2020

Adult Intellectual Developmental Disorder: Adverse Childhood Experiences and Problem Behaviors

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Recommended Citation

Adult Intellectual Developmental Disorder:

Adverse Childhood Experiences and Problem Behaviors

by

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DISSERTATION

Submitted in partial fulfillment of the requirements for the degree of
Doctor of Psychology in the Department of Clinical Psychology
at Antioch University New England, 2020

Keene, New Hampshire

Department of Clinical Psychology
DISSERTATION COMMITTEE PAGE
The undersigned have examined the dissertation entitled:

ADULT INTELLECTUAL DEVELOPMENTAL DISORDER:
ADVERSE CHILDHOOD EXPERIENCES AND PROBLEM BEHAVIORS

presented on July 13, 2020

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Dedication

To my husband, Brian: thank you for helping me realize my dreams. Somehow you always knew when to push, when to cheer, and when to listen. I am so grateful and proud to have you by my side on this journey.

Acknowledgments

First and foremost, I would like to express my deep gratitude to my advisor and dissertation chair, Gargi Roysircar, Ed.D. I have learned so much as your advisee, both academically and personally. I am appreciative of your ever-present support, even from across the country, even after your retirement, and even during a global pandemic. Words cannot express my gratitude for the hours you have spent working with me toward the finish line.

I also want to thank my committee members and professional mentors, Anthony Giuliano, Ph.D. and Laurie Guidry, Psy.D. This dissertation would not have been possible without your unwavering support. Dr. Giuliano, thank you for taking the time to check-in and offer your guidance and expertise. I truly appreciate your professionalism, warmth, and sense of humor. Dr. Guidry, thank you for your mentorship over the past several years. You have been an incredible source of hope and inspiration for me. Thank you for your innovative work and advocacy on behalf of adults experiencing trauma, intellectual developmental disorder, and severe mental illness.

Thank you to the leadership team at The Moore Center in Manchester, NH, especially Maureen Rose-Julian, Vice President of Individual and Family Services, and Greg Steelman, former Director of Moore Clinical Services for your support of my study. I admire your mission to bring trauma-informed mental health services to adults with IDD.

Additionally, I would like to thank Ashland Thompson, Psy.D., for your statistical consultation, and Ashley Espitia, M.A., soon to be Psy.D., for your formatting expertise and encouragement.

Finally, I want to express my appreciation for my fellow-cohort member, Alyssa Maiuri, Psy.D. candidate. Thank you for your friendship these past five years.

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Abstract

Adverse childhood experiences (ACEs) have detrimental effects on health and psychological

outcomes in the general population (Felitti et al., 1998). Individuals with the diagnosis of

intellectual developmental disorder (IDD) are at increased risk for adverse events and may be

vulnerable to poor outcomes, including problem behaviors (Hatton & Emerson, 2004;

Hulbert-Williams et al., 2014). The present study examined relationships among Adverse

Childhood Experiences (ACE) questionnaire (Felitti et al., 1998) items, total score, and problem

behaviors for adults with IDD receiving community-based care. Participants ($N = 41$) were

referred by a developmental services agency for a review of their archived records, which were

used to rate the ACE questionnaire and count incidents of problem behaviors. Odds Ratios

revealed the ACE item Parental Drug Abuse increased the odds 6-fold for elopement ($p < .05$),

and 11-fold for property destruction ($p < .01$). Kendall's Tau-B correlations revealed significant

positive correlations of Parental Alcohol Abuse and elopement ($Tb = .34$, $p < .05$). Adoption had

a significant, but small positive correlation with total incident reports ($Tb = .27$, $p < .05$), and

total ACE scores of 4 or greater increased the odds for criminal charges (OR = 6.23, 95% CI=

1.39, 27.84, $p < .05$). There were also significant negative correlations between the ACE items,

Witnessing Domestic Violence, Forced Rape, and Parental Incarceration with aggression ($p <$

.05). Total ACE scores and ACE item, Forced Rape, also had significant negative correlations

with total incident reports ($p < .05$). These results, as well as improvements in the collection of

patient data for trauma-informed care among development service agencies, are discussed.

Keywords: intellectual disability, adverse childhood experiences, problem behaviors

Chapter 1

Literature Review and Purpose of the Study

The apparent consequences of adverse life events, including Adverse Childhood

Experiences (ACEs) include higher rates of mental health symptoms and problem behaviors

(Hulbert-Williams et al., 2014). Research suggests that poor outcomes for individuals with IDD

and ACEs can be attributed to several factors. Contextual factors include lower socioeconomic

status (Maulik et al., 2010), cognitive vulnerability, and gaps in the reporting of abuse which

contribute to decreased treatment access (Chung & Bemak, 2012). While efforts promoting

de-institutionalization within the United States may have decreased exposure to unique

environmental stressors, access to treatment is also limited (O'Driscoll, 2009).

In response to the clinical research on ACEs in the general population, the Substance

Abuse and Mental Health Services Administration (SAMHSA; 2015) developed a model of

Trauma-Informed Care (TIC). TIC is an overarching term to describe system adaptations which

help to identify and treat individuals who have experienced traumatic events, such as ACEs.

SAMSHA further acknowledged the need for assessment within agencies and systems, such as

those that support individuals with IDD. Research suggests that individuals with IDD and ACEs

may be more likely to experience trauma sequelae, including problem behaviors, later in life

(Wigham & Emerson, 2015). Problem behaviors may significantly impair quality of life in adult

services (Mevissen et al., 2016; Wigham & Emerson, 2015).

Purpose of the Study

The purpose of the present study was to examine the impact of ACEs on problem

behaviors in adults with IDD who were receiving community-based care. Scores on a trauma

screening measure were correlated with frequencies of problem behaviors, including incidents of

aggression to self and others, problematic sexual behavior, property destruction, and elopement. I hoped that the findings could inform the implementation of trauma-informed screening and interventions at the systems level. Addressing the underlying psychological mechanisms of problem behavior may decrease the long-term costs of service delivery, improve safety for individuals and support staff, and improve the quality of life for individuals as they are supported in community-based settings.

Significance of the Study

The present research was relevant to two issues of quality improvement in developmental services: (a) quality of life for adults with IDD, and (b) the financial burden of supporting those with problem behaviors. Historically, clients with IDD and problem behavior were isolated within institutional settings (O'Driscoll, 2009). Treatment for problem behaviors was provided through psychopharmacological and behavioral interventions (O'Driscoll, 2009). There is increasing recognition of the inadequacy of this model as, historically, the potential impact of trauma sequelae had been overlooked (Keesler, 2014; O'Driscoll, 2009; Schuengel et al., 2012).

The movement toward de-institutionalization has created the need to provide services to individuals with IDD within least-restrictive community-based settings, such as Enhanced Family Care, an adult foster care model. As such, there are limited institutional settings in which to manage problem behaviors and community providers are now challenged with this task. Mitigating problem behaviors in community settings requires increased staffing ratios and, therefore, presents a financial burden (New Hampshire Bureau of Developmental Services, 2010).

Trauma-Informed Care Model

Following the Adverse Childhood Experiences study in 1998, SAMSHA adopted a model of Trauma-Informed Care (TIC; SAMSHA, 2015). TIC is a systems-based approach which requires philosophical and pragmatic changes on multiple systemic levels within organizations. TIC promotes the paradigmatic shift of viewing maladaptive behavior as adaptive in the context of adverse life events (Levenson, 2017). Adopting a TIC framework requires organizations to make structural changes to improve screening for external stressors and promote access to evidence-based interventions for symptoms of trauma (Levenson, 2014). The four goals of TIC involve (a) realizing the impact of trauma on overall well-being, (b) recognizing trauma-reactive behaviors in clients and families, (c) responding with revised policies and practices, and (d) avoiding the re-traumatization of individuals (SAMSHA, 2015). Core values of TIC have been outlined by Fallot and Harris (2002), which include: enhancing a sense of safety, trustworthiness between client and service provider, choice, collaboration, and client empowerment. The present research sought to inform the development of screening measures within community-based developmental services.

Significance to the New Hampshire Service System

The New Hampshire developmental services system was chosen for the present study for two reasons. New Hampshire was among the first states to de-institutionalize services for the IDD population in 1991, marked by the closing of Laconia State School, the state institution for individuals with developmental disabilities (Plourde & Rodolico, 2015). Presently, most services are provided to individuals with problem behavior within community-based settings (New Hampshire Code of Administrative Rules, 1994). Additionally, previous research on the development of problem behavior in adults with IDD has examined participants within inpatient

or institutionalized settings (Owen et al., 2004). As such, there is a lack of research conducted in community-based settings which examines relationships among adverse childhood experiences and problem behavior.

The impact of problem behaviors is especially pertinent to the New Hampshire service system. In a 2010 survey by the Department of Health and Human Services (DHHS), the leading conditions that contributed to high costs of individualized service budgets included the following:

> Behavioral issues (injuries to others or self, emotional outbursts, fire setting), psychiatric issues (anxiety, depression, schizophrenia, personality disorder), living situation (staffed residence, home provider, family home, number of people in the home), institutional admission history (New Hampshire Hospital, Secure Psychiatric Unit), [and] history of residential moves during the last 5 years. (page 2)

> Of the 433 individuals sampled, only 39% were found to have had a stable living situation, as defined by an absence of residential transitions (New Hampshire Bureau of Developmental Services, 2010, p. 2). Eighty-nine percent of the population sampled exhibited behavioral issues that resulted in higher individualized service costs, including physical aggression, property destruction, and emotional outbursts. Twenty-one percent of this group exhibited sexual aggression (New Hampshire Bureau of Developmental Services, 2010).

To gather further information, DHHS completed qualitative interviews with family members and individuals who received developmental services. The researchers conducted interviews with families and legal guardians of the individuals receiving services. They inquired about family and guardian satisfaction with service support for behavioral and therapeutic needs (New Hampshire Bureau of Developmental Services, 2010). The researchers concluded from

these interviews that behavioral needs were met in 50% of the cases examined, and therapeutic

needs were met in 61% of cases (New Hampshire Bureau of Developmental Services, 2010).

Forty-five percent of the individuals experienced ongoing crises, and "the responses to these

crises had produced a negative effect on the care and supports for [these] individual[s]" (New

Hampshire Bureau of Developmental Services, 2010, p. 4). Recommendations from the study

included the changes to budget proposals for individual service plans, which would include

increased and adequate clinical supports, staff training, and interagency collaboration. It was also

advised that agencies identify crisis response services as an alternative to in-patient psychiatric

services due to limited resources in this area (New Hampshire Bureau of Developmental

Services, 2010).

A Review of the Literature

Psychologists have long accepted that adverse events during early development have an

impact on psychological well-being later in life (Karen, 1998). It was not until 1998 that the

long-term effects of adverse experiences on overall health became known (Felitti et al., 1998).

The Kaiser Permanente health organization (Felitti et al., 1998) established this connection in a

study on Adverse Childhood Experiences (ACEs). ACEs are defined as environmental and

relational stressors that occur prior to age 18, and are comprised of household dysfunction,

physical and sexual victimization, and neglect (Felitti et al., 1998). The study estimated that 64%

of adults in the United States had experienced at least one ACE (Felitti et al., 1998). Individuals

who endorsed having experienced one or more items on the ACE questionnaire were at increased

risk for the development of several medical conditions, including heart disease, liver disease, and

cancer (Felitti et al., 1998). Subsequent studies have found significant correlations between

ACEs and mental health symptoms in adulthood, which include substance abuse, depression,

high-risk sexual activity, and suicide attempts (Centers for Disease Control and Prevention, as cited in Cronholm et al., 2015). Suicide risk for individuals with any ACE indicator is increased by two to five-fold (Dube et al., 2001). As such, individuals with a history of ACEs are considered clinically vulnerable by psychologists and physicians alike (Cronholm et al., 2015; Felitti et al., 1998; Finkelhor et al., 1990).

ACEs and Intellectual Disability

Individuals with the diagnosis of intellectual developmental disorder (IDD) are vulnerable to adverse life events. Those with IDD are four times as likely to experience ongoing abuse throughout the lifespan, including sexual, physical, and emotional abuses (Sullivan & Knuston, 2000, as cited in Keesler, 2014). A comparative study of children with and without the diagnosis of IDD found that the IDD group was at a higher risk for the presence of ACEs (Hatton & Emerson, 2004). Specifically, children with IDD were more likely than the non-IDD group to have experienced the separation of parents, familial police involvement, bereavement of a close friend, and hospitalization for a serious illness (Hatton & Emerson, 2004).

The above findings have been replicated within multiple studies. One study examined a sample of 177 individuals with mild and moderate intellectual disability. Descriptive statistics indicated that 75% of the sample had experienced at least one traumatic event in their lifespan (Martorell et al., 2009). Further, 50% had experienced at least one traumatic event within 12 months preceding data collection (Martorell et al., 2009). Martorell et al. hypothesized that increased prevalence of traumatic events may be due to factors related to dependence on others, as well as underdeveloped coping abilities.

Research further suggests that individuals with IDD may experience a greater breadth of adverse experiences across the lifespan. A study that examined cyber victimization found that

individuals with IDD who had previous experiences of sexual and physical abuse were more likely to be victims of cyber perpetration (Normand & Sallafranque-St-Louis, 2016). Individuals with IDD were also more likely to become institutionalized, increasing the chances of exposure to institutional traumas (Keesler, 2014). These included experiences of physical restraint and becoming a victim of abuse by a caregiver or peer (Hulbert- Williams et al., 2014; Keesler, 2014; O'Driscoll, 2009).

Psychiatric Problems and Problem Behavior in IDD

As the research on the impact of ACEs on mental health becomes widely integrated into mental health services, research is emerging regarding the link between trauma and the development of psychopathology. A study by Hulbert-Williams et al. (2014) investigated the longitudinal effects of 20 different negative life events on the development of psychiatric symptoms and maladaptive behaviors in individuals with IDD. The examined variables included anger, self-injurious behavior, and psychiatric symptoms (Hulbert-Williams et al., 2014). Psychiatric symptoms were measured using The Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist (PAS-ADD; Moss et al., 1996), which screens for the presence of affective disorders (e.g., compulsive symptoms), organic disorders (e.g., confusion, memory decline), and psychotic disorders (Hulbert-Williams et al., 2014). The researchers found a significant prediction of negative life events for the development of aggression (F change = 40.82; $p < .001$), psychotic symptoms (F change = 31.66; $p < .001$), and affective symptoms (F change = 20.16; $p < .001$) (Hulbert-Williams et al., 2014). A counterpart regression model was then used to test for bidirectionality of psychopathology and negative life events. It was found that mental health variables did not significantly predict the occurrence of negative life events, which suggested a unidirectional positive prediction of negative life events on psychopathology

(Hulbert-Williams et al., 2014). Maladaptive behaviors of aggression and self-injurious behavior were also associated with the presence of ACEs (Hulbert-Williams et al., 2014).

Martorell et al. examined the connection between early traumatic events, adverse life events in adulthood, and the development of psychopathology among 177 participants. Within this sample, male participants were found to be significantly more likely to develop a mental health diagnosis than female participants (Martorell et al., 2009). Age was not found to be correlated with number of adverse life events. Cumulative exposure to early traumatic events and adverse life events were found to increase the odds of psychopathology (OR = 1.7; 95% CI = 1.2-2.4; Martorell et al., 2009).

The impact of trauma on problem behavior has also been explored with juvenile offenders. One study by Brown et al. (1999) examined the effects of trauma on the development of mental health disorders and associated behaviors in 120 juvenile offenders. The diagnoses and behaviors included: conduct disorder, major depression, social phobia, obsessive-compulsive disorder, mania, and anorexia (Brown et al., 1999). The researchers found that experiences of sexual abuse were predictive of mental health symptoms, especially comorbidity of disorders $[F(1, 110) = 13.54, p = .0004]$ (Brown et al., 1999). There was also a small positive correlation with sexual abuse and internalizing problems ($r = .23, p < .012$). The moderating variables for the relationship between sexual abuse and internalizing problems included: verbal intelligence, emotional bonding with peers, and female gender (Brown et al., 1999). Exposure to violence was modestly correlated with the development of criminal behavior ($r = .26, p < .004$; Brown et al., 1999). Though significant, these coefficients show modest correlations. As such, additional moderating variables might have been responsible for the development of criminal behavior in the sample.

A subsequent study by Coleman (2005) replicated Brown et al.'s (1999) findings in a sample of 86 incarcerated juveniles. Coleman conducted a multiple regression of the predictor variables of sexual abuse exposure and witnessing a traumatic event (Coleman, 2005). The criterion variables were suicidal ideation and suicide attempts (Coleman, 2005). Colman also measured problem behavior with the internalizing and externalizing indices of the Achenbach Child Behavior Checklist (Achenbach, 1991). There was a moderate statistical significance of sexual abuse for internalizing problems (regression model R2 =.36, β = .42). Witnessing violence was also moderately predictive of externalizing problems (model R2 = .31, β = .40) (Coleman, 2005). These findings suggest predictive relationships between trauma experiences and mental health problems, although they also suggest considerable unexplained variance. The factors of low socioeconomic status, familial substance abuse, and lower IQ are additional known risk factors for the development of observable symptoms, which need to be entered into regression models (McNally, 1999).

Problematic Sexual Behavior. Research has examined the links between early maltreatment and the development of problematic sexual behavior. Problematic sexual behavior is defined as any act that is sexual in nature and presents a danger to self or others (Chaffin et al., 2008). These acts may include use of coercion within pre-adolescent individuals, behavior which is developmentally inappropriate (Chaffin et al., 2008). For the purpose of the present study, the definition does not include behavior which appears sexual in nature and is a symptom of sensory disintegration, such as disrobing.

A study by Tarren-Sweeney (2008) did exploratory analyses within a larger epidemiological study. The study examined the relationships of numerous demographic predictor variables with problematic sexual behavior in a sample of 347 children between the ages of 6–11

(Tarren-Sweeney, 2008). Demographic variables included age, exposure to maltreatment, age of entry into foster care, and number of adverse events within the last year. The criterion variables included scores for behavioral and psychiatric problems on the following measures: the Achenbach Child Behavior Checklist (Achenbach, 1991), the Assessment Checklist for Children (Tarren-Sweeney, 2007), as well as the Assessment Checklist for Children Sexual Behavior Problem (Tarren-Sweeney, 2007, 2008). The participants included individuals with intellectual disability diagnosis, who were reported to be 22.5% of the total sample (n = 347; Tarren-Sweeney, 2008). Factors that were correlated with higher scores on the Sexual Behavior Scale of the Assessment Checklist for Children were age of entry into the foster system (r=.28, p = .002) and contact sexual abuse (OR = 3.9, p = .002; Tarren-Sweeney, 2008). However, the diagnosis of intellectual disability was not found to be associated with the development of problematic sexual behavior within the sample (Tarren-Sweeney, 2008).

Another study by Levenson et al. (2016) surveyed rates of ACEs across a sample of 679 adult males who were participating in sex-offender programs across the United States. Twenty-seven percent of the population also included individuals who were civilly committed (Levenson et al., 2016). The Adverse Childhood Experiences questionnaire was administered to the participants, and the results were compared with ACE scores within a sample of general population males, collected by the Centers for Disease Control (CDC; 2013, as cited in Levenson et al., 2016). Compared with the CDC sample, the sex-offender sample had nearly 3 times the odds of experiencing childhood sexual abuse and 2 times the odds of having experienced physical abuse during childhood (Levenson et al., 2016). Additionally, the sex-offender sample had 13 times the odds of childhood verbal abuse and 4 times the odds of having experienced neglect during childhood, as compared with the general CDC sample (Levenson et al., 2016).

Aggression. Operationally, aggression can include physical assaults on others, especially support staff (Reed et al., 2004). It can also include threatening behavior that is directed toward inanimate objects, such as destruction of property or throwing objects (Visser et al., 2013). Another defining characteristic is that aggressive behavior threatens, or has the potential to threaten, the safety of others (Visser et al., 2013).

Owen et al. (2004) examined the cumulative effects of traumatic experiences on problem behaviors of adults with IDD. Participants (*N*= 93) were adults who resided in a long-term care hospital in the United Kingdom (Owen et al., 2004). Problem behavior was measured using the Behavior Problems Inventory (BPI; González et al., 2009) and adaptive behavior was measured using The Adaptive Behavior Scale Short Form (SABS; Hatton et al., 2001). Adverse events were measured using a self-report inventory that was created for the specific population and included events specific to those in institutionalized settings (Owen et al., 2004). The self-report included events such as having been a victim of attack by a peer, changes in family visitation, physical injury, and loss of a preferred support staff (Owen et al., 2004). Notable findings included that participants in the sample who were more likely to experience adverse life events were males, as well as individuals with higher adaptive functioning, specifically in the Community Self Sufficiency subscale of the SABS (Owen et al., 2004). There was a significant positive correlation between number of adverse experiences and aggressive behavior ($r = .20$, $p=.05$). The mediating variables for number of adverse experiences and aggressive behavior were age and additional disabilities, including physical health problems, hearing or vision impairment, and epilepsy (Owen et al., 2004).

Self-Injurious Behavior. Self-injurious behavior (SIB) describes broad behavioral expressions of self-harm (Glaesser & Perkins, 2013). Behaviors include suicidal behavior, and non-suicidal self-injury, such as cutting (Glaesser & Perkins, 2013). Individuals with IDD may also exhibit stereotypic behaviors, such as head-banging or skin and hair-picking (Glaesser & Perkins, 2013). These behaviors commonly lead to tissue damage or physical injury, and in the case of suicidal behavior, can result in death (5th ed.; DSM-5; American Psychiatric Association, 2013, as cited in Glaesser & Perkins, 2013).

Research suggests that the prevalence of internalized problem behavior, specifically, self-injurious behavior, is negatively correlated with intellectual ability (Rojahn & Esbensen, 2002). As such, individuals with more severe intellectual disability are more likely to engage in self-injurious behavior (Rojahn & Esbensen, 2002). Matson et al. (2008) examined the relationship between self-injurious behavior and other problem behaviors in adults with IDD, such as stereotypy and irritability, among others. Participants ($N=202$) of an equal number of males and females were confirmed by clinicians to present with self-injurious behavior (Matson et al., 2008). A control group was matched with the experimental group. Using the Aberrant Behavior Checklist (ABC; Aman & Singh, 1986), the researchers gathered data on the presence of lethargy, stereotypy, hyperactivity, and inappropriate speech for each participant (Matson et al., 2008). Additionally, data were collected on the presence or absence of the following maladaptive behaviors: tantrums, physical aggression, verbal aggression, property destruction, noncompliance, problematic sexually inappropriate behaviors, and eating-related behaviors (Matson et al., 2008). The analysis revealed significant effects of self-injurious behaviors and the following problem behaviors: physical aggression [$x2(1) = 5.52$, p < .020], sexually inappropriate behaviors [$x2(1) = 6.38$, p < .013], and property destruction [$x2(1) = 5.67$, p <

.018] (Matson et al., 2008). Sexually inappropriate behaviors were found to have the highest correlation with self-injurious behaviors (Matson et al., 2008). The researchers did not collect data on the presence of traumatic or adverse life events in order to explore a potential relationship between exposure to trauma and maladaptive behaviors (Matson et al., 2008).

Neurobiological Impacts. Research on the impact of trauma on neurobiology appears to parallel the above findings in the general population. To date, there has been minimal research involving structural neuroimaging in adults with IDD as it relates to trauma.

In the general population, early experiences of trauma have been found to change the course of structural neurological development, which increases vulnerability to acute stressors (Creeden, 2009). A literature review by Tyrka et al. (2013) summarized findings from neuroendocrine, neurotrophic, and neuroimaging studies which focused on the impact of chronic stress on neurobiology. Normative exposure to stress has been shown to initiate secretions of corticotropin-releasing hormone and arginine vasopressin from the hypothalamus (Tyrka et al., 2013). This allows for the release of cortisol to initiate fight-or-flight responses during acute stress (Tyrka et al., 2013). This normative hormonal imbalance requires a process of homeostasis following acute stress responses (Tyrka et al., 2013). During prolonged exposure to stress, the endocrine system is prohibited from returning to baseline, imposing long-term alterations in the autonomic and immune systems (Tyrka et al., 2013).

Childhood adversity has also been linked with structural abnormalities (Tyrka et al., 2013). Abnormalities have been observed by structural neuroimaging, specifically in the areas of the prefrontal cortex, corpus callosum, amygdala and hippocampus (Hart & Rubia, 2012). These areas are implicated in self-regulation, communication, and the development of interpersonal

relationships (Creeden, 2009). It has been hypothesized that damage to these areas can lead to the development of maladaptive behavior in affected individuals (Creeden, 2009).

Assessment Measures of Trauma for IDD

SAMSHA (2015) advocates for the use of screening measures to identify clients for whom TIC would be beneficial. The unique characteristics that are present within the mild IDD adult population require further consideration. The ACE questionnaire (Felitti et al., 1998) is routinely used in medical settings with the general population. However, the ACE questionnaire has not been empirically validated on the IDD population (Wigham et al., 2011). Instead, collateral interviews with direct support staff and family members are commonly used to gather psychosocial data (Wigham et al., 2011). These informant accounts may overlook the subjective experience of individuals who have experienced trauma (Wigham et al., 2011). The reliance solely on informant data has been a considerable limitation within previous research on prevalence of adverse or potentially traumatic experiences in the IDD population (Martorell et al., 2009). This is due, in part, to the potential for underreporting or misreporting by informants (Martorell et al., 2009).

The utilization of self-reports presents other challenges in the IDD population, due to potential deficits in comprehension, communication, and emotion recognition (Wigham et al., 2011). A chapter by Mevissen et al. (2016) summarized the literature on assessment of trauma and IDD. The authors identified three previously published measures with favorable psychometric properties, which collectively incorporated both informant and self-report responses (Mevissen et al., 2016). The three measures were: (a) the Impact of Event Scale – Intellectual Disabilities (Hall et al., 2014), (b) the Lancaster and Northgate Trauma Scales (Wigham et al., 2011), and (c) the Adapted Anxiety Disorder Interview Schedule PTSD section

(Mevissen et al., 2014, 2016). These measures focus on characterizing the symptoms of PTSD which may be present in adults with IDD, rather than on exposure to adverse life events.

Measures of Problem Behavior

Research within other institutionalized settings has measured the presence of problem behavior with incident reports completed by direct-care staff (Morrison, 1988). The use of incident report data for this purpose has been shown to have advantages and disadvantages (Gifford & Anderson, 2010; Lion et al., 1981; Morrison, 1988). Incident reporting can provide information about environmental triggers and prompting events which may have contributed to a problem behavior (Morrison, 1988).

The use of incident reports and behavioral data for tracking frequency of behavior is subject to human error. Direct support staff are often responsible for documenting the type of behavior and providing critical details (Archer et al., 2019). Research by Lion et al. (1981) has shown that incidents of aggression are often underreported by direct-care staff in inpatient settings. Phenomenological studies have indicated several barriers for direct support staff to reporting behavioral incidents, including: cultural and sociological characteristics of individual staff members (Archer et al., 2019), the quality of the relationship between the staff member and patients or clients (Gifford & Anderson, 2010), and fear of blame or reprimand by supervisors, among others (Gifford & Anderson, 2010).

Research Questions

This study used a quantitative method to explore the relationship between ACEs and problem behaviors in a community-based sample of adults with IDD. My research questions were:

1. Do total Adverse Childhood Experiences (ACE) questionnaire scores increase the odds of problem behaviors, such as physical aggression and problematic sexual behavior? That is, do higher scores on the ACE questionnaire correlate with higher frequencies of problem behaviors?

2. Which individual items from the ACE questionnaire respectively correlate with specific problem behaviors (self-injurious behavior, problematic sexual behavior, property destruction, aggression toward others, and elopement)?

3. Are there differences among scores on the ACE and frequencies of problem behaviors within different demographic groups (e.g., males and females, age groups, racial and/or ethnic groups, and early foster care involvement)? Do some demographics act as moderator variables?

Definition of Terms

Below are definitions of terms that were used for the study:

1. Intellectual developmental disorder (IDD): Diagnostic criteria for IDD is derived from the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; *DSM-5*, American Psychiatric Association, 2013). Characteristics include impairments in three major skill domains (a) conceptual, (b) social, and (c) practical. These areas include accompanying deficits in academic skills, functional abilities, emotion regulation, executive functioning and communication (American Psychiatric Association, 2013). IDD is diagnosed through an examination of developmental history, a measure of adaptive functioning, and a standardized test of intellectual functioning (American Psychiatric Association, 2013). For the purpose of the study, individuals were assumed to carry the diagnosis of IDD, as they were previously determined eligible for supported services through the Bureau of

Developmental Services (New Hampshire Code of Administrative Rules, 1994). As most

research in IDD has examined individuals with mild and moderate severity, the scope of

the study focused on this diagnostic category.

2. Problem Behaviors: Although the term "challenging behavior" has been used in the study

of intellectual disabilities, the associated behaviors are broad and include instances of

yelling and screaming (Myrbakk & Tetzchner, 2008). The term "problem behavior" was

adopted in the present study, as it encompasses behaviors which pose a risk to the

individual and others in the community. Problem behavior includes self-injurious acts,

aggression, sexually aggressive behavior, and property destruction (Luiselli, 2012). These

acts negatively impact the quality of life for individuals who engage in them due to the

likelihood of increased programmatic restrictions, legal consequences, and the negative

impact on support systems (Lloyd & Kennedy, 2014).

Chapter 2

Method

The present study explored relationships among Adverse Childhood Experiences (ACEs) and a series of problem behaviors of adults with intellectual developmental disorder (IDD). I used archival data consisting of psychological evaluations, behavioral data, and incident reports to code independent and dependent variables. Independent variables were total ACE score and individual ACE items from the ACE questionnaire (Felitti et al., 1998), and the dependent variables were frequencies of problem behaviors. Furthermore, I examined relationships among demographic variables, ACEs and problem behaviors.

Participants

The study participants ($N = 41$) were individuals residing in staffed residences and enhanced family care. The age range of the sample was 22–67 years, with 48.8% ($n = 20$) men and 51.2% ($n = 21$) women. Most participants, 90.2% ($n = 37$), were White, 7.3% ($n = 3$) Hispanic/Latinx, and 2.4% ($n = 1$) Mixed Race. The majority of the participants, 95.1% ($n = 39$), spoke English as their first language, and for 4.9% ($n = 2$) English was not their first language.

Regarding residential arrangements, 78% ($n = 32$) lived in enhanced family care and 22% ($n = 9$) lived in a staffed residence. Individuals living in an Enhanced Family Care setting resided with a single staff provider. Information regarding foster care and adoption during childhood was collected. The majority, 63.4% ($n = 26$), did not live in foster care, and about a third, 36.6% ($n = 15$), had been placed in foster care prior to age 18. Most of the participants, 90.2% ($n = 37$), resided with biological parents, while 9.8% ($n = 4$) were adopted. See Table G.1 for participant demographic information.

Regarding criminal history, 65.9% ($n = 27$) had never been charged with a criminal offense, 14.6% ($n = 6$) was charged with a sex offense, 14.6% ($n = 6$) was charged with a violent offense, and 4.9% ($n = 2$) was charged with a stalking offense or given a restraining order. Most participants did not have a criminal history.

Diagnoses were also collected from the records, which included two diagnostic categories: (a) a primary disability diagnosis, and (b) a psychiatric diagnosis. Regarding the primary disability diagnoses, the most frequent diagnosis was Mild Intellectual Disability (58.5%, $n = 24$). Other primary diagnoses included: Moderate Intellectual Disability (17.1%, $n = 7$), Autism Spectrum Disorder (4.9%, $n = 2$), Borderline Intellectual Functioning (4.9%, $n = 2$), Pervasive Developmental Disorder (4.9%, $n = 2$), Dementia-Related Disorders (4.9%, $n = 2$), Down's Syndrome (2.4%, $n = 1$), and Huntington's Disease (2.4%, $n = 1$). There were 15 secondary diagnoses including: Bipolar Disorder (17.1%, $n = 7$), Post-traumatic Stress Disorder (PTSD; 14.6%, $n = 6$), and Anxiety Disorder (9.8%, $n = 4$). Another 7.3% ($n = 3$) of participants had not been diagnosed with a psychiatric disorder. A diagnosis of obesity was present for 19.5% ($n = 8$). All participants met criteria for intellectual or developmental disabilities in order to receive funding for developmental services.

Almost two-thirds of participants remained in a specific residence for longer than 24 months (63.6%, $n = 26$). The other third lived in the current residence for two years or less (36.4%, $n = 15$). Most participants did not experience a residential transition during the period of observed data (63.4%, $n = 26$). There were 14 participants who experienced one residential transition (34.1%), and one participant had two transitions over 24 months (2.4%). Table G.1 summarizes participant demographics (see Appendix G for all tables).

Inclusion Criteria

The eligibility criteria included residence in an intensive treatment program, enhanced family care, or staffed residence. Individuals also received specialty services funding for enhanced clinical services, such as individual therapy and behavior management. Individuals with the primary diagnosis of a traumatic brain injury were excluded.

Measures

I collected the following demographic information on each participant: (a) biological sex, (b) foster care involvement, (c) ethnicity, (d) age, (e) primary language, (f) history of foster care, (g) history of adoption, (h) current residential placement, (i) number of months in current residential placement, and (j) whether the individual had a diagnosis of obesity. See Appendix D for the list of demographic variables.

BRFSS Adverse Childhood Experiences Questionnaire (Felitti et al., 1998)

The Adverse Childhood Experiences (ACE) scale is a 11-item measure which assesses the presence of seven specific areas of maltreatment and dysfunction in early childhood (Felitti et al., 1998). The measure was developed by Felitti et al. at the Kaiser Permanente Health Organization in conjunction with the Centers for Disease Control and Prevention. ACE items were constructed utilizing existing measures. Items related to psychological and physical abuse were adapted from the Conflicts Tactics Scale (Straus & Gelles, 1990). These items include questions about being hit by a parent, insulted by a parent, among others (Felitti et al., 1998). Four items related to sexual abuse were derived from Wyatt's (1985) research on childhood sexual abuse. The corresponding items include inquiry about sexual touching and attempts at engaging in sexual acts by an adult or individual 5 years older than the respondent (Felitti et al., 1998). The 1988 National Health Interview Survey (National Center for Health Statistics, 1991)

was also utilized to identify questions related to household dysfunction (Felitti et al., 1998). These items include questions regarding instances of aggression directed toward the respondent's mother or stepmother by another adult in the home (Felitti et al., 1998). During typical administration of the ACE questionnaire, participants respond to items by marking *yes, no, refuse, don't know,* or *not applicable* (Felitti et al., 1998). All *yes* responses are scored as 1, and all other responses to items are scored as 0 and are not included in the total score. The sum of the *yes* responses is the total ACE score. Therefore, an individual may receive a total ACE score between 0 and 11.

Scores of 4 or greater on the ACE questionnaire have been shown to have significant positive relationships with negative health outcomes, including suicidality, depression, high-risk sexual behavior, and substance abuse (Centers for Disease Control and Prevention, as cited in Cronholm et al., 2015; Felitti et al., 1998). The presence of ACE items increased the odds that an individual would be diagnosed with the aforementioned mental health problems. The odds ratio for suicidality has been shown to have the highest elevation, especially for ACE scores of 4 or greater (OR = 12.2; Felitti et al., 1998). ACE scores of 2 were found to increase the odds of depression (OR = 2.4) and ACE scores of 4 or greater nearly doubled the odds for depression (OR = 4.6; Felitti et al., 1998). Internal consistency reliability of the ACE is acceptable, given the low number of items ($\alpha = .78$; Ford et al., 2014). Although the ACE questionnaire was not designed with subscales, further examination of the measure's factor structure suggested that three indices exist reliably within the measure: emotional/physical problems, household dysfunction, and sexual abuse (Ford et al., 2014). For the purpose of the present study, individual ACE items and total ACE scores were analyzed as ordinal variables.

Rating of ACE Scores for the Present Study. The BRFSS ACE Module is not

copyrighted and is free for research uses (see Appendix E). A modified version of the ACE

questionnaire was used to identify the presence of adverse events in historical records available

in an archived database. I utilized psychological evaluations, clinical risk assessments, and

neuropsychological assessment reports from an electronic database to review a comprehensive

psychosocial history of each participant. One point was allotted for each item which was clearly

documented as present in a participant's record. For example, if an evaluation noted prenatal

exposure to cocaine, the ACE item regarding parental substance abuse was coded as "present."

Items which were not detailed specifically in the record were coded as missing variables. For the

9 participants with missing ACE item variables, the mean number of missing variables was

10.33. For these participants ($n = 9$), I utilized mean replacement for the variable total ACE

score. Kang (2013) notes mean replacement may be used when there is a normative distribution

of the variable. This approach was selected as the total ACE score was normatively distributed

among participants without missing items ($n = 32$; total ACE score $M = 4.72$; total ACE score

$SD = 2.47$). The overall mean for total ACE score was 3.39 for the present sample ($N = 41$).

Therefore, all missing total ACE scores ($n = 9$) were replaced with a value of 3. Each point on

the ACE questionnaire was summed for the overall ACE questionnaire score (0-11). The median

total ACE score was 4.00 and mode total ACE score was 3 ($N = 41$). The maximum ACE score

was 9 and the minimum was 1; the range of total ACE scores was 8 ($N = 41$).

Internal consistency reliability for the modified ACE measure was within the

questionable range, although nearing the acceptable range (λ-2 = .66). A lower internal

consistency reliability may be attributable to the small number of items and multidimensional

structure of the ACE questionnaire. Modification of administration in order to use the ACE for archival data may have also contributed to a lower internal consistency reliability.

Rating of Incident Reporting: Criterion Variables. Frequencies of types of problem behaviors were collected from a sample of incident reports and behavioral data, spanning over a period of 24 months from May 31, 2017 to June 1, 2019. The 24-month window for observed data was intended to capture potential variability due to effects of medication changes, residential transitions, and other extraneous variables. The frequencies of the following variables were observed: (a) total behavioral incidents, (b) aggression toward others, (c) property destruction, (d) problematic sexual behavior, (e) self-injurious behavior, and (f) attempted or succeeded elopement. Operational definitions of problem behaviors are outlined in Chapter 1.

As incident reporting may present problems with construct validity (Gifford & Anderson, 2010; Lion et al., 1981; Morrison, 1988), I implemented a validity rating system during data collection. Incident reports and behavioral data were categorized by me into 3 validity ratings based on the quality and extensiveness of information provided in each document. Ratings of 0 were prescribed for documents which did not provide enough detail to determine the type of behavior that was present. Incidents with a rating of 0 were, therefore, excluded. A rating of 1 indicated that a document likely provided enough information for me to categorize the type of behavior. For example, an incident report with a rating of 1 would include information such as, "the client then became aggressive," without a description of the observable behavior. Behavioral data which only included frequencies of aggression were also categorized with a rating of 1 because qualifiable details were not provided. Incidents with a rating of 2 indicated that an incident report most likely provided enough information to accurately categorize the behavior. An example of an incident report with a rating of 2 included information such as: "the

client postured and ran toward me, striking me on the shoulder with a closed fist." This type of

narrative provided details of the observable behavior which aided in accuracy of categorization.

Data for each problem behavior consisted of frequencies of 1-ratings, frequencies of 2-ratings,

and total frequencies of each type of problem behavior. To calculate Odds Ratios with Chi

-Square tests of association, the above continuous criterion variables were translated into

dichotomous variables (e.g., present and not present), and were categorized as nominal data.

Procedure

      Prior to the start of data collection, I obtained exempt status for the study through two

review boards, the Antioch University New England Institutional Review Board and the New

Hampshire Committee for the Protection of Human Subjects. As the study was determined to be

exempt, individual and legal guardian consent to participate were not required. After consultation

with the Moore Center HIPAA Officer and the completion of a formal non-disclosure agreement,

I reviewed personally identifiable information.

Sampling

      Convenience sampling was the primary method of recruiting participants. I provided the

Moore Center Clinical Director with a list of the inclusion criteria. The Moore Center Clinical

Director identified a nominated sample of 51 clients who were receiving individual therapy and

community-based developmental services in New Hampshire. The clients were from the

caseloads of four Moore Center clinicians. Clients' archival data were provided to me by the

Moore Center Clinical Director. Individuals residing with family were excluded from the sample

($n = 10$). The list of participant names was provided to me in a sealed envelope that was

available at the reception desk at The Moore Center office and addressed to me.

Data Collection

I conducted the first phase of de-identifying subjects and gathering demographic information on location at The Moore Center office on June 3, 2019. I performed subsequent data collection remotely at my residence between August 2019 and December 2020. I utilized a digital spreadsheet for data collection and analysis. I coded each participant on the spreadsheet with an identification number. I maintained identification numbers in a password-encrypted digital document which was available on a password-encrypted computer owned by me. I obtained non-identifiable demographic information from the encrypted online database service, Harmony. I entered each variable with a numeric label into the SPSS version 26 program. The spreadsheet included the following raw data: demographic variables, primary and secondary diagnoses, ACE questionnaire items and total raw score, and raw frequencies of behavioral data (e.g., number of incident reports). The spreadsheet did not contain any personally identifying information.

I utilized a separate database for archived information containing personal histories of each participant, which was used to score the ACE questionnaire as well as recent behavioral incidents. I accessed the database through the agency's password-encrypted portal. Access to the portal and access to the database both required a password specific to me.

Confidentiality

Raw data were only accessed by me. I maintained a password-encrypted document of all data. This password-encrypted document was destroyed upon completion of the dissertation. Confidentiality was observed in the reporting of results. Specifically, as the results involved correlational analyses, I was not required to present any specific case (e.g., "26-year-old man with diagnosis of cerebral palsy ….").

Anonymity

Participant anonymity was not guaranteed due to the nature of archival data collection. As such, I collected minimal identifying information to prevent identity disclosure. The names of participants, town names, and other identifying information were excluded from the dissertation and will be excluded from subsequent research reports and presentations.

Research Hypotheses

The hypotheses for the study were as follows:

1. Total ACE scores will have a positive significant correlation at $p < .05$ with frequencies of the problem behaviors of aggression, self-injurious behavior, substance abuse, elopement, and property destruction, respectively.

2. There will be a positive significant correlation between exposure to sexual abuse on the ACE questionnaire and frequencies of problematic sexual behavior at $p < .05$ and self-injurious behavior at $p < .05$.

3. There will be a significant positive correlation between the ACE item, witnessing domestic violence, and frequencies of aggression toward others at $p < .05$.

4. Scores on the ACE, diagnostic classifications, and their respective interactions with demographic variables will predict the total frequency of problem behaviors at a significant level of $p < .05$ for a medium effect size.

Data Analyses

Descriptive statistics were calculated to identify mean, median, and standard deviation for total ACE scale score, each problem behavior, and total problem behavioral incidents. Two non-parametric analyses were used to assess for the presence of a relationship among ACE scores and problem behaviors. A Kendall's Tau-B correlation ($p=.05$) was used to examine the

strength and direction of correlations. Odds ratios (OR) with Chi-Square analyses were used to determine if the presence of ACE items increased the odds of the presence of problem behaviors (CI=95%). A hierarchical multiple regression was performed with the ACE scores, diagnostic classifications, select demographic variables, and interactions of demographics with ACE scores and diagnostic classifications as predictor variables, with problem behaviors as the criterion variable.

Conclusion

The proposed study used correlational and odds ratio analyses to explore relationships between adverse experiences and the presentation of problem behavior among adults with IDD. Data on trauma exposure were collected with the empirically validated instrument, the ACE questionnaire (Felitti et al., 1998), which was adapted for use as a screening tool with a review of archival records. Frequencies of problem behavior over the last 24 months were obtained from The Moore Centers' database, located in Manchester, NH. Problem behavior was also examined for different demographic groups, such as age, sex, and family/foster care involvement.

The goal of the study was to contribute to the growing literature on the impact of trauma on the IDD population. It also sought to provide pragmatic information to The Moore Center that may help the agency improve screening procedures for existing and future clients. Improved screening could assist The Moore Center in adhering to the model of Trauma-Informed Care and will help to determine level of support and treatment that are needed for its clients.

Chapter 3

Results

The purpose of the study was to explore relationships of the independent variables, total ACE Scores and individual ACE items, and the dependent variables, frequencies of problem behaviors of 41 participants. These participants were adults receiving community-based day, residential, and clinical programming at The Moore Center, Manchester, NH. The Clinical Director of the program referred me to the participants' archived data for a record review.

Sample Determination

For nine participants, an average of 10.33 out of 11 ACE items were not scored due to incomplete information in their respective archived records. As such, I used pairwise deletion to examine correlations among individual ACE items, which resulted in a sample size of $n=32$. As a second step, a mean replacement of 3 was used to calculate the total ACE Score for participants who were missing individual ACE items, which resulted in a sample of $N=41$ for the analyses with total ACE scores. For the Odds Ratios and Chi-Square analyses, missing individual ACE items were treated as missing (i.e., scored "not present") and not provided a mean replacement.

Total ACE Score Descriptive Statistics

For the total ACE score after mean replacement ($N= 41$), 49% received a total ACE score of 3 and below ($n=20$), and 51% received a Total ACE Score of 4 or greater ($n=21$), resulting in a total ACE score mean of 4.34 and a standard deviation of 2.29. Figure 1 depicts frequencies of scores on the ACE. Assessing for normality with a z-test (Kim, 2013), it was found that total ACE scores were normally distributed, showing a slight positive skewness of 0.545 (SE = 0.369) and kurtosis of 0.533 (SE = 0.724). Figure F.1 shows the distribution of total ACE scores. A positive skew among Total ACE scores was also observed in epidemiological research with

larger sample sizes (Cronholm et al., 2015; Ujhelyi Nagy et al., 2019). Despite the normative

distribution of total ACE scores, the ACE scores were rated ordinally which required me to use

non-parametric statistical tests, such as Odds Ratios, Chi-square analyses, and Kendall's Tau-B

correlations (Kim, 2013; Laerd Statistics, 2015).

Internal Consistency Reliability of the ACE

The Cronbach's alpha for the ACE was $\alpha = .61$. Lambda-2 was also calculated, which

was nearing the acceptable range (λ-2 $= .66$). While both measures of internal consistency

reliability were moderately low, they fell within the acceptable range because of its small

number of items (11) and a small sample (Anastasi & Urbina, 1997). A previous study showed

an internal consistency reliability of $\alpha = .78$, meeting the standard of acceptability (Ford et al.,

2014). I adapted the ACE by rating archived information, which may have contributed to the

lower internal consistency reliability.

Correlations of ACE items

Correlations of individual ACE items with the total ACE score were examined. The

sample size was $n = 32$ for the correlation analyses (see previous explanation for sample

determination). A two-tailed Kendall's Tau-B correlation was utilized as a non-parametric

alternative to a Pearson Correlation. Table G.2 lists individual ACE item correlations with Total

ACE Score.

More than half of the ACE items (7) were positively correlated with the Total ACE Score

at $p < .01$ and one item correlated at $p < .05$. The item with the highest correlation with the total

ACE Score was Parental Incarceration ($p < .01$). Other items with significant correlations were:

Forced Rape ($p < .01$), Physical Abuse ($p < .01$), Molestation ($p < .01$), Coerced to Touch

($p < .01$), Emotional Abuse ($p < .01$), and Parental Alcohol Abuse ($p < .05$).

ACE Questionnaire Subscales

The ACE incorporates three constructs of childhood adversity: (a) household dysfunction, (b) physical and emotional abuse, and (c) sexual abuse (Ford et al., 2014). Correlations among scores on the ACE items in the present study supported the presence of two indices, household dysfunction and abuse. Kendall's Tau-B correlation coefficients for each ACE sub-scale are presented in Tables G.3 and G.4.

ACE items 2 (Parental Alcohol Abuse), 3 (Parental Drug Abuse), and 4 (Parental Incarceration) were significantly positively correlated with each other at a moderate level. ACE item 6 (Witnessing Domestic Violence) was also significantly positively correlated with ACE item 4 (Parental Incarceration, $p < .05$). Internal consistency reliability for ACE subscale household dysfunction was not indicative of a relationship among variables ($\alpha = .44$). When items Parental Mental Illness and Divorce/Separation were removed from internal consistency reliability analysis, the Cronbach's alpha neared the acceptable range ($\alpha = .63$).

ACE item 7 (Emotional Abuse) had a significant moderate positive correlation with ACE item 8 (Physical Abuse) at $p < .01$. Physical Abuse also had a significant moderate correlated with item 9 (Molestation) and item 10 (Coercive Touching) at $p < .01$. Items related to sexual abuse, item 9 (Molestation), item 10 (Coercive Touching), and item 11 (Forced Rape) all had significant, moderate positive correlations with each other at $p < .01$. Internal consistency reliability for ACE items of emotional, physical, and sexual abuse was acceptable ($\alpha = .76$).

Problem Behaviors Descriptive Statistics

The distributions for all problem behaviors were positively skewed. Total incident reports had a skewness of 4.829 (SE = 0.369) and kurtosis of 26.533 (SE = 0.724). Skew statistics for specific problem behaviors are listed in Table G.5. The standard deviations for all items were

higher than the mean, showing unusually high range among scores. Analyses of differences using chi square were not expected to show significant differences. Table G.5 shows descriptive statistics.

Internal Consistency Reliability of Problem Behaviors

The internal consistency reliability of frequencies of problem behaviors was $\alpha = .72$, which fell within the acceptable range. A two-tailed Kendall's Tau-B correlational analysis was used to examine the relationship of each problem behavior with the total problem behaviors score. Table G.6 provides the Kendall's correlation coefficients.

Aggression was shown to have a significant strong positive correlation with overall behavioral incidents ($p < .01$). Self-injurious behavior ($p < .01$), property destruction ($p < .05$), and elopement ($p < .01$) were also moderately correlated with total behavioral incidents.

Research Question 1: Relationship of Total ACE Score with Problem Behaviors

The first question asked about the relationship between total ACE scores and frequencies of types of problem behaviors: (a) aggression, (b) property destruction, (c) self-injurious behavior, (d) problematic sexual behavior, and (e) elopement. Two kinds of relationships were examined. First, a question asked was whether the presence of an elevated ACE score (4 or greater) increased the odds of the presence of problem behaviors. Odds Ratios and Chi-square analyses were used to examine this question. A Fisher's Exact Test ($p < .05$) was also employed for interpretation of Odds Ratios and Chi-Square coefficients. Second, a question asked about the strength and direction of correlations between total ACE score and problem behaviors. Two-tailed Kendall's Tau-B correlations were used to examine potential relationships.

Hypothesis 1 also stated that total ACE scores would have positive significant correlations *($p < 0.05$)*, with frequencies of the problem behaviors of aggression, self-injurious

behavior, elopement, and property destruction, respectively. Hypothesis 1 was rejected. There were no significant positive correlations between Total ACE Score and incidents of aggression, self-injurious behavior, elopement, and property destruction. However, there were two significant negative correlations ($p < .05$) between total ACE score and total incident reports and total self-injurious behaviors, which included incident reports with ratings of 1 and 2. Table G.7 provides the Kendall's correlation coefficients for the total sample with mean replacement for total ACE score ($N = 41$). Table G.8 provides the Kendall's correlation coefficients for the sample with listwise deletion for missing total ACE scores ($n = 32$).

Ratings of 1 for total incident reports and total self-injurious behavior resulted in significant moderate negative correlations with total ACE score. Incident reports with validity ratings of 2 for problem behaviors of aggression, self-injurious behavior, elopement, and property destruction showed no significant positive correlations with the total ACE score.

When Kendall's Tau-B correlations were used with listwise deletion ($n = 32$), significant negative correlations among total ACE score with incident reports and self-injurious behavior were also observed ($p < .01$). There was a stronger association observed between total ACE score and incident reports using listwise deletion. Additionally, a moderate significant negative correlation was observed between total ACE score and aggression ($p < .01$).

Research Question 2: Relationship of Individual ACE Items with Problem Behaviors

For the second research question, relationships of individual ACE items 1–11 and frequencies of types of problem behaviors (aggression, property destruction, self-injurious behavior, problematic-sexual behavior, and elopement) were examined. The first relationship examined was whether the presence of each ACE item increased the odds of the presence of each problem behavior. Odds Ratios and Chi-Square analyses were used to test for this relationship. A

Fisher's Exact Test ($p < .05$) was also employed for interpretation of Odds Ratios. The second relationship examined was the strength and direction of the relationship between the presence of each ACE item and the frequency of each problem behavior. Two-tailed Kendall's Tau-B correlations were used to examine these relationships.

Hypothesis 2 also stated that there would be a positive significant correlation ($p < .05$) between exposure to sexual abuse (ACE items 9–11) and frequencies of problematic sexual behavior and self-injurious behavior, respectively. Hypothesis 2 was rejected because correlations among these variables were not significant. Table G.9 shows the Odds Ratios, Chi -square analyses, and Kendall's Tau-B correlations.

Hypothesis 3 stated that there would be a significant positive correlation ($p < .05$) between Witnessing Domestic Violence and frequency of aggression. Odds Ratio and Chi-square analyses indicated that witnessing domestic violence did not significantly increase the odds of aggression. The two-tailed Kendall's Tau-B correlation yielded a significant negative correlation ($p < .05$) between Witnessing Domestic Violence and aggression. Other ACE items, however, demonstrated a significant positive relationship with problem behaviors. Table G.10 provides these results.

The results suggested that Parental Alcohol Abuse and Parental Drug Abuse both increased the odds of participants engaging in elopement (3-fold, and 6-fold, respectively, $p < .05$). Parental Drug Use further increased the odds of the problem behavior, property destruction by 11-fold ($p < .01$). The results of the Kendall's Tau-B correlations also supported findings of the Odds Ratios, as there was a moderate positive correlation for both Parental Drug Use and Parental Alcohol Use and elopement ($p < .01$, $p < .05$, respectively). Parental Drug Use also had a moderate positive correlation with property destruction ($p < .05$).

Parental Incarceration and Forced Rape both had a significant negative correlation with the problem behavior of aggression ($p < .05$). Furthermore, Forced Rape had a significant negative correlation with total incidents reports ($p < .01$).

Research Question 3: Relationship of Demographic Variables to Problem Behaviors

Last, the predictive power of demographic variables and total ACE score for problem behavior was examined. Hypothesis 4 stated that scores on the ACE, diagnostic classifications, and their respective interactions with demographic variables would predict total incident reports ($p < .05$). I did not proceed with a hierarchical multiple regression analysis, as proposed for the data analyses in Chapter 2, due to a violation of a test assumption, which requires linear relationships among the independent and dependent variables. There were no significant correlations for total ACE score, demographic variables, and the dependent variable, total incident reports.

To further examine the impact of demographics on problem behaviors, I conducted Odds Ratios, Chi-square analyses, and two-tailed Kendall's Tau-B correlations for the following demographic variables: male sex, presence of a mood disorder diagnosis, history of foster care, and history of adoption. Table G.11 outlines the results of these tests.

The results yielded no significant relationships among the demographic variables, male sex, presence of a mood disorder, and history of foster care, with total incident reports. History of adoption did not increase the odds of a participant engaging in problem behavior; however, history of adoption had a significant low positive correlation with frequency of total incident reports ($p < .05$).

Supplemental Analyses

Relationship of Demographic Variables to Total ACE Score

Finally, I conducted Odds Ratios with Chi-square analyses to determine whether a total ACE score of 4 or greater increased the odds of having been placed in foster care, having been charged with a crime, having been diagnosed with a mood disorder, and having been diagnosed with obesity. Table G.12 gives these results.

The results suggested the odds of being placed in foster care increased 14-fold when total ACE score was 4 or greater ($p < .01$). Additionally, the odds of having been charged for a criminal offense were increased 6-fold when total ACE score was 4 or greater ($p < .05$). The findings did not suggest that total ACE score increased the odds for the diagnoses of both obesity and a mood disorder.

Bonferroni Correction

A post-hoc Bonferroni correction was applied to reduce the potential for familywise error for each set of analyses (Field, 2013). The first research question required 11 correlational analyses at alpha level .05. Therefore, the adjusted p-value for the Kendall's Tau-B correlations was .004. No significant correlations were observed among total ACE score and problem behaviors at the adjusted significance level. The second research question utilized 66 Kendall's Tau-B correlations at the alpha level .05, wherein the adjusted p-value was calculated to be .00075. Similarly, there were no significant correlations observed at the adjusted significance level. For the third research question and supplemental analyses, an adjusted p-value of .0125 was utilized. With the adjusted significance level, there were no significant correlations among total incident reports and demographic variables. The Odds Ratio for total ACE score of 4 or greater and criminal charges was also not significant with the adjusted p-value. However, the

correlation for ACE score of 4 or greater and foster care remained significant with the

Bonferroni correction ($p = .001$).

Conclusion

For a sample of adults with developmental disabilities receiving community-based care,

archival data on these patients were examined to rate the ACE Questionnaire and frequencies of

incident reports for problem behaviors over a 24-month period. Regarding individual ACE items,

the presence of the ACE item, Parental Drug Abuse, increased the odds 6-fold for the presence of

elopement ($p < .05$), and 11-fold for the presence of property destruction ($p < .01$). Kendall's

Tau-B correlations also supported these relationships, suggesting a significant moderate positive

correlation of Parental Drug Abuse with property destruction ($Tb = .47$, $p < .01$) and elopement

($Tb = .42$, $p < .05$). Individual ACE item, Parental Alcohol Abuse, similarly demonstrated a

significant moderate positive correlation with elopement ($Tb = .34$, $p < .05$).

The individual ACE items, Witness Domestic Violence, Forced Rape, and Parental

Incarceration had significant moderate negative correlations with aggression ($p < .05$). ACE Item

11, Forced Rape, also had a significant moderate negative correlation with total incident reports

($p < .01$). Having been adopted had a significant but small positive correlation with total incident

reports ($p < .05$).

Kendall's Tau-B correlations, Odds Ratios, and Chi-square analyses examined

relationships among total ACE score, individual ACE items, and select demographic variables

with frequencies of types of problem behaviors. Results showed no significant positive

relationships between total ACE score and types of problem behaviors. The Kendall's Tau-B

correlations showed a significant small negative correlation for total ACE score and total

incident reports ($Tb = -.29$, $p < .05$), and a significant moderate negative correlation between

total ACE score and self-injurious behavior (Tb = -.33; $p < .05$). When listwise deletion was

used, the significant negative correlations were also significant at the $p < .01$ level, and there was

also a significant negative correlation observed between total ACE score and aggression

(Tb = -.39, $p < .01$). The presence of adoption had a significant small positive correlation with

total incident reports ($p < .05$). Total ACE scores of 4 or greater increased the odds for the

presence of the demographic variables, foster care (OR = 6.23, $p < .05$) and criminal charges

(OR = 14.62, $p < .01$). The only finding which remained significant with adjusted p-values was

the association between ACE score of 4 or greater and foster care.

Chapter 4

Discussion

The study examined relationships among adverse childhood experiences and problem

behaviors for adults diagnosed with intellectual developmental disorder (IDD) who received

community-based care. I reviewed participants' archival case histories to collect data on

demographic variables and problem behaviors. The case histories were used, in addition, to score

the Adverse Childhood Experiences (ACE) questionnaire. Current literature suggests that

individuals with IDD are more likely than the general population to experience traumatic events

(Sullivan & Knuston, 2000), and that exposure to trauma may be associated with poor mental

health and high-risk behaviors (Hulbert-Williams et al., 2014). The study also examined

relationships among demographic variables and problem behaviors, as well as total ACE scores

and criminal involvement. The discussion interprets the findings and relates them to previous

research. Clinical implications, study limitations, and recommendations for future research are

also provided.

Descriptive Statistics

Total ACE Score

About half of the sample had a total ACE score of four or greater (51.2%, $n = 21$), and

about half had a score lower than four (48.8%, $n = 20$). ACE scores of 4 or greater have been

shown to double the risk of depression and suicidality (Cronholm et al., 2015) and are considered

to be elevated (Cronholm et al., 2015; Felitti et al., 1998; Vallejos et al., 2017). The most

commonly endorsed individual ACE item for the sample was divorce and separation (65.9%, $n =$

27), followed by physical abuse (46.3%, $n = 19$), emotional abuse (41.5%, $n = 17$), parental

mental illness (41.5%, $n = 17$), molestation (39%, $n = 16$), parental alcohol abuse (31.7%,

n = 13), forced rape (29.3%, *n* = 12), and coerced touch (26.8%, *n* = 11). Total ACE scores in

the sample were higher than ACE scores of the general population; however, elevated total ACE

scores are observed among clinical populations (Cleare et al., 2018; Vallejos et al., 2017;

Whitfield et al., 2005). The original ACE survey was completed by a non-clinical sample of

adults (Felitti et al., 1998). One-fourth of the original ACE sample had a total ACE score of

greater than or equal to 2, and only 6.2% of the sample received a total score of 4 or more (Felitti

et al., 1998). In contrast, clinical and forensic samples have shown higher percentages with ACE

scores of 4 or greater, including men diagnosed with schizophrenia (63%; Vallejos et al., 2017),

inpatients with repeat self-injurious behavior (62%; Cleare et al., 2018), and male sex offenders

and male perpetrators of intimate-partner violence (48%; Reavis et al., 2013).

There remains minimal research on trauma exposure, as measured by the ACE

questionnaire, among adults with IDD. One case-file study among Dutch youth with IDD in

residential care found that 21.5% had an ACE score of 4 or greater (Vervoort-Schel et al., 2018).

Given that individuals with IDD are estimated to be four times as likely to experience traumatic

events throughout the lifespan (Sullivan & Knuston, 2000), the elevated ACE scores in the

present study appeared to support previous conclusions that individuals with IDD have a higher

prevalence of adverse life events as compared with the general population.

Problem Behaviors

The most common problem behavior among the sample was aggression, which occurred

within 82.9% of participants (*n* = 34). Other common behaviors were self-injurious behavior

(41.5%, *n* = 17), elopement (34.1%, *n* = 14), and property destruction (26.8%, *n* = 11). Research

on problem behaviors in adults with IDD in community programming found similar percentages,

where physical aggression (51.9%, *n* = 124) and verbal aggression (39.7%, *n* = 95) were most

common, followed by property damage (23.8%, $n = 57$; Lindsay et al., 2010). In another study,

which measured problem behaviors with the Aberrant Behavior Checklist (Aman & Singh,

1986), aggression toward others was the second most common problem behavior for the sample

(38%, $n = 27$), after temper tantrums/outbursts (Myrbakk & Von Tetzchner, 2008).

Despite the amount of existing research on adults with IDD who engage in problematic

sexual behavior, sexualized behavior was not common among the present sample. While it was

possible that the 24-month window of data collection on problem behaviors might not have

included prior sexualized behaviors, there were also few participants who had been charged with

sexual crimes during their lifetime (15.6%, $n = 5$). It is, therefore, possible that individuals with

IDD who have engaged in problematic sexual behavior may have greater representation in

institutionalized or correctional settings, rather than within community-based settings. Overall,

the characteristics of problem behaviors in the sample seem to be reflective of the minimal

existing research on adults with IDD in community-based settings.

Analyses

Odds Ratios, Chi-Square, and Fisher's Exact Tests

Odds ratios showed no significant relationships between individual ACE items and

problem behaviors. The exception was for Parental Drug Use which significantly increased the

odds of (a) elopement by 6-fold, and (b) property destruction by 11-fold. These findings suggest

that individuals in the sample who were exposed to substance abuse by parents during formative

years showed greater propensity toward externalized behaviors, which was consistent with

previous research (Bailey et al., 2009). Owen et al. (2004) found that the presence of adverse

childhood experiences was significantly correlated with aggression in adults with IDD, including

aggression toward inanimate objects. Owen et al. also found that there may be variables which

mediate the relationship between ACEs and aggression, which include comorbidity of epilepsy and physical disabilities. While diagnostic information was collected for the present study, information on physical disabilities was not available, and there were no individuals with comorbid epilepsy to examine its potential mediating effect on ACEs and aggression.

Research has also supported the specific negative impact of parental substance abuse on psychosocial and behavioral development within the general population. For instance, one longitudinal study with neurotypical adolescents found that parental substance abuse predicted externalized behavior, including property destruction and running away from home (Bailey et al., 2009). There is a lack of research investigating similar relationships for adults with IDD, although there are studies examining adverse biological impacts of prenatal substance abuse, particularly when there is prenatal substance exposure (Dixon et al., 2008; Weinberg, 1997). It was not possible to understand the potential biological impacts of parental drug use in the present sample because information regarding prenatal exposure and types of substances used in parents of the participants was not provided.

A total ACE score of 4 or greater did increase the odds of participants having been charged for a criminal offense, including sexual crimes, stalking/restraining orders, and assaults (OR = 6.23, CI=1.39, 27.84). These results seemed to support the existing literature for forensic populations. Adult sex offenders were found to have 3 times the odds of experiencing sexual abuse and twice the odds of experiencing physical abuse, as compared with the original ACE sample (Levenson et al., 2016). Research on juvenile offenders has found that exposure to familial violence was moderately correlated with criminal behavior (Brown et al., 1999), and that elevated ACE scores increased the odds of sexual offending (DeLisi et al., 2017). It is also possible that criminal behavior may have been overrepresented within the present sample.

Criminal histories of participants might have served to identify these participants of needing

additional clinical supports, such as individual therapy. Individuals with higher acuity and

potentially legal involvement might have been more likely to meet participant criteria, due to

requiring a higher level of support and higher cost budget.

Of note, male sex did not significantly increase the odds of problem behaviors in the

sample. Previous research has demonstrated mixed results regarding the predictive power of sex

on problem behaviors. Females have been shown to be less likely to engage in externalized

behavior (Tsiouris et al., 2011), although one study found no differences in aggression among

males and females (Sigafoos et al., 1994). However, given that the confidence interval for the

OR was large (CI = .30, 33.31), it is possible that a significant relationship between male sex and

problem behaviors would be observed in a larger sample.

Kendall's Tau-B Correlations

The results of the Kendall's Tau-B correlations yielded similar findings as the results of

the Odds Ratios and Chi-square analyses. Total ACE score did not have any significant positive

correlations with problem behaviors, although two negative correlations were observed. Total

ACE Score had a significant moderate negative correlation with both total incident reports and

total self-injurious behaviors. This suggested that individuals with higher ACE scores

demonstrated lower rates of overall problem behaviors, and specifically self-injurious behavior.

The analysis was also completed with only frequencies of incident reports with validity ratings of

1 or 2, the second value indicating the incident reports were more descriptive and included a

narrative of the incident. There were no significant positive correlations between total ACE score

and any problem behaviors with validity ratings of two.

These findings were not consistent with previous findings of significant correlations between adverse life events and problem behaviors among adults with IDD (Hulbert-Williams et al., 2014; Owen et al., 2004). This may be due to larger sample sizes and methodological differences, such as the use of informant reports to measure problem behavior. Regarding self-injurious behavior, previous researchers have found that self-injury frequency is negatively correlated with intellectual functioning, which is, that individuals with higher intellectual functioning may be less likely to engage in self-injury (Rojahn & Esbensen, 2002). The most frequent primary diagnosis among the present sample was mild intellectual disability. Furthermore, the present sample likely represents individuals with higher intellectual and adaptive functioning, due to their ability to engage in individual therapy.

Regarding individual ACE items, there were mixed results with observed positive and negative correlations. Consistent with the significant results of the Odds Ratios and Chi-Square analyses, Parental Drug Abuse was positively correlated with property destruction ($p < .05$) and elopement ($p < .01$). There was an additional significant positive correlation between Parental Alcohol Abuse and elopement ($p < .01$), which also almost reached significance for the Odds Ratios.

There were several negative correlations among individual ACE items and problem behaviors. Parental incarceration, witnessing domestic violence, and forced rape had moderate negative correlations with aggression. Forced rape also had a moderate negative correlation with total incident reports. This was an unexpected finding: that individuals in the sample who witnessed physical violence or who were sexually victimized had lower frequencies of aggression. There are several possible explanations for these findings. It is possible that these individuals continued to experience internalized psychological distress, such as depression and

anxiety, rather than externalized behaviors. It is also possible that individuals who were rated on these ACE items might have had more behavioral problems in the past prior to the 24-month data collection period. Last, it is feasible that individuals who had been involved in individual therapy were benefiting from these clinical supports, and therefore, displayed overall lower frequencies of problem behaviors.

There was one significant finding among demographic variables. The presence of adoption showed a mild positive correlation with total incident reports. This was a notable finding because foster-care involvement did not provide a similar significant correlation. While there are many potential explanations for this relationship, it is likely that the relationship was influenced by one or more mediating variables. It is, therefore, not possible to draw a conclusion about adoption and problem behaviors without collecting further information about each participant with a history of adoption.

Clinical Implications

The study supports several implications for improving trauma-informed care among systems supporting individuals with IDD. The current sample showed elevated rates of ACE, as compared with the general population, and previous research suggests that individuals with IDD are 4 times as likely to experience adverse events throughout their lifetimes (Sullivan & Knuston, 2000). Although there were no significant associations between the total ACE score and problem behaviors in the present sample, there were increased odds for criminal charges with total ACE scores of 4 and above. Clinicians should be aware that exposure to trauma can increase the risk for symptoms of mental illness, health risk behaviors, and chronic illnesses in the general population (Felitti et al., 1998).

Agencies and clinicians that support adults with IDD can screen for exposure to ACEs by adding trauma screening measures to their intake and interval clinical review procedures. While the present sample had greater exposure to ACEs than the general population, individual participants did not present with the same behaviors and symptoms. As such, comprehensive screening should include both a measurement of past exposure, such as with the ACE Questionnaire, as well as tools to screen for persisting symptoms and behaviors related to trauma. The Lancaster and Northgate Trauma Scales (Wigham et al., 2011) and the Impact of Event Scale – Intellectual Disabilities (Hall et al., 2014) are two existing measures that were designed for adults with IDD. Assessment of behavior may include self-report and informant questionnaires, such as the Aberrant Behavior Checklist, which includes forms for residential or community-based settings (Aman & Singh, 1986). Clinicians and agencies should also understand that individuals with IDD may also experience unique forms of trauma, such as abuse by a former caregiver and physical restraint (Hulbert-Williams et al., 2014; Keesler, 2014), as well as bullying (Normand & Sallafranque-St-Louis, 2016). As such, clinicians should inquire about such experiences and understand the potential for psychological impact. In accordance with trauma-informed care, clinicians should avoid asking about ACEs until rapport has been established (McLennan et al., 2020). As such, multiple sources are more likely to yield an accurate picture of individuals' exposure to ACEs, including informant reports and historical records, at least in the beginning phases of treatment.

Parental alcohol and drug abuse were two ACE items which had significant associations with elopement and property destruction in the present sample. Clinicians and agencies should consider gathering a family history of substance abuse in addition to other historical information, as these ACE areas may contribute to greater externalized behaviors. Elopement and property

destruction are behaviors which carry potential financial consequences. Agencies who support individuals with IDD who elope from supervision will likely need to access additional staff support. Similarly, direct support staff who are responsible for ensuring the safety of clients with IDD may utilize police and emergency services in such situations. Destruction of property is also likely to result in a need for repairs. It may benefit agencies to consider all factors which may contribute to problem behaviors during screening and treatment planning.

Last, agencies who wish to examine the impact of interventions on problem behaviors should be intentional about the process of data collection. To ensure that the data are accurate and consistent across cases, it is essential that the measures used to collect data are consistent. As of May 2019, developmental service agencies in New Hampshire had not implemented a standardized incident report form to be used across service agencies. This variability among data collection tools may present concerns for inter-rater reliability among direct support staff. Direct support staff who report behavioral data should utilize the same form and receive training in the operational definitions of behaviors. Agencies should further be aware that previous research has found staff frequently underreport behavioral incidents (Lion et al., 1981; Reilly et al., 2019). Possible reasons for underreporting include biases of staff members as well as fear of retaliation (Archer et al., 2019). Agencies may, therefore, consider providing education and support to staff on the importance of reliable incident reporting.

Multicultural Implications

As the research was conducted in a predominantly White community, I was unable to examine the relationships of racial and ethnic background with ACE scores and problem behaviors for the present sample. It is reasonable to hypothesize that ACE scores could be even higher among Black and Hispanic/Latino adults with IDD. In a study using Behavioral Risk

Factor Surveillance System ACE survey data, Hispanic/Latino respondents reported the highest

prevalence of ACEs, followed by non-Hispanic Black respondents, while non-Hispanic Whites

reported the lowest frequencies (Strompolis et al., 2019). Research also suggests that behavioral

outcomes from ACE may vary across racial groups. One study of incarcerated youth found

significant differences in the odds of homicide, property destruction, and sexual offending

among White, Hispanic/Latinx, and African American participants, where Hispanic/Latinx youth

with elevated ACE scores were more likely to have charges of homicide (DeLisi et al., 2017). It

is possible that contextual factors, such as poverty and less access to services, may contribute to

prevalence of ACEs for individuals with IDD from minority racial and ethnic backgrounds.

Limitations of the Study

Representativeness of the Sample

There were several limitations to the sampling and data collection methods. First, the

small sample of 41 participants does not allow for greater generalization of findings to the larger

IDD population; nor could mediating variables be studied. The research was carried out at a

single developmental services agency in the state of New Hampshire. As such, demographic

diversity was limited and specific to the geographic area. Conversely, diagnostic classifications

were heterogenous for the participants. It was difficult to make conclusions about individuals

with specific diagnoses due to limited numbers of participants within each diagnostic category,

although this heterogeneity may be representative of clients in similar community-based settings.

This diagnostic heterogeneity also limited the possibility for stratification of sub-groups of IDD

in order to examine potential variance. The use of convenience sampling by referral from the

agency also contributed to the lack of generalizability because there was no comparison group of

adults who were not receiving individual therapy. Such a comparison group would allow for stronger conclusions regarding the relationship of ACE scores with problem behavior.

Reliability of Data

The use of historical records for data collection raised concern for issues of validity. Incidents of problem behaviors were likely underrepresented. The cultural beliefs and biases of direct-support staff along with administrative dynamics may have been a barrier to the reliable reporting of behavioral incidents. Similarly, archival records were likely inaccurate in documenting adverse life events. Martorell et al. (2009) noted the use of informant reports often underrepresent the incidence of trauma among individuals with IDD. Given that trauma-informed care is a relatively recent movement in mental health, individuals who underwent diagnostic evaluations more than 20 years ago may have been less likely to have been asked about traumatic exposure. Presently, underreporting of adverse life events is more common among the IDD population, especially for sexual abuse (Chung & Bemak, 2012). A research method which utilizes self-report measures along with record reviews would be more likely to accurately capture ACE prevalence.

Finally, records were reviewed by only me. Having a single rater could lead to confirmation bias if I had favored a particular outcome for the study. Interrater reliability for the scoring of the ACE measure and incident reports was not performed. I may not have consistently scored the participants' records. The addition of a second rater was not possible because of the confidential nature of the archival records, and which would require permissions from the agency.

Type I and Type II Errors

The study presents potential for both Type I and Type II errors. The results should be interpreted tentatively due to a small sample size, missing variables, and multiple correlational analyses. First, the overall sample size of the present study was 41 participants. The sample was reduced further when listwise deletion was used ($n = 32$). Within the sample of $N = 41$, 11 participants presented with property destruction, and 14 participants displayed elopement behaviors. Small samples may decrease statistical power, thereby increasing Type II error rates (Field, 2013).

Conversely, the use of many correlations among variables increased potential familywise errors (Field, 2013). Both Chi-square analyses and Fisher's Exact Tests were utilized to interpret Odds Ratios to test for significance of the association between Total ACE score, ACE items, and problem behaviors. To reduce potential for Type I error, a post-hoc Bonferroni correction was used to adjust *p*-values. Almost all significant findings were no longer significant with adjusted *p*-values, except for the OR for ACE of 4 or above and the demographic variable, foster care. The Bonferroni correction is a conservative method to control for familywise error. In a small sample, this correction may underestimate significant findings (Field, 2013). Type I error could have been prevented with fewer analyses (Voelkl, 2019). However, I adopted an exploratory approach to analyses. The disadvantage to this approach is increased potential for spurious correlations (Voelkl, 2019).

Additionally, the Odds Ratios may have also underestimated relationships among variables. As individual ACE items were coded dichotomously (e.g., present or not present), missing or unknown ACE items were coded as "not present." It is, therefore, possible that there

might have been additional relationships among total ACE score, individual ACE items, and problem behaviors, had each ACE item been scorable for every participant.

Future Directions for Research

Future researchers who wish to examine the relationships between ACE scores and problem behaviors of IDD clients can make several changes to the current research. First, researchers should seek larger samples to allow for robustness of the findings. A larger sample would reduce the risk of both Type I and Type II errors. While a longitudinal design is preferred over retrospective data (Hardt & Rutter, 2004), the addition of a comparison group may be more feasible using archival data. A comparison group could assist the researcher in contextualizing findings. Comparison groups might consist of participants without ACEs, participants without problem behaviors, or participants with IDD who are not receiving treatment compared with those who are. It may also be useful to recruit participants from different developmental services agencies to achieve generalization.

Due to the issues of reliability with the use of incident reports and ACE rating based on archival records, future researchers should consider gathering data through alternative sources and using more than one rater. Other sources of information include informant and self-report measures, for example, in-person administration of the ACE questionnaire. Due to respondent bias, data may be more valid using both informant and self-report measures. Alternatively, clinicians who provide services to adults with IDD may consider gathering information on ACEs and making these data available for future research. Data should be entered regularly and monitored for accuracy by agencies seeking to conduct research.

The utility of the ACE questionnaire for adults with IDD remains unclear. Previous research suggests that cumulative exposure to adverse life events is associated with poor mental

health outcomes for individuals with IDD (Hatton & Emerson, 2004; Hulbert-Williams et al.,

2014). Researchers seeking to understand the relationship between adverse childhood

experiences and problem behaviors should consider studying variables which may be more

specific to the IDD population, such as the loss of a parent, experiencing physical restraint, and

abuse by a caregiver (Hatton & Emerson, 2004; Hulbert-Williams et al., 2014; Keesler, 2014).

These variables could be examined in addition to the 11 ACE Questionnaire items in future

studies.

Conclusion

The study examined the relationship among the variables total ACE scores, individual

ACE items, and types of problem behaviors. Forty-one adult participants with Intellectual

developmental disorder were referred from a developmental services agency for archival record

data collection. I scored the Adverse Childhood Experiences Questionnaire based on archival

records. I also collected frequencies of the problem behaviors (aggression, property destruction,

problematic sexual behavior, self-injurious behavior, and elopement) by reviewing

documentation of incidents and behavioral data.

Odds ratios, Chi-square analyses, and Kendall's Tau-B correlations were used to examine

the association, strength, and direction of relationships among variables. The variable total ACE

score did not show any significant positive relationships with problem behaviors but did have

significant negative correlations with total incident reports and total self-injurious behavior

($p < .05$). Total ACE scores of 4 or greater did increase the odds of participants having been

charged for a criminal offense. Most individual ACE items were not associated with problem

behaviors, except for moderately significant positive correlations between Parental Drug Use and

property destruction ($p < .05$) and elopement ($p < .01$). There were also moderately significant

negative correlations between Parental Incarceration, Witnessing Domestic Violence, and Forced Rape with aggression ($p < .05$). Forced rape was also significantly negatively correlated with total incident reports ($p < .01$). The demographic variable, having been adopted, was significantly correlated with total problem behaviors ($p < .05$). These results are not supportive of previous findings, which suggested that individuals who were victims of emotional, physical and sexual abuse were more likely to show mental health symptoms (Brown et al., 1999; Coleman, 2005), sexualized behaviors (Tarren-Sweeney, 2008; DeLisi et al., 2017), and aggression (Owen et al., 2004).

There were several implications for improving trauma screening for adults with IDD. The findings suggested that parental substance abuse may be an important adverse childhood experience for clinicians and agencies to consider when doing intake interviews because it may be associated with costly externalized behaviors, such as elopement and property destruction. Additionally, agencies may improve research on outcomes for trauma-focused interventions by establishing a consistent standard for the collection and storage of behavioral data. Future research is needed to further understand the impact of ACE on problem behaviors in adults with IDD. Further investigation may also illuminate potential contextual factors which may predict poor mental health and behavioral outcomes or mitigate the negative impacts of trauma.

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Appendix A

Letter of Support from The Moore Center

The Moore Center
Creating opportunities for a good life.TM

April 12, 2019

Mental Health Center of Greater Manchester
Attn. Committee for the Protection of Human Research Subjects 1555
Elm St.
Manchester, NH 03101

Dear Committee for the Protection of Human Research Subjects,

We are excited to support Jacqueline Gilbert in her research thesis investigating the impact of adverse childhood experiences and developmental trauma on the population of adults with intellectual disabilities that we serve. Our understanding is that the research will involve file review only, that no Protected Health Information (PHI) will be released, nor will any of our clients be involved directly with any interviews or assessments.

We understand that this study will be reviewed and monitored by the New Hampshire Bureau of Behavioral Health Committee for the Protection of Human Subjects (CPHS). In accordance with their procedures, we state the following:

- ▪ This site recognizes the principles of respect for persons, beneficence (including minimization of harms and maximization of benefits), and justice and will apply these principles in this research project.

- This site acknowledges and accepts its responsibilities for protecting the lights and welfare of human research subjects.

- This site acknowledges and accepts its responsibilities for complying with Federal, state and local laws as they may relate to this research.

- This site encourages and promotes constructive communication among the institutional officials, research administrators, department heads, research investigators, clinical care staff, human subjects, and all other relevant parties as a means of maintaining a high level of awareness regarding the safeguarding of the rights and welfare of the subjects.

195 McGregor Street, Unit 400 • Manchester, NH 03102 • 603-206-2700 • www.moorecenter.org

- Site research investigators shall report promptly to the Principal Investigator (PI) proposed changes in this research activity and the changes shall not be initiated without CPHS review and approval except where necessary to eliminate apparent immediate hazards to the subjects.

- Site research investigators shall report promptly to the PI any unanticipated problems involving risks to subjects and others.

We look forward to the results of this research thesis as this is an important area of study and impacts a number of individuals served at the Moore Center.

Sincerely,

President/Chief Executive Officer

Appendix B

Notification of Exempt Research Status

DATE: April 24, 2019

TO: Jacqueline Dye, M.S.

FROM: State of New Hampshire DHHS CPHS

STUDY TITLE: [1421477-1] Adults with Intellectual Developmental Disorder in Community

Care: Trauma and Problematic Behavior

IRB REFERENCE #: 264

SUBMISSION TYPE: New Project

ACTION: DETERMINATION OF EXEMPT STATUS

DECISION DATE: April 24, 2019

REVIEW CATEGORY: Exemption category # 4

Thank you for your submission of New Project materials for this research study. State of New

Hampshire DHHS CPHS has determined this project is EXEMPT FROM IRB REVIEW

according to federal regulations. We will put a copy of this correspondence on file in our office.

Please include your study title and reference number in all correspondence with this office.

cc:

Appendix C

Modified BRFSS Adverse Childhood Experience (ACE) Module

1. Did the individual live with anyone who was depressed? Had a mental illness?

2. Did the individual live with anyone who drank a lot of alcohol?

3. Did the individual live with anyone who used drugs? Was high on drugs a lot?

4. Did the individual live with anyone who went to prison or jail?

5. Were the individual's parents separated? Divorced?

6. Did adults in the home physical hurt one another?

7. Did adults in the home ever hurt the individual?

8. Did adults in the home emotionally abuse the individual (e.g., swear at or insult the

individual?)

9. Did anyone older than the individual touch his or her body sexually?

10. Did anyone older than the individual coerce the individual to touch their body sexually?

11. Was the individual ever forced to have sex?

Response Options

 1=Yes

 0=No

 0=DK/NS

Appendix D

Demographic Variables

1. Age (years)

2. Biological sex (1=female; 2=male)

3. Racial/Ethnic group (1=White; 2=Black/African American; 3=Hispanic/Latin Origin;

   4=Asian/Indian; 5=American Indian/Pacific Islander; 6=Mixed Race)

4. Primary language is English (1=Yes; 2=No)

5. Primary disability diagnosis (e.g., Intellectual Disability, Cerebral Palsy):

6. Secondary diagnosis (e.g., Anxiety Disorder, PTSD):

7. Foster care involvement (1=Yes; 2=No)

8. Adopted (1=Yes; 2=No)

9. Residential placement prior to age 21 (1=Yes; 2=No)

10. Current residential placement/arrangement (1=Staffed Residence; 2=Enhanced Family

    Care)

11. Length of time at current residence (months)

12. Medical diagnosis of obesity (1=Yes; 2=No):

13. Criminal charges (0=None or Unknown; 1=Sexual Offense; 2=Violent Offense; 3=Drug

    Offense; 4=Both Sexual and Violent Offense; 5=Stalking/Restraining Order)

Appendix E

BRFSS ACE Module Permission for Use

BRFSS ACE Module   —

The BRFSS Adverse Childhood Experiences (ACE) module was adapted from the original CDC-Kaiser ACE Study and is used to collect information on child abuse and neglect and household challenges. The module is available in English and Spanish.

The questionnaires are not copyrighted, and there are no fees for their use. If you include the ACE Study questionnaires in your research, a copy of the subsequent article(s) is requested (send to dvpinquiries@cdc.gov).

BRFSS ACE Module (English)
BRFSS ACE Module (Spanish)

Data and Statistics   +

Major Findings   +

Top of Page

Page last reviewed: April 3, 2020
Content source: National Center for Injury Prevention and Control, Division of Violence Prevention

Retrieved from https://www.cdc.gov/violenceprevention/acestudy/ace-brfss.html

Appendix F

Figure F.1

Frequencies of Total ACE Scores
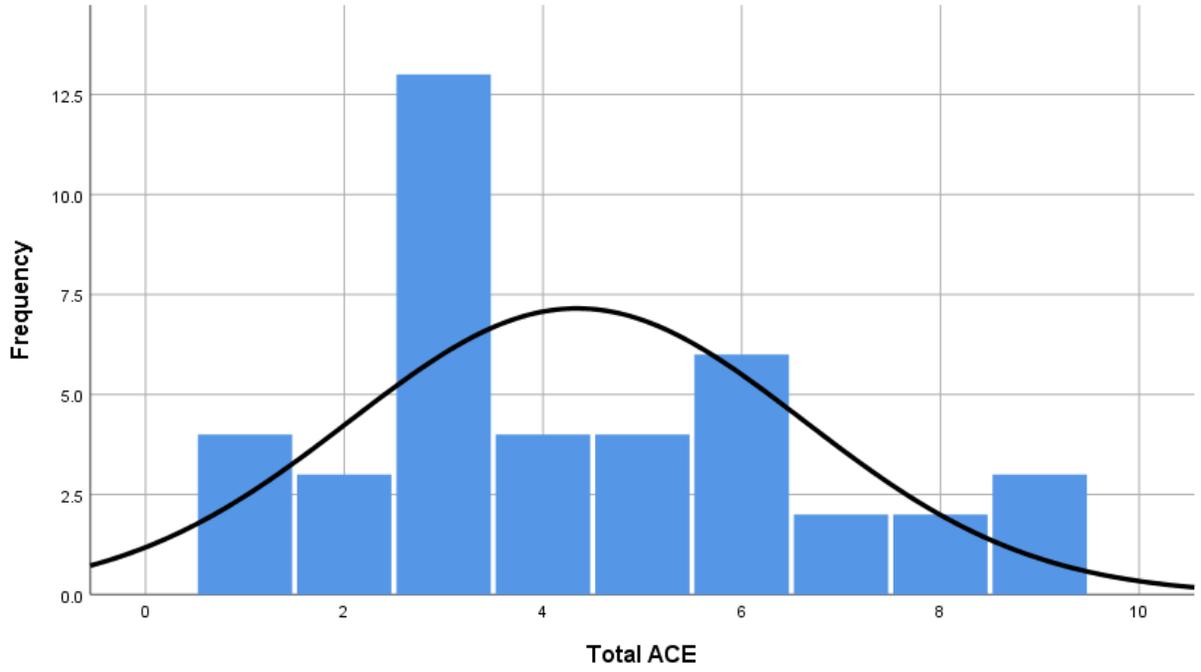
Note. N=41

Appendix G

Table G.1

Participant Demographics

	n	*%*
Age Group		
21-30	11	26.8
31-40	8	19.5
41-50	8	19.5
51-60	9	22.0
61-70	5	12.2
Sex		
Men	20	48.8
Women	21	51.2
Race		
White	37	90.2
Hispanic/Latinx	3	7.3
Mixed Race	1	2.4
Native English Speaker		
Yes	39	95.1
No	2	4.9
Residential Model		
Enhanced Family Care	32	78.0
Staffed Residence	9	22.0
Months at Current Residence		
0-12	5	12.1
13-24	10	24.3
25-36	1	2.4
37-48	5	12.1
49-60	3	7.3
61-72	1	2.4
73-84	1	2.4
85-119	13	32.2
>120	2	4.8
Number of Transitionsa		
0	26	63.4
1	14	34.1
2	1	2.4

Note. N=41.

aResidential transitions within 24-month period of sample data.

Table G.2

ACE Item Correlations with Total ACE Score

ACE Item	Tb
1: Parent with Mental Illness	.14
2: Parental Alcohol Abuse	.36*
3: Parental Drug Abuse	.25
4: Parental Incarceration	.63**
5: Divorce/Separation	.12
6: Witness Domestic Violence	.23
7: Physical Abuse	.52**
8: Emotional Abuse	.37**
9: Molestation	.48**
10: Coerced to Touch	.41**
11: Forced Rape	.59**

Note. N=32.

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

Table G.3

Correlations for ACE Subscale Household Dysfunction

Variables	Parental MI	Parental Alc	Parental Drug	Parental Inc	Divorce/Sep	Witness DV
Parental MI	-	.02	-.02	.13	-.28	.06
Parental Alc		-	.48**	.32*	-.01	.25
Parental Drug			-	.45**	-.08	-.14
Parental Inc				-	.12	.39*
Divorce/Sep					-	.14
Witness DV						-

Note. n=32. MI=Mental illness, Alc=alcohol abuse, Inc=Incarceration, Sep=Separation,

DV=Domestic violence.

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

Table G.4

Correlations for ACE Subscale Emotional, Physical, and Sexual Abuse

Variables	Emotional Abuse	Physical Abuse	Molestation	Coercive Touch	Forced Rape
Emotional Abuse	-	.48**	.29	.13	.27
Physical Abuse		-	.56**	.31**	.17
Molestation			-	.45**	.45**
Coercive Touch				-	.58**
Forced Rape					-

Note. n=32.

**p < .01.

Table G.5

Distribution of Problem Behaviors

Variable	*M*	*SD*	*Mdn*	Minimum	Maximum	Skewness[a]	Kurtosis[b]
Total IR	23.49	51.25	8.00	0	313	4.829	26.533
Aggression	16.20	34.56	4.00	0	207	4.585	24.153
PD	1.02	3.12	0	0	19	5.098	28.955
PSB	.63	2.47	0	0	15	5.327	30.439
SIB	5.39	17.54	0	0	105	5.039	27.530
Elopement	.51	.89	0	0	4	2.250	5.635

Note. N=41. IR=Incident reports, PD=Property destruction, PSB=Problematic sexual behavior,

SIB=Self-injurious behavior.

aSE=0.369, bSE=0.724.

Table G.6

Correlations of Individual Problem Behaviors to Total Problem Behaviors

Problem Behavior	*T*b
Aggression	.76**
Property Destruction	.28*
Problematic Sexual Behavior	.14
Self-Injurious Behavior	.40**
Elopement	.33**

Note. N=41.

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

Table G.7

Correlation of Total ACE Score with Total IR's and Total SIB for Total Sample

ACE Item	Total IR	Total SIB
Total ACE Score	-.29*	-.33*

Note. *N*=41. IR=Incident report, SIB=Self-injurious behavior.

p < .05.

Table G.8

Correlations of Total ACE Score with Problem Behaviors Using Listwise Deletion

ACE Item	IR	Aggression	PD	PSB	SIB	Elopement
Total ACE Score	-.41**	-.39**	.01	.05	-.38**	-.03

*Note. n=*32. IR=Incident reports, PD=Property destruction, PSB=Problematic sexual behavior,

SIB=Self-injurious behavior.

**p* < .01.

Table G.9

Correlations Among ACE Items 9-11 (Sexual Abuse) and Problematic Sexual Behavior and Self-

Injurious Behavior

Variables	OR	*X2*	*T*b
ACE 9: Molestation			
PSB	.27	1.48	-.09
SIB	.50	1.13	-.15
ACE 10: Coerced Touch			
PSB	.50	.37	-.09
SIB	.43	1.23	-.17
ACE 11: Forced Rape			
PSB	.79	2.91	-.21
SIB	.36	1.89	-.15

Note. n=32. PSB=Problematic sexual behavior, SIB=Self-injurious behavior.

Table G.10

Correlations Between Individual ACE Items and Problem Behaviors

Variables	OR	95% CI	X2	Tb
ACE 2: Parental Alc				
Elopement	3.50	[.87, 13.99]	3.28	.34*
ACE 3: Parental Drug				
PD	11.67	[1.81, 75.08]	8.55**	.42*
Elopement	6.95	[1.14, 42.36]	5.22*	.47**
ACE 4: Parental Inc				
Aggression	.58	[.05, 6.57]	.19	-.34*
ACE 6: Witness DV				
Aggression	.54	[.08, 3.45]	.44	-.34*
ACE 11: Forced Rape				
Total IR's	.37	[.05, 2.99]	.92	-.48**
Aggression	1.04	[.17, 6.29]	.00	-.38*

Note. N=32. IR=Incident reports, DV=Domestic violence, Alc=Alcohol abuse,

Inc=Incarceration, PD=Property Destruction.

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

Table G.11

Correlations Among Select Demographic Variables and Total Incident Reports

Variables	OR	95% CI	*X2*	*T*b
Total Incident Reports				
Male	3.17	[.30, 33.31]	1.00	-.02
Mood Disorder	.84	[.71, .99]	2.84	.18
Foster Care	.16	[.01, 1.70]	2.82	-.16
Adopted	.89	[.79, .99]	.48	.27*

Note. N=41.

*p<.05.

Table G.12

Odds Ratios and Chi-square Analyses for Total ACE Score of 4 or Greater and Foster Care,

Criminality, Mood Disorder, and Obesity

Variables	OR	95% CI	$X2$
ACE Score 4 or more			
Foster care	14.62	[2.66, 80.52]	11.89**
Criminal charges	6.23	[1.39, 27.84]	6.37*
Mood Dx	.26	[.07, .97]	4.19
Obesity	2.00	[.41, 9.78]	.75

Note. $N=41$. Dx=diagnosis.

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