay, & Andrade, 2012). Although originally normed on populations with serious emotional and behavioral disorders, recent studies examined use of the CGSQ with IDD populations (Benninger & Witwer, 2017; Khanna et al., 2012; Kirby et al., 2015). Psychometric analysis within these studies, including IDD populations, revealed excellent reliability of $\alpha = .95$ (Benninger & Witwer, 2017) and $\alpha = .94$ (Khanna et al., 2012) across different respondents (e.g., parents, other caregivers) and settings (e.g., inpatient, outpatient).

Assessment scores were collected from the staff member who most closely interacts with the participant, assigned by the agency. If the clinical file included administration of multiple CGSQ assessments, the researcher averaged the scores across the study period. Repeated administrations appeared in 36 participant files. The average range of CGSQ scores for these participants was .406. Reliability and consistency analyses were conducted revealing excellent reliability ($\alpha = .91$) across the administrations, justifying the use of a single score for the present study.

Disruptive Behavioral Severity through Assessment. The Developmental Behaviour Checklist 2 (DBC), a validated measure of emotional and behavioral disturbances for individuals with IDD (Mohr, Tonge, & Einfeld, 2005) was examined on all individuals receiving DD residential or EFH services. The DBC is a 107-item checklist completed by the primary staff person caring for the individual, who rates behavior over the prior six months. Respondents score each item on a Likert scale ranging from 0-2 (0=not true as far as you know, 1=somewhat or sometimes true, and 2=very true or often true). The checklist has been normed in a variety of settings such as community care (Mohr, Tonge, Taffe, et al., 2011) and across multiple functioning levels of IDD (Forster et al., 2011; Mohr et al., 2012). The researcher utilized the DBC full-scale score to measure behavioral and emotional disturbance severity, and specifically the severity of challenging and aggressive behaviors.

In addition to the full-scale scores, the DBC is comprised of the following five subscales: disruptive, communication and anxiety disturbance, self-absorbed, depressive, and social relating. Subscale scores were also collected to examine a more detailed level of disturbance severity. Individuals scoring high in the disruptive subscale generally

exhibit behaviors depicted as disruptive, challenging, or aggressive such as kicking, hitting, injuring others, seeking attention, or being irritable. The communication and anxiety disturbance subscale measures behaviors that relate to problems with communication (e.g., bizarre speech, hallucinations, and delusions) or anxious and obsessive behaviors. Behaviors measured in the self-absorbed subscale consist of self-injurious behaviors (e.g., head banging, hitting or biting oneself), stereotypic motor mannerisms, and repetitive activities. The depressive subscale assesses symptoms of mood disorders such as sleep disturbances, poor self-esteem, appetite loss, poor self-care skills, confusion, and social withdrawal. Lastly, the social relating subscale evaluates behaviors that involve social disengagement and avoidance.

Psychometric studies of the DBC and corresponding subscales indicate high internal consistency, test-retest reliability, and interrater reliability in U.S. samples, across respondents (e.g., parents, teachers, professional caregivers), and throughout intellectual disability severities. Total scale internal consistency (α) is 0.95. Subscale internal reliability ranged from 0.77-0.91 (Disruptive, $\alpha=0.91$; Communication and Anxiety Disturbances, $\alpha=0.86$; Self-Absorbed, $\alpha=0.84$; Antisocial, $\alpha=0.84$; Depressive, $\alpha=0.80$; Social Relating, $\alpha=0.77$) (Mohr, Tonge, Einfeld, & Taffe, 2011; Mohr, Tonge, Taffe, et al., 2011). Test-retest reliabilities ranged from .82 to .99, with a median of .98 across scales and forms. Full-scale scores ranged from 0-167 where higher scores indicate higher levels of disruption. Data from the full scale score and six sub-scales were collected from client files.

Disruptive Behavior Typology and Frequency Tracking. Using similar methodology as other studies measuring behavior (Lee & Thompson, 2009), this study

measured behavior frequency by aggregating the number of behaviors reported by staff. Each time an individual displays a disruptive behavior, staff members complete an incident report (GER) to document the type of incident, duration of the incident, precipitating factors, and other contextual information about the incident. Reports generated through the electronic records system aggregate the number of each incident type for the specified time-period. The researcher utilized incident report data for each participant to generate an aggregated total number of incidents for the study time period and a monthly rate of each of the following behaviors:

- 1) *Threatening Behavior.* Behavior where a participant verbally threatens another individual or utilizes physically threatening positioning. Threatening behavior differs from other aggressive acts such as assault and altercation in that physical contact is not achieved during the interaction.
- 2) *False Allegation.* False allegations include reports in which the participant wrongly accuses an individual of abuse or neglect, where evidence clearly disproves the participant's account of events.
- 3) *Assault.* Assaults include incidents where a participant engages in physically aggressive behavior towards another individual during the study period. Physical aggression involves behavior causing physical harm towards others, including hitting, kicking, biting, using weapons, throwing items, and scratching with a clear aggressor and victim.
- 4) *Altercation.* Although similar to assault in the appearance of the behavior, an altercation differs from assault as it includes a physical interaction in which

both parties mutually assert aggression towards the other, obscuring who is the primary aggressor or victim.

- 5) *Behavioral Outbursts.* A behavioral outburst includes events that require staff intervention to preserve the safety of the participant or other individuals but only when the event is not accounted for by any other behavioral category.
- 6) *Self-Injurious Behavior.* Self-injurious behavior involves overt acts that produce injury to the individual's own body, including self-neglect or physical harm. Examples include head banging, scratching, cutting, hitting/bruising, self-biting, and consuming nonfood items.
- 7) *Suicide.* Suicidal behavior includes self-report or observed experiences of suicidal thoughts, gestures, attempts, and threats.
- 8) *Substance Abuse.* Derived from incident report data, substance abuse refers to the incidents in which the participant utilized alcohol or drugs resulting in an unsafe situation that requires staff intervention to maintain safety for the individual or community members.
- 9) *Theft/Larceny.* Incidents where the participant intentionally took another person's or company's property without permission.
- 10) *Property Destruction.* Property destruction is defined as any intentional damage and/or destruction of public or private property. Property destruction includes ripping, scratching, or denting an item, damaging the item where it interferes with normal functioning, or completely destroying the object.
- 11) *Fire Setting.* This behavior includes an individual's attempt to start a fire or actually starts a fire with the intent to harm or destroy the property of others.

- 12) Elopement.* Elopement includes the participant leaving residential grounds, vocational settings, or specified community locations without the permission or knowledge of staff for longer than a 15-minute period.
- 13) Emergency Safety Personal Physical Intervention (ESPI).* An ESPI represents a staff intervention that applies physical force in response to an emergency situation for the purpose of restraining the free movement of an individual's body. An ESPI is only used in an emergency to preserve the safety of the individual (i.e., prevent or stop self-harm), staff (i.e., prevent harm to the staff member due to physical aggression), or community members and is never utilized as a behavioral consequence, coercion, discipline, convenience, or retaliation by staff. ESPI incidents represent a significant escalation of behavior requiring hands-on assistance to maintain safety. An ESPI does not include mechanical or chemical restraints, which are prohibited practices within the agency.
- 14) Police Contacts.* Police contacts include any time the individual had contact with a police officer due to either someone calling for assistance or a police officer witnessing an event in which he/she intervenes for public safety.
- 15) Incarceration.* Incarceration incidents include any time the individual is detained and stays overnight in a correctional facility or jail. Each day of incarceration was aggregated to generate a total number of days incarcerated during the study period.
- 16) Acute hospitalizations.* Inpatient hospitalizations remain the most costly physical and mental health intervention (de Oliveira et al., 2016). Despite

economic impact, hospitalizations also represent increased acuity in mental or physical conditions that require elevated intervention and assistance.

Hospitalizations were calculated by adding the total number of instances where the participant was transported to the hospital and admitted for at least one overnight stay during the study period based on clinical records and incident reports.

17) Emergency Room. Emergency room visits were calculated by adding the total number of instances where the participant was transported to the hospital emergency room and released the same day during the study period based on clinical records and incident reports.

Following Varghese, Khakha, and Chadda, (2016) typology, behavioral incident data was categorized into the following four categories for analyses: verbal aggression, aggression against others, aggression against self, and aggression against property. Verbal aggression included threatening behavior and false allegations. Aggression against others included assaults, altercations, and behavioral outbursts, while aggression against self involved self-injurious behavior, substance abuse, and suicide. Aggression against property included theft/larceny, property destruction, and fire setting. Although Crocker, Mercier, et al., (2007) and Crotty et al., (2014) developed a consistent typology to categorize aggressive behaviors among individuals with IDD, data for the present study did not include sexually inappropriate behavior, so that category was not tested in the present study.

Finally, behavioral response outcomes included ESPIs, police contacts, incarceration, acute hospitalization, and ER visits. Assumingly, depending on the

intensity of the outburst, physical behaviors more likely result in a request for additional supports captured by the behavior response outcomes. Separation of these categories should reduce overestimating the impact of these physical behaviors since both may occur in the same incident. To procedurally control for varying service lengths, the researcher generated monthly rates for each behavioral variable categories.

Cost Methods

Service costs served as a proxy measure to quantify service utilization such that higher costs imply greater service and treatment needs and strain on public health resources. Increased service costs also represent either more intense services or additional service amounts needed to maintain the individual in the existing level of community care. Consistent with cost methodologies in other studies, direct service costs were calculated by summing a variety of service-user level costs derived from actual resources consumed in the treatment of individuals receiving mental health services (Harrington & Kang, 2016; Kancherla et al., 2012; Knapp et al., 2005; Laidi et al., 2017; Strydom et al., 2010; Vohra et al., 2017). The actual costs were then added to estimated costs of various public health services and medical services utilized during the same period to generate a total service cost per participant (see Appendix I). The researcher transformed aggregated figures into average monthly service costs to account for the varying service duration among study participants. Summation of the following data generated the total cost for each participant:

- 1) *Residential treatment services.* Residential costs were measured by residential and treatment reimbursement for each participant during the study period.
After NDHHS sets the residential rates, providers must apply for additional

funding for individuals with higher needs, referred to as exception funding. When state officials approve exception funding, the subsequent month's reimbursement reflects retrospective compensation, which distorts the actual service cost for that month. To accommodate funding variability, monthly totals were aggregated to generate a total service cost, consistent with methodology from similar studies. NDHHS funded residential treatment services for all participants in the study. Residential costs are typically the largest cost for mental health-based cost figures.

- 2) *Room and board.* Government benefits such as Social Security or disability typically cover room and board costs, which include rent, food, personal hygiene items, and minor incidental items. Although these figures typically remain constant across individuals in residential care, they represent utilization of public funds required to care for this population. The participant or guardian typically pays the provider for these costs.
- 3) *Physician care.* Since medical services were not provided by the agency, the researcher did not have access to medical claims. Therefore, physical health care cost estimates were calculated by multiplying the total number of physician appointments attended by the participant during the study period with the average cost of an outpatient physician visit. According to data derived from the 2014 Medical Expenditure Panel Survey (AHRQ, 2014a) from 33,162 individuals and 13,421 families, the average cost of outpatient office-based physician services is \$222 per visit. These services include all primarily care appointments, physicals, and specialized physician

appointments (e.g., psychiatrists, dentists, medication checks, occupational therapist, physical therapist, etc.). All per diem service costs were aggregated to capture the total outpatient health care costs per participant.

- 4) *Nursing care.* Nursing care costs were calculated by the total number of hours each individual was seen by a nurse employed at Omni and multiplied by the average hourly nursing wage of \$38.01. Nursing wages were averaged across all nurses employed by the agency.
- 5) *Police contact cost.* Estimated police contact costs were calculated by multiplying the amount of time individuals encounter police officers (derived from GER records) during the study period by \$27.66, which is the average hourly wage of a police officer in Nebraska (Bureau of Labor Statistics, 2018).
- 6) *Emergency Room Visits.* Emergency room costs were calculated by multiplying the number of hospitalizations, excluding those followed by an inpatient stay, by \$1,048, which is the average cost of an emergency room visit (AHRQ, 2014a).
- 7) *Vocational services.* Vocational treatment costs were collected from billing records indicating the actual cost reimbursement to Omni from the NDHHS per participant. Most agencies bill vocational services separately from residential services, and include assistance with job training, employment assistance, and supported employment programming.
- 8) *Mental health treatment.* Mental health treatment costs were calculated by aggregating the actual amount of treatment services (e.g., evaluation,

assessment, therapy by a mental health professional) reimbursed to Omni by Medicaid, Medicare, private insurance, or the NDHHS.

9) *Nutrition Services.* Nutritional costs were gathered by aggregating actual nutrition treatment services (e.g., evaluation, assessment, therapy by registered dietician) reimbursed to Omni by Medicaid, Medicare, private insurance, or the NDHHS.

10) *Property Destruction.* Incidents of property destruction were identified in the participant's clinical record and cross-referenced with property repair and expenditure records for the facility or item replacement costs to depict the actual cost of each incident. The sum of all incidents generated a total property destruction cost for the study period.

11) *Medication.* Medication administration records were utilized to identify all medications consumed by the individual during the study period. Medication costs were then totaled for the study period using the contracted pharmacy medication invoices, comprised of the actual cost paid by the client, guardian, and insurance carrier.

Data Analysis Methods

The Statistical Package for Social Sciences (SPSS) for windows, version 26, was used to obtain descriptive information about the participants and to test hypotheses. The characteristics of subjects and assessment variables were analyzed through descriptive statistics and correlations to generate a general description of participants and identify the prevalence and type of comorbidity among the sample population.

Preliminary analyses explored the relationship between program, gender, and age and the dependent variables. Although age and gender shared no significant relationship with either cost or caregiver strain, analyses with service program (coded as group home = 0, EFH = 1) showed a significant correlation with both cost $r(73) = -.498, p < .001$ and caregiver strain $r(72) = -.236, p < .05$, indicating that group home service programs (vs. EFHs) were associated with greater cost as well as strain. Therefore, service program was added as a covariate to analyses to control for these effects.

Visual inspection of scatterplot graphs followed by examination of skewness and kurtosis values revealed non-normal distribution of aggression rates and DBC subscale scores. Due to non-normal distribution, outliers, and small sample size (Field, 2013; Siebert & Siebert, 2018), nonparametric analyses and transformations were performed for affected variables. Spearman's rho correlation analysis was used with the DBC subscales and aggression rates for bivariate comparisons. Log transformations were conducted on aggression rate variables for multivariate regression analyses. Examination of collinearity statistics and results of the Durbin-Watson test were utilized to test other statistical assumptions in the regression models.

Three multivariate regression models were analyzed and compared to examine the relationship with participant characteristics, aggression, caregiver strain, and cost. The first model included all four aggression types. The second and third models were compared using an R^2 change F -test to identify the optimal cost model. In these models, the trimmed model included adaptive functioning and IQ, which is the existing cost model used to set rates with NDHHS. The full model included the variables from the first two models and then added behavior severity and caregiver strain, while controlling

for service program. Finally, path analysis was used to evaluate the direct and indirect relationship between caregiver strain and service cost.

G*Power 3.1.9.4 was used to conduct post hoc sensitivity analyses to estimate the power to detect the effects given the existing sample size. DBC and caregiver strain scores were missing for one participant, so pairwise deletion techniques were utilized for affected analyses. No other data fields contained missing data.

CHAPTER 4

RESULTS

Seventy-three participants met the inclusion criteria for the study, 26 group home participants and 47 EFH participants. Demographic information was collected from intake forms in the client file and consisted of age, gender, race/ethnicity, IQ, mental and physical conditions, medications, and intellectual disability severity (mild, moderate, severe, and profound). Of the 73 participants, 55 (75%) were white, 13 (18%) were African American, 3 (4%) were Native American, and 2 (3%) were other or unknown. Additionally, 49 (67%) were male and 24 (33%) were female, and the average length of stay in their program was 742 days. Table 4.1 summarizes the demographic data by program.

TABLE 4.1*Sociodemographic Characteristics of Participants*

Variable	Univariate Statistics					
	PROGRAM					
	<u>Group Home</u>		<u>EFH</u>		<u>All Participants</u>	
Age	<i>M</i> =32.51	<i>SD</i> =9.42	<i>M</i> =31.18	<i>SD</i> =12.86	<i>M</i> =31.65	<i>SD</i> =11.70
Length of Stay	<i>M</i> =606.04	<i>SD</i> =399.90	<i>M</i> =817.89	<i>SD</i> =474.61	<i>M</i> =742.44	<i>SD</i> =458.12
Gender						
Male		17 (65%)		32 (68%)		49 (67%)
Female		9 (35%)		15 (32%)		24 (33%)
Race/Ethnicity						
White		23 (88%)		32 (68%)		55 (75%)
African American		1 (4%)		12 (26%)		13 (18%)
Native American		1 (4%)		2 (4%)		3 (4%)
Other/Unknown		1 (4%)		1 (2%)		2 (3%)

Note. Group Home (*N* = 26); EFH (*N* = 47); All Participants (*N* = 73)

The participants experienced an array of mental health and physical health conditions. The most common mental health conditions included bipolar disorder (37%), depression (30%), attention deficit hyperactivity disorder (23%), borderline personality disorder (19%), and impulse control disorder (19%) (see Table 4.2). All of the participants experienced mental health conditions, and 96% of participants possessed more than one mental health diagnosis.

TABLE 4.2*Prevalence of Mental Health Conditions among Participants*

	Participants	
	<i>N</i>	%
Mental Health Conditions		
Bipolar Disorder ^a	27	37%
Depression ^b	22	30%
ADHD	17	23%
Borderline Personality Disorder	14	19%
Impulse Control Disorder	14	19%
Post Traumatic Stress Disorder	13	18%
Intermittent Explosive Disorder	13	18%
Mood Disorder NOS	11	15%
Oppositional Defiant Disorder	9	12%
Obsessive Compulsive Disorder	8	11%
Schizophrenia	7	10%
Schizoaffective Disorder	7	10%
Pedophilia Disorder	5	7%
Anxiety Disorder	4	5%
Conduct Disorder	4	5%
Disruptive Behavior Disorder	3	4%
Antisocial Personality Disorder	3	4%
Psychotic Disorder	2	3%
Hoarding Disorder	1	1%
Dependent Personality Disorder	1	1%
Reactive Attachment Disorder	1	1%
Paraphilia Disorder	1	1%
Fetishistic Disorder	1	1%
Frotteuristic Disorder	1	1%
Pica	1	1%
Stereotypic Movement Disorder	1	1%
Tourette's Syndrome	1	1%

Note. *N* = 73.

^aBipolar disorder includes bipolar I, bipolar II, episodic mood disorder, and cyclothymic disorder.

^bDepression includes depressive disorder, major depression, dysthymia/persistent depressive disorder, disruptive mood dysregulation disorder, and premenstrual dysphoric disorder.

High rates of comorbid physical health conditions also emerged in the population. Obesity (49%; body mass index, $M = 31.37$, $SD = 8.17$), endocrine disease (47%), seizure disorder (37%), and gastrointestinal disorder (34%) were the most common physical conditions (see Table 4.3). While 84% of participants experienced physical health conditions, clinical records revealed that 79% of participants possessed more than one medical condition.

TABLE 4.3

Prevalence of Physical Health Conditions among Participants

Physical Health Conditions	Participants	
	<i>N</i>	%
Obesity	36	49%
Endocrine Disease	34	47%
Seizure Disorder	27	37%
Gastrointestinal Disorders	25	34%
Circulatory Problems	17	23%
Respiratory Problems	10	14%
TBI	9	12%
None	7	10%
Heart Disease/Attacks	5	7%
Infectious Disease	4	5%
Blood Diseases	2	3%
Other Medical Conditions ^a	42	58%

Note. $N = 73$.

^aOther Medical Conditions includes joint/muscle disease, hydrocephalus, fetal alcohol syndrome, sleep disorders, Pruritus, etc.

The sample also showed high rates of comorbidity. All participants in the sample were diagnosed with an intellectual disability as well as a mental health condition, while 59% of those were considered serious and persistent mental health conditions. Clinical records revealed that the majority of participants (82%) had mental health and physical health conditions, while 58% had serious and persistent mental illness and physical health diagnoses. The prevalence of comorbid conditions is summarized in Table 4.4.

TABLE 4.4*Frequency Results for Comorbidity Variables by Program (N = 73)*

Variable	Univariate Statistics		
	<u>Group Home</u>	<u>EFH</u>	<u>Both</u>
IDD diagnosis present	26 (100%)	47 (100%)	73 (100%)
MH diagnosis present	26 (100%)	47 (100%)	73 (100%)
SPMI diagnosis present	18 (69%)	25 (53%)	43 (59%)
PH diagnosis present	23 (88%)	38 (81%)	61 (84%)
Comorbidity			
IDD only	0 (0%)	0 (0%)	0 (0%)
IDD + MH	3 (12%)	10 (21%)	13 (18%)
IDD + MH + PH	23 (88%)	37 (79%)	60 (82%)
SPMI Comorbidity			
IDD only	3 (12%)	8 (17%)	11 (15%)
IDD + SPMI or PH	5 (19%)	15 (32%)	20 (27%)
IDD + SMPI + PH	18 (69%)	24 (51%)	42 (58%)

Note. IDD = Intellectual/Developmental Disability; MH = mental health diagnosis; PH = physical health condition; SPMI = serious and persistent mental illness.

Participants showed a range of functional abilities and assessment scores.

Participant IQ scores ranged from 20-100 ($M=58.73$, $SD=15.62$). Ten (14%) participants were diagnosed as borderline functioning, 37 (51%) were diagnosed mild IDD, 18 (25%) fell under moderate IDD, 7 (9%) were diagnosed as severe IDD, and one individual (1%) possessed a profound IDD diagnosis. Participant ICAP scores ranged from 4 to 90

($M=47.81$, $SD=18.96$). CGSQ scores for participants ranged from 1 to 4 ($M=1.76$, $SD=0.68$). Fifty-three percent of respondents scored in the low level of strain, while 47% scored strain in the medium to high levels. Data collected from participant files revealed full-scale DBC scores ranging from 7 to 127 ($M=60.67$, $SD=29.88$). Subscale scores ranged from 0 to 45 with means ranging from 5.67 to 22.06. Descriptive statistics for adaptive functioning and assessment variables are summarized in Table 4.5.

TABLE 4.5*Descriptive Statistics for Functioning and Assessment Variables*

Variable		Descriptive Statistics	
IDD Severity			
	Borderline	10 (14%)	
	Mild	37 (51%)	
	Moderate	18 (25%)	
	Severe	7 (9%)	
	Profound	1 (1%)	
	IQ	$M = 58.73$	$SD = 15.62$
	CGSQ	$M = 1.76$	$SD = 0.68$
	ICAP	$M = 47.81$	$SD = 9.42$
DBC	Full-Scale Score	$M = 60.67$	$SD = 29.88$
	Disruptive subscale	$M = 22.06$	$SD = 11.10$
	Communication & Anxiety	$M = 11.31$	$SD = 7.42$
	Self-Absorbed subscale	$M = 10.43$	$SD = 7.97$
	Depressive subscale	$M = 5.67$	$SD = 4.19$
	Social Relating subscale	$M = 5.01$	$SD = 3.61$

Note. $N = 73$ for IDD Severity, IQ and ICAP; $N = 72$ for CGSQ and DBC. IDD severity = Intellectual Disability Severity; IQ = Intelligence quotient; CGSQ = caregiver strain; ICAP = adaptive functioning; DBC = Developmental Behaviour Checklist.

Participants displayed a wide range of disruptive, aggressive behaviors. Ninety-three percent ($N=68$) of participants displayed at least one type of disruptive behavior.

Aggression against others and aggression against property emerged as the most common types of aggression displayed by participants. Incidents of assault, behavioral outbursts, and property destruction emerged as the most frequent behavior displayed by participants. A summary of the descriptive information for aggression frequency variables is summarized in Table 4.6. Emergency safety physical interventions and police contacts emerge as the most common behavior response interventions. Although the mean for incarceration appears high, visual inspection of the data shows that this value is driven by one participant in the sample. After controlling for length of stay, the monthly rate of incarceration is 0.011, and the least frequent intervention. Descriptive information for the behavior response variables are included in Table 4.7.

TABLE 4.6*Means, Standard Deviations, and Ranges for Aggression Types*

Variable	<i>M</i>	<i>SD</i>	Range
Verbal Aggression			
Threatening Behavior	0.36	0.823	0-4
False Allegations	1.08	2.080	0-10
Subtotal	1.44	2.404	0-11
Aggression Towards Others			
Altercations	0.45	0.851	0-4
Assault	8.58	15.082	0-80
Behavioral Outbursts	7.88	13.137	0-58
Subtotal	16.9	25.781	0-108
Aggression Towards Self			
Self-Injurious Behaviors	3.03	6.978	0-37
Suicide/Suicidal Gestures	0.21	0.600	0-4
Substance Abuse	0.03	0.164	0-1
Subtotal	3.26	7.138	0-38
Aggression Towards Property			
Theft/Larceny	0.10	0.340	0-2
Property Destruction	5.22	11.728	0-77
Fire Setting	0.05	0.283	0-2
Subtotal	5.37	11.796	0-77
Elopement	1.01	2.781	0-21
Total Disruptive Behavior	27.99	38.95	0-161

Note. $N = 73$. Subtotals refers to the total number of incidents for that aggression category. Total Disruptive Behavior combines incidents from all aggression types.

TABLE 4.7*Means, Standard Deviations, and Ranges for Behavioral Response Variables*

Variable	M	SD	Range
Emergency Safety Physical Interventions	6.47	11.414	0-48
Police Contacts	3.36	4.523	0-19
Incarcerations	6.67	54.764	0-468
Inpatient Hospitalizations	0.89	2.052	0-14
Emergency Room Visits	2.63	3.138	0-16

Note. N = 73.

Total costs for study participants ranged from \$26,219.32 to \$1,315,890.85 ($M=458,266.00$, $SD=302,529.14$). After procedurally controlling for length of service, the average monthly cost per participant ranged from \$5,050.03 to \$48,743.34 ($M=\$21,236.66$, $SD=\$10,115.09$). In this study, residential costs emerged with the highest contributor to the total cost variable and ranged from \$21,055 to \$1,021,828 ($M=\$382,113.13$, $SD=254,622.36$) for the study period. Summary statistics are displayed in Table 4.8 for all participants, Table 4.9 for group home participants, and Table 4.10 for EFH program participants.

TABLE 4.8*Means, Standard Deviations, and Ranges for Cost Variables – Participant Cost Data*

Variable	Minimum	Maximum	<i>M</i>	<i>SD</i>
Medication Cost	\$176.08	\$124,827.83	\$19,209.49	\$25,817.04
Residential Treatment Cost	\$21,055.03	\$1,021,764.47	\$382,113.13	\$254,622.36
Room & Board	\$0.00	\$26,840.00	\$13,221.24	\$10,235.74
Physician Cost	\$0.00	\$34,854.00	\$8,095.40	\$6,811.12
Nursing Cost	\$0.00	\$5,482.94	\$1,268.91	\$1,195.07
Police Contact Cost	\$0.00	\$1,161.72	\$170.22	\$251.22
ER Cost	\$0.00	\$16,768.00	\$2,756.38	\$3,288.69
Vocational Service Costs	\$0.00	\$280,498.98	\$24,894.80	\$51,582.00
Nutrition Service Cost	\$0.00	\$200.00	\$11.78	\$42.41
Mental Health Service Cost	\$0.00	\$96,076.63	\$4,150.41	\$12,117.45
Property Destruction Cost	\$0.00	\$27,216.96	\$2,374.24	\$5,325.05
Total Costs	\$26,219.32	\$1,315,890.85	\$458,266.00	\$302,529.14
Average Monthly Cost	\$5,050.03	\$48,743.34	\$21,236.66	\$10,115.09

Note. $N = 73$. With the exception of Average Monthly Cost, statistical descriptions are based on raw data before any procedural control for length of stay.

TABLE 4.9*Means, Standard Deviations, and Ranges for Cost Variables - Group Home Participants*

Variable	Minimum	Maximum	<i>M</i>	<i>SD</i>
Medication Cost	\$292.34	\$124,827.83	\$17,714.08	\$27,506.58
Residential Treatment Cost	\$59,492.28	\$1,021,764.47	\$438,912.97	\$310,521.62
Room & Board	\$0.00	\$26,840.00	\$11,686.88	\$8,901.71
Physician Cost	\$1,110.00	\$23,310.00	\$6,941.77	\$5,067.27
Nursing Cost	\$95.03	\$4,827.27	\$1,386.27	\$1,299.68
Police Contact Cost	\$0.00	\$1,106.40	\$242.03	\$283.00
ER Cost	\$0.00	\$8,384.00	\$3,466.46	\$2,915.92
Vocational Service Costs	\$0.00	\$280,498.98	\$48,431.47	\$72,042.35
Nutrition Service Cost	\$0.00	\$200.00	\$21.54	\$56.83
Mental Health Service Cost	\$0.00	\$20,275.00	\$2,194.54	\$4,794.47
Property Destruction Cost	\$0.00	\$27,216.96	\$4,684.45	\$8,017.52
Total Costs	\$124,962.10	\$1,315,890.85	\$535,682.44	\$378,360.55
Average Monthly Cost	\$9,943.93	\$44,991.63	\$27,968.65	\$9,063.19

Note. $N = 26$. With the exception of Average Monthly Cost, statistical descriptions are based on raw data before any procedural control for length of stay.

TABLE 4.10*Means, Standard Deviations, and Ranges for Cost Variables - EFH Program Participants*

Variable	Minimum	Maximum	<i>M</i>	<i>SD</i>
Medication Cost	\$176.08	\$92,017.00	\$20,036.73	\$25,101.46
Residential Treatment Cost	\$21,055.03	\$764,432.05	\$350,692.95	\$215,036.25
Room & Board	\$0.00	\$26,840.00	\$14,070.03	\$10,902.12
Physician Cost	\$0.00	\$34,854.00	\$8,733.57	\$7,582.17
Nursing Cost	\$0.00	\$5,482.94	\$1,203.99	\$1,142.51
Police Contact Cost	\$0.00	\$1,161.72	\$130.50	\$225.23
ER Cost	\$0.00	\$16,768.00	\$2,363.57	\$3,444.55
Vocational Service Costs	\$0.00	\$145,206.48	\$11,874.52	\$29,283.83
Nutrition Service Cost	\$0.00	\$180.00	\$6.38	\$31.24
Mental Health Service Cost	\$0.00	\$96,076.63	\$5,232.38	\$14,627.84
Property Destruction Cost	\$0.00	\$11,365.00	\$1,096.25	\$2,182.44
Total Costs	\$26,219.32	\$992,687.53	\$415,439.89	\$245,338.01
Average Monthly Cost	\$5,050.03	\$48,743.34	\$17,512.58	\$8,701.58

Note. $N = 47$. With the exception of Average Monthly Cost, statistical descriptions are based on raw data before any procedural control for length of stay.

In addition to cost differences, other variations emerged between the two service programs in the study. Analyses of variance (ANOVAs) revealed several significant differences between participants served in group home and EFH settings. For instance, group home participants incurred higher costs, displayed higher rates of aggressive behaviors, and induced more caregiver strain than EFH participants. Interestingly, the

severity of behaviors, IQ, and adaptive functioning did not significantly differ between the programs (see Table 4.11). The data suggests participants in the EFH program display lower overall rates of aggressive behaviors while in care yet exhibit equally severe emotional and behavioral problems (across all subscales of the DBC), even slightly higher depressive and social relating subscale scores. Although the DBC measures aggressive behaviors, typically captured on the disruptive subscale, the DBC assesses the intensity of emotional (e.g., withdrawn, irritable, anxious, etc.) and behavioral problems (e.g., displays temper tantrums, eats nonfood items, inappropriate sexual activity, uncooperative, etc.), which may or may not relate to frequency rates. Therefore, the DBC scores represent an overall severity of emotional and behavior issues and a larger range of issues compared to the aggression rates. The remaining results are reported according to the research questions in order of hypothesis testing.

TABLE 4.11

Means, Standard Deviations, Ranges, and One-Way Analysis of Variance of Major Study Variables by Program

Variable	Program	Univariate Statistics			ANOVA	
		<i>M</i>	<i>SD</i>	Range	<i>F</i>	<i>p</i>
IQ	1	62.04	15.66	36-100	$F(1,71) = 1.837$.180
	2	56.89	15.46	20-93		
ICAP	1	48.30	21.00	4-90	$F(1,70) = .026$.873
	2	47.54	18.02	4-90		
Caregiver Strain	1	1.98	0.80	1-4	$F(1,70) = 4.144$.046*
	2	1.65	0.59	1-3.21		
DBC	1	63.68	27.05	21-126	$F(1,70) = .386$.536
	2	59.06	31.44	7-127		
DBC-D	1	23.64	9.74	7-42	$F(1,70) = .778$.381
	2	21.21	11.77	1-45		
DBC-C	1	11.88	6.83	3-27	$F(1,70) = .227$.635
	2	11.00	7.77	0-33		
DBC-SA	1	11.08	7.81	0-29	$F(1,70) = .252$.617
	2	10.09	8.12	0-30		
DBC-Dep	1	5.40	4.31	0-19	$F(1,70) = .153$.697
	2	5.81	4.17	1-19		
DBC-SR	1	4.52	3.83	0-14	$F(1,70) = .714$.401
	2	5.28	3.50	0-14		
Verbal Aggression	1	0.19	0.31	0-1.11	$F(1, 71) = 6.162$.015*
	2	0.06	0.13	0-.62		
Aggression Against Others	1	1.87	1.80	.03-8.51	$F(1, 71) = 45.597$.000**
	2	0.34	0.56	0-2.87		
Aggression Against Self	1	0.39	0.66	0-2.35	$F(1, 71) = 9.136$.003**
	2	0.09	0.19	0-.85		
Aggression Against Property	1	0.54	0.65	0-2.58	$F(1, 71) = 19.474$.000**
	2	0.11	0.19	0-.96		
COST	1	\$27,968.65	\$9,063.19	\$9,943.93- \$44,991.63	$F(1,71) = 23.470$.000**
	2	\$17,512.58	\$8,701.58	\$5,050.03- 48,743.34		

Note. Program 1 = Group home ($N=26$); Program 2 = EFH ($N=47$); Aggression type and cost statistics are calculated using the adjusted monthly figures opposed to raw data. IQ = Intelligence Quotient; ICAP = adaptive functioning; DBC = Developmental Behaviour Checklist; DBC-D = disruptive subscale; DBC-C = communication & anxiety subscale; DBC-SA = self-absorbed subscale; DBC-Dep = depressive subscale; DBC-SR = social relating subscale.

* = significant at $p < .05$; ** = significant at $p < .01$.

Hypothesis 1: A range of bivariate relationships with average monthly service expenditures is predicted to appear in the sample.

- a. *Individuals with lower IQs will be associated with significantly higher monthly service expenditures.*
- b. *Individuals with lower adaptive functioning indicated by lower scores on the ICAP will be associated with significantly higher monthly service expenditures.*
- c. *Higher caregiver/staff strain, measured by the Caregiver Strain Questionnaire, will be associated with significantly higher monthly service expenditures.*
- d. *Individuals with more severe behaviors, measured by higher full scale scores on the Developmental Behaviour Checklist (total score), will be associated with significantly higher monthly service expenditures.*
- e. *Individuals with higher rates of challenging behavior (aggregated frequency of all incidents including self-injurious behaviors, suicide, property destruction, altercations, assaults, theft/larcenies, behavioral outbursts, threatening behavior, false allegations, substance abuse, elopement, and fire setting) will be associated with significantly higher monthly service expenditures.*

Correlation analysis revealed several bivariate relationships with average monthly service expenditures. Higher caregiver strain, $r(72) = .278, p < .05$, higher rates of aggressive behaviors, $r_s(73) = .728, p < .001$, and more severe behaviors $r_s(72) = .314, p < .01$, were associated with significantly higher monthly service expenditures. Higher IQ scores, $r(73) = .222, p = .059$, were also associated with higher monthly service expenditures, but only marginally significant.

Adaptive functioning was not significantly correlated with monthly service expenditures, $r(73) = -.003, p = .983$. Therefore, results indicate partial support for the first hypothesis. As predicted, higher caregiver strain, higher rates of aggressive behaviors, and more severe behaviors were associated with higher service expenditures (see Table 4.12).

TABLE 4.12

Correlations with Cost

	COST	IQ	ICAP	CGSQ	DBC	Aggression
COST	–					
IQ	.222	–				
ICAP	-.003	.483**	–			
CGSQ	.278*	-.030	-.146	–		
DBC	.314**	-.216	-.367**	.563**	–	
Aggression	.728**	.028	-.109	.348**	.409**	–

Note. Spearman's rho correlation used for aggression rate comparisons. COST = average monthly service cost; IQ = Intelligence Quotient; ICAP = adaptive functioning; CGSQ = Caregiver Strain Questionnaire; DBC = Developmental Behaviour Checklist; Aggression = monthly rate of all aggression types aggregated.

* $p < .05$ ** $p < .01$

Since aggression rates included all four types of aggression, follow-up analyses were conducted to offer a more comprehensive picture of the relationship between aggression and cost. Results of the follow-up correlations are displayed in Table 4.13. Although all aggressive behavior types were significantly and positively correlated with cost, closer inspection revealed the strongest correlations were between cost and aggression against others $r_s(73) = .698, p < .001$, and aggression against property $r_s(73) =$

.586, $p < .001$. However, correlational analysis still shows substantial positive relationships with all the aggression types and behavioral severity. In addition, all four types of aggressive behaviors were positively correlated with each other, and the association between aggression against others and aggression against property was particularly strong, $r_s(73) = .750, p < .001$. High inter-correlations raise potential issues of collinearity for future analyses, so collinearity diagnostics such as variance inflation factors (VIF) and tolerance statistics will be examined for those analyses. Pearson's correlation and Kendall tau procedures yielded similar results.

TABLE 4.13

Correlations between Types of Aggressive Behavior and Cost

	COST	AggVA	AggAO	AggAS	AggAP	DBTotal
COST	–					
AggVA	.282*	–				
AggAO	.698**	.450**	–			
AggAS	.406**	.326**	.542**	–		
AggAP	.586**	.537**	.750**	.471**	–	
DBTotal	.728**	.532**	.941**	.667**	.822**	–

Note. $N = 73$. Spearman's rho used for all correlations. All variables were procedurally controlled by calculating monthly averages to account for length of stay. COST = monthly service costs; AggVA = Verbal Aggression; AggAO = Aggression Against Others; AggAS = Aggression Against Self; AggAP = Aggression Against Property; DBTotal = average monthly count of all disruptive behaviors.

* $p < .05$ ** $p < .01$

Hypothesis 2: Individuals who suffer from comorbid mental and physical health conditions will be associated with significantly higher average monthly service expenditures compared to those with only one or the other type of condition.

Since all participants in the sample experienced a mental health condition, comorbidity was defined as those with a physical health condition or without. A one-way ANOVA (comorbidity: with physical conditions, without physical conditions) revealed that the average monthly service cost difference was not statistically significant $F(1, 71) = .123, p = .73$ (see Table 4.14). Although individuals with comorbid mental and physical health conditions incurred higher average monthly service costs ($M = \$21,431.10, SD = \$9,536.64$) compared to individuals without comorbid physical health conditions ($M = \$20,339.24, SD = \$12,871.29$), the mean difference was not significantly different suggesting lack of support for the hypothesis.

A one-way ANOVA with individuals diagnosed with serious and persistent mental health comorbidity (SPMI and physical condition, no SPMI or physical condition) rendered similar non-significant results, $F(1, 71) = .907, p = .344$ (See Table 4.15). Conditions considered serious and persistent mental illnesses (SPMI) included Major Depression, Schizophrenia, Bipolar, and Borderline Personality Disorder. A post hoc sensitivity analysis indicated that the power to detect obtained effects at the .05 level was .06 for the first analysis and .16 for the second analysis with SPMI suggesting limited power may have influenced the non-significant results.

TABLE 4.14

Means, Standard Deviations, and One-Way Analysis of Variance in Comorbidity Level and Monthly Service Cost

Level of Comorbidity	<i>M</i>	<i>SD</i>	<i>N</i>	<i>F</i> (1, 71)	<i>p</i>
Comorbidity without PH	\$20,339.24	\$12,871.29	13	0.123	0.73
Comorbidity with PH	\$21,431.10	\$9,536.64	60		

Note. PH = physical health condition

TABLE 4.15

Means, Standard Deviations, and One-Way Analysis of Variance in SPMI Comorbidity Level and Monthly Service Cost

Level of Comorbidity	<i>M</i>	<i>SD</i>	<i>N</i>	<i>F</i> (1, 71)	<i>p</i>
Comorbidity without SPMI	\$19,923.22	\$12,136.35	31	0.907	0.344
Comorbidity with SPMI	\$22,206.10	\$8,344.72	42		

Note. SPMI = serious and persistent mental illness.

Hypothesis 3: Individuals with more severe forms of IDD (moderate, severe, and profound), as noted in the diagnosis or IQ scores, and comorbid physical health and serious mental illness will be associated with significantly higher average monthly service expenditures than those with less severe forms of IDD.

Due to small sample size and few participants in a few IDD severity categories, the analysis included collapsed categories of high (moderate, severe, and profound) and low (borderline and mild) IDD severity. Cost was submitted to a 2 (intellectual disability

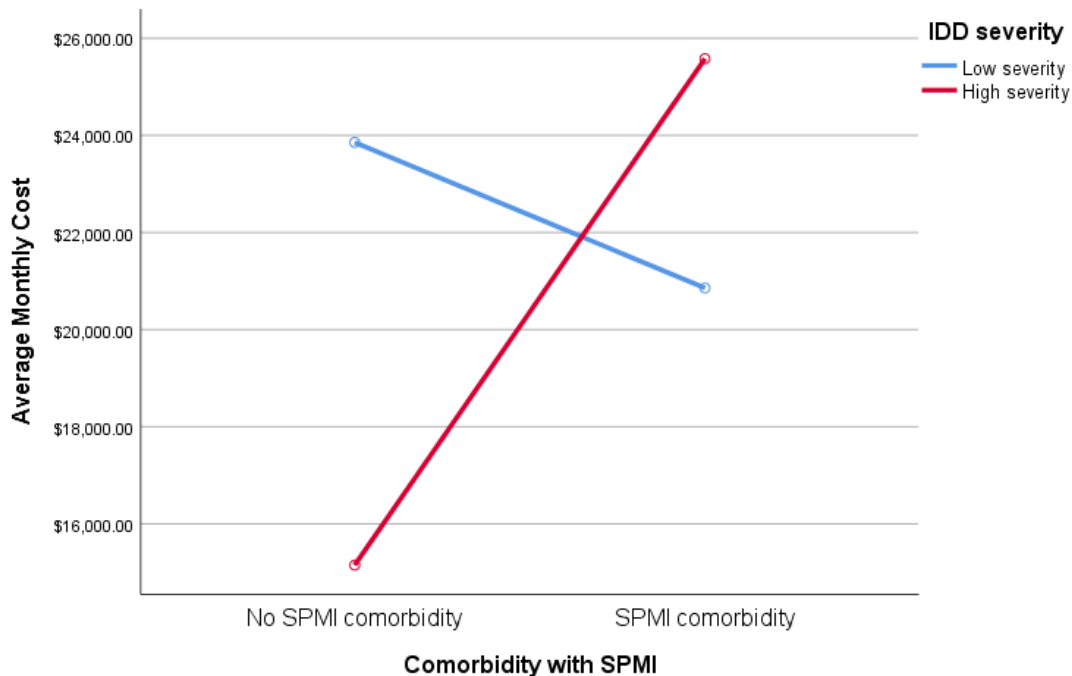
severity: high, low) x 2 (SPMI Comorbidity: with SPMI, without SPMI) between participants ANOVA. Neither the main effect for intellectual disability severity, $F(1, 69) = .683, p = .412$, nor SPMI comorbidity, $F(1,69) = 2.375, p = .128$, was significant. As hypothesized, however, individuals with higher rates of comorbidity and IDD severity incurred higher service costs. Specifically, there was a significant interaction between intellectual disability severity and SPMI comorbidity, $F(1, 69) = 7.754, p = .007$ emerged. Simple effects with least significant difference (LSD) follow-ups were used to interpret this interaction (see Table 4.16) and revealed that SPMI comorbidity resulted in higher average service expenditures only when intellectual disability severity was also high. Individuals with low comorbidity and/or those without SPMI, rendered higher average service expenditures when intellectual disability was also low. Costs are by far lowest when intellectual disability severity is high and SPMI is absent. Figure 4.1 offers a visual depiction of this interaction. A post hoc sensitivity analysis indicated that the power to detect obtained effects at the .05 level was .76 for the interaction analysis.

TABLE 4.16

Summary of Monthly Service Cost by SPMI Comorbidity and Intellectual Disability Severity

Comorbidity	ID Severity		
	Low	High	
Low	\$23,855.64 _a	\$15,148.14 _b	\$19,923.22
High	\$20,856.75 _a	\$25,579.46 _a	\$22,206.10
	\$21,941.46	\$19,962.59	

Note. Means with different subscripts differ at the $p < .05$ level, using least significant difference post hoc follow-up (minimum mean different = \$6,426.30).

**FIGURE 4.1**

Plot of Interaction Effect of IDD Severity and SPMI Comorbidity on Cost

Hypothesis 4: Individuals who display higher rates of aggression against others (rates of behavioral incidents including assault, altercations, and behavioral outbursts) will be positively associated with an array of behavioral response outcomes.

- a. *Individuals with higher rates of aggression against others will be associated with significantly higher rates of emergency safety physical interventions.*
- b. *Individuals with higher rates of aggression against others will be associated with significantly higher rates of police contacts.*
- c. *Individuals with higher rates of aggression against others will be associated with significantly higher rates of incarcerations.*
- d. *Individuals with higher rates of aggression against others will be associated with significantly higher rates of ER visits.*
- e. *Individuals with higher rates of aggression against others will be associated with significantly higher rates of psychiatric hospitalizations.*

Correlational analysis revealed several bivariate relationships with aggression against others and behavioral response outcomes. As hypothesized, individuals with higher rates of aggression against others also experienced significantly higher rates of emergency safety physical interventions, $r_s(73) = .786, p < .001$, police contacts, $r_s(73) = .575, p < .001$, emergency room visits, $r_s(73) = .601, p < .001$, and acute hospitalizations, $r_s(73) = .351, p = .002$. Contrary to hypothesis 4c, incarcerations were not associated with aggression against others, $r_s(73) = .122, p = .302$. However, a low monthly incidence rate of 0.011 may have influenced the results of this analysis.

Further inspection revealed several significant correlations between the behavioral response outcomes. For instance, higher rates of emergency safety personal interventions

(ESPIs) were positively correlated with higher rates of police contacts, $r_s(73) = .563, p < .001$, more hospitalizations, $r_s(73) = .363, p < .001$, and more emergency room visits, $r_s(73) = .588, p < .001$. Higher rates of emergency room visits were also associated with more police contacts, $r_s(73) = .755, p < .001$, and more hospitalizations, $r_s(73) = .602, p < .001$. Table 4.17 summarizes the correlational results.

TABLE 4.17

Correlations Between Aggression Against Others and Behavior Response Outcomes

	AggAO	ESPI	PC	IC	Hosp	ER
AggAO	–					
ESPI	.786**	–				
PC	.575**	.563**	–			
IC	.122	.150	.260*	–		
Hosp	.351**	.363**	.447**	.278**	–	
ER	.601**	.588**	.755**	.224	.602**	–

Note. $N = 73$. All variables were procedurally controlled by calculating monthly averages to account for length of stay. AggAO = aggression against others; ESPI = emergency safety physical intervention; PC = police contacts; IC = incarcerations; Hosp = acute hospitalizations; ER = emergency room visits.

* $p < .05$ ** $p < .01$

Hypothesis 5: Disruptive subscale scores on the Developmental Behaviour

Checklist (DBC), will significantly predict higher average monthly service expenditures than full scale scores.

Individuals with more severe disruptive behaviors, as measured by the DBC full scale, incurred significantly higher average monthly service expenditures, $r_s(72) = .314, p < .01$. More specifically, higher monthly service expenditures were significantly

associated with greater disruptive subscale scores, $r_s(72) = .412, p < .001$, and higher communication and anxiety subscale scores, $r_s(72) = .239, p < .05$ (see Table 4.18). While higher monthly service expenditures were significantly associated with more severe behaviors (DBC full-scale) and more severe disruptive behaviors (disruptive subscale), Steiger's Z test analysis suggested the correlations with cost were not significantly different from each other, $Z = -1.526, p = .127$. Therefore, contrary to hypothesized, the correlation between cost and the disruptive subscale was not stronger than the association between cost and the DBC full scale.

Follow-up analysis revealed significant correlations emerged between the full scale and each subscale ranging from .556 to .834, suggesting significant interrelationships. The substantial correlation between the full scale and disruptive subscale indicates potential multi-collinearity. Substantial positive correlations also appeared among the subscales, except between the disruptive and social relating subscales. These relationships are important to note in future multivariate analyses as multi-collinearity may impact analyses that examine individual contributions in multivariate models. Correlations are summarized in Table 4.18.

TABLE 4.18*Correlations Between Cost and Behavior Severity*

	COST	DBC	DBC-D	DBC-C	DBC-SA	DBC-Dep	DBC-SR
COST	–						
DBC	.314**	–					
DBC-D	.412**	.834**	–				
DBC-C	.239*	.779**	.505**	–			
DBC-SA	.186	.815**	.504**	.657**	–		
DBC-Dep	.088	.665**	.533**	.452**	.453**	–	
DBC-SR	-.110	.556**	.226	.426**	.573**	.313**	–

Note. $N = 72$. Spearman's rho used for all correlations. COST = average monthly service costs; DBC = Developmental Behavior Checklist total score; DBC-D = disruptive subscale; DBC-C = communication subscale; DBC-SA = self-absorbed subscale; DBC-Dep = depression subscale; DBC-SR = social relating subscale.

* $p < .05$ ** $p < .01$

Hypothesis 6: A range of bivariate relationships with caregiver strain, measured by the Caregiver Strain Questionnaire (CGSQ), is predicted to appear in the sample, including the following:

- a. *Caring for individuals with more severe forms of IDD will be associated with significantly higher caregiver strain when compared to individuals with less severe forms of IDD.*
- b. *Higher rates of mental health and physical health comorbidity will be associated with significantly higher caregiver strain when compared to those with no mental or physical health comorbidity and one or the other condition.*
- c. *Higher rates of aggression against others (rate of assaults, altercations, and behavioral outbursts) will be associated with significantly higher caregiver strain.*

- d. *Higher rates of aggression against self (rate of self-injurious behaviors and substance abuse) will be associated with significantly higher caregiver strain.*
- e. *Higher rates of verbal aggression (rate of threatening behavior and false allegations) will be associated with significantly higher caregiver strain.*
- f. *Higher rates of aggression against property (rate of theft/larceny, property destruction, and fire setting) will be associated with significantly higher caregiver strain.*
- g. *More severe behaviors, measured by higher scores on the DBC, will be associated with significantly higher caregiver strain.*

Correlation analysis revealed several bivariate relationships with caregiver strain.

As hypothesized, higher caregiver strain was associated with significantly higher rates of aggression against others, $r_s(72) = .419, p < .001$, aggression against self, $r_s(72) = .393, p < .001$, verbal aggression, $r_s(72) = .413, p < .001$, aggression against property, $r_s(72) = .526, p < .001$, and more severe behaviors based on DBC scores, $r_s(72) = .563, p < .001$. Table 4.19 summarizes the correlated comparisons. Contrary to hypothesis 6a, a one-way ANOVA with intellectually disability severity (high, low) revealed a non-significant association between caregiver strain and severity of intellectual disability, $F(1, 70) = 0.95, p = .758$. A one-way ANOVA with comorbidity (with physical conditions, without physical conditions) showed a non-significant relationship between caregiver strain and comorbidity, $F(1, 70) = .021, p = .886$, revealing lack of support for hypothesis 6b as well.

TABLE 4.19

Correlations between Types of Aggression, Behavior Severity, and Caregiver Strain

	CGSQ	AggAO	AggAS	AggVA	AggAP	DBC
CGSQ	–					
AggAO	.419**	–				
AggAS	.393**	.542**	–			
AggVA	.413**	.450**	.326**	–		
AggAP	.526**	.750**	.471**	.537**	–	
DBC	.563**	.401**	.216	.300*	.493**	–

Note. $N = 72$. CGSQ = Caregiver Strain Questionnaire; AggVA = Verbal Aggression; AggAO = Aggression Against Others; AggAS = Aggression Against Self; AggAP = Aggression Against Property; DBC = Developmental Behavior Checklist total score.

* $p < .05$ ** $p < .01$

Considering the significant correlations with aggression against others described in hypothesis 4, follow-up correlations were conducted comparing caregiver strain and the behavior response variables. Higher caregiver strain was associated with significantly higher monthly rates of emergency safety physical interventions, $r_s(71) = .390, p < .001$, police contacts $r_s(71) = .368, p < .001$, and emergency room visits $r_s(71) = .341, p < .001$. Table 4.20 summarizes the correlational comparisons.

TABLE 4.20

Correlations Between Caregiver Strain and Behavior Response Outcomes

	CGSQ	ESPI	PC	IC	Hosp	ER
CGSQ	–					
ESPI	.390**	–				
PC	.368**	.557**	–			
IC	.103	.083	.213	–		
Hosp	.174	.339**	.437**	.250*	–	
ER	.341**	.569**	.765**	.182	.589**	–

Note. $N = 71$. Behavior response variables were procedurally controlled by calculating monthly averages to account for length of stay. CGSQ = Caregiver Strain; ESPI = Emergency Safety Physical Intervention; PC = police contacts; IC = incarcerations; Hosp = acute hospitalizations; ER = emergency room visits.

* $p < .05$ ** $p < .01$

Hypothesis 7: The frequency of aggressive behaviors including verbal aggression, aggression against others, aggression against self, and aggression against property will significantly predict average monthly service expenditures, with aggression against others achieving the highest predictive value in the model.

Multiple Regression analysis examined the relationship between cost and each type of aggression. Examination of scatter plots, histograms, collinearity statistics, Durbin-Watson test results (1.472), and P-Plots suggests no violations to linear model assumptions.

Prior correlational analyses showed average monthly cost was positively correlated with the frequency of all four types of aggression. As hypothesized, results of the multiple regression analysis indicates that the model significantly predicted average

monthly service expenditures, $F(4, 68) = 11.975, p < .001$. The model accounted for approximately 41% of the variance in average monthly service expenditures ($R^2 = .413$, Adjusted $R^2 = .379$). The unstandardized regression coefficients (B), and standardized regression coefficients (β) are summarized for each variable in Table 4.21.

As illustrated Table 4.21, aggression against others and aggression against self predicted costs when controlling for the other types of aggression. As hypothesized, aggression against others emerged as the strongest predictor based on the standardized regression coefficient values. Interestingly, when controlling for other types of aggression, verbal aggression and property destruction were no longer significant. It appears that aggression against others and aggression against self are the strongest individual predictors of cost. A post hoc sensitivity analysis indicated that the power to detect obtained effects at the .05 level was .99 for the regression model, suggesting adequate power for the analysis.

TABLE 4.21

Regression Coefficients of Aggression Types on Cost

Variable	B	β	SE	t	p
Constant	15307.93		1295.67	11.82	.000
AggVA	2190.79	.015	16938.72	0.13	.897
AggAO	16269.22	.356	7419.48	2.19	.032*
AggAS	27694.30	.308	9082.76	3.05	.003**
AggAP	10031.91	.118	11797.80	0.85	.398

Note. $N = 72$. AggVA = verbal aggression; AggAO = aggression against others; AggAS = aggression against self; AggAP = aggression against property.

* $p < .05$ ** $p < .01$

Hypothesis 8: Aggression against others, verbal aggression, aggression against self, aggression against property, IQ, behavior severity (DBC total score), caregiver strain (CGSQ score), and adaptive functioning (ICAP score) will significantly predict average monthly service expenditures better than existing rate structures that only include adaptive functioning and IQ.

Multiple Regression analysis was conducted to examine the relationship between cost and aggression type, behavior severity, caregiver strain, gender, IQ, and adaptive functioning between two models. Examination of scatter plots, histograms, collinearity statistics, Durbin-Watson test results (1.369), and P-Plots suggested no violations to linear model assumptions.

Existing rate models primarily utilize IQ and adaptive functioning to develop residential reimbursement rates. Therefore, the first model included IQ, adaptive functioning, and service program (for control) as predictors of cost. Results indicated that the model significantly predicted average monthly service expenditures, $F(3, 68) = 8.741, p < .001$. The model accounted for approximately 28% of the variance in average monthly service expenditures ($R^2 = .278$, Adjusted $R^2 = .246$). Interestingly, adaptive functioning did not predict cost, and IQ only marginally predicted cost. Only service program predicted cost. These effects mirror the (lack of significant) results that emerged between adaptive functioning and IQ and cost at the bivariate level. These results suggest that the variables that are used to determine costs in existing models are inadequate--an issue I return to in the discussion.

When the four types of aggression, caregiver strain, and behavior severity (DBC) were also added to the model, the model significantly predicted average monthly service

expenditures, $F(9, 62) = 6.209, p < .001$. The model accounted for approximately 47% of the variance in average monthly service expenditures ($R^2 = .474$, Adjusted $R^2 = .398$). Only aggression against self significantly predicted cost in the full model. Interestingly, service program no longer predicted cost in the larger model.

As hypothesized, comparison of the nested model with the full model using the R^2 change F-test, revealed that the full model performed better than the nested model, R^2 change = .196, F -change (6, 62) = 3.845, $p = .003$. The unstandardized regression coefficients (B) and standardized regression coefficients (β) are summarized for each variable along with model comparison in Table 4.22. Examination of collinearity diagnostics for all the models suggests that the collinearity concerns were not significant enough to invalidate the models, since variance inflation factor (VIF) values fell well below 10, and the tolerance statistics remained well above .2 (Field, 2013). A post hoc power analysis indicated that the power to detect obtained effects at the .05 level was .99 for both regression models, suggesting adequate power for the analyses.

TABLE 4.22

Regression Coefficients of Aggression Types, Behavior Severity, Caregiver Strain, and Adaptive Functioning on Cost

Variable	Correlation with Cost	Model 1				Model 2			
		<i>B</i>	β	<i>SE</i>	<i>p</i>	<i>B</i>	β	<i>SE</i>	<i>p</i>
Constant		22722.63		4590.78	.000	11808.30		5958.85	.052
IQ	.222	129.47	.200	77.35	.099	106.30	.164	77.32	.174
ICAP	-.003	-57.70	-.108	62.91	.362	11.63	.022	69.96	.869
Program	-.446**	-9833.41	-.469	2193.80	.000**	-3693.66	-.176	2654.60	.169
DBC	.314**					49.90	.147	39.75	.214
CGSQ	.278*					-1613.73	-.109	1874.95	.393
AggVA	.282*					7616.97	.053	18.329.63	.679
AggAO	.698**					11501.80	.252	8805.40	.196
AggAS	.406**					27869.11	.310	9286.02	.004**
AggAP	.586**					6155.04	.720	13339.74	.646
<i>R</i> ²		.278				.474			
ΔR^2						.196			

Note. *N* = 72. IQ = Intelligence Quotient; ICAP = adaptive functioning; DBC = Developmental Behaviour Checklist; CGSQ = caregiver strain questionnaire; AggVA = verbal aggression; AggAO = aggression against others; AggAS = aggression against self; AggAP = aggression against property. Model 1 included IQ, ICAP, and service program. Model 2 included additional predictor variables.

* *p* < .05 ** *p* < .01

Hypothesis 9: Aggression against others and aggression against property will directly predict average monthly service expenditures, but will also indirectly influence service expenditures by significantly increasing caregiver strain.

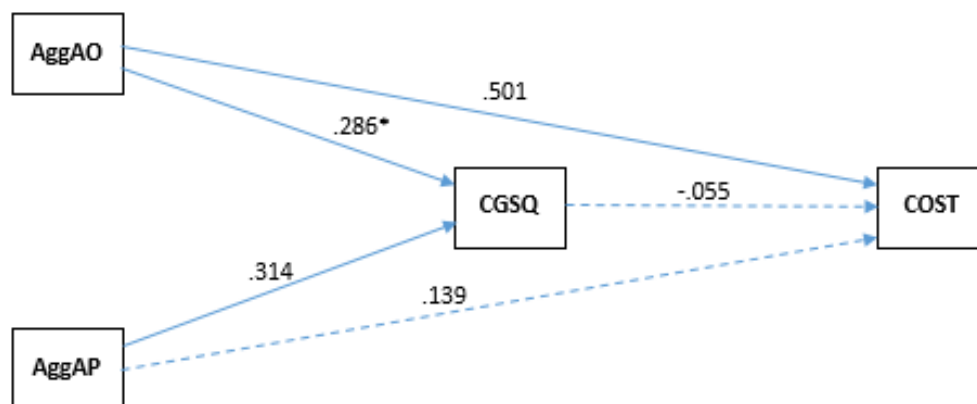
A series of regression analyses were conducted to test the direct relationship between aggression against others and aggression against property on cost, as well as the

indirect relationship between both types of aggression through caregiver strain on cost. Following Baron and Kenny's (1986) approach, the first analysis included aggression against others and aggression against property predicting caregiver strain. The second analysis included aggression against others, property destruction, and caregiver strain predicting cost. The unstandardized regression coefficients (B) and standardized regression coefficients (β) are summarized for each variable in Table 4.23. Although aggression against others directly predicted cost ($\beta = .501, p < .05$), the indirect pathway from aggression against others through caregiver strain was not significant based on analysis of the Sobel test statistic ($-.451, p = .326$). In addition, the indirect pathway from aggression against property through caregiver strain was also not significant based on the Sobel test statistic ($-.454, p = .325$). Contrary to the hypothesis and despite a significant correlation, path analyses revealed that aggression against others and aggression against property indirectly predicted average monthly service expenditures through caregiver strain (see Figure 4.2).

TABLE 4.23*Summary of Path Analysis Regression Coefficients*

Variable	<i>B</i>	<i>SE</i>	β	<i>p</i>
Step 1				
AggAO	.877	.458	.286	.060
AggAP	1.801	.857	.314	.039
Step 2				
AggAO	22756.34	6882.58	.501	.002
AggAP	11770.65	12933.65	.139	.366
CGSQ	-817.84	1761.28	-.055	.644

Note. AggAO = aggression against others; AggAP = aggression against property; CGSQ = caregiver strain questionnaire.



Note. Reported standardized coefficients for each path. Dashed lines indicate non-significant pathways. Solid lines indicate significant paths at $p < .05$ unless otherwise noted. AggAO = Aggression Against Others; AggAP = Aggression Against Property; CGSQ = Caregiver Strain Questionnaire; COST = average monthly service costs.

* Marginally significant, $p = .06$.

FIGURE 4.2

Path Analysis Model of Associations between Caregiver Strain and Average Monthly Service Expenditures

CHAPTER 5

DISCUSSION

As state agencies and managed care organizations accept the responsibility of expanding their scope of management across chronic populations, they must continue to analyze the complex populations they serve to achieve efficient models of healthcare while preserving or improving quality care. Individuals with IDD represent a unique and diverse group that experiences high rates of comorbid physical and mental health conditions and exhibit a range of behaviors, yet remain one of the most vulnerable populations due to cognitive limitations. However, historic service reimbursement structures, those where payments come from multiple state and federal funding sources across multiple providers, complicate researchers' ability to fully explore the economic impact of this population.

As healthcare costs continue to rise and reform efforts become imminent, it is important that vulnerable populations continue to receive the services they need without arbitrary limitations. Therefore, policy makers must develop a better way to efficiently predict and manage the costs associated with the care for individuals with IDD. The intent of the present study was to examine various factors that influence caregiver strain and the cost of caring for individuals with IDD, specifically focusing on complexity factors such as functional ability, comorbidity and challenging, aggressive behaviors.

Factors Related to Cost

As prior research (Knapp et al., 2005; Einfeld et al., 2010) discovered higher costs were associated with greater levels of challenging behavior, the present study examined challenging behavior in more detail by exploring frequency, type, and severity of those

behaviors. Correlation analyses revealed several significant relationships with monthly service costs, showing partial support for hypothesis 1. Of particular interest, the presence, frequency, and severity of challenging behaviors were all significantly associated with higher monthly service costs. More specifically, higher rates of verbal aggression, aggression against others, aggression against self, and aggression against property related to higher monthly service costs. The bivariate relationship with aggression against others and aggression against property were particularly strong.

In addition to more frequent problem behaviors, increasingly severe behaviors, indicated through DBC full-scale and subscale scores, particularly more serious disruptive and communication and anxiety behaviors, positively correlated with monthly service cost. When examined more closely as a whole, the behavioral associations portray a clearer, more consistent picture. More frequent and more severe behaviors, predominantly aggressive behaviors as well as those related to mental health symptomology (i.e., delusions, hallucinations, obsessive behaviors) significantly related to higher monthly service costs.

In addition to actual cost figures, various cost proxies also showed positive relationships with rates of aggression. Individuals who displayed higher rates of aggression against others also experienced significantly higher rates of emergency safety physical interventions, police contacts, emergency room visits, and acute hospitalizations, revealing partial support for hypothesis 4. Although the relationship with incarcerations was not significant, a low incident rate likely impacted the outcome of the analysis. Each of these interventions translate to a higher burden on public health resources. For

instance, inpatient hospitalizations remain the most costly physical and mental health intervention (de Oliveira et al., 2016).

The implications for these findings suggest that these more challenging individuals likely require more staff, differentially experienced clinicians, enhanced clinical oversight, increased supervision and monitoring, and specialized interventions. All of these requirements translate into higher direct costs. For instance, behaviors that result in emergency safety physical interventions require physical management of unsafe behaviors through additional staffing, supplementary staff training, additional contact and coordination with law enforcement, and collaboration and transportation to the hospital.

Examination of participant demographic characteristics, adaptive functioning scores, and IQ demonstrated no significant bivariate relationship with cost (IQ marginally significant). However, the relationship with comorbidity and cost appears a little more complex. A nonlinear relationship emerges with comorbidity, but only when comorbidity includes SPMI conditions and for individuals with more severe forms of intellectual disability (hypothesis 2 and 3). Showing support of hypothesis 3, an analysis of variance test revealed a significant interaction such that when IDD severity is high (moderate, severe, or profound) and the individual has higher rates of comorbidity with physical health and SPMI, they incur the highest average monthly cost. When IDD severity is low (borderline or mild) and comorbidity is low (no SPMI diagnosis), higher monthly costs emerged. In other words, comorbidity impacts cost when IDD severity is high, whereas comorbidity is less influential on cost when individuals have low IDD severity.

Considering all of the obstacles related to caring for individuals with IDD, complex mental health conditions combined with severe cognitive limitations generates a complicated situation for caregivers. To manage individuals with poorly regulated mental health symptoms stemming from SPMI conditions in addition to physical health conditions, staff members must have specialized education and training in mental health and some health literacy to navigate specialized physical health services. Clinical supervisors managing direct staff and developing care plans must possess specialized knowledge of mental health symptomology, comorbidity, and interventions but also characteristics and treatment options for individuals with IDD. Interventions appropriate for managing mental health symptoms require alterations to accommodate individuals with cognitive deficits, such as a higher frequency of interventions, longer intervention sessions, and modifications to the intervention strategies (e.g., use of pictures).

Prior research, predominantly conducted with non-disabled individuals, indicated a linear relationship with comorbidity and cost (Barnett et al., 2012; Lehnert et al., 2015). Although the present study did not find similar results (hypothesis 2), the study expands the literature by enhancing our understanding of the influence of comorbidity. Interpreting the effects of comorbidity must include a thorough understanding of the individual components of each condition contributing to the comorbid diagnoses. The presence and severity of IDD and SPMI conditions differentially influence cost when compared to individuals with other comorbid conditions.

Cost Model Structures

The primary goal of this study was to develop a better understanding of factors influencing cost with the ultimate objective of developing a predictive cost model.

Although other studies show that challenging behaviors, comorbidity, and severity of intellectual disability relate to higher costs (Einfeld et al., 2010; McGill & Poynter, 2012; Unwin et al., 2017), no studies examine whether certain behaviors drive costs or develop a cost model to predict cost trends.

As previously stated, correlational analyses showed that average monthly cost was positively and significantly correlated with all four aggression types, caregiver strain, and behavior severity (DBC). A series of regression analyses in the present study extended existing literature by assessing the relationship between specific aggressive behaviors and generating a more robust cost model. The first model consisted of examining average monthly cost with rates of the four aggression types. Providing support for hypothesis 7, the model significantly predicted average monthly cost, and aggression against others and aggression against self individually contributed to the model after controlling for the other types of aggression.

The second model examined rate methodologies currently utilized in Nebraska, which are primarily driven by IQ and adaptive functioning, measured through the ICAP assessment. The model accounted for approximately 28% of the variance in average service cost, but service program (EFH vs. group home) emerged as the only significant individual contributor to the model when controlling for the other variables in the model. IQ marginally contributed to the model and adaptive functioning did not contribute to the model.

Although NDHHS sets residential rates primarily through ICAP results, which would be captured in the residential costs, a few conditions are important to note. First, the cost variable in this study includes residential service reimbursement but it also

includes other public health costs to generate a more comprehensive measure of direct costs (e.g., police, physician, nursing, ER visits, medications, etc.). Second, agencies can apply for exception funding, which are extra residential funds for additional support (i.e., to cover higher staffing ratio or supervision needs). Although this model significantly predicted monthly service cost, this researcher believes a model that accounts for specialized needs, for example comorbidity and aggression (frequency and severity), predicts agency cost better, which is captured in the final model.

The final model combined the first two multivariate models and incorporated behavior severity and caregiver strain. The researcher excluded comorbidity from the regression models due to limited variability in the sample (e.g., high prevalence among participants) and non-linear relationship noted in previous analyses with ID severity. The model successfully predicted services cost. However, despite several significant bivariate correlations, many variables did not individually contribute to the multivariate model. Since behavior severity, caregiver strain, verbal aggression, aggression against others, and aggression against property shared significant bivariate relationships with cost but lacked significant contribution to the multivariate model, multi-collinearity may affect individual model contribution. However, closer examination of collinearity diagnostics suggests that collinearity concerns are not significant enough to invalidate the model (Field, 2013).

Further complicating the model, caregiver strain creates an interesting effect. Although not significantly contributing to the model independently, caregiver strain has a negative regression weight in the model (opposite sign from its correlation with the

criterion), indicating that after accounting for all the other variables, participants with lower [staff] caregiver strain predicted have higher monthly service costs.

When comparing the second and third multiple regression models, the final model performed much better than the nested model, consistent with hypothesis 8. These results suggest that although existing rate models in the state successfully predict cost, those models cannot account for 72% of the variation in cost. In other words, existing rate methodologies appear inefficient or inadequately account for challenging behaviors. Models that incorporate challenging behaviors, particularly more frequent aggressive and severe behaviors, predict costs better at least for specialized populations tested in the present study such as those with complex mental health and physical health conditions.

Comorbidity and aggression clearly capture only a portion of factors driving costs. Other factors such as the type of physical health condition will likely impact service and public health costs. For instance, conditions such as heart disease, cancer, and diabetes have much higher health costs compared to less severe or acute conditions (Kockaya & Wertimer, 2010). Similarly, pharmaceutical costs contribute to lifetime disease cost estimates of chronic conditions. Research also suggests that characteristics such as verbal communication skills (Unwin et al., 2017), older age (Strydom et al., 2010), and the presence of additional disabilities such as hearing and vision problems (Harrington & Kang, 2016) impact cost.

Considered together, these results lead to significant social and policy implications. Comorbidity and challenging behaviors, both in frequency and severity, should be considered when developing rate methodologies and policies towards staff development. Better rate models direct funds to individuals who need services the most

and improve economic predictability and future forecasting options for funders. Many of these individuals, such those in the present study, already receive services and funding through exception processes, but this process is unpredictable and inconsistent. The criteria is subjective and lacks the objective methodology of traditional approaches used for the general population receiving LTSS. Instead, new policies should direct better assessment of individual needs at intake that include identification of mental, physical, and behavioral health issues, and then set appropriate funding rates based on that objective assessment process. Policymakers leading rate development initiatives must thoroughly understand the population and service challenges to recognize the factors impeding successful care.

Poorly managed mental and behavioral health conditions increase strain on providers and other caregivers. However, a better understanding of the population also provides opportunities to adjust subsequent policies to combat existing challenges. For instance, if research shows high rates of comorbidity and challenging behaviors, staff training should include those factors to best prepare those individuals for caregiving tasks.

Unfortunately, adjusting rate structures require delicate transitions and careful consideration of the entire system. According to systems theory, reality is socially constructed, and changing one part of a system may affect other parts or the whole system. Furthermore, each entity within a system responds to different motivating factors (Luhmann, 1996), but may share some systemic goals. Although not the sole factor, economic incentives clearly influence motivation (Friedland & Cole, 2019), and subsequent behavior (Hoff & Stiglitz, 2016). Adding additional criteria to rate models,

such as frequent and severe aggression, can inadvertently reinforce providers over-reporting aggressive behaviors or incentivize poor management of behaviors to maintain funding or promote higher funding. Providers experience conflicting motivation if funding is tied to factors somewhat under their control, like reporting certain behaviors (or lack of behaviors). Therefore, initial cost-setting procedures should account for prior acts of aggression through an independent assessment, whereas ongoing cost determinations could use objective emotional/behavioral severity assessments like the DBC to direct funds and promote desired outcomes. In addition, instead of incentivizing shorter treatment durations like traditional value-based contracts, states could fiscally incentivize providers to reduce costly consumer behaviors, such as aggression.

Another factor to consider in order to maintain homeostasis in the state funding systems, those that regulate LTSS, while facilitating significant change is how to ensure funding is simply not redirected from one individual to the next. Although states use rate methods to control costs, incorporating assessment techniques to better identify consumer needs also reduces inefficient use of funds such as duplicated services, extended care episodes, and inefficient care coordination. If the state utilized assessment results to purposefully match providers/caregivers, develop training and policies to support those needs, they will strategically direct funds towards necessary services instead of redirecting funds from one individual to the next.

Finally, incorporation of these changes should be communicated with and integrated between the systems. System integration continues to be a significant aspect of systemic evolution (Luhmann, 1996). To achieve system change or cross-system change, collaboration must occur within and between systems (Hodges et al., 2012).

Representatives from the healthcare, education, LTSS, and legal system should be involved in discussions to integrate care improvements as each system has its own role in reducing unnecessary costs and improving care. These collaborations allow for alignment of shared goals and identification of individual and systemic action steps.

Caregiver Strain and Impacts

Despite successful explanation of variance in monthly service costs, the relationship between caregiver strain and cost remains less obvious, and significant bivariate relationships with caregiver strain and other study variables add a layer of complexity when conceptualizing overall cost. Correlational analyses revealed that higher levels of caregiver strain were not associated with demographic characteristics (age, gender), adaptive functioning, comorbidity, IQ and ID severity, but more frequent (all types of aggression) and severe aggressive behaviors related to higher caregiver strain, providing partial support for hypothesis 6. These results help pinpoint that client behaviors are driving caregiver strain, which is important when considering the relationship between caregiver strain and cost.

Although bivariate analysis of caregiver strain and cost uncovered a modest linear relationship, non-significant results from regression and path analyses in the present study (i.e., individual contribution of caregiver strain in the regression analysis in hypothesis 8; non-significant indirect pathway from aggression against others and aggression against property through caregiver strain in hypothesis 9) imply that the relationship with caregiver strain and cost is not clearly explained in the study, yet it shares overlapping relationships with several variables. One must consider the following explanations: 1) either subjective or objective strain is related to cost, 2) caregiver strain

and cost share a weaker linear relationship or a curvilinear relationship, 3) caregiver strain is not captured in the way cost is operationalized in the current study, or 4) the types of aggression and behavior severity are differentially related to cost and caregiver strain.

Unfortunately, data for the objective and subjective strain subscales of caregiver strain were unavailable in this study, which may have offered a reasonable explanation for the relationship. Emerging research with child populations suggests a relationship between caregiver strain and cost (Zhao et al., 2019), where higher objective strain was more predictive of higher costs, whereas subjective strain was associated with lower costs (Brennan et al., 2003). Analyzing the relationship between objective and subjective strain may have offered a clearer understanding of the role of caregiver strain in the present study.

Another explanation for results in the current study emerges after unbundling the methodology and components of the cost variable. Average monthly service expenditures were composed of actual incurred costs of care from a direct service model with exception of a few public health cost estimates (e.g., police, physician, ER costs). Despite clear strengths for these methodological decisions, unfortunately, this type of model minimizes the potential impact of indirect costs. Not only are indirect costs difficult to measure, my understanding of per diem reimbursement models utilized by most funders is that reimbursement for direct services assumes coverage of some indirect costs. In other words, most funders only reimburse for direct care through per diem reimbursement and do not cover costs such as hiring, training, and retraining staff to perform the direct care (but account for a portion of those costs in the rate structure).

Furthermore, agencies may incorporate those costs into rate development when they input into the rate setting process.

Unfortunately, as previously stated, labor studies propose that the direct service workforce who care for individuals with IDD experience serious challenges (Test et al., 2003), arguably higher than many other professions. Accumulation of this information leads one to assume that current rates structures, even those that account for some indirect costs, would not adequately cover all the costs for these individuals. Therefore, these indirect costs likely remain under-represented in the present study cost variable as well as existing rates.

Workforce issues such as high turnover and vacancy rates along with difficulties recruiting and keeping direct support staff, place a higher burden on direct service professionals. These added stressors lead to emotional problems, lower job satisfaction, reduced staff morale, and affects service quality (Test et al., 2003). Agencies serving individuals with more intensive needs encounter even higher turnover (Hewitt et al., 2008). Several studies suggest that working with challenging behavior over time leads to negative emotional responses and eventually burnout (Hastings, 2002; Mitchell & Hastings, 2001; Rose et al., 2004).

Considering the relationship with caregiver strain and workforce challenges, the present study expands existing literature by identifying a better understanding of the relationship between caregiver strain and cost. Although previously discussed research shows caregiver strain influences cost, results from the present study highlights that the relationship likely emerges through indirect costs, not captured in existing rate structures or the cost variable in this study. Indirect costs include the financial impact of reduced

job efficacy (Zhao et al., 2019), but also existing workforce issues of recruiting, hiring, retaining, and training new direct care workers.

Lastly, the various types of behaviors differentially influence caregiver strain and cost. According to the proposed conceptual model (see Figure 5.1), aggression against others and aggression against self primarily predict cost (direct costs), whereas behavior severity, verbal aggression, and aggression against property primarily predict caregiver strain (indirect costs), despite significant overlap and interrelationships between the behavioral variables. Aggression against others and aggression against self often require additional staffing to maintain safety, which should be captured in the cost variable of the current study. Individuals who display aggression against others also require increased staff interventions such as emergency safety physical interventions, police contacts, hospitalizations, and emergency room visits to maintain immediate safety. However, aggression against self, which includes suicidal gestures or actions, typically occurs in isolation. Once identified, the caregiver exerts considerable energy attempting to determine the contextual factors related to the self-injurious behavior. Although management of this type of behavior may not require additional staff, it would require additional staff training, often lacking in agencies not specializing in mental health care.

Management of both situations may contribute to increases in caregiver strain, but they also contribute to increased direct costs, clearly captured in the cost variable in the study. Contrarily, the pathway from verbal aggression and aggression against property becomes more predictive of caregiver strain, but less individually represented in the direct costs analyzed. Caregivers rarely receive training to manage aggression against

property, yet often experience the financial strain associated with replacing damaged items or the burden of arranging repairs.

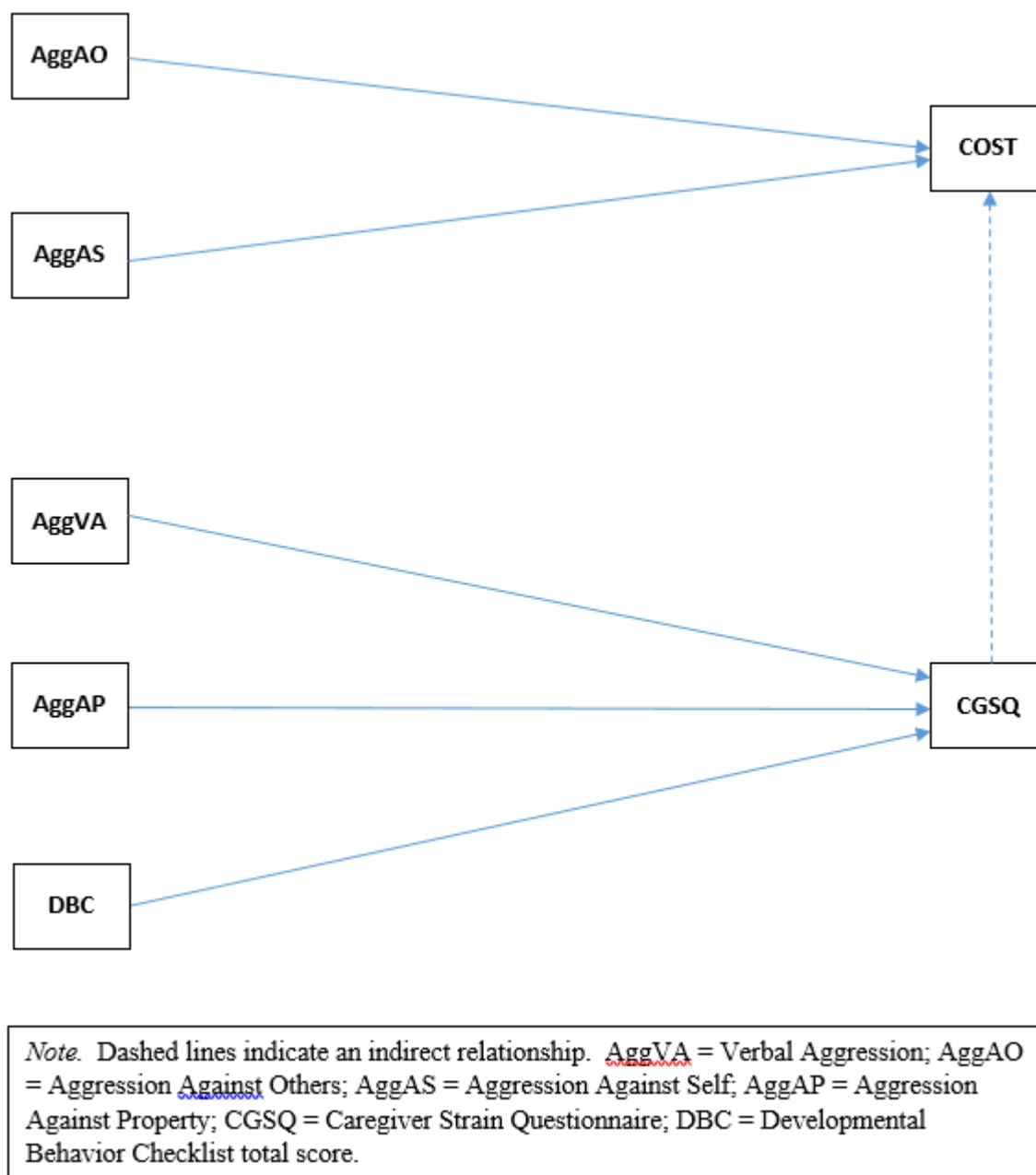


FIGURE 5.1

Conceptual Model of Associations between Caregiver Strain and Average Monthly Service Expenditures

Classic notions of attribution theory offer further explanation of this relationship. Attribution theory posits that individuals seek to explain behavior by attributing a cause. Based on that attribution, individuals develop attitudes and beliefs about the person and/or situation, which subsequently shape their behavioral and emotional responses, such as perceived caregiver strain. Although individuals with multiple problems could lead to more negative attributions, the amount of control over the cause influences perceptions of responsibility (Wiener, 1995; Williams et al., 2015). One study examining staff attributions of individuals with profound intellectual and multiple disabilities found that staff members tend to attribute challenging behaviors to biomedical causes (Poppes et al., 2015). Other studies examining challenging behavior from individuals with ID suggest that when individuals perceive external causes of challenging behavior, they respond with a more positive affect and engage in helping behavior (Dagnan & Cairns, 2005; Dagnan et al., 1998; Hill & Dagnan, 2002; McGuinness & Dagnan, 2001; Stanley & Standen, 2000). However, a systematic review revealed inconsistent outcomes associated with notions of control and helping behavior (Willner & Smith, 2008).

The present study offers guidance to clarify the previously conflicting literature because the results suggest that the certain types of challenging behaviors, in this case, different types of aggression, differentially affect caregivers. Although caregiver attributions were not explicitly measured in the study, the various types of aggression elicited different amounts of strain, which account for emotional strain. By applying attributional theory, one may assume that the different types of behaviors induce varying perceptions of attributional causes and subsequent level of control. For instance, higher rates of comorbidity may influence staff attributions towards biomedical causes (client

less responsible for behavior) for particular types of challenging behavior (e.g. aggression against others and aggression against self), reducing the perceived strain. Contrarily, staff may internalize verbal aggression directed towards that caregiver, which may stimulate negative emotions and ultimately increase perceived strain. In addition to the aforementioned discussion of indirect costs, consideration of attributional influences demonstrates that caregiver strain plays a very complex role in explaining variations in cost and impacts service quality for individuals with IDD.

Impact of Programming and Setting

Finally, service program plays a critical role in this study as it represented two distinct care settings between participants and influenced relationships with several variables in the study. For instance, results show significant mean differences in caregiver strain, cost, and all aggression rates such that group home participants incur higher costs, display higher rates of aggressive behaviors, and induce more caregiver strain. Interestingly, the severity of behaviors, IQ, and adaptive functioning do not significantly differ between the programs. The data suggests participants in the EFH program display lower overall rates of aggressive behaviors while in care, yet exhibit equally severe behaviors (across all subscales of the DBC), even slightly higher depressive and social relating subscale scores. Considered together, the data provides compelling support for setting effects.

Although largely unexamined in adult populations, conduct disorder literature suggests congregate care yields poorer outcomes among adolescent populations. In particular, peer contagion through deviancy training amplifies problem behaviors such as violence and sexual promiscuity (Dishion, 2000; Dishion & Tipsord, 2011, Dishion, et

al., 2010). Peer contagion refers to a mutual influence that occurs between an individual and a peer where each party inadvertently influences the other. Similarly, deviance training characterizes the process when the mutual influence unconsciously reinforces and subsequently increases the deviant behavior. However, some studies show that self-regulation moderates the effects of peer deviance (Gardner et al., 2008). Sijtsema et al. (2010) found evidence of a peer contagion influence for various types and functions of aggression (e.g., instrumental, reactive, and relational aggression). Furthermore, evidence of peer contagion becomes particularly problematic in group homes settings because individuals placed in those environments are vulnerable to the effects of peer contagion and the effects counteract intended progress and treatment outcomes (Gifford-Smith et al., 2005; Robst et al., 2011; Sekol, 2013). Placing several individuals with deviant behavior together creates an environment rich for reinforcing existing maladaptive behavior and teaching additional deviancy.

However, the literature suggests that the social influence of peers becomes less critical in adulthood (Gardner & Steinberg, 2005) and aggression decreases and becomes less overt and reactive as adolescents get older (Tremblay, 2000) likely because adolescents become more cognitively sophisticated, improve self-regulation, and prefer reduced detection. Unfortunately, adults with IDD lack the cognitive sophistication that may facilitate the developmental pathways that promote reduced peer influence and decline in aggressive responses. Furthermore, an analysis of qualitative studies show that individuals with IDD attribute peer behaviors and staff attitudes and reactions as factors influencing aggressive and challenging behaviors (van der Bogaard et al., 2019).

In the present study, individuals residing in the group home setting displayed higher rates of all four types of aggression, and caregivers experienced more strain. If applied to the literature on peer contagion, group home settings may serve as an environment conducive to deviancy training. In addition, considering lower levels of self-regulation among individuals with IDD and a higher desire for social acceptance compared to peers without IDD (Nader-Grosbois, 2014), one may assume that cognitive limitations impede sophisticatedly planned behavioral responses, so these individuals maintain a reactive aggressive response. Therefore, results of the present study suggest that adults with IDD, who have cognitive impairments, may differentially respond to peer actions, remain susceptible to peer contagion and deviancy training, and maintain physically aggressive behaviors into adulthood when exposed to others with similar behaviors.

For example, consider the following situation. Two individuals with IDD reside in a group home. One individual frequently displays aggressive behaviors, oftentimes resulting in “hands-on” staff interventions such as an ESPI. Staff exert considerable time, energy, and attention into managing that individual while unintentionally reducing attention to the other individual in the home. The second individual then begins to exhibit similar behaviors, mimicking his/her peer (social learning) and seeking social acceptance and attention. In response, staff increase attention towards that individual to manage the behavior and inadvertently reinforce the aggression with the second individual. The cycle continues between the two individuals, resulting in increased frequency of aggressive behaviors, potentially increasing the severity of aggressive behaviors, and amplifying strain on staff caring for both individuals.

In contrast to the group home setting, individuals served in the EFH setting oftentimes live with non-disabled peers and caregivers. If other individuals in the home also receive services, individualized programming leads to fewer interactions among the service recipients and fewer opportunities for peer contagion or deviancy training. Despite consistent acuity based on similar behavioral severity, IQ, and adaptive functioning scores, individuals served in EFH settings displayed fewer aggressive behaviors and induced less strain on their caregivers while receiving services at over \$10,000 per month cost saving compared to their counterparts served in group home settings. The annual cost savings amount to \$5,640,000 just for the 47 EFH participants in the present study. Services rendered in EFH settings appear more cost effective and result in better outcomes such as fewer aggressive behaviors.

Statistical differences between the programs lead to a closer examination of program structures. Although programmatically similar in regards to rehabilitative treatment, supervision levels can differ between programs. For example, individuals living in group home settings receive staff supervision 24 hours per day with awake staff throughout the night. Although individuals in the EFH program receive similar supervision throughout the day, they do not receive awake caregivers or staff overnight. The nature of increased supervision enhances the opportunity to “catch” individuals engaging in negative behaviors, which may explain the increased frequency of aggressive behaviors for participants residing in a group home. Individuals in group home settings may also interact with an increased number of staff members, which introduces variations in expectations and adherence to individualized treatment plans. Subtle variables in staff responses can affect client behaviors.

Finally, results of this study clearly support notions from the Behavioral Model of Health Services Use. The model assumes that individuals with higher service needs utilize services at higher rates if resources are available (Andersen, 1995). Individuals who displayed with more frequent and more severe behaviors and those with higher rates of comorbidity suggest higher clinical needs, and in this study, clearly relate to higher costs. Higher costs often serve as a proxy for increased services or higher service utilization. Therefore, individuals in care with higher needs are utilizing services at a higher rate than those with fewer needs.

CONCLUSION

Results of the present study suggest that participant characteristics such as comorbidity, severity of intellectual disability, frequency and severity of challenging and aggressive behaviors, and service setting significantly influence cost, which are largely ignored in existing rate setting methods. Systems theory (Luhmann, 1996) offers a broad theoretical understanding of how these factors influence the various systems financially affected by inadequate rate structures, but also provides a pathway for viable solutions. In addition, caregiver strain appears highly receptive to participant behaviors, especially more frequent and severe aggression. Commonly accepted stress models, such as the Stress Process Model (Pearlin et al., 1990), suggest various stressors affect caregiver strain. The current study reinforces the notion of behavioral influences on caregiver strain, but also shows that some behaviors such as property destruction induce higher amounts of strain.

The present study contributes to existing literature in a number of ways. First, literature examining setting differences within community services for adults with IDD remains largely unexplored. Prior research primarily examines setting effects from a deinstitutionalization perspective comparing institutional and community setting differences. However, in response to national pressure for community integration, several types of community services emerged. This study not only offers preliminary evidence to extend adolescent peer contagion and deviance training literature to adult IDD populations in congregate care settings, the results also suggest evidence to support better outcomes for particular community settings, like EFH homes. Research with adolescents shows an array of negative outcomes related to congregate care due to peer

contagion (Dishion & Tipsord, 2011). Although the group homes in the present study were single-family homes in the community, they still represent a congregate care setting. Alternatively, EFH services offer similar service programming, treating individuals with similar acuity as those in group home settings, also in the community but in a more home-like setting.

The present study also includes a more robust analysis of individuals with IDD, the characteristics unique to this population, and an economic analysis of primarily actual, directly incurred costs associated with community care. Individuals with IDD experience a large range of deficits, which differentially affects service needs and the intensity of care required to preserve community integration. These results provide implications for future rate design and staffing considerations (e.g., training, hiring criteria) to improve care and reduce caregiver strain while maintaining economic efficiency.

Third, the study examines incidence-based data including various types of disruptive and challenging behaviors, specifically types of aggression that affect the care, services, and needs of the individuals. Although prior studies examined the economic impact of challenging behavior, few identify which types of behaviors actually influence service utilization and cost. Despite significant interrelationships between the types of aggression in the present study, further analysis revealed unique contributions to cost dependent on the type of behavior. Therefore, the type of problem behavior differentially influences cost, which is an important distinction for future research. In addition, the present study not only examines the frequency but also the severity of such behaviors.

Implications for this knowledge significantly guide future service design, workforce development, and funding allocation decisions.

Fourth, care for individuals with IDD crosses multiple public health systems and funders. According to Cuffel (1997), “disruptive behavior is likely to affect costs in mental health, public health, criminal justice, and other social service sectors” (p. 1,565). Although the present study lacks direct cost comparisons of some of those community contacts (e.g., acute hospitalizations), the incident rates serve as a proxy for interpreting greater impact on the community and public health entities. In order to truly understand the economic impact of this population and achieve better monetary decisions, we must recognize all the sources involved, which are not just mental or physical health care costs. Significant changes to any system involved in caring for this population, which is highly driven by public services, would considerably impact several public entities with separate budgets. For instance, the Department of Health and Human Services operates with a different budget than the Department of Justice. However, both use resources to care for individuals with IDD especially when national efforts significantly change the service structures for those individuals (e.g., national deinstitutionalization efforts). Therefore, understanding those fiscal components allows departments to work together more efficiently.

Next, the study includes American participants. Studies that incorporate more holistic cost analysis methods as illustrated in this study typically test international populations (Doran et al., 2012; Genereaux et al., 2016; Järbrink et al., 2003). Funding reimbursement structures and treatment patterns significantly differ from country to country, which affect the utility of study findings and generalizability of cost analyses.

The current study also examines cost differences among distinct levels of impairment severity and specific comorbidity combinations. Investigating subgroups among highly heterogeneous populations facilitates higher scientific accuracy, reduces inconsistent results due to highly dependent relationships, and improves generalizability of research. Acknowledging and accounting for these differences informs funders and policymakers how to differentially direct resources by creating a more efficient system and reduce wasteful spending. Furthermore, conceptualizing comorbidity and multimorbidity from a multidisciplinary perspective, initiates a dialogue for future researchers to explore interactive effects between various mental and physical health conditions for individuals with IDD.

Finally, this study examines a very unique population that few studies recognize. Ninety-three percent of participants displayed co-occurring challenging and aggressive behaviors and diagnosed mental health conditions. Fifty-seven percent of the sample showed coexisting challenging behavior with SPMI diagnoses. When compared to studies where 10-27% of their sample reach this combination of conditions (Niven et al., 2017; Holden & Gitlesen, 2003; Borthwick-Duffy, 1994; Kiernan & Qureshi, 1993), the present study was able to examine detailed characteristics of a niche population unavailable to most researchers. The sample was selected from a clinical population, so the high prevalence of mental health conditions should be assumed. Although a significant strength, exceptional samples also translate to restricted generalizability and other limitations. Furthermore, the high rates of comorbidity and homogeneity of the sample regarding comorbidity also influenced statistical analysis and limited options for

group comparisons. A larger sample with greater heterogeneity would lend to greater generalizability, potentially increased effect sizes, and greater statistical opportunities.

Limitations

Unfortunately, this study only begins the process of evaluating the relative economic impact of deinstitutionalization and the special care needs of individuals with IDD. The study only includes participants from one agency in Nebraska limiting the generalizability of the study. Indicative of the high rates of comorbidity (100% with mental illness) and challenging behaviors, referral sources and admission criteria likely affect the characteristics of individuals admitted to an agency. For instance, referral sources may refer clients with particular issues, such as those with IDD and mental health conditions, to certain agencies based on their expertise or past experiences. Therefore, future studies should include multiple agencies across multiple states to validate the methodology and outcomes.

Although the use of direct and accrued costs offer a significant strength to this study, the measure of cost also includes some limitations. First, due to lack of access to police and medical claims data, the researcher estimated costs for physician appointments, police contacts, and emergency medical services based on incident review data. To improve the accuracy of police cost estimates, the number of law enforcement officers and the time of contact were incorporated into the calculations. Furthermore, acute hospital care costs were excluded from the study due to dramatic variations in such costs. Unfortunately, the use of estimates increases error and may influence results.

Cost figures also excluded any indirect costs. For instance, police estimates included only direct time with participants, and did not include costs for paperwork or

drive time. For other types of services, some studies calculate the cost of lost wages or time required to care for the individual with IDD (Genereaux et al., 2016; Järbrink et al., 2003) and transportation costs (Doran et al., 2012). However, those costs were intentionally excluded from the proposed study due to the subjective nature of calculating indirect costs as well as the growing focus and literature on physical care. In addition, most individuals in residential care minimally rely on family members for day-to-day needs. Therefore, care primarily comes from staff members or contracted individuals, and those expenses are incorporated into residential treatment costs. Furthermore, other indirect costs typically estimated in economic impact studies rely primarily on the loss of earnings or employment productivity. Approximately 23.9% of individuals with cognitive disabilities maintain employment, and those who maintain paid employment typically work fewer hours and for lower wages (Butterworth et al., 2011). Consequently, productivity loss estimates appear less relevant when considering the relative cost of caring for this population. Furthermore, some indirect costs related to the administration of services, staff training, recruitment and retention are presumably included in existing treatment rates. However, as previously discussed, higher rates of turnover and elevated vacancy rates remain unique to the workforce caring for individuals with IDD, and would affect cost. Future studies should aim to include actual medical costs and account for additional indirect costs. Unfortunately, claim data is difficult and costly to obtain, and indirect costs can be extremely subjective and difficult to measure.

An additional limitation of the current study comes from the use of archival data. Although many common limitations in using secondary data were minimized since the

primary researcher had access to the entire participant clinical files and thus the entire dataset (Hinds et al., 1997), other limitations emerge from the use of secondary data. For instance, missing and incomplete data is a common limitation when using health records for secondary data analysis (Gloyd et al., 2016). The completeness and quality of the data are unknown. Multiple staff members input information into the clinical file, so knowledge, expertise, and documentation quality vary between individuals and across participants. However, these effects should be random and equally prevalent across the sample. Most likely, many behaviors are actually underreported. For instance, some behaviors are easier to conceal (e.g., self-harm), so likely remain underestimated across all participants. Cross-referencing multiple sources of documentation across multiple care providers to verify accuracy minimized documentation errors and omissions in the current study.

Next, the choice of assessments and data fields are limited to the original authors. In the current study, the agency utilized the Caregiver Strain Questionnaire to measure caregiver strain, and no other measure of caregiver strain was available. Unfortunately, only global scores were available in the client file, so subscale scores were unavailable to the researcher. The CGSQ also does not account for strain generated from caring for multiple individuals or challenges placed on caregivers outside of client care that may affect strain when working with individuals (e.g., work, family, school, etc.). However, a review of literature on caregiver strain methods revealed similar issues when measuring strain in clinical populations, and several studies confirm excellent reliability and validity for the measure on populations similar to the present study.

The study also included the ICAP and DBC with the same population. Original research examined the ICAP in institutional populations, which many would argue significantly differ compared to those in community settings. Intended to measure adaptive functioning, the ICAP includes questions on maladaptive behavior, which are also captured separately in the present study. However, the ICAP lacked a significant linear relationship with any of the aggression types. These results suggest that the ICAP underestimates the presence of maladaptive behavior in specialized populations as described in this study. Furthermore, consistent with other studies, the ICAP serves as a poor predictor of cost or funding allocation (Arnold et al., 2015) despite heavy reliance by state funders, including the state of Nebraska.

The researcher also acknowledges potential problems with use of the DBC assessment. Client files only included the adult version of the Development Behaviour Checklist even though eight adolescent participants (3 youth ages 14-16, 5 youth age 17) received services. The adolescents were included in the study because sample selection included all clients receiving group home and EFH services. Follow-up analysis of the regression models removing the adolescents, revealed that behavior severity becomes a significant individual contributor to the model ($B = 83.279$, $\beta = .270$, $p = .01$), and the model then accounts for 68% of the variance ($R^2 = .682$, Adjusted $R^2 = .628$) in cost, which is a significant increase from initial analyses. Use of the adult version of the DBC assessment for adolescents may have increased measurement error in the original analyses. Since the adolescent version of the DBC differs from the adult version in total score and subscale factors, the versions should not be included in the same analysis.

Therefore, follow-up studies should include only adult populations or alternative assessments to measure problem behavior severity.

In addition, some analyses should be interpreted with caution. Although consistent with a priori hypotheses, conducting multiple statistical analyses increases the risk for type I errors. Correction techniques were not employed in this study due to the risk of artificially increasing type II errors, which are highly sensitive to sample size and statistical power. Inadequate statistical power driven by a modest sample size ($N=73$) likely played a role in limiting the significance of some of the statistical comparisons conducted in the current study. Studies with a smaller sample size run the risk of type II errors and certainly limit analytical options. Post hoc power analysis of initial comorbidity tests suggests limited power may have influenced the non-significant results. Unfortunately, the population examined in this study includes individuals receiving long-term care services, who typically remain in services for several years. Therefore, new clients rarely enter services during a year, and options to increase sample size remain a challenge for ongoing research. Although several significant relationships emerged in the current study, the sample size reduced the number of variable options for multivariate analyses. Considering the multi-collinearity between the aggression types, an increased sample size would have allowed for inclusion of each behavior variable individually opposed to using the aggression categories. Examining each behavior individually could offer more robust information on which behaviors influence caregiver strain and cost. Additionally, an increased sample may improve variability in some of the measures.

Lastly, more modern approaches, such as those described by Preacher and Hayes (2004) using bootstrapping to test indirect effects, could have been utilized as alternative

path analysis techniques. Although Baron and Kenny's (1986) approach remains accepted in the field, more contemporary techniques have been gaining popularity and may have been useful considering sample size constraints in the present study. Utilizing both techniques and then comparing the results would have provided additional strength to the study.

Future Research

Future studies should address these shortcomings and continue to clarify the factors influencing the cost of caring for individuals with IDD. Studies using a larger sample would allow researchers to examine the impact of other challenging behaviors in addition to aggressive acts. Behaviors such as sexually inappropriate behaviors, noncompliance, elopement, and other socially disruptive behaviors may influence cost and caregiver strain and should be examined. A larger sample would also improve sample heterogeneity and allow a better analysis of the effects of comorbidity and IDD severity with cost.

Future research should also explore additional factors affecting caregiver strain and explicitly examine the application of attribution theory for explaining caregiver perceptions. Research examining the influence of objective and subjective strain on cost is also recommended. Finally, as national deinstitutionalization efforts continue, future studies should explore setting effects across other types of community programs and functioning levels. Although the present study included participants with a wide range of functioning limitations, a larger sample would increase statistical analysis options to evaluate setting differences across functioning levels.

Continued national pressure for healthcare reform is imminent, and managed care arrangements appear to serve as one possible solution to control rising healthcare costs. Whether state agencies and managed care organizations continue fee-for-service reimbursement structures or shift towards value-based contracts, it is clear that healthcare needs vary across populations and some subsets of individuals will require higher funding or alternative funding structures. A better understanding of the unique characteristics of individuals with IDD offers policymakers insight into the heterogeneity of this group to enhance resource allocation, design management techniques to more efficiently support high-risk populations, and improve the quality of care. Unveiled from unbundling costs, a subset of individuals with IDD, those with more severe forms of impairments, higher rates of comorbidity, and increased incidents of aggressive behavior, cost more than other populations, which will require different approaches from managed care companies to efficiently manage rising costs while preserving quality care.

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APPENDIX A
CODING MANUAL

Variable & Coding

	VARIABLE NAME	BRIEF DESCRIPTION	VARIABLE LEVEL	VALUE/CODING	SPECIAL INSTRUCTIONS/OPERATIONAL DEFINITIONS
Demographic Variables	Client Name	Name of client (Last, First)	Name	N/A	None
	Service Program	OMNI Service Program	Service	0=group home 1=EFH	The OMNI service program in which the participant is placed during the study period
	Client Number	OMNI Client Number	Number	N/A	individual unique identifier
	Date of Birth	Date of birth	DOB	N/A	used to calculate age
	Age	Age of participant at time of study	Age	N/A	based on date of birth calculation (in years as of 8/31/19)
	Gender	Gender of participant	Sex	0=male 1=female	None
	Intake Date	Date admitted to OMNI	Intake	N/A	None
	Discharge Date	Date discharged from OMNI	Discharge	N/A	None
	Length of Stay	Number of days in treatment at OMNI	LOS	N/A	Calculated by subtracting the discharge date from the intake date; if the participant is still in care, the discharge date will be 05/31/19
	Race/Ethnicity	Race/Ethnicity of participant	Race	1=Caucasian 2=African American 3=Native American 4=Hispanic 5=Asian American 6=Other/Unknown	None
	IQ	Verified IQ of the participant	IQ	N/A	None
ID Severity	IDD diagnostic severity rating provided in IDD diagnosis	IDS	0=No IDD diagnosis	If not included with IDD diagnosis in clinical records, used the following IQ ranges:	

			1=Borderline 2=mild 3=moderate 4=severe 5=profound	Borderline=70-80 Mild=50-55 to 70 Moderate=35-40 to 50-55 Severe=20-25 to 35-40 profound=20-25 or below
IDD Diagnosis	the presence of an IDD diagnosis	IDD	0=No IDD diagnosis 1=IDD diagnosis present	None
Mental Health Diagnosis	the presence of a mental health condition	MHD	0=no diagnosed mental health condition 1=diagnosed mental health condition present in records	None
SPMI Diagnosis	the presence of a serious and persistent mental health diagnosis based on Nebraska statute definition	SPMI	0=no diagnosed SPMI 1=diagnosed with SPMI	Diagnoses include Major Depression, Schizophrenia, Bipolar, and Borderline Personality Disorder
Physical Health Diagnosis	the presence of a physical health condition	PHD	0=no diagnosed medical condition 1=diagnosed medical condition present in records	Individuals with visual, auditory, and dental problems are not considered physical health conditions in this study
Comorbidity	The degree of comorbidity verified in the client record	CM	1=Presence of only IDD diagnosis 2=Presence of IDD diagnosis and either a mental health or a physical health diagnosis 3=Presence of IDD, mental health, and physical health diagnosis	The degree to which participants possess an IDD diagnosis, mental health diagnosis, and physical health diagnosis (e.g., if have an IDD diagnosis and a medical condition without a mental health condition, would receive a score of 2)
	The degree of comorbidity	CSPMI	1=Presence of only IDD diagnosis	The degree to which participants possess an IDD

	SPMI Comorbidity	verified in the client record		2=Presence of IDD diagnosis and either an SPMI or a physical health diagnosis 3=Presence of IDD, SPMI, and physical health diagnosis	diagnosis, SPMI diagnosis, and physical health diagnosis (e.g., if have an IDD diagnosis and a medical condition without an SPMI, would receive a score of 2)
Measures/Assessments	Adaptive Functioning	The ICAP score assigned by DHHS	ICAPH	N/A	None
	Adaptive Functioning	The ICAP score assigned by OMNI	ICAPO	N/A	None
	Total Staff Strain	the CGSQ assessment total score	CGSQ	N/A	The total CGSQ score from the identified lead staff member working with the participant
	Total Staff Strain Level	the clinical level derived from the CGSQ total score	CGSQL	1=Low	Scores less than 1.9
				2=Medium	Scores ranging from 1.9-3.4
				3=High	Scores higher than 3.4
	Objective Staff Strain	the CGSQ objective sub-scale score	CGSQO	N/A	The CGSQ objective sub-scale score from the identified lead staff member working with the participant
	Objective Staff Strain Level	the clinical level derived from the CGSQ objective sub-scale score	CGSQOL	1=Low	Scores less than 1.25
				2=Medium	Scores ranging from 1.25-3.0
				3=High	Scores higher than 3.0
Subjective Staff Strain	the CGSQ subjective sub-scale score	CGSQS	N/A	The CGSQ subjective sub-scale score from the identified lead staff member working with the participant	
Subjective Staff Strain Level	the clinical level derived from the CGSQ subjective sub-scale score	CGSQSL	1=Low	Scores less than 2.3	
			2=Medium	Scores ranging from 2.3-4.3	
			3=High	Scores higher than 4.3	
Behavior Severity	Developmental Behaviour Checklist (DBC) - behavior severity	DBC	N/A	Total Problem Behavior Score-full scale score	

	DBC-Disruptive	The disruptive sub-scale score on the DBC	DBC-D	N/A	Sub-scale score
	DBC-Comm & Anxiety	The communication and anxiety disturbances subscale score on the DBC	DBC-C	N/A	Sub-scale score
	DBC-Self Absorbed	The Self-Absorbed subscale score on the DBC	DBC-SA	N/A	Sub-scale score
	DBC-Depressive	The Depressive subscale score on the DBC	DBC-Dep	N/A	Sub-scale score
	DBC-Social Relating	The Social Relating subscale score on the DBC	DBC-SR	N/A	Sub-scale score
Verbal Aggression	Threatening Behavior	Number of time participant verbally threatened another individual or utilized physically threatening positioning	TB	N/A	from general event records (GER)
	False Allegation	Number of times participant wrongly accused an individual of abuse or neglect	FA	N/A	from general event records (GER)
	Verbal Aggression Total	Total number of incidents of verbal aggression	AggVA	N/A	(TB + FA)

Aggression Against Others	Altercation	Number of altercations participant engaged in	ALT	N/A	from general event records (GER); an altercation between a participant and any other person in which both parties mutually assert physical aggression towards the other, and an aggressor and victim cannot be identified
	Assault	Number of times participant was physical aggressive towards another individual	ASSA	N/A	from general event records (GER)-a physical altercation in which the participant is the aggressor and physically caused harm or attempted to inflict harm on another individual
	Behavioral Outburst	Number of behavioral outbursts requiring staff intervention to preserve safety of participant or other individual not accounted for by any other behavioral category	BO	N/A	from general event records (GER)
	Aggression Against Others Total	Total number of incidents of aggression against others	AggAO	N/A	(ALT + ASSA + BO)
Aggression Against Self	Self-Injurious Behavior	Number of incidents of self-harm	SIB	N/A	from general event records (GER)
	Suicide	Number of incidents or reported or observed suicidal thoughts, gestures, attempts, and threats	SU	N/A	from general event records (GER)

	Substance Abuse	Number of times participant inappropriately used alcohol or drugs resulting in an unsafe outcome	SA	N/A	from general event records (GER)
	Aggression Against Self Total	Total number of incidents of aggression against self	AggAS	N/A	(SIB + SU + SA)
Aggression Against Property	Theft/Larceny	Number of times participant took another person or company's property without permission	TL	N/A	from general event records (GER)
	Property Destruction	Number of incidents of property destruction	Dest	N/A	from general event records (GER)
	Fire Setting	Number of times participant attempted or intentionally started a fire with intent to harm property or others	FS	N/A	from general event records (GER)
	Aggression Against Property Total	Total number of incidents of aggression against property	AggAP	N/A	(TL + Dest + FS)
	Elopement	Number of times the individual elopes	Elope	N/A	from general event records (GER)
	Disruptive Behavior Total	Sum of all disruptive behaviors	DBTotal	N/A	(Elope + FS + Dest + TL + SA + SU + SIB + BO + ASSA + ALT + FA + TB)
Behavior	ESPI	Number of emergency safety physical interventions	ESPI	N/A	from general event records (GER)

	Police Contacts	Number of police contacts	PC	N/A	from general event records (GER)
	Incarceration	Number of times detained and stayed overnight in a correctional facility or jail	IC	N/A	from general event records (GER)
	Acute Hospitalization	Number of acute hospitalization contacts	Hosp	N/A	from general event records (GER); number of incidents where the individual was transported to the hospital and admitted for more than one day
	ER Visits	Number of ER Visits	ER	N/A	from general event records (GER); number of incidents where the individual was transported to the hospital for evaluation and/or treatment and released the same day
Cost Only	Police Contact Time	The amount of time police were involved during a police contact (in hours)	PCTime	N/A	from general event records (GER); rounded to the nearest 15 minute increment
	Medical Appointments	Number of medical appointments	Appt	N/A	The number of medical appointments attended during the study period
	Nurse Time	The amount of time nurses cared for the participant, consulted with provider, and documented the interaction (in hours)	Nurse Time	N/A	time rounded to the nearest 15 minutes increment
	Medications	Number of medications	Med	N/A	The number of medications filled by the pharmacy for the participant during the study period - based on pharmacy invoice records

	Medication Cost	Total cost of medications filled	MedCost	N/A	The total cost (in dollars) of medications filled during the study period - based on pharmacy invoice records
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Physical Health Condition Coding	Medical conditions will be categorized for descriptive purposes (confirmed conditions at intake)	Medical	0=None	
			1=Circulatory Problems	E.g., hypertension, blot clots, etc.
			2=Heart disease/attack	E.g., cardiomyopathy, congenital heart defect
			3=Endocrine Disease	E.g., diabetes, thyroid disease, growth disorder, sexual dysfunction, metabolic syndrome, hyperlipidemia, hypercholesterolemia, etc.
			4=Respiratory	E.g., COPD, asthma, lung disease, etc.
			5=Infectious Disease	E.g., STDs, measles, tuberculosis, onychomycosis, impetigo, etc.
			6=Traumatic Brain Injury (TBI)	
			7=Seizure Disorder	E.g., Epilepsy
			8=Obesity	BMI over 30
			9=Gastrointestinal Disorders	E.g., GERD, ulcers
			10=Blood Diseases	E.g., Anemia, sickle cell anemia
			11=Other medical condition	E.g., joint/muscle disease, hydrocephalus, fetal alcohol syndrome, sleep disorders, Pruritus, premenstrual dysphoric disorder, etc.

Cost & Calculation Variables

NAME	VARIABLE LABEL	DESCRIPTION	UNIT COST (UC; per incident cost)	CALCULATION (when costs aren't directly tracked)
Residential Treatment Services	RTC Cost	amount directly billed to DHHS for residential services	N/A	N/A
Room & Board	RAB Cost	amount directly billed to the client's guardian for room & board (to cover personal hygiene products, food, etc.)	N/A	N/A
Physician Care	PCC Cost	estimated cost of physician services	\$222*	UC * Appt
Nursing Care	NSC Cost	cost of in-home nurse care provided by Omni nursing staff	\$38.01	UC * nursing hours
Police Contacts	Pol Cost	estimated cost of police contacts	\$27.66**	UC * PCTime
ER visit	ERC Cost	estimated cost of ER visits	\$1048*	UC * ER
Vocational Services	Voc Cost	amount directly billed to DHHS for vocational services	N/A	N/A
Mental Health Treatment	MHC Cost	amount directly billed to Medicaid or insurance company for mental health treatment with a therapist at Omni	N/A	N/A
Nutrition	Nutr Cost	amount directly billed to Medicaid or insurance company for nutrition evaluations, consultation, and treatment with a registered dietician at Omni	N/A	N/A
Property Destruction	Dest Cost	cost to repair the destruction	N/A	N/A
Medication	Med Cost	cost of medications filled	see coding	N/A

Total Aggregated Cost	TotCost	Sum of all costs	N/A	RTCost + RABCost + PCCost + NSCost + PolCost + ERCost+ VocCost + MHCost + NutrCost + MedCost + DestCost
Average Monthly Cost	COST	Average monthly cost considering length of service stay	N/A	(TotCost/LOS)*30

*Agency for Healthcare Research and Quality. (2014a). [Table 1. Total utilization and mean expenses per visit by type of ambulatory health care service, 2014]. Medical Expenditure Panel Survey. Retrieved from https://meps.ahrq.gov/data_stats/summ_tables/hc/mean_expend/2014/table1.htm

**Bureau of Labor Statistics. (2018). State Occupational Employment and Wage Estimates Nebraska Bureau of Labor Statistics. Retrieved from https://www.bls.gov/oes/current/oes_ne.htm#33-0000

***Agency for Healthcare Research and Quality. (2014b). [Table 2. Total utilization and mean expenses for inpatient stays by length, 2014]. Medical Expenditure Panel Survey. Retrieved from https://meps.ahrq.gov/data_stats/summ_tables/hc/mean_expend/2014/table2.htm

OMNI Hourly Staffing Rates

POSITION	STAFF	HOURLY RATE
Nursing	ME	\$32.70
	BL	\$35.00
	MM	\$28.37
	TS	\$45.00
	CC	\$45.00
	LT	\$35.00
	MB	\$45.00
<i>Nursing Average</i>		\$38.01
<i>Psychologist</i>		\$45.87

APPENDIX B

ICAP

ICAP INVENTORY for CLIENT and AGENCY PLANNING

RESPONSE BOOKLET

9-22890

Robert H. Bruininks
Bradley K. Hill
Richard F. Weatherman
Richard W. Woodcock

CLIENT

Name _____
LAST FIRST MI.

Address _____
STREET

_____ CITY STATE ZIP

Phone () _____

Residential Facility _____

School/Day Program _____

County/District Responsible _____

Case Manager _____ Phone _____

Parent or Guardian _____ Phone _____

Respondent (Your Name) _____ Your Phone _____

Relationship to Client _____

Reason for Evaluation _____

Client ID _____

Residence ID _____

Day Program ID _____

Co./District ID _____

Case Manager ID _____

Other ID _____

Evaluation Date _____
YEAR MONTH DAY

(-) Birth Date _____

Age _____

_____ YRS. MOS.

CALCULATION OF AGE Calculate the client's age by subtracting the birth date from the evaluation date. If the number of days in the client's exact age is less than 15, the client's age is the number of years and months calculated. If the number of days is 15 or greater, the number of months is increased by one.

ICAP Training Implications Profile

MOTOR SKILLS

0	1	2	4	8	12	16	20	24	28	32	36	38	42	46	50	52	53	54		
0	1	2	4	8	12	16	20	24	28	32	36	38	42	46	50	52	53	54	54	
<0-3	0-3	0-5	0-7	0-9	1-0	1-4	1-8	2-0	2-6	3	4	5	6	8	10	12	15	18	22	adult

SOCIAL AND COMMUNICATION SKILLS

0.1	2	3	4	5	6	8	10	12	16	20	24	28	32	36	38	42	46	50	53	55	58	57	
0.1	2	3	4	5	6	8	10	12	16	20	24	28	32	36	38	42	46	50	53	55	58	57	57
>0-3	0-3	0-5	0-7	0-9	1-0	1-4	1-8	2-0	2-6	3	4	5	6	8	10	12	15	18	22	adult			

PERSONAL LIVING SKILLS

0.1	2	3	4	5	6	7	10	13	17	22	28	34	40	44	50	55	60	63	63		
0.1	2	3	4	5	6	7	10	13	17	22	28	34	40	44	50	55	60	63	63	63	
>0-3	0-3	0-5	0-7	0-9	1-0	1-4	1-8	2-0	2-6	3	4	5	6	8	10	12	15	18	22	adult	

COMMUNITY LIVING SKILLS

0	1	2	3	5	8	11	14	17	20	25	32	38	44	50	54	56	57		
0	1	2	3	5	8	11	14	17	20	25	32	38	44	50	54	56	57		
>0-5	0-5	0-7	0-9	1-0	1-4	1-8	2-0	2-6	3	4	5	6	8	10	12	15	18	22	adult



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40 41 42 43 44 45-LSC/D-30 19 18 17

The ICAP should be completed by a respondent who knows the client well. The respondent should refer to the ICAP manual for more detailed information, definition of terms, and directions for completing the ICAP.

A. Descriptive Information

1. SEX *(Mark one)*
 - 1. Male
 - 2. Female
2. HEIGHT _____ ft. _____ in. (or _____ cm.)
3. WEIGHT _____ lbs. (or _____ kg.)
4. RACE *(Mark one)*
 - 1. White
 - 2. Black
 - 3. Oriental, Asian, or Pacific Islander
 - 4. American Indian or Alaskan Native
 - 5. Other: _____
5. HISPANIC ORIGIN *(Mark one)*
 - 1. Not Hispanic
 - 2. Hispanic
6. PRIMARY LANGUAGE UNDERSTOOD *(Mark one)*
 - 1. English
 - 2. Spanish
 - 3. Other: _____
7. PRIMARY MEANS OF EXPRESSION *(Mark one)*
 - 1. None
 - 2. Gestures
 - 3. Speaks
 - 4. Sign Language or finger spelling
 - 5. Communication board or device: _____
 - 6. Other: _____
8. MARITAL STATUS *(Mark one)*
 - 1. Never married
 - 2. Married
 - 3. Separated
 - 4. Divorced
 - 5. Widow or widower
9. LEGAL STATUS *(Mark one)*
 - 1. Legally competent adult
 - 2. Parent or relative is guardian or conservator
 - 3. Non-relative is guardian or conservator
 - 4. State or county is guardian or conservator
 - 5. Other: _____

B. Diagnostic Status

1. PRIMARY DIAGNOSIS *(Mark one)* AND
2. ADDITIONAL DIAGNOSED CONDITIONS *(Mark all that apply)*
 - 1. None
 - 2. Autism
 - 3. Blindness
 - 4. Brain or neurological damage; chronic brain syndrome
 - 5. Cerebral palsy
 - 6. Chemical dependency
 - 7. Deafness
 - 8. Epilepsy or seizures
 - 9. Mental retardation
 - 10. Physical health problems requiring medical care by licensed nurse or physician: _____
 - 11. Mental illness (formal diagnosis); psychosis, schizophrenia, etc.
 - 12. Situational mental health problem (formal diagnosis); depression, anxiety, fearfulness, mood disturbance
 - 13. Other: _____

Comments:

C. Functional Limitations and Needed Assistance

1. LEVEL OF MENTAL RETARDATION *(Mark one)*

1. Not mentally retarded
2. Mild (IQ 52–70)
3. Moderate (IQ 36–51)
4. Severe (IQ 20–35)
5. Profound (IQ under 20)
6. Unknown, delayed, at risk

2. VISION *(Mark one)*

1. Sees well (may wear glasses)
2. Vision problems limit reading or travel (may wear glasses)
3. Little or no useful vision (even with glasses)

3. HEARING *(Mark one)*

1. Hears normal voices (may use hearing aid)
2. Hears only loud voices (may use hearing aid)
3. Little or no useful hearing (even with hearing aid)

4. FREQUENCY OF SEIZURES *(Mark one)*

1. None, or controlled
2. Less than monthly seizures
3. Monthly seizures
4. Weekly or more often

5. HEALTH *(Mark one)*

1. No limitation in daily activities
2. Few or slight limitations in daily activities
3. Many or significant limitations in daily activities

6. REQUIRED CARE BY NURSE OR PHYSICIAN *(Mark one)*

1. Less than monthly
2. Monthly
3. Weekly
4. Daily
5. 24-hour immediate access

7. CURRENT MEDICATIONS *(Mark all that apply)*

1. None
2. For health problem: _____
3. For mood, anxiety, sleep or behavior: _____
4. For epilepsy, seizures: _____
5. Other: _____
6. Unknown

8. ARM/HAND *(Mark one)*

1. No limitation in daily activities
2. Some daily activities limited
3. Most daily activities limited

9. MOBILITY *(Mark one)*

1. Walks (with or without aids)
2. Does not walk
3. Limited to bed most of the day
4. Confined to bed for entire day

10. MOBILITY ASSISTANCE NEEDED *(Mark all that apply)*

1. None
2. Needs assistive devices (cane, walker, wheelchair): _____
3. Occasionally needs help of another person
4. Always needs help of another person

Comments:

D. Adaptive Behavior

DIRECTIONS

- Rate how well the client *presently* performs each task *completely* and *without* help or supervision.
- Mark the rating that best describes the client's performance for each task.
- Mark the highest rating (3: Does very well) for tasks that are now too easy for the client.
- Estimate by rating how well the client *could* do the task now on his or her own without further training, if you have not had the opportunity to observe performance on a task or the client does not have opportunity to do it.
- Consult the ICAP manual for further instructions.

1. MOTOR SKILLS

Does (or could do) task completely without help or supervision:

0. NEVER OR RARELY—even if asked

1. DOES, BUT NOT WELL—or $\frac{1}{4}$ of the time—may need to be asked

2. DOES FAIRLY WELL—or $\frac{3}{4}$ of the time—may need to be asked

3. DOES VERY WELL—always or almost always—without being asked

0	1	2	3	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	1. Picks up small objects with one hand.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	2. Transfers small objects from one hand to the other hand.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3. Sits alone for thirty seconds with head and back held straight and steady (without support).
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	4. Stands for at least five seconds by holding on to furniture or other objects.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	5. Pulls self into a standing position.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	6. Puts small objects into containers and takes them out again.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	7. Stands alone and walks for at least six feet.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	8. Scribbles or marks with a pencil or crayon on a sheet of paper.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	9. Removes wrappings from small objects such as gum or candy.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	10. Turns knob or handle and opens a door.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	11. Walks up and down stairs by alternating feet from step to step. (May hold handrail.)
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	12. Climbs a six-foot ladder (for example, a stepladder or a slide).
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	13. Cuts with scissors along a thick, straight line.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	14. Prints first name, copying from an example.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	15. Picks up and carries a full paper bag of groceries at least twenty feet and sets it down (without using handles).
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	16. Folds a letter into three equal sections and seals it in an envelope.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	17. Threads a sewing needle.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	18. Assembles objects that have at least ten small parts that must be screwed or bolted together (for example, unassembled toys or furniture).

$\frac{\text{SUM}}{x0}$	$\frac{\text{SUM}}{x1}$	$\frac{\text{SUM}}{x2}$	$\frac{\text{SUM}}{x3}$	
<input type="text"/>	+	<input type="text"/>	+	<input type="text"/>
				= <input type="text"/> MOTOR SKILLS
				RAW SCORE (54)

2. SOCIAL AND COMMUNICATION SKILLS

Does (or could do) task completely without help or supervision:

0. NEVER OR RARELY—even if asked

1. DOES, BUT NOT WELL—or $\frac{1}{4}$ of the time—may need to be asked

2. DOES FAIRLY WELL—or $\frac{3}{4}$ of the time—may need to be asked

3. DOES VERY WELL—always or almost always—without being asked

0	1	2	3	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	1. Makes sounds or gestures to get attention.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	2. Reaches for a person whom he or she wants.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3. Turns head toward speaker when name is called.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	4. Imitates actions when asked, such as waving or clapping hands.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	5. Hands toys or other objects to another person.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	6. Shakes head or otherwise indicates "yes" or "no" in response to a simple question such as "Do you want some milk?"
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	7. Points to familiar pictures in a book on request.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	8. Says at least ten words that can be understood by someone who knows him or her.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	9. Asks simple questions (for example, "What's that?").
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	10. Speaks in three- or four-word sentences.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	11. Waits at least two minutes for turn in a group activity (for example, taking turns at batting a ball or getting a drink of water).
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	12. Offers help to other people (for example, holds a door open for one whose arms are full or picks up an object dropped by someone else.)
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	13. Acts appropriately without drawing negative attention while in public places with friends (for example, a movie theater or library).
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	14. Responds appropriately to most common signs, printed words, or symbols (for example, STOP, MEN, WOMEN, DANGER).
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	15. Summarizes and tells a story so that it is understood by someone else (for example, a TV program or a movie).
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	16. Locates or remembers telephone numbers and calls friends on the telephone.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	17. Writes, prints, or types understandable and legible notes or letters for mailing.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	18. Locates needed information in the telephone yellow pages or the want ads.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	19. Calls a repair service or the caretaker if something major such as the furnace or the refrigerator breaks down in the home.

$\frac{\text{---}}{\times 0}$ SUM
 $\frac{\text{---}}{\times 1}$ SUM
 $\frac{\text{---}}{\times 2}$ SUM
 $\frac{\text{---}}{\times 3}$ SUM

+ + = SOCIAL AND COMMUNICATION SKILLS
 RAW SCORE (57)

3. PERSONAL LIVING SKILLS

Does (or could do) task completely without help or supervision:

0. NEVER OR RARELY—even if asked

1. DOES, BUT NOT WELL—or $\frac{1}{4}$ of the time—may need to be asked

2. DOES FAIRLY WELL—or $\frac{3}{4}$ of the time—may need to be asked

3. DOES VERY WELL—always or almost always—without being asked

0	1	2	3	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	1. Swallows soft foods.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	2. Picks up and eats foods such as crackers.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3. Holds out arms and legs while being dressed.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	4. Holds hands under running water to wash them when placed in front of a sink.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	5. Eats solid foods with a spoon with little spilling.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	6. Stays dry for at least three hours.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	7. Removes pants and underpants.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	8. Uses the toilet at regular times when placed on the toilet or when taken to the bathroom.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	9. Puts on T-shirt or pullover shirt, although it may be on backward.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	10. Uses the toilet, including removing and replacing clothing, with no more than one accident per month.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	11. Closes the bathroom door when appropriate before using the toilet.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	12. Dresses self completely and neatly, including shoes, buttons, belts, and zippers.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	13. Cuts food with a knife instead of trying to eat pieces that are too large.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	14. Washes, rinses, and dries hair.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	15. Washes and dries dishes and puts them away.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	16. Mixes and cooks simple foods such as scrambled eggs, soup, or hamburgers.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	17. Cleans bedroom, including putting away clothes, changing sheets, dusting, and cleaning the floor.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	18. Prepares shopping list for at least six items from a grocery store.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	19. Loads and operates a washing machine using an appropriate setting and amount of detergent.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	20. Plans, prepares, and serves main meal for more than two people.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	21. Repairs minor damage to clothing, such as tears or missing buttons, or arranges for these repairs outside the home.

$\frac{\text{SUM}}{x0}$	$\frac{\text{SUM}}{x1}$	$\frac{\text{SUM}}{x2}$	$\frac{\text{SUM}}{x3}$	
[]	+	[]	+	[] = [] PERSONAL LIVING SKILLS
RAW SCORE (63)				

4. COMMUNITY LIVING SKILLS

Does (or could do) task completely without help or supervision:

0. NEVER OR RARELY—even if asked

1. DOES, BUT NOT WELL—or $\frac{1}{4}$ of the time—may need to be asked

2. DOES FAIRLY WELL—or $\frac{3}{4}$ of the time—may need to be asked

3. DOES VERY WELL—always or almost always—without being asked

0	1	2	3	
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	1. Finds toys or objects that are always kept in the same place.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	2. Finds own way to a specified room when told to go (for example, "Go wait in the kitchen").
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3. Indicates when a chore or assigned task is finished.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	4. Stays in an unfenced yard for ten minutes when expected without wandering away.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	5. Uses the words "morning" and "night" correctly.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	6. Trades something for money or another item of value (for example, trades one book for another one or for money).
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	7. Buys items from a vending machine (for example, candy, milk or soda pop).
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	8. Crosses nearby residential streets, roads, and unmarked intersections alone.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	9. Buys specific items requested on an errand, although may not count change correctly.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	10. States day, month, and year of birth.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	11. Uses a watch or a clock daily to do something at the correct time (for example, catch a bus or watch a TV program).
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	12. Correctly counts change from a five-dollar bill after making a purchase.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	13. Operates potentially dangerous electrical hand tools and appliances with moving parts (for example, a drill or a food mixer).
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	14. Writes down, if necessary, and keeps appointments made at least three days in advance.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	15. Budgets money to cover expenses for at least one week (recreation, transportation, and other needs).
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	16. Works at a steady pace on a job for at least two hours.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	17. Completes applications and interviews for jobs.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	18. Receives bills in the mail and pays them before they are overdue.
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	19. Balances a checkbook monthly.

$\frac{\text{SUM}}{\times 0}$	$\frac{\text{SUM}}{\times 1}$	$\frac{\text{SUM}}{\times 2}$	$\frac{\text{SUM}}{\times 3}$	
<input style="width: 40px; height: 20px;" type="text"/>	+	<input style="width: 40px; height: 20px;" type="text"/>	+	<input style="width: 40px; height: 20px;" type="text"/>
				=
				<input style="width: 60px; height: 20px;" type="text"/>
				COMMUNITY LIVING SKILLS
				RAW SCORE (57)

E. Problem Behavior

DIRECTIONS: For each category, indicate whether the client exhibits problem behaviors. If yes, describe the client's *primary problem* and indicate its *frequency* and *severity*.

PROBLEM BEHAVIOR CATEGORIES:

- Hurtful to Self
- Hurtful to Others
- Destructive to Property
- Disruptive Behavior
- Unusual or Repetitive Habits
- Socially Offensive Behavior
- Withdrawal or Inattentive Behavior
- Uncooperative Behavior

1. HURTFUL TO SELF

Injures own body—for example, by hitting self, banging head, scratching, cutting or puncturing, biting, rubbing skin, pulling out hair, picking on skin, biting nails, or pinching.

a. If yes, describe the **PRIMARY PROBLEM**:

If none, mark *never* (0) for frequency and *not serious* (0) for severity.

b. **FREQUENCY:** How often does this behavior usually occur? (Mark one)

- 0. Never
- 1. Less than once a month
- 2. One to 3 times a month
- 3. One to 6 times a week
- 4. One to 10 times a day
- 5. One or more times an hour

c. **SEVERITY:** How serious is the problem usually caused by this behavior? (Mark one)

- 0. Not serious; not a problem
- 1. Slightly serious; a mild problem
- 2. Moderately serious; a moderate problem
- 3. Very serious; a severe problem
- 4. Extremely serious; a critical problem

Comments: _____

2. HURTFUL TO OTHERS

Causes physical pain to other people or to animals—for example, by hitting, kicking, biting, pinching, scratching, pulling hair, or striking with an object.

a. If yes, describe the **PRIMARY PROBLEM**:

If none, mark *never* (0) for frequency and *not serious* (0) for severity.

b. **FREQUENCY:** How often does this behavior usually occur? (Mark one)

- 0. Never
- 1. Less than once a month
- 2. One to 3 times a month
- 3. One to 6 times a week
- 4. One to 10 times a day
- 5. One or more times an hour

c. **SEVERITY:** How serious is the problem usually caused by this behavior? (Mark one)

- 0. Not serious; not a problem
- 1. Slightly serious; a mild problem
- 2. Moderately serious; a moderate problem
- 3. Very serious; a severe problem
- 4. Extremely serious; a critical problem

Comments: _____

3. DESTRUCTIVE TO PROPERTY

Deliberately breaks, defaces or destroys things—for example, by hitting, tearing or cutting, throwing, burning, marking or scratching things.

a. If yes, describe the **PRIMARY PROBLEM**:

If none, mark *never* (0) for frequency and *not serious* (0) for severity.

b. **FREQUENCY:** How often does this behavior usually occur? (Mark one)

- 0. Never
- 1. Less than once a month
- 2. One to 3 times a month
- 3. One to 6 times a week
- 4. One to 10 times a day
- 5. One or more times an hour

c. **SEVERITY:** How serious is the problem usually caused by this behavior? (Mark one)

- 0. Not serious; not a problem
- 1. Slightly serious; a mild problem
- 2. Moderately serious; a moderate problem
- 3. Very serious; a severe problem
- 4. Extremely serious; a critical problem

Comments: _____

4. DISRUPTIVE BEHAVIOR

Interferes with activities of others—for example, by clinging, pestering or teasing, arguing or complaining, picking fights, laughing or crying without reason, interrupting, yelling or screaming.

a. If yes, describe the **PRIMARY PROBLEM**:

If none, mark *never* (0) for frequency and *not serious* (0) for severity.

b. **FREQUENCY:** How often does this behavior usually occur? (Mark one)

- 0. Never
- 1. Less than once a month
- 2. One to 3 times a month
- 3. One to 6 times a week
- 4. One to 10 times a day
- 5. One or more times an hour

c. **SEVERITY:** How serious is the problem usually caused by this behavior? (Mark one)

- 0. Not serious; not a problem
- 1. Slightly serious; a mild problem
- 2. Moderately serious; a moderate problem
- 3. Very serious; a severe problem
- 4. Extremely serious; a critical problem

Comments: _____

5. UNUSUAL OR REPETITIVE HABITS

Unusual behaviors that may be done over and over—for example, pacing, rocking, twirling fingers, sucking hands or objects, twitching (nervous tics), talking to self, grinding teeth, eating dirt or other objects, eating too much or too little, staring at an object or into space, or making odd faces or noises.

a. If yes, describe the PRIMARY PROBLEM:

If none, mark never (0) for frequency and not serious (0) for severity.

b. FREQUENCY: How often does this behavior usually occur? (Mark one)

0. Never
 1. Less than once a month
 2. One to 3 times a month
 3. One to 6 times a week
 4. One to 10 times a day
 5. One or more times an hour

c. SEVERITY: How serious is the problem usually caused by this behavior? (Mark one)

0. Not serious; not a problem
 1. Slightly serious; a mild problem
 2. Moderately serious; a moderate problem
 3. Very serious; a severe problem
 4. Extremely serious; a critical problem

Comments: _____

6. SOCIALLY OFFENSIVE BEHAVIOR

Behavior that is offensive to others—for example, by talking too loud, swearing or using vulgar language, lying, standing too close or touching others too much, threatening, talking nonsense, spitting at others, picking nose, belching, expelling gas, touching genitals, or urinating in inappropriate places.

a. If yes, describe the PRIMARY PROBLEM:

If none, mark never (0) for frequency and not serious (0) for severity.

b. FREQUENCY: How often does this behavior usually occur? (Mark one)

0. Never
 1. Less than once a month
 2. One to 3 times a month
 3. One to 6 times a week
 4. One to 10 times a day
 5. One or more times an hour

c. SEVERITY: How serious is the problem usually caused by this behavior? (Mark one)

0. Not serious; not a problem
 1. Slightly serious; a mild problem
 2. Moderately serious; a moderate problem
 3. Very serious; a severe problem
 4. Extremely serious; a critical problem

Comments: _____

7. WITHDRAWAL OR INATTENTIVE BEHAVIOR

Difficulty being around others or paying attention—for example, keeping away from other people, expressing unusual fears, showing little interest in activities, appearing sad or worried, showing little concentration on a task, sleeping too much, or talking negatively about self.

a. If yes, describe the PRIMARY PROBLEM:

If none, mark never (0) for frequency and not serious (0) for severity.

b. FREQUENCY: How often does this behavior usually occur? (Mark one)

0. Never
 1. Less than once a month
 2. One to 3 times a month
 3. One to 6 times a week
 4. One to 10 times a day
 5. One or more times an hour

c. SEVERITY: How serious is the problem usually caused by this behavior? (Mark one)

0. Not serious; not a problem
 1. Slightly serious; a mild problem
 2. Moderately serious; a moderate problem
 3. Very serious; a severe problem
 4. Extremely serious; a critical problem

Comments: _____

8. UNCOOPERATIVE BEHAVIOR

Behavior that is uncooperative—for example, refusing to obey, do chores, or follow rules; acting defiant or pouting; refusing to attend school or go to work; arriving late at school or work; refusing to take turns or share; cheating; stealing; or breaking laws.

a. If yes, describe the PRIMARY PROBLEM:

If none, mark never (0) for frequency and not serious (0) for severity.

b. FREQUENCY: How often does this behavior usually occur? (Mark one)

0. Never
 1. Less than once a month
 2. One to 3 times a month
 3. One to 6 times a week
 4. One to 10 times a day
 5. One or more times an hour

c. SEVERITY: How serious is the problem usually caused by this behavior? (Mark one)

0. Not serious; not a problem
 1. Slightly serious; a mild problem
 2. Moderately serious; a moderate problem
 3. Very serious; a severe problem
 4. Extremely serious; a critical problem

Comments: _____

9. RESPONSE TO PROBLEM BEHAVIORS IN ANY OF THE 8 CATEGORIES

How do you or other people usually respond when the client exhibits problem behaviors? (Mark one)

0. No problem behaviors in any of the 8 categories
 1. Do nothing, or offer comfort
 2. Ask client to stop, reason with him or her
 3. Purposely ignore, reward other behavior
 4. Ask client to amend or correct the situation
 5. Structure or restructure surroundings, remove material
 6. Ask client to leave room, sit elsewhere (time out)
 7. Take away privileges from client
 8. Physically redirect, remove or restrain client
 9. Get help (two or more people needed to control client)
 10. Other: _____

Comments: _____

F. Residential Placement

1. CURRENT RESIDENCE
(Mark One)

-
-
-
-
-
-
-
-
-
-
-
-
-

2. RECOMMENDED CHANGE
within next two years, if any
(Mark One)

-
-
-
-
-
-
-
-
-
-
-
-
-
-
-

1. With parents or relatives
2. Foster home
3. Independent in own home or rental unit
4. Independent with regular home-based services or monitoring
5. Room and board without personal care
6. Semi-independent unit with supervisory staff in building
7. Group residence with staff providing care, supervision and training (includes all sizes and ICF-MR/DD)
Number of residents: _____
8. Personal care facility with staff providing care, but no training or nursing services
9. Intermediate care nursing facility
10. Skilled nursing facility
11. State institution
12. Other: _____
13. No change recommended

Comments:

G. Daytime Program

1. CURRENT FORMAL DAYTIME ACTIVITY
(Mark One)

-
-
-
-
-
-
-
-
-
-
-

2. RECOMMENDED CHANGE
within next two years, if any
(Mark One)

-
-
-
-
-
-
-
-
-
-
-
-

1. No formal daily program outside the home
2. Regular volunteer activities outside the home
3. School: _____
4. Day care
5. Daytime activity center (personal, social, prevocational activities)
6. Work activity center (social and vocational training)
7. Sheltered workshop
8. Supervised or supported on-site job placement
9. Competitive employment
10. Other: _____
11. No change recommended

Comments:

H. Support Services

1. PRESENTLY BEING USED
(Mark all that apply)

2. NOT USED NOW, BUT EVALUATION NEEDED
(Mark all that apply)

1. None
2. Case management: _____
3. Home-based support service: _____
4. Specialized dental care: _____
5. Specialized medical care: _____
6. Specialized nursing care: _____
7. Specialized mental health services: _____
8. Specialized nutritional or dietary services: _____
9. Therapies—occupational, physical or speech: _____
10. Respite care (to aid caretaker or parent): _____
11. Specialized transportation services: _____
12. Vocational evaluation: _____
13. Other: _____

Comments:

I. Social and Leisure Activities

1. SOCIAL AND LEISURE ACTIVITIES WITHIN LAST MONTH
(Mark all that apply)

1. None
2. Talked to family or friends on telephone
3. Visited with family
4. Visited with friends or neighbors from outside residence
5. Went shopping or out to eat (alone or with someone else)
6. Attended outside social or recreational activity
7. Engaged in hobby or personal leisure activity
8. Other: _____

2. FACTORS LIMITING SOCIAL ACTIVITIES
(Mark all that apply)

1. None
2. Lack of interest
3. No one to accompany the client
4. Lack of transportation
5. Lack of money
6. Health problem
7. Behavior problem
8. Other: _____

Comments:

Do these results provide an accurate representation of the client's present functioning: _____ 1. Yes _____ 2. No
If not, what is the reason for questioning results? _____

J. General Information and Recommendations

Important information for program decisions from Section B, **Diagnostic Status**, and Section C, **Functional Limitations**

Information from other sources:

Test	Date	Scores
_____	_____	_____
_____	_____	_____
_____	_____	_____

Additional information needed to make program decisions for this client:

PROGRAM GOALS

ADAPTIVE BEHAVIOR:

Motor Skills: _____

Social and Communication Skills: _____

Personal Living Skills: _____

Community Living Skills: _____

PROBLEM BEHAVIOR:

SERVICE GOALS

Physical, Medical, Therapeutic Care: _____

Residential Services: _____

Daytime and Social Activities: _____

Educational Services: _____

Support Services: _____

Social and Leisure Activities: _____

Other recommendations, future reviews and needed actions: _____

SUMMARY OF SCORES

Adaptive Behavior

(Norms based on subject's age)

SCALE	INSTRUCTIONAL RANGE		±1 SE _M CONFIDENCE BAND							
	Raw Score	(a) Domain Score	(b) SE _M	Age Score	Easy	Difficult	(c) Average Domain Score	(d) Domain Difference Score	(e) Domain Difference Score -1 SE _M	(f) Domain Difference Score +1 SE _M
Motor Skills	(54)	a Table A	b Table A	Table A	_____	_____ to _____ Table A	c Table F	a-c=d Table F	d-b=e Table F	d+b=f Table F
Social and Communication Skills	(57)	a Table B	b Table B	Table B	_____	_____ to _____ Table B	c Table F	a-c=d Table F	d-b=e Table F	d+b=f Table F
Personal Living Skills	(63)	a Table C	b Table C	Table C	_____	_____ to _____ Table C	c Table F	a-c=d Table F	d-b=e Table F	d+b=f Table F
Community Living Skills	(57)	a Table D	b Table D	Table D	_____	_____ to _____ Table D	c Table F	a-c=d Table F	d-b=e Table F	d+b=f Table F
Sum of the Four Domain Scores		Total								
Broad Independence		a a = Total ÷ 4	b Table E	Table E	_____	_____ to _____ Table E	c Table F	a-c=d Table F	d-b=e Table F	d+b=f Table F

MALADAPTIVE BEHAVIOR WORKSHEET

Calculating Maladaptive Indexes

Instructions:

Step 1. Circle the Part Scores for each of the client's Frequency and Severity ratings.

Step 2. Circle the Part Scores for the client's age in years.

Step 3. Total the circled Part Scores for each index and record in the space labeled "Sum."

Step 4. Subtract this sum from 100 to obtain the Maladaptive Index. Record a "+" or "-" as appropriate.

Step 5. Transfer these scores to the Maladaptive Behavior Indexes Profile on the back cover.

Interpretation:

The indexes have a mean of zero for normal clients of the same age. Negative scores indicate problem behavior toward the maladaptive end of the scale. The typical standard deviation observed in various clinical samples at several age levels is 10 points. Nonhandicapped groups typically have standard deviations of about 8 points. Evaluating the clinical significance of the Maladaptive Behavior Indexes may be aided by using the levels of seriousness in the following table. These levels of seriousness also appear at the bottom of the Maladaptive Behavior Indexes Profile on page 16.

Level of Seriousness	Index Value
N—Normal	+10 to -10
MgS—Marginally Serious	-11 to -20
MdS—Moderately Serious	-21 to -30
S—Serious	-31 to -40
VS—Very Serious	-41 and below

Problem Behavior		Part Scores for Ratings					
		INTERNALIZED					
Step 1	1. Hurtful to Self	0	1	2	3	4	5
	Raw score _____ Frequency:	16	18	20	22	23	25
	Raw score _____ Severity:	16	19	22	25	28	—
	2. Hurtful to Others						
	Raw score _____ Frequency:						
	Raw score _____ Severity:						
	3. Destructive to Property						
	Raw score _____ Frequency:						
	Raw score _____ Severity:						
	4. Disruptive Behavior						
	Raw score _____ Frequency:						
	Raw score _____ Severity:						
	5. Unusual or Repetitive Habits	0	1	2	3	4	5
	Raw score _____ Frequency:	16	17	18	20	21	22
	Raw score _____ Severity:	16	19	21	24	27	—
	6. Socially Offensive Behavior						
	Raw score _____ Frequency:						
	Raw score _____ Severity:						
	7. Withdrawal or Inattentive Behavior	0	1	2	3	4	5
	Raw score _____ Frequency:	16	18	20	21	23	25
	Raw score _____ Severity:	16	19	22	25	29	—
	8. Uncooperative Behavior						
	Raw score _____ Frequency:						
	Raw score _____ Severity:						
Step 2	Part Scores for Age in Years	1-8	9-15	16+			
	_____	0	1	2			
	Client's Age						
Step 3	Sum of Part Scores				100		
					—	SUM	
Step 4	Maladaptive Index						
							+ or -
							Internalized Maladaptive Index (IMI)

Part Scores for Ratings

	ASOCIAL	EXTERNALIZED	GENERAL
Step 1			0 1 2 3 4 5 6 7 7 8 9 10 6 7 8 10 11 —
		0 1 2 3 4 5 15 17 19 22 24 26 15 18 21 24 27 —	0 1 2 3 4 5 6 7 8 10 11 12 6 7 9 11 13 —
		0 1 2 3 4 5 15 17 20 23 25 28 15 18 22 25 29 —	0 1 2 3 4 5 6 7 9 10 12 13 6 8 10 12 14 —
		0 1 2 3 4 5 15 16 18 19 21 22 15 17 20 22 25 —	0 1 2 3 4 5 6 6 7 8 9 10 6 7 9 10 12 —
			0 1 2 3 4 5 6 6 6 7 7 8 6 7 7 8 9 —
		0 1 2 3 4 5 23 25 27 30 32 34 23 26 30 33 36 —	0 1 2 3 4 5 6 6 7 8 9 9 6 7 8 9 10 —
			0 1 2 3 4 5 6 6 7 7 8 8 6 7 8 9 10 —
		0 1 2 3 4 5 23 26 28 31 33 35 23 27 30 34 37 —	0 1 2 3 4 5 6 7 8 8 9 10 6 7 8 10 11 —
Step 2	1-7 0 16-18 4	8-10 1 19-21 5	11-12 2 22+ 6
	1-6 0 14-15 4	7-10 1 16 5	11 2 17-18 6
	12-13 3 19+ 7	1-7 0 8-11 1	12-13 2 14 3
	15+ 4		
Step 3	100 — SUM	100 — SUM	100 — SUM
Step 4	<input type="text"/> + or - Asocial Maladaptive Index (AMI)	<input type="text"/> + or - Externalized Maladaptive Index (EMI)	<input type="text"/> + or - General Maladaptive Index (GMI)

Maladaptive Behavior Indexes Profile (Plot indexes from pp. 14–15)

INSTRUCTIONS:

- Record scores for each of the Maladaptive Behavior Indexes from pp. 14–15 in column a.
- Subtract the SE_M in column b from each score in column a, and record this difference in column c.
- Add the SE_M in column b to each score in column a, and record the sum in column d.
- Draw a bar from the $-1SE_M$ value (c) to the $+1SE_M$ value (d) for each index.
- Draw a vertical line through the profile at the point corresponding to the GMI score in column a.

	(a) Index	(b) SE_M	a - b = (c) Index - 1 SE_M	a + b = (d) Index + 1 SE_M
Internalized (IMI)	_____	3	_____	_____
Asocial (AMI)	_____	4	_____	_____
Externalized (EMI)	_____	3	_____	_____
General (GMI)	_____	2	_____	_____

	VERY SERIOUS	SERIOUS	MODERATELY SERIOUS	MARGINALLY SERIOUS	NORMAL
Internalized (IMI)	-70 -65 -60 -55 -50 -45 -40 -35 -30 -25 -20 -15 -10 -5 0 +5 +10	(IMI)			
Asocial (AMI)	-70 -65 -60 -55 -50 -45 -40 -35 -30 -25 -20 -15 -10 -5 0 +5 +10	(AMI)			
Externalized (EMI)	-70 -65 -60 -55 -50 -45 -40 -35 -30 -25 -20 -15 -10 -5 0 +5 +10	(EMI)			
General (GMI)	-70 -65 -60 -55 -50 -45 -40 -35 -30 -25 -20 -15 -10 -5 0 +5 +10	(GMI)			

ICAP Service Level Profile

INSTRUCTIONS:

- Circle the column number that includes the subject's Total Adaptive Behavior Raw Score at the top of the ICAP Service Level Profile.
- Circle the row number that includes the subject's General Maladaptive Behavior Index (from above profile) in the left column of the ICAP Service Level Profile.
- Circle the number in the profile at the intersection of the two scores (step 1 and 2 above).

ADAPTIVE BEHAVIOR	RAW SCORES
Motor Skills (p. 4)	_____
Social and Communication Skills (p. 5)	_____
Personal Living Skills (p. 6)	_____
Community Living Skills (p. 7)	_____
Total Adaptive Behavior Raw Score	SUM

Adaptive Behavior Raw Score

	0	7	14	21	28	35	42	49	56	63	70	77	84	91	98	105	112	119	126	133	140	147	154	161	168	175	182	189	196	203	210	217	224	
2 to 4	2	2	2	2	3	3	3	3	3	4	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	7	8	8	8	8	9	9	9	9
-1 to 1	1	2	2	2	3	3	3	3	3	4	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	7	8	8	8	8	9	9	9	
-2 to -4	1	1	2	2	2	2	3	3	3	3	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	7	8	8	8	8	9	9	9	
-5 to -7	1	1	1	2	2	2	3	3	3	3	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	7	8	8	8	8	9	9	9	
-8 to -10	1	1	1	1	2	2	2	2	3	3	3	3	4	4	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	7	8	8	8	
-11 to -13	1	1	1	1	1	2	2	2	3	3	3	3	4	4	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	7	8	8	8	
-14 to -16	1	1	1	1	1	1	2	2	2	3	3	3	3	4	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	7	8	8	8	
-17 to -19	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	7	8	8	8	
-20 to -22	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	7	8	8	8	
-23 to -25	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	7	8	8	
-26 to -28	1	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	7	8	
-29 to -31	1	1	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	7	
-32 to -34	1	1	1	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	5	6	6	6	6	7	7	7	
-35 to -37	1	1	1	1	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	5	6	6	6	6	7	7	
-38 to -40	1	1	1	1	1	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	5	6	6	6	6	7	
-41 to -43	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	5	6	6	6	6	
-44 to -46	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	5	6	6	6	
-47 to -49	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	5	6	6	6	
-50 to -52	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	5	6	6	
-53 to -55	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	5	6	
-56 to -58	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	5	
-59 to -61	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	5	
-62 to -64	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	2	2	2	3	3	3	4	4	4	4	5	5	
less than -65	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	

ICAP Service Levels

Client's ICAP Service Score Table 1

Level	Score	Description	Level	Score	Description
1	1-19	Total personal care and intense supervision	6	60-69	Limited personal care and/or regular supervision
2	20-29	Extensive personal care and/or constant supervision	7	70-79	
3	30-39		Regular personal care and/or close supervision	8	80-89
4	40-49			9	90+
5	50-59				

APPENDIX C

DBC-2

DBC2-A
Adult Form

Response Sheet



DBCTM2

Developmental Behavior Checklist 2

Stewart Einfeld, MD, FRANZCP Bruce Tonge, MD, FRANZCP
Caroline Mohr, PhD

Name of individual being assessed		Date of birth	
Name of person completing form		Age	Gender <input type="checkbox"/> Male <input type="checkbox"/> Female
Relationship to individual being assessed		Date completed	
Presence of any major physical disabilities <input type="checkbox"/> Vision impairment <input type="checkbox"/> Hearing impairment <input type="checkbox"/> Unable to use arms/legs <input type="checkbox"/> Cannot/does not speak <input type="checkbox"/> Other (please specify): _____			
Please describe the individual in terms of the following:			
Medical conditions			

What he or she does best			

What others like most about him or her			

What his or her favorite activities are			

What he or she does as well as or better than others			

Programs or activities that he or she has been unable to participate in due to emotional or behavioral problems			

Previous services/help for emotional or behavioral problems			

Directions

Below is a list of behaviors that describe some individuals. Please read each item carefully and rate how well it describes the behavior of the individual being assessed (currently and over the past 6 months*). Select only one response (0, 1, or 2) according to the guidelines below. Please provide a response to every item. Some items include a space to describe specifics of the behavior—please be detailed in your descriptions.

Rating	Description	Example
0	Not true as far as you know (Not true, not applicable, or the individual is incapable of the action)	If the individual speaks slowly or cannot speak at all, <i>Talks too much or too fast</i> would be rated 0.
1	Somewhat true or sometimes true	If the individual only occasionally talks too quickly, <i>Talks too much or too fast</i> would be rated 1.
2	Very true or often true	If the individual talks too quickly most of the time, <i>Talks too much or too fast</i> would be rated 2.

* If this form is being completed as a follow-up, and fewer than 6 months have passed since the previous rating, rate the behaviors seen during the time period since the previous rating.

Modified scoring descriptors for the DBC2 copyright © 1981 by T. M. Achenbach. Used with permission.

	Not true	Somewhat true or sometimes true	Very true or often true
1. Appears depressed, down, or unhappy.	0	1	2
2. Avoids eye contact. Won't look you straight in the eye.	0	1	2
3. Is distant, in his or her own world.	0	1	2
4. Is abusive. Swears at others.	0	1	2
5. Arranges objects or routine in a strict order. Please describe: _____	0	1	2
6. Bangs head.	0	1	2
7. Becomes overexcited.	0	1	2
8. Bites others.	0	1	2
9. Has bizarre speech. Please describe: _____	0	1	2
10. Cannot attend to one activity for any length of time. Has poor attention span.	0	1	2
11. Chews or mouths objects or body parts.	0	1	2
12. Cries easily for no reason or over small things.	0	1	2
13. Covers ears or is distressed when hears particular sounds. Please describe: _____	0	1	2

Continued on next page

	Not true	Somewhat true or sometimes true	Very true or often true
14. Confuses the use of pronouns (e.g., uses <i>you</i> instead of <i>I</i>).	0	1	2
15. Deliberately runs away.	0	1	2
16. Has delusions: has a firmly held belief or idea that can't possibly be true. Please describe: _____	0	1	2
17. Is distressed about being alone.	0	1	2
18. Doesn't show affection.	0	1	2
19. Doesn't respond to others' feelings (e.g., shows no response if a close friend or family member is crying).	0	1	2
20. Is easily distracted from tasks (e.g., by noises).	0	1	2
21. Is easily led into trouble by others.	0	1	2
22. Eats nonfood items (e.g., dirt, grass, soap).	0	1	2
23. Is excessively distressed if separated from familiar person.	0	1	2
24. Fears particular things or situations (e.g., the dark, insects, crowds). Please describe: _____	0	1	2
25. Has facial twitches or grimaces.	0	1	2
26. Flicks, taps, or twirls objects repeatedly.	0	1	2
27. Is a picky eater.	0	1	2
28. Eats greedily. Will do anything to get food (e.g., takes food out of garbage bins or steals food).	0	1	2
29. Gets obsessed with an idea or activity. Please describe: _____	0	1	2
30. Grinds teeth.	0	1	2
31. Has become confused or forgetful.	0	1	2
32. Has become more withdrawn.	0	1	2
33. Has nightmares, night terrors, or walks in his or her sleep.	0	1	2
34. Has temper tantrums (e.g., stamps feet, slams doors).	0	1	2
35. Hides things.	0	1	2
36. Hits, bites, or injures self.	0	1	2
37. Hums, whines, grunts, squeals, or makes other nonspeech noises.	0	1	2
38. Is impatient.	0	1	2
39. Has inappropriate sexual activity with another.	0	1	2

Continued on next page

	Not true	Somewhat true or sometimes true	Very true or often true
40. Has an increase in appetite.	0	1	2
41. Is impulsive, acts before thinking.	0	1	2
42. Is irritable.	0	1	2
43. Is jealous.	0	1	2
44. Kicks, hits, or injures others.	0	1	2
45. Lacks self-confidence. Has poor self-esteem.	0	1	2
46. Laughs or giggles for no obvious reason.	0	1	2
47. Lights fires.	0	1	2
48. Likes to hold or play with an unusual object (e.g., string, twigs) or is overly fascinated with something (e.g., water). Please describe: _____	0	1	2
49. Has a loss of appetite.	0	1	2
50. Has lost enjoyment or interest in usual activities.	0	1	2
51. Has lost self-care skills.	0	1	2
52. Makes gloomy statements.	0	1	2
53. Masturbates or exposes self in public.	0	1	2
54. Mood changes rapidly for no apparent reason.	0	1	2
55. Moves slowly, underactive, does little (e.g., only sits and watches others).	0	1	2
56. Is noisy or boisterous.	0	1	2
57. Doesn't communicate as much as usual.	0	1	2
58. Is very active or restless. Can't sit still.	0	1	2
59. Is overly affectionate.	0	1	2
60. Hyperventilates, vomits, has headaches, or complains of being sick for no physical reason.	0	1	2
61. Seeks attention more than others.	0	1	2
62. Has great interest in looking at, listening to, or dismantling mechanical things (e.g., lawn mower, vacuum cleaner).	0	1	2
63. Panics. Sweats, flushes, or trembles.	0	1	2
64. Has a poor sense of danger.	0	1	2
65. Prefers to do things alone. Tends to be a loner.	0	1	2
66. Is preoccupied with only one or two particular interests. Please describe: _____	0	1	2
67. Has problems with cigarettes, alcohol, or caffeine.	0	1	2

Continued on next page

	Not true	Somewhat true or sometimes true	Very true or often true
68. Has problems with illegal drugs.	0	1	2
69. Refuses to go to college, activity center, or work.	0	1	2
70. Has repeated movements of hands, body, head, or face (e.g., hand flapping or rocking).	0	1	2
71. Resists being cuddled, touched, or held by close friends or family.	0	1	2
72. Repeats back what others say like an echo.	0	1	2
73. Repeats the same word or phrase over and over.	0	1	2
74. Smells, tastes, or licks objects.	0	1	2
75. Scratches or picks his or her skin.	0	1	2
76. Screams a lot.	0	1	2
77. Sleeps too little. Has disrupted sleep.	0	1	2
78. Stares at lights or spinning objects.	0	1	2
79. Sleeps too much or is overly drowsy.	0	1	2
80. Soils outside toilet, although toilet-trained. Smears or plays with feces.	0	1	2
81. Speaks in a whisper, high-pitched voice, or other unusual tone or rhythm.	0	1	2
82. Spits.	0	1	2
83. Switches lights on and off, pours water over and over, or does some other similar repetitive activity. Please describe: _____	0	1	2
84. Steals.	0	1	2
85. Is stubborn, disobedient, or uncooperative.	0	1	2
86. Is shy.	0	1	2
87. Strips off clothes or throws away clothes.	0	1	2
88. Says he or she can do things that he or she is not capable of.	0	1	2
89. Stands too close to others.	0	1	2
90. Sees or hears something that isn't there. Has hallucinations. Please describe: _____	0	1	2
91. Talks about or attempts suicide.	0	1	2
92. Talks too much or too fast.	0	1	2
93. Talks to self or imaginary people or objects.	0	1	2
94. Tells lies.	0	1	2
95. Has unconnected thoughts. Different ideas are jumbled together with unclear meaning.	0	1	2

Continued on next page

	Not true	Somewhat true or sometimes true	Very true or often true
96. Is tense, anxious, or worried.	0	1	2
97. Throws or breaks objects.	0	1	2
98. Tries to manipulate or provoke others.	0	1	2
99. Underreacts to pain.	0	1	2
100. Is unrealistically happy or elated.	0	1	2
101. Has unusual body movements, posture, or way of walking. Please describe: _____	0	1	2
102. Is upset and distressed over small changes in routine or environment. Please describe: _____	0	1	2
103. Urinates outside toilet, although toilet-trained.	0	1	2
104. Is very bossy.	0	1	2
105. Wanders aimlessly.	0	1	2
106. Whines or complains a lot.	0	1	2
107. Overall, do you feel the person has problems with feelings or behavior, in addition to problems with development? If not, select 0; if yes but minor, select 1; if major, select 2.	0	1	2

APPENDIX D

CGSQ

How Things Have Been for the Environment

Client Name: _____

Date: _____

Staff completing survey: _____

Please look back over the last two weeks and try to remember how things have been in this environment. We are trying to get a picture of how life has been in the environment over that time.

Please read each statement carefully, then place an 'X' in the one box that best matches how you feel things have been for this environment over the past month .

	In the last two weeks, how much of a problem were the following:	Not At All	A Little	Some-What	Quite a Bit	Very Much
1	Interruption of your personal time resulting from this individual's problems?					
2	You missing work or neglecting other duties because of this individual's problems?					
3	Disruption of your routine due to this individual's problems?					
4	Having to do without things because of this individual's problems?					
5	Financial strain as a result of this individual's problems?					
6	Disruption or upset of relationships due to this individual's problems?					
7	How frustrated did you feel as a result of this individual's problems?					
8	How worried did you feel about this individual's future?					
9	How much influence did you feel you had over this individual's problems?					
10	How tired or strained did you feel as a result of this individual's problems?					