PSYCHOLOGICAL IMPLICATIONS OF AFFILIATE STIGMA ON SIBLINGS OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES

A DISSERTATION
SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY
IN THE GRADUATE SCHOOL OF THE
TEXAS WOMAN'S UNIVERSITY

DEPARTMENT OF PSYCHOLOGY AND PHILOSOPHY
COLLEGE OF ARTS AND SCIENCES

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DENTON, TX
AUGUST 2021

DEDICATION

To my husband, partner, best friend, and my person. Your endless support, unwavering belief in my dreams, and constant encouragement means more to me than you will ever know.

To my son, Niam, who inspires me each day through his creativity, kindness, and laughter. I completely adore you. You are my sunshine.

To my brother, Neil, whose spirit has given shape and value to my life. You have inspired my life's purpose and for that I am forever grateful.

ACKNOWLEDGMENTS

There are many people in my life that have played a significant role in the completion of my dissertation and success in the program. First, I want to thank my dissertation Chair, Dr. Debra Mollen, who has provided me with consistent support, feedback, and encouragement throughout this project as well as throughout my doctoral program. You have been a tremendous role model for me as a teacher, mentor, researcher, and advocate. I am deeply grateful to have a mentor who genuinely is interested in my professional and personal life, devoted to my success, and has always been a validating presence. There are insufficient words to express my gratitude for your commitment and belief in me.

I want to thank each of my committee members as they have played a pivotal role in my development and success within the program as well. Dr. Stabb, thank you for being a continual source of support and an advocate for me throughout the program. The conversations we have had together have been immensely powerful and will always remain in my heart. Dr. Rosen, thank you for your feedback, guidance, and most of all I am grateful for you always believing in me. Your faith in my abilities and consistent encouragement has played a significant part in my success in the program. Dr. DeOrnellas, thank you for your wealth of knowledge and encouragement. Your research and work inspired me, and I am grateful that you are a part of my project.

Thank you to all my friends that I have made along the way through the doctoral program. Erin, Keely, and Kaitlyn, thank you all for the special memories we have created during internship. I could not have asked for a better group of individuals to have spent the last year with. To Kaity and Megha, thank you both for your support, encouragement, and motivation throughout the years. I will always cherish our time together and am honored that you are a part of my life.

Lastly, I want to give thanks to my family for the love, patience, and support over the years. I want to give a special thanks to my sister, Roshni. You have always been there for me and I am deeply grateful that you are in my life. I am immensely proud to call you my sister and am excited to see what great things you will do in the future.

ABSTRACT

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PSYCHOLOGICAL IMPLICATIONS OF AFFILIATE STIGMA ON SIBLINGS OF INDIVIDUALS WITH INTELLECTUAL DISABILITIES

AUGUST 2021

Siblings of people with intellectual disabilities (PWID) are a growing population in the United States (US). The literature on siblings of PWID has often been contradictory with some researchers claiming that growing up with a PWID has positive effects while others have found some siblings are at risk of developing psychological difficulties. While investigators have not explored the factors that impact some siblings to be at higher risk of poorer psychological functioning, the literature on caregivers suggests affiliate stigma may negatively impact parents' mental health. Therefore, the researcher aimed to be the first to investigate whether the relationships previously found in the literature between affiliate stigma and caregivers are significant for adult siblings. Through the proposed study, the researcher explored the relationship among affiliate stigma, depression, anxiety, perceived behavioral problems, and psychological well-being among siblings. The investigator recruited 110 participants electronically through social media websites and listservs specifically associated with intellectual disability organizations and sibling support groups. Using PsychData, participants completed a short demographic questionnaire and respond to six surveys measuring affiliate stigma, psychological well-being, depression, anxiety, social desirability, and their siblings' behavioral problems. The researcher used correlation and regression analyses to explore the relationships between these variables. A mediation analysis was conducted to examine the mediating role of affiliate stigma on the association between behavioral problems of the PWID and dependent variables (i.e., psychological well-being, depression, and anxiety). Results revealed Hypotheses 1–3 were confirmed suggesting affiliate stigma was associated with higher levels of depressive and anxiety symptoms and lower psychological well-being. However, Hypotheses 4–6 revealed a full mediation suggesting the behavioral problems of the PWID do not have a significant impact on a sibling’s psychological well-being, depression, or anxiety when affiliate stigma is accounted for. Experiencing affiliate stigma appears to serve a role in the mental health of siblings of PWID. The current study contributes to the sparse literature on the experiences of adult siblings of PWID.

TABLE OF CONTENTS

Chapter

APPENDICES

LIST OF TABLES

LIST OF FIGURES

CHAPTER I

INTRODUCTION

According to the 2015 U.S. Census Bureau, approximately 56.7 million people live with a disability. Of these, 6.5 million people have an intellectual disability (ID; U.S. Census Bureau, 2015). Throughout history, people with disabilities (PWD) have been stigmatized for not conforming to societal norms and subsequently treated unfairly. Although there are some notable exceptions, unfair treatment has occurred universally across time, cultures, and contexts. Such treatments ranged from putting PWDs in cellars for others to gawk over for an admission price in early colonial America to being sent to schools referred to as “Institution for Idiots” in Massachusetts in the 1800s (Seguin, 1907). Other inhumane treatments consisted of individuals sterilizing people with intellectual disabilities, often without their consent, out of fear of passing along “inferior” traits to children and excluding individuals from attending school (Ferri & Connor, 2005). While U.S. society has significantly progressed since these times with the emergence of the disability rights movement and the Americans with Disabilities Act of 1990 (ADA), individuals with disabilities have continued to face stigmatization by being discriminated against and denied access to housing, education, and equal opportunities in the workplace (Beart et al., 2005; Cooney et al., 2006; Jahoda et al., 1989; Linton, 1998; Miller & Keys, 1996).

Definition of Intellectual Disability

According to the ADA of 1990, a person with a disability is defined as an individual who has a physical or mental impairment that imposes a restriction on one or more major life activities. Major life activities include walking, talking, seeing, hearing, thinking, learning, reading, caring for oneself, and other types of activities not specifically detailed (ADA, 1990). While the ADA does attempt to provide a comprehensive definition of the term disability, it fails to outline and discuss specifically the various types of disabilities people face.

According to the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*), the term *intellectual disability* has replaced the antiquated and derogatory term of mental retardation (American Psychiatric Association, 2013). ID encompasses impairments in cognitive functioning that impact daily functioning in three domains: 1) skills in language, reading, writing, knowledge and memory; 2) socially, such as having empathy, ability to maintain and retain relationships, and interpersonal communication; and 3) self-management skills such as the ability to manage money, personal care, job responsibilities, and complete school or work activities (American Psychiatric Association, 2013). IDs include fetal alcohol syndrome (FAS), Down syndrome (DS), and fragile X syndrome (FXS). There are many other types of intellectual disorders, some with known causes and others whose etiology is unknown.

Stigma toward Intellectual Disabilities

People with intellectual disabilities (PWID) are one of the most socially excluded and stigmatized groups within society (Ali et al., 2012). The public's awareness and understanding of PWID is limited across various cultures, which further perpetuates misconceptions and creates inaccurate assumptions about the person and their families. Stigma refers to negative views or stereotypes attributed to a person or groups of people when their attributes are considered different from or inferior to societal norms (Corrigan, 2000; Dudley, 2000; Goffman, 1963). Stigma is typically directed toward individuals of marginalized groups such as those disadvantaged by gender, race/ethnicity, sexual orientation, disability status, size, age, faith orientation, and nationality.

Types of stigma include public, self-stigma, stigma by association (courtesy stigma), and affiliate stigma (Chang et al., 2016; Corrigan, 2000). Public stigma refers to the attitudes and reactions about a stigmatized group and/or person from the general population (Corrigan, 2000). For instance, some individuals may endorse negative stigma related to mental illness, such as erroneously believing that those with mental illnesses should be feared and excluded from society due to their sometimes-unusual behaviors (Corrigan & Watson, 2002). Self-stigma refers to internalizing society's stigmatizing ideas which in turn may negatively impact one's self-esteem (Corrigan & Watson, 2002). Researchers have found that stigma has an adverse impact on PWDs' psychological well-being as it negatively affects their self-esteem (Dagnan & Waring, 2004; Szivos-Bach, 1993). Individuals who perceive higher levels of stigma are more likely to report lower levels of self-esteem (Paterson et al., 2012).

Courtesy stigma refers to the experiences of those who are close to the stigmatized individual such as parents, siblings, friends, and professionals (Ali et al., 2012). Courtesy stigma contains the "stereotypes of blame, shame, and contamination" (Larson & Corrigan, 2008, p. 88), which may result in family members being teased, blamed, or held responsible for the person's disability (Larson & Corrigan, 2008). An example of courtesy stigma is when other adults may think poorly of a parent whose child has been diagnosed with attention deficit/hyperactivity disorder (ADHD). Courtesy stigma is a frequent occurrence for individuals with disabilities and their families as it has impacted parents of children with disabilities such as ADHD (Mikami et al., 2015), physical disabilities (Green, 2003), and IDs (Shin et al., 2006). Historically, parents have been blamed for their child's disability, with others assuming that the child may have received inadequate parenting or that the parents were genetically flawed (Lebowitz et al., 2016). Researchers have found that courtesy stigma against parents may lead them to internalize these experiences which results in affiliate stigma (Mikami et al., 2015).

Mak and Cheung (2008) differentiated between the stigmatic perceptions of the general population about family members (i.e., courtesy stigma) and the family members' internalization of these evaluations. The latter has been termed *affiliate stigma*, which refers to the self-stigmatization of negative emotions and experiences by association of the marginalized person (Werner & Shulman, 2015). An example of this occurs when a parent of a child with a disability feels shame or distress taking their child out in public and chooses to avoid contact with others as a result. Stigma, particularly courtesy stigma, is correlated with higher levels of parental distress (Baxter & Cummins, 1992; Shin et al., 2006), burden (Green, 2004; Mak & Cheung, 2008), and decreased quality of life (Chou et al., 2009). While there has been considerable research conducted on public and self-stigma, there has been a relative lack of research on affiliate stigma. Of those extant studies on affiliate stigma, researchers have focused primarily on the parents of the children with IDs rather than considering the experiences of other family members such as siblings, who may also experience affiliate stigma. The current proposed investigation aims to help fill this gap in the literature.

Caregivers of People with Intellectual Disabilities

While there is a limited amount of research on affiliate stigma, the primary focus of these few studies has been to examine the implications of affiliate stigma on parents' well-being (Mak & Cheung, 2008; Mak & Kwok, 2010; Ntswane & Van Rhyn, 2007). Researchers have found the internalization of courtesy stigma in caretakers results in affective responses (i.e., shame and embarrassment), cognitive distortions (i.e., worry and self-blame), and behavioral consequences (i.e., social disconnection and isolation; Mak & Cheung, 2008; Mak & Kwok, 2010; Ntswane & Van Rhyn, 2007). Additionally, caretakers are more likely to report feeling unhappy about their affiliation with the stigmatized individual that prompts them to withdraw from social relations and/or isolating themselves from the stigmatized individual to avoid being associated with them (Mak & Cheung, 2008; Mikami et al., 2015). Such internalized stigma may result in caregivers experiencing high levels of depression and anxiety as well as lower psychological well-being (Ali et al., 2012; Dako-Gyeke, 2018; Malli et al., 2016; Norvilitis et al., 2002; Werner & Hess, 2016).

A key factor that has been argued to account for parental distress is the extent of the child's behavioral problems (Gallagher et al., 2008). *Behavioral problems* are emotional and conduct disturbances conceptualized as deviations from the norm, such as social withdrawal, stereotypical behaviors, aggression, social skill impairment, self-destructive acts, hyperactivity, and irritability (Aman et al., 1985; Edelbrock & Costello, 1988). Researchers have found a child’s behavioral problems can be a significant source of psychological distress, including depressive and anxiety symptoms, in parents of children with ID (Baker et al., 2003; Blacher & McIntyre, 2006).

Certain behaviors common among children with autism spectrum disorder (ASD), DS, or Tourette’s syndrome (TS) elicit strong stigmatizing responses from the public (Butler & Gillis, 2011; Lam & Mackenzie, 2002; Malli et al., 2016). Researchers have found caregivers of children with more severe behavioral problems experience affiliate stigma and decreased psychological well-being (Butler & Gillis, 2011; Mak & Kwok, 2010). The research findings have suggested a majority of the population may have a misunderstanding as well as a stigma toward individuals who struggle with behavioral and emotional difficulties (Broomhead, 2016). For caregivers, perceived public stigma can lead to feelings of shame and embarrassment (Mak & Cheung, 2008; Wong et al., 2016), thoughts of losing face within the community (Adithyan et al., 2017; Ho, 1976; Mak & Cheung, 2008), and use of avoidant coping styles (Chen et al., 2016; Grover et al., 2017; Liegghio, 2017; Mak & Cheung, 2008; McCann & Lubman, 2018; Mikami et al., 2015; Singh et al., 2016; Werner & Hess, 2016; Wong et al., 2016). Unlike research available on caregivers, there is a dearth of literature on how PWID’s behavior problems impact their non-disabled sibling’s psychological well-being.

Siblings of People with Intellectual Disabilities

The sibling relationship is one of the longest lasting relationships people have and can impact psychological well-being and physical health (Cicirelli, 1982). From a family system theoretical perspective, when a family member has a disability, everyone within the family is affected (Fingerman & Bermann, 2000). The sibling relationship is marked by unique stressors as the non-disabled sibling may be expected to take on specific responsibilities such as adopting a caregiving role or to take on such guardianship responsibilities by their parents (Burke et al., 2012; Greenberg et al., 1999; Rossetti & Hall, 2015). While some researchers have found siblings of PWID have more empathy, compassion, and understanding for their sibling with ID (Carr, 1988; Cuskelly & Gunn, 2006; Hodapp et al., 2010; Levy-Wasser & Katz, 2004; Sage & Jegatheesan, 2010; Seltzer et al., 2005; Summers et al., 1994), others have found that some siblings of PWID may be at risk for developing psychological difficulties such as stress, depression, anxiety, and poorer well-being (Giallo et al., 2012; Petalas et al., 2009; Rossiter & Sharpe, 2001; Shivers, 2017). As these researchers did not explore the factors impacting poorer psychological functioning among siblings of PWID, the researcher of the current study aims to explore whether affiliate stigma may be correlated with impaired well-being among siblings.

Researchers have found sibling relationships are also negatively impacted when the PWID exhibits severe behavioral problems (Hodapp et al., 2017; Shivers et al., 2013). For instance, siblings of individuals with ASD are more likely to report negative attitudes, poorer health, and depressive symptoms compared to siblings of individuals with other disabilities (Doody et al., 2010; Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007). Similarly, siblings of individuals with Prader-Willi syndrome (PWS) exhibited high levels of depressive symptoms, anger, worry, and isolation due to atypical behaviors by their sibling with ID (Mazaheri et al., 2013). Therefore, the researcher of the current study aimed to expand the existing literature to examine if affiliate stigma would partially mediate the relationship between behavior problems and psychological well-being.

To date, there has been a dearth of research on the experiences of siblings of PWID. Most research has been limited to looking at either primarily mothers (who often serve as or are assumed to be primary or exclusive caregivers) of PWID (Lam & Mackenzie, 2002; Mak & Cheung, 2008; Werner & Shulman, 2015; Wong et al., 2016), young children (Carr, 1988; Dyson, 1999; Gath & Gumley, 1984; Giallo & Gavidia-Payne, 2006; Rossiter & Sharpe, 2001; Skotko et al., 2011), or siblings of people with mental illness such as mood disorders, schizophrenia, or depression (Corrigan, 2004; Grover et al., 2017; Östman & Kjellin, 2002; Ow & Katz, 1999). Given the role siblings play in providing care to their siblings with IDs, this omission is striking and one the current investigator aimed to rectify with her study.

Purpose of Study

While studies have researched the typical sibling relationship across the lifespan, the literature to date provides limited data on adult siblings of those with an ID. There is evidence that many caregivers of PWID experience affiliate stigma as well as elevated levels of depression and anxiety (Mak & Cheung, 2008; Mak & Kwok, 2010; Ntswane & Van Rhyn, 2007). As a result, caregivers report avoidant coping styles, reduced social support, self-defeating thoughts, and feelings of shame and worry (Chan & Lam, 2018; Mak & Cheung, 2008; Werner & Shulman, 2013, 2015; Wong et al., 2016). While siblings may not always be primary caregivers of PWID, they sometimes serve a supplementary caretaking role and are impacted by the family dynamics. The adult sibling of PWID still remains a uniquely under-researched population and accordingly, the ways the PWID impacts the non-disabled sibling's psychological well-being is unclear. Since the caregiving literature indicates that parents experience internalized stigma, it is important to investigate if siblings may also experience similar affiliate stigma. Therefore, the primary purpose of the current study was to determine if and to what extent adult siblings of PWID experience affiliate stigma. The second purpose of the study was to explore whether there is a relationship between affiliate stigma and psychological well-being among adult siblings of PWID. Finally, the researcher intended to examine whether the PWID's behavioral problems impact the sibling's psychological well-being.

The research questions that guided this study were as follows:

1. Do adult siblings of PWID experience affiliate stigma and to what extent?
2. Is there a relationship between affiliate stigma and psychological well-being among adult siblings of PWID?
3. Do PWIDs' behavioral problems impact their non-disabled sibling's psychological well-being?

Definition of Key Terms

Affiliate Stigma refers to the extent to which associated individuals internalize the stigma of the general public toward the discredited (Mak & Cheung, 2008) and is composed of three psychological responses: stigmatized cognition, affect, and behavior.

Behavioral problems are emotional and conduct disturbances that are conceptualized as deviations from the norm, such as social withdrawal, stereotypical behaviors (i.e., pacing, rocking, flapping hands, spinning objects, etc.), aggression, social skill impairment, self-destructive acts, hyperactivity, and irritability (Aman et al., 1985; Edelbrock & Costello, 1988).

Caregiving occurs across five domains of caregiving specific to siblings who serve in this role: providing "residential arrangements, financial arrangements, legal guardianship, interacting with the service system, and providing companionship and emotional support" (Burke et al., 2012, p. 37). Each domain can be designated by the degree of responsibility accorded to the caregiver: primary responsibility, shared responsibility, or someone else (not the sibling) will be responsible.

Courtesy Stigma is "prejudice and discrimination…extended to people without the manifest marks of stigmatized characteristics because of their relationship to a person with a stigmatized mark" among family members, particularly caregivers (Chang et al., 2016, p. 45).

Intellectual Disability (ID) is a disability characterized by significant limitations in both intellectual functioning and adaptive behavior, impacting everyday social and practical skills. The disability originates before the age of 18 (American Association on Intellectual and Developmental Disabilities [AAIDD], 2002; American Psychiatric Association, 2013). Common intellectual disabilities include: DS, FAS, FXS, and PWS (AAIDD, 2002).

CHAPTER II

LITERATURE REVIEW

In the US, approximately 12.6% of people have a disability, of whom 4.3% are individuals with an ID (Kraus, 2017; U.S. Census Bureau, 2015). Approximately 8 million individuals with an ID are between the ages of 18–64 and roughly 3 million are 65 years or older (Kraus, 2017). When someone has a mental illness or disability, family members may share psychological distress and experience a lower quality of life due to associated stigma (Tint & Weiss, 2016; van der Sanden et al., 2016; Warren & Brady, 2007).

While some researchers have examined the parent-child relationship, including the high levels of caregiving burden reported by parents who have a child with an ID (Baker et al., 2003; Eisenhower et al., 2005; Hayes & Watson, 2013; Lee, 2013), there is limited research on siblings' experience such as the psychological impact of having a sibling with an ID. Thus, the researcher of the study aims to increase understanding the psychological implications of having a sibling with an ID and explore whether siblings may share the experience of stigma by association of having a family member with ID. In this chapter, the researcher provides the definition of IDs, explore the historical context of disability, examine how stigma impacts individuals with disabilities, discuss various types of stigma, and investigate how sibling relationships are impacted by stigma. To conclude the chapter, the researcher identifies gaps in the literature, laying the foundation for the study, and explicate hypotheses.

Intellectual Disability

Over the last 200 years, terminology for IDs has varied and included feeblemindedness, mental deficiency, mental disability, idiocy, mental handicap, and most recently, mental retardation (Goodey, 2005; Mercer, 1992; Schalock et al., 2007; Stainton, 2001; Trent, 1994; Wright & Digby, 1996). After lengthy deliberations, the American Association on Mental Retardation decided to change the term of *mental retardation*, considered offensive to many people, to *intellectual and developmental disabilities* (Bouras & Jacobson, 2002). Congruent with the debate regarding the term for IDs, scholars wrestled with identifying the criteria for IDs. In 1983, Grossman identified three diagnostic benchmarks that continue to be utilized today: lower levels of intelligence (i.e., having an IQ score of 70 or below), deficits in adaptive behaviors, and onset of the disability during childhood. The current definition of an ID encompasses Grossman's criteria as ID is "…characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18" (AAIDD, 2002, np).

The AAIDD definition is notably similar to the definition in the *DSM-5* (American Psychiatric Association, 2013). The three primary criteria remain the same between the AAIDD and *DSM-5*; however, the *DSM-5* primarily focuses on identifying limitations with more specificity compared to the AAIDD. Practitioners use the *DSM-5* definition primarily as a diagnostic tool to identify PWID and the AAIDD definition for the purpose of rehabilitating PWID (AAIDD, 2002). According to the *DSM-5* (American Psychiatric Association, 2013), intellectual disabilities are neurodevelopmental disorders that require the presence of three criteria: 1) “deficits in intellectual functioning, which can include reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience” (p. 33); 2) deficits in adaptive functioning that significantly impact one’s daily living such as the ability to communicate, interact effectively with others, independently take care of oneself, and learn new tasks and knowledge at school or work; and 3) these limitations initially occur during one’s childhood or adolescence.

Most individuals with ID face social difficulties along with performing below age expectations on cognitive tasks (Leffert & Siperstein, 2002). However, due to ID’s heterogeneity of cognitive and behavioral profiles along with the comorbidity with other disorders such as ASD, it makes it more complicated to decipher which neurodevelopmental disorders constitute ID (Matson & Shoemaker, 2009). For this study, the researcher includes siblings of individuals diagnosed with DS, FXS, WS, PWS, and other IDs that satisfy the *DSM-5* (American Psychiatric Association, 2013) criteria as they are consistent with the criteria for ID. People with siblings whose conditions or disorders that occur comorbidly with an ID but are not considered IDs by themselves (i.e., cerebral palsy and ASD) are excluded from the study.

Down Syndrome

It is estimated that 1 in 691 individuals is diagnosed with DS, making it the most prevalent disorder among all IDs (Parker et al., 2010). DS is a genetic disorder resulting from a dysfunction within chromosome 21 (Mutton et al., 1996). Individuals with DS have distinct facial characteristics, congenital heart defects, a short stature, immune abnormalities, muscle hypotonia, and mild to moderate ID (Chapman & Hesketh, 2000; Korenburg et al., 1994). Regarding expressive language abilities, people with DS display difficulties in vocabulary and syntax (Chapman & Hesketh, 2000). They may also have difficulties with auditory short-term memory, episodic memory, and executive functioning, making it challenging for them to remember tasks, engage in decision-making, and recall particular life experiences (Daunhauer & Fidler, 2011; Edgin et al., 2010; Fidler et al., 2005). While individuals with DS have certain relative weaknesses, they demonstrate strengths in nonverbal communication, visual imitation, and a majority exhibit high levels of social relatedness (Channell et al., 2015; Daunhauer & Fidler, 2011).

Fragile X Syndrome

FXS is a common inherited disorder that causes ID (Crawford et al., 2001). The syndrome results from a mutation in the gene, FMR1, on the X chromosome, which is critical for maturation and pruning of synapses (Churchill et al., 2002). Boys are more likely to be affected (1 in 4,000) than girls (1 in 6,000) due to the mutation occurring on the X chromosome (Brown, 2002). Individuals diagnosed with FXS typically display behavioral symptoms comorbid with numerous other disorders such as social anxiety, social avoidance, and ASD. For instance, individuals with FXS may have difficulties with consistent eye gaze, inattention, hyperactivity, and hypersensitivity to sensory stimuli (Abbeduto & Murphy, 2004; Chromik et al., 2015). Nearly 50% of the FXS population has co-morbidity with ASD and displays symptoms such as lower cognitive ability, difficulties in social relatedness, intelligible speech, and problems with expressive syntax (Abbeduto & Murphy, 2004; Bailey et al., 2001; Chromik et al., 2015; McDuffie et al., 2012).

Williams Syndrome

WS is a neurodevelopmental disorder caused by deletion of multiple genes on a chromosome (Meyer-Lindenberg et al., 2004). The prevalence of WS is approximately 1 in 7,500 births (Strømme et al., 2002). Individuals with WS typically have developmental delays, a mild to moderate ID, dysmorphic facial features, heart and tissue abnormalities, and growth deficiency (McDuffie & Abbeduto, 2009; Mervis & Morris, 2007). People with WS are highly sociable as they are overly friendly, talkative, and have a strong desire to connect with others relationally (Gosch & Pankau, 1997; Klein-Tasman et al., 2011). Although language is a relative strength for individuals with WS, they may struggle at times with producing words, relational concepts (i.e., spatial, temporal, quantitative, and dimensional), and contributing new information to conversations (Mervis & John, 2008; Mervis et al., 2003; Stojanovik, 2006).

Prader-Willi Syndrome

PWS is a rare genetic disorder that affects approximately 1 in 10,000–30,000 people worldwide (National Library of Medicine [NLM], 2018b). PWS is caused by a deletion, duplication, or rearrangement of the genes resulting in a loss of functioning (NLM, 2018b). During childhood, people with PWS begin to develop an insatiable hunger, which can lead to overeating and issues such as obesity (Driscoll et al., 2017). People with PWS typically have a mild to moderate ID and learning disabilities (Driscoll et al., 2017). Physically, people with PWS have distinctive facial features such as a narrow forehead, short stature, almond shaped eyes, and small limbs (Driscoll et al., 2017). Individuals with PWS report hormonal imbalances that delay or prevent puberty (Driscoll et al., 2017). They also tend to have behavioral concerns at home, school, and relationally as they may have frequent outbursts, stubbornness, and engage in compulsive behaviors such as face picking (NLM, 2018b). Many of the behavioral and psychiatric problems associated with PWS tend to impact one's quality of life during adolescence and adulthood (Driscoll et al., 2017). Due to the rarity of the disorder, there has been a relative lack of research on the psychological well-being of persons living with PWS and the impact of those associated with the disorder.

Other Intellectual Disabilities

The research on ID primarily consists of those disorders discussed to this point. However, there is a dearth of knowledge and information on ID that are not widely known. Due to the lack of visibility and relative, concomitant lack of understanding regarding these other types of ID, the researcher has chosen to explore and expand upon this topic by including siblings of PWD that satisfy the *DSM-5* (American Psychiatric Association, 2013) criteria for an ID. Examples of other such intellectual disabilities include Smith-Magenis syndrome, cri-du-chat syndrome**,** angelman syndrome, FASD, and DiGeorge syndrome (DGS)**.**

Smith-Magenis Syndrome

Smith-Magenis syndrome is a rare and complex neurodevelopmental disorder that impacts multiple parts of the body (Poisson et al., 2015). Individuals diagnosed with

Smith-Magenis syndrome exhibit speech delays, behavioral disturbances (e.g., outbursts, self-injury), sleep disturbances, and have mild to moderate ID (Poisson et al., 2015).

Cri-du-Chat Syndrome

Cri-du-chat syndrome (also known as cat cry syndrome) is a rare genetic disorder caused by the deletion of chromosome 5 (Mainardi, 2006). The disorder exists in 1 out of 15,000–50,000 individuals (Mainardi, 2006). The primary clinical features of the disorder include a high-pitched cry, microcephaly, low birth weight, severe psychomotor movement, and severe ID (Mainardi, 2006).

Angelman Syndrome

Angelman syndrome is a genetic disorder that primarily affects the nervous system. There are fewer than 200,000 cases of individuals diagnosed with angelman syndrome in the US annually (NLM, 2018a). Symptoms include impaired or lack of speech, frequent smiling, balance issues that impede the ability to move or walk, seizures, sleep disturbances, and severe ID (Clayton-Smith & Laan, 2003).

Fetal Alcohol Spectrum Disorder

FASD is a group of conditions that occur when a child is exposed to alcohol during pregnancy (Williams et al., 2015). The disorder is known to cause severe birth defects, small head size, low body weight, poor coordination, attentional difficulties, hyperactive behavior, and ID (Williams et al., 2015). Individuals with FASD also may exhibit high levels of aggression, antisocial behavior, and irritability (Williams et al., 2015).

DiGeorge Syndrome

DGS is considered one of the most common microdeletion syndromes in humans. Microdeletion syndromes occur when there is a deletion or loss of one or more genes on a single chromosome (Weise et al., 2012). DGS occurs in 1 in every 3,000–6,000 births (Kraus et al., 2018). Individuals with DGS have an increased risk of developing psychiatric disorders such as schizophrenia, ADHD, and/or anxiety (Kraus et al., 2018). They also have delayed development and may have mild to moderate ID (Phillip & Bassett, 2011).

Historical Context of People with Disabilities

Historically, the examination of attitudes toward PWD suggests that social perceptions are heterogeneous. The earliest conception of society's perception regarding PWD can be traced back to the ancient Greeks who viewed disability as a disease that one acquired primarily due to a personal fault or a crime their ancestors had committed (Sontag, 1996). Plato claimed that PWD were deformed offspring who needed to be placed in a "mysterious, unknown place" (Plato ca. 375 B.C.E/1943, p. 460). These punitive, marginalizing myths were also prevalent and persistent in other parts of the world in the 16th century when many Europeans and Asians believed PWD were the workings of the devil (McDaniel, 1969). Various religious leaders proposed that the only treatment to rid the individual of the disability was to perform an exorcism (Thomas, 1957). Individuals with ID, physical disabilities, and blind people were commanded not to enter places of worship in fear of an irrational dread of contamination and contagion

(McDaniel, 1969). Because of society’s myth of contagion, PWD were often stigmatized, abused, condemned, and isolated from others.

Beginning in the 19th century, researchers found that there were vast differences in societal attitudes toward PWD cross-culturally. While some settings treated PWD as liabilities or burdens, other cultures viewed them as respectable citizens and openly welcomed PWDs to participate fully in society (Hanks & Hanks, 1948). For instance, among a Ghana tribe, PWID were viewed as a reincarnation of a deity; accordingly, they were treated with compassion, kindness, and patience (Munyi, 2012). Similarly, the prevalent philosophy in Scandinavian countries is acceptance of all members of society, creating an environment in which treatment of PWD is widely considered and valued (Munyi, 2012).

While certain cultures have been more accepting of PWID, characteristically society has demonstrated fear, ignorance, neglect, and superstitions throughout history, all significant factors that have exacerbated the isolation of PWD. Various historical events exemplify the social isolation of PWD such as supporters of social Darwinism who opposed the acceptance of PWD receiving any aid, as they reasoned it would hinder the process of natural selection (Hobbs, 1973). In some communities in Kenya and Zimbabwe, a child with a disability is seen as a curse that has fallen upon the entire family (Choruma, 2006; Gona et al., 2011). This shame causes family members to be rejected from their communities, further isolating them from connecting with others. Consequently, the children with the disability, along with their family members, are viewed as deviants by society’s standards. In some troubling cases, the shame imposed upon the family, coupled with society's negative attitudes toward children with IDs, is so intense that parents abandon their children as they believe that their offspring cannot be integrated into society (Tait et al., 2016; Won et al., 2017).

Negative societal attitudes and myths concocted around disabilities can be explained by several psychological factors. Meng (1938) proposed three unconscious reactions to disease, injury, and/or disability: the belief that disorders are a punishment or sin from a higher being due to one's crime; the belief that a person with a disability has been unjustly chastised and therefore needs to engage in evil behaviors to balance the unjust; and a projection of one's own improper desires upon an unlucky person. These three reactions result in a tendency to fear the person with the disability due to a misperception of their being dangerous. While Meng (1938) attempted to explain the primitive reactions that society has regarding individuals with disabilities, he did not fully explain why certain types of disabilities provoked greater amounts of anxiety and aversion in children and adults. For instance, certain types of disabilities such as cerebral palsy, body deformations, and skin disorders create higher levels of aversion for individuals compared to blindness, paralysis, or deafness (DeLoach & Greer, 1981; Siller & Chipman, 1964; Thompson, 1982).

There are several disability-related factors that impact attitudes toward PWD, such as functionality versus organicity of the disability, level of severity, degree of visibility, degree of cosmetic involvement, contagiousness, the body part(s) affected, and the degree of predictability. For this study, the researcher specifically looked at how disability-related factors impact siblings of PWID to better understand the stigmatization caused by society. Generally, society perceives PWD more negatively when they have decreased functionality; people with intellectual and or developmental disabilities may therefore elicit the impression that they are not as useful in society for work or other daily activities (Greenberg et al., 2002; Hebl et al., 2000). Additionally, PWID are also more negatively perceived by society than people with physical disabilities as increases in the severity of disability are more likely to produce an adverse reaction (Wilson & Scior, 2015).

Historically, the more visible the disability, the more negative the attitude it tended to generate; accordingly, others were more likely to have negative feelings about people with cerebral palsy, DS, or FXS (Safilios-Rothschild, 1968; Shontz, 1975; Siller & Chapman, 1964). Siller and Chapman (1964) found individuals reported more feelings of disgust and discomfort when they were in contact with a person who had a visible disability (i.e., cerebral palsy, body deformities, amputations), a construct known as aesthetic aversion. Recently, however, researchers have found dissimilar results. People still tend to generate negative feelings about individuals with cerebral palsy (Al-Dababneh & Al-Zboon, 2018; Muderedzi et al., 2017); however, non-disabled individuals experience less of a disgust reaction and more of a pity reaction for individuals with DS (Leiter, 2018). Attitudes toward individuals with FXS have not been systematically studied.

Historically, researchers have found society’s perception of contagious disabilities aroused more negative reactions and attitudes toward the PWD; if someone feared that they would personally contract the disability, they were more likely to avoid any contact and isolate the PWD (Safilios-Rothschild, 1968). While an ID is not a contagious disease, individuals who are ambivalent regarding a disability or disease tend to employ strategies of avoidance to ensure that they do not haphazardly catch a disease (Lakhan & Sharma, 2010). The specific body part affected by the disability has traditionally played a significant role in society's attitudes toward PWD (Safilios-Rothschild, 1968; Weinstein et al., 1964). Finally, the more curable the disability, the more it was considered predictable and far less negatively perceived by society (Freidson, 1965; Safilios-Rothschild, 1968; Yamamato, 1971). Accordingly, the incurable nature of IDs generates feelings of apprehension from others and further exacerbates the prejudicial attitudes and discrimination toward PWID. While recent literature suggests society may no longer evoke strong negative reactions such as disgust toward PWD, stigmatization continues to be a pressing concern (Buljevac et al., 2012). Reviewing the disability factors that impact negative perceptions, it is evident that PWID have been stigmatized and discriminated against due to negative societal attitudes.

Historical Context of Stigma

The word *stigma* dates back to Greek etiology meaning tattoo-mark, a symbol or mark imprinted upon individuals to show that they were either slaves or criminals (Osborne, 1974). While these bodily rituals are antiquated and no longer used, the modern usage of the term continues to denote an internal mark of degradation to the individual who is the target of discrimination. Goffman (1963) was the first researcher to define the term stigma and explicitly describe how the types of stigma impact the stigmatized as well as those with whom they may be associated due to proximity.

Goffman (1963) denoted stigma as an attribute that discredits and reduces the person "from a whole and usual person to a tainted, discounted one…not quite human" (p. 3). Stigma implies a significant mark of shame and degradation held by the person due to being a member of a devalued social group (Hinshaw, 2007). Thus, the process of stigmatization occurs when an individual's attributes deviate from the social norm (Goffman, 1963). However, societal reactions to norm transgressions vary to some degree. For instance, adults who enjoy childhood activities such as trainspotting may be considered eccentric, but their behavior may not be stigmatized unless there is evidence of an attribute such as mental illness (Page, 1984). Therefore, people typically enact stigma against individuals with attributes considered inferior and commonly considered as significant norm infractions (Page, 1984).

Characteristics of Stigma

Goffman (1963) identified three groups of personal characteristics likely to be stigmatized by non-stigmatized observers, 1) physical, 2) tribal, and 3) conduct. The first, physical stigma, involves individuals with physical deformities or disabilities, what Goffman refers to as "abominations of the body" (Goffman, 1963, p. 4). These include, but are not limited to, obesity, physical disabilities, or facial or bodily disfigurements. The second category, tribal stigma, includes inheritable tribal characteristics, markers that denote racial, religious, and national status that differ from those who are privileged (Goffman, 1963). This type of stigma can be passed down through lineages and may impact all members of the family. The last category, conduct stigma, includes blemishes of character which refers to traits or behaviors looked down upon by others such as having a “weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty, these being inferred from a known record of mental disorder, imprisonment, addiction, alcoholism, homosexuality, unemployment, suicidal attempts, and radical political behavior” (Goffman, 1963, p. 4).

Goffman’s (1963) argument was that society infers the out-group’s character entirely based on stereotypes and the accompanying reputation of those with such traits. For instance, knowing someone has a history of mental illness may engender stigmatization before having met the individual. Furthermore, individuals with conduct stigma are not granted nearly as much social acceptance as individuals with physical and tribal stigmas due to the perception that they are responsible and blameworthy of their behaviors (Gottman, 1963). For instance, researchers have found aberrant behaviors (i.e., yelling, crying, expression of agitation) in children and adults elicit strong negative reactions from perceivers such as rejection, blame, hostility, and punishment due to an assumption that the negative behaviors are controllable (Hinshaw, 2007).

Dimensions of Stigma

To understand the constructs undergirding and shaping stigma responses better, it is important to explore the multiple pathways through which stigma can develop. Jones (1984) adapted the basic concepts of Goffman’s theory, extending his model to identify six fundamental dimensions of stigma: a) concealability, b) course, c) disruptiveness, d) peril, e) origin, and f) aesthetics.

First, *concealability* refers to the visibility of stigmatized attributes. Usitalo (2002) suggested that stigmatized attributes such as craniofacial or musculoskeletal conditions that cannot be concealed allows society to stigmatize merely based on the visibility of the individual. His research supported this finding that individuals with more visible conditions experienced more stigma than individuals with hidden disabilities. Although this dimension primarily pertains to visible non-concealable marks, Hinshaw (2007) posited that relatives may attempt to conceal the person with the stigma due to fear of additional stress, judgment, or blame from perceivers. Such concealability tends to be a coping strategy that both the stigmatized individual as well as associated family members may engage in to prevent feelings of anxiety, shame, and exclusion from others (Dako-Gyeke, 2018; Malli et al., 2016; Werner & Hess, 2016).

The second dimension, *course*, explores the duration and recovery time of the disability (Jones, 1984). A longer term course is associated with greater degrees of stigmatization. For instance, people with chronic illnesses such as paralysis and AIDS tend to receive more stigmatization than those with acute disorders (Hinshaw, 2007). When disabilities are perceived as more severe, stigmatizing attitudes are more likely to emerge (Pelleboer-Gunnink et al., 2017). Regarding IDs, PWID experience fewer negative attitudes compared to people with mental illness such as schizophrenia (Corrigan, 2004). It is unclear whether this finding is due to the perception that mental illness is more severe and chronic of the disorders or due to a misconception by the public that people with mental illness can control their disability. To this researcher's knowledge, there have been limited studies to compare stigmatizing attitudes of individuals with a dual diagnosis of ID and mental illness.

The third dimension, *disruptiveness*, assesses the intensity of the disorder's symptoms upon interpersonal relationships and society (Jones, 1984). If an individual's disorder is less disruptive (i.e., the individual can maintain a job and relationships), they are less likely to be stigmatized by perceivers (Corrigan, Edwards et al., 2001). On the other hand, if an individual is perceived as irrational or inconsistent, they are more likely to receive negative associations with that disability or disorder (Hinshaw, 2007). For instance, researchers who have conducted studies on children with ASD have found that perceivers deem the children as naughty and disorganized due to difficulties with social interaction, communication, and repetitive behaviors (Constantino, 2011; Gill & Liamputtong, 2011).

Peril is the fourth dimension and considered an integral aspect of stigma development as it suggests that individuals use social cues to determine if certain attributes are dangerous and threatening (Jones, 1984). For instance, in the past, individuals with Hansen's disease, previously known as leprosy, were isolated from society by displacing them from their homes in order to live in leper colonies. These facilities were meant to keep afflicted individuals away in hopes of limiting contamination. Fear of contagion continues to plague not only individuals who have Hansen's disease but also their caregivers. Society devalues and stigmatizes caregivers of people affected by leprosy due to the suspicion that they may also be carrying the disease (Dako-Gyeke, 2018). Such fear and rejection by others can prevent caregivers from securing secondary jobs or forming intimate relationships.

The fifth dimension, *origin*, is another topic well documented in the literature. This term refers to the idea that certain disorders such as intellectual and developmental disabilities are developed from biological and genetic factors (Hinshaw, 2007; Jones, 1984). The dimension of origin is closely linked to another dimension of controllability (Corrigan, Green et al., 2001). Corrigan, Green et al. (2001) suggested that if a mental or behavioral disorder is controllable and if they cannot get better on their own, others blame, judge, and reject them. On the other hand, perceived uncontrollable negative behaviors induce compassion and sympathy rather than blame (Weiner et al., 1988). Accordingly, Weiner et al. (1988) found that when deviant behaviors arose from conditions outside of one's control (i.e., physical disabilities), perceivers were more likely to report feelings of sympathy and compassion toward the stigmatized individual; however, if the behaviors were linked to one's control (i.e., behavioral issues), perceivers were more likely to have feelings of hostility and rejection toward the stigmatized individual. Similar results were found among people with DS, as perceivers reported PWID as being dependent and felt pity for them (Fiske, 2012).

These studies indicate that society appears to be less stigmatizing toward people with ID regarding this dimension, as they believe that it is not a controllable condition. However, this conflicts with the literature in which researchers have found that caregivers of children with ID are blamed, judged, and ostracized from their communities due to perceivers believing that the caregivers are at fault for their child's condition (Lim et al., 2013; Milačić-Vidojević et al., 2014). Therefore, while PWID may not be overtly stigmatized due to their origin, those in association may be more likely to encounter more hostile rather than empathic responses.

The last dimension, *aesthetics*, refers to the appearance and attractiveness of certain attributes and strong propensities to reject those who appear not to adhere to social norms (Jones, 1984). Emotional reactions such as disgust and discomfort can result when certain disorders are considered displeasing and often leads perceivers to readily label individuals behaviors as abnormal and avoid the stigmatized person altogether (Corrigan et al., 2003; Jones, 1984).

Types of Stigma

Stigma is a set of prejudicial attitudes, stereotypes, discriminatory behaviors, and oppressive social structures to discredit a marginalized subgroup (Corrigan, 2000). Researchers have discussed three principal types of stigma: 1) public stigma, 2) self-stigma, and 3) family or courtesy stigma (Corrigan & Watson, 2002; Goffman, 1963; Larson & Corrigan, 2008; Link et al., 1997). More recently, another type of stigma, affiliate stigma, has been theorized (Mak & Cheung, 2008). Affiliate stigma is an extension of courtesy stigma; however, the literature is scanter than the other types of stigma. The researcher of the current study concentrated primarily on this latter type of stigma to expand the narrow body of knowledge within this area.

Public Stigma

Public stigma refers to negative attitudes of the general population toward people who possess characteristics deemed undesirable and/or out of the norm (Corrigan et al., 2011). Public stigma is conventionally associated with negative stereotypes from society about the marginalized population as being dangerous, weak, inept, or blameworthy (Rusch et al., 2005). Such stereotypes frequently result in prejudicial attitudes and discriminatory behaviors (Corrigan & Shapiro, 2010). Link and Phelan (2001) argued that stigma is the result of various processes including labeling, stereotyping, separating, loss of status, and discrimination. Labeling allows individuals to identify easily and categorize people readily into groups as part of a social selection process to determine which differences exist (Link & Phelan, 2001). Certain differences, such as those with visible disabilities, become easily identifiable for society to pinpoint and react to, giving rise to stereotyping and separation (Link & Phelan, 2001). When society has deemed that the characteristics of a specific group are unattractive, hierarchical categories are created, making the group members victims of any status and preventing them from being fully integrated and accepted into society (Link & Phelan, 2001).

While great efforts have been made to reduce the public stigma toward those with ID, it continues to be prevalent among PWID (Staniland & Byrne, 2013). Butler and Gills (2011) found that certain behaviors of children with ASD elicited strong stigmatizing responses from the public. These behaviors ranged from language impairments to inappropriate affective expression (i.e., eyerolling, aversion to eye gaze), poor social skills, and self-destructive acts (Butler & Gills, 2011). Stigmatizing responses for PWID can result in exclusion from social activities with others as well as being treated with less empathy and compassion (Gray, 1993; Kinnear et al., 2016). Similarly, youth with TS report experiencing devaluation from their peers such as discriminatory behaviors and/or bullying as a response to their tics (Malli et al., 2016). Children with TS report having a lower quality of life compared to children with epilepsy due to more social rejection by their peers and stronger difficulty socializing with others (Eddy & Cavanna, 2013). Such victimization leads children with TS to attempt to mask their tics in hopes to conceal their “spoiled identity” and prevent social interactions with others (Malli et al., 2016, p. 136). This entire process can be frustrating and embarrassing for those who have been publicly stigmatized, creating self-stigma in certain individuals.

Self-Stigma

Self-stigma occurs when individuals of a marginalized group internalize perceived public stigma (Corrigan & Watson, 2002). There has been increasing research on the psychological effects that stigma has on the targeted individuals themselves (Bambauer & Prigerson, 2006; Fife & Wright, 2000; Mak et al., 2007). When individuals internalize society’s negative views, targeted individuals are more likely to develop negative emotions, such as anger and despair, have a negative self-concept, socially withdraw, and attempt to conceal their stigmatized status (Corrigan & Watson, 2002). Furthermore, self-stigmatization can lead to a sense of shame, guilt, and lack of self-esteem (Malli et al., 2016). As with Link and Phelan’s labeling theory (2001), Weiner (1995) proposed that the fear of being labeled causes the targeted individual to feel stigmatized, prompting emotional reactions such as shame, embarrassment, anger, and isolation.

Among PWID, many people are aware of being treated negatively (i.e., discriminated against by society); however, not all individuals report internalizing the stigma (Ali et al., 2012). People who self-stigmatize are more likely to report lower levels of psychological well-being, such as increased levels of depressive and anxiety symptoms (Ali et al., 2012). Ali et al. (2012) suggested one’s psychological well-being may or may not be affected depending on their coping mechanisms. Stigma can harm PWID and impact those closely associated with them such as their parents and siblings, a term referred to as *courtesy stigma* (Werner & Shulman, 2013).

Courtesy Stigma

The potential of excluding and rejecting family members of individuals with disabilities illustrates Goffman’s notion of courtesy stigma, in which people associated with the publicly stigmatized person are themselves devalued in society (Goffman, 1963). Goffman (1963) suggested that stigma can spread easily from the stigmatized individual to those with whom they are associated, bonding all individuals in close association to “share some of the disgrace of stigmatized people because they are related to them” (p. 30). This tends to be a significant problem for families of PWD as they frequently experience negative attitudes from society (Ali et al., 2012).

Family members are often blamed or considered responsible for the condition of the person who has been discredited rather than stigmatized for their own personal features (Gray, 2002; Malli et al., 2016). A prime example of this stigma occurs with mothers of mass murderers (i.e., the Columbine and Sandy Hook shootings), who are singled out and deemed as socially deviant themselves, ostracized by the public, their identities tarnished due to their sons’ actions (Melendez et al., 2016). The impact of courtesy stigma on family members appears to be a widespread phenomenon across various disorders and illnesses. For instance, parents of children with ADHD experience courtesy stigma as a result of other adults believing that they have caused their children's ADHD through inferior parenting techniques or that their children are genetically flawed (Lebowitz et al., 2016; Norris & Lloyd, 2000; Olaniyan et al., 2007). Similarly, parents of children with TS cope with courtesy and affiliate stigma in the same manner, primarily constraining their relationships with family and friends (Malli et al., 2016).

Courtesy stigma impacts family members who support an adult family member with substance misuse (McCann & Lubman, 2018). McCann and Lubman (2018) conducted semi-structured interviews with 31 affected family members to investigate their stigma experience and how they made sense of their life experiences. The researchers found three primary themes based on the affected family members' experiences: a) secrecy and isolation; b) lack of knowledge, empathy, and judgmental attitudes from others; and c) attempting to be open with others and challenge others' misconceptions selectively in order to moderate the effect of internalized stigma (McCann & Lubman, 2018). While affected family members play an integral role in supporting members with substance abuse, they similarly face their own internal challenges such as embarrassment and shame, which ultimately leads to isolation (McCann & Lubman, 2018). Furthermore, behavioral actions of isolation and secrecy prevent many family members from accessing informal and formal support for themselves and the person who struggles with substance misuse.

Courtesy stigma not only impacts parents of children but also has an impact on other caregivers associated with a stigmatized individual. Werner and Hess (2016) found that foreign healthcare workers caring for people with Alzheimer's disease experience affiliate and courtesy stigma. Participants reported that they experienced more public courtesy stigma from family members, friends, and peers who expressed negative stereotypes regarding people with Alzheimer's, showed discriminatory behaviors as a result of being associated with a person with Alzheimer's, and experienced negative emotions such as disgust from others (Werner & Hess, 2016).

Fear of contagion appears to be a significant reason why some caregivers experience courtesy stigma (Dako-Gyeke, 2018). The most commonly adopted strategies to respond to courtesy stigma among caregivers has been to conceal their identity, disregard hurtful comments, and attempt to educate others regarding myths associated with the disease (Dako-Gyeke, 2018). While these strategies appear to assist caretakers cope with the stigma they experience, they may lead to emotional stress, anxiety, and depressive symptoms.

In addition to caregivers, researchers have found that educators of stigmatized people also face courtesy stigma. Educational practitioners who work with children who experience behavioral, emotional and social difficulties (BESD) experience courtesy stigma (Broomhead, 2016). Findings revealed how these teachers experienced courtesy stigma from colleagues as not being perceived as a "proper teacher" due to their interest in working with their students as well as a larger stigma viewing children with BESD as "naughty" and "bad" (Broomhead, 2016, p. 60). This study highlighted the misunderstanding of the greater population regarding educational practitioners' work as well as the stigma toward individuals who struggle with behavioral and emotional difficulties.

Research regarding the effects of courtesy stigma upon family members of PWID has been limited. Among families of individuals with ID, the stigma attached to the disability results in fear of being criticized, judged, and disgraced by others (Lam & Mackenzie, 2002). For instance, in China, mothers of children with DS reported having difficulty taking their child out to public places due to fear of receiving stares and rejection (Chen & Tang, 1997; Lam & Mackenzie, 2002). Shin et al. (2006) similarly found that stress and courtesy stigma were positively correlated among parents of individuals with ID. While these studies showcase the critical effects of stigma upon family members, there are a few limitations to these studies. These researchers predominantly surveyed Asian parents so results may not be generalizable cross-culturally. Additionally, while parents have been found to take on the primary caretaker role across cultures and may experience stigma more prominently than other family members (Yip, 2003), the experiences of other family members who provide caretaking, such as siblings, have largely been ignored. Accordingly, much remains to be learned about the internal stigmatization process experienced by family members with close relatives with ID.

Affiliate Stigma

Affiliate stigma refers to the extent to which associated individuals internalize courtesy stigma (Mak & Cheung, 2012). An example of affiliate stigma occurs when a parent of a child with a disability feels shame and embarrassment, which may lead to the parent’s infrequent social interactions, further isolating them from others. Researchers’ findings suggest that internalizing courtesy stigma is the primary reason caregivers experience shame and embarrassment (dosReis et al., 2010). The internalization of such emotions can be detrimental to one's well-being and contributes to parents' increased depression and anxiety (Norvilitis et al., 2002). The primary literature has been on the psychological impact of affiliate stigma upon parental caregivers of individuals with various disorders; however, there is no known research to date on the effect of affiliate stigma on siblings' experiences, an omission the researcher of the current study intended to rectify.

Researchers have differentiated between courtesy and affiliate stigma by stating that the latter type of stigma encompasses three psychological components: stigmatized cognition (perception of lower competence and worth), affect (feelings of shame and embarrassment due to status of being stigmatized), and behavior (reactions such as withdrawal and self-condemnation; Corrigan & Watson, 2002; Link & Phelan, 2001; Mak & Cheung, 2008). To better understand the psychological impact of affiliate stigma upon family members, these three psychological components, problematic behaviors of the individual with ID as well as cultural considerations for affiliate stigma are detailed in the ensuing subsections.

Cognition

The cognitive component of affiliate stigma occurs when individuals report thoughts of other people discriminating against them due to their affiliation with a stigmatized family member, their reputation being damaged, thoughts of incompetence, perception that they are lesser than others, and beliefs that they will "lose face" (Mak &

Cheung, 2008, p. 538). The primary literature in this component of affiliate stigma has been centered on caregivers of individuals with mental illness or ASD.

Among caregivers of patients with mental illnesses such as schizophrenia, bipolar disorder, and recurrent depressive disorder, those who experienced greater stigma reported having far more suicidal thoughts compared to caregivers who did not experience stigma (Grover et al., 2017; Östman & Kjellin, 2002). Similarly, caregivers of individuals with Alzheimer's expressed fear and concern that they may eventually "get" Alzheimer's being consistently near a person with Alzheimer's (Werner & Hess, 2016). These studies suggest that psychologists should be assessing the needs of caregivers of individuals with mental illness as they may require further knowledge about the individual's illness as well as more support.

Among caregivers of individuals with ASD, greater stigma has been related to caregivers reporting that their child had a negative impact upon them compared to caregivers of persons with physical or intellectual disabilities (Werner & Shulman, 2015). For example, caregivers of individuals with ASD were more likely to state "being a parent of a child with a disability imposes a negative impact" upon them compared to caregivers of PWID or physical disabilities (Werner & Shulman, 2015, p. 277). Caregivers who reported negative cognitions also experienced emotional distress, indicating the cognitive component may also impact the affective component of affiliate stigma.

Affect

The affective component of affiliate stigma occurs when individuals report feeling inferior, emotionally disturbed, embarrassed, helpless, sad, worried, and under duress (Mak & Cheung, 2008). Specifically for mothers of children with disabilities, there may be a sense of personal responsibility for their child's condition that may lead them to feelings of blaming or thoughts that they could have done something differently before or during their pregnancy (Buscaglia, 1983). These feelings may give rise to stronger feelings of self-condemnation and ultimately reduce one's self-worth (Buscaglia, 1983). Many family members face considerable challenges to their well-being when attempting to support members with disabilities. Family members of individuals with substance misuse frequently felt ashamed and embarrassed and many times were highly self-judgmental (McCann & Lubman, 2018). Several participants narrated how they feared being judged by others, which made them even more reluctant to seek assistance (McCann & Lubman, 2018). When experiencing affiliate stigma, feelings of fear and shame were the most prevalent affective response among caregivers of PWID (Mak & Cheung, 2008), ASD (Wong et al., 2016), substance misuse (McCann & Lubman, 2018), Alzheimer's (Werner & Hess, 2016), ADHD (Mikami et al., 2015), and severe mental disorders (Amaresha et al., 2018; Chen et al., 2016; Grover et al., 2017; Liegghio, 2017).

Such strong emotions may also give rise feelings of anxiety and sadness (Buscaglia, 1983). Chen et al. (2016) found that caregivers' affiliate stigma was positively correlated with their mood symptoms, suggesting that higher reported levels of affiliate stigma was associated with more severe anxiety and depressive symptoms. Chen et al. (2016) failed to mention the nature of the relationship between the caregiver and the patient. Since parents are most often the primary caretakers, they may report higher levels of caretaking duties adding further stress and possible burden, which could ultimately impact their mood state. However, for siblings who may serve as the primary caregivers or take on a supplementary caregiving role, it is important to understand better if such correlations between affiliate stigma and mood symptoms exist.

Behavior

The behavioral component of affiliate stigma involves individuals reporting avoidance of contact with the stigmatized relative, concealing their identity, reducing the amount of time going out with their stigmatized relative, and isolating themselves from others (Mak & Cheung, 2008). Feelings of shame and embarrassment had a significant impact on the caregiver's behavior, as they were more likely to have tendencies to conceal, isolate, and avoid interactions with others as much as possible (Chen et al., 2016; Grover et al., 2017; Mak & Cheung, 2008; McCann & Lubman, 2018; Liegghio, 2017; Mikami et al., 2015; Singh et al., 2016; Werner & Hess, 2016; Wong et al., 2016). Caregivers may engage in these behavioral responses as a defense mechanism against pain (Buscaglia, 1983). Caregivers who are more vulnerable to experiencing affiliate stigma and its associated psychological distress may employ these maladaptive coping strategies (Chen et al., 2016). Caregivers withdraw not only from other family members and friends, but also tend to disconnect themselves from the stigmatized individual (Mikami et al., 2015). Effects of affiliate stigma may impact not only the caregivers' own well-being but also negatively impact the person receiving the caregiving (Mikami et al., 2015). Therefore, it is important to understand the stigma experienced by the associated family member so that mental health practitioners can intervene to assist both the stigmatized person as well as the one experiencing affiliate stigma.

To date, there has not been a specific study assessing how affiliate stigma impacts siblings of PWID. While there has not been research on this topic, there have been limited studies on siblings' experiences with having a brother or sister with a mental health concern. Liegghio (2017) conducted a qualitative study of adolescents who reported having negative experiences of their brother or sister with a mental health problem. The siblings believed that their brother or sister generated considerable stress upon the family. Those siblings who described their experiences as negative were those who had a sibling with a mental health issue that was chronic, severe, interfered with daily family activities, and created conflict within the familial relationship (Lieggio, 2017). The young siblings also reported experiencing overt stigma consisting of shame, rejection by peers, verbal abuse and "contagion associations" (negative perception regarding the young sibling due to their brother or sister's mental health issue; Liegghio, 2017, p. 1241). Such stigma faced by the young siblings resulted in further isolation from peers as well as the refusal to take part in mental health treatment for formalized support.

Behavior Problems

While the three components of affiliate stigma may provide insight into the psychological well-being of the caregiver, another variable that may also impact whether a person experiences affiliate stigma is the behavior of the individual with the intellectual disability. Researchers have found that a child's behavioral problem is a key factor and source of psychological distress among parents of children with ID (Baker et al., 2003; Blacher & McIntyre, 2006; Dunn et al., 2001). Behavioral problems are considered disturbances that are deemed as deviations from the societal norm of what is considered acceptable (Aman et al., 1985). Examples of perceived behavioral problems include social withdrawal, stereotypical behaviors (repetitive behaviors that are not used for communicative purposes), aggression, social skill impairment, self-destructive acts, hyperactivity, and irritability (Aman et al., 1985; Edelbrock & Costello, 1988).

Certain behaviors common among children with ASD, DS, or TS elicit strong stigmatizing responses from the public (Butler & Gillis, 2011; Lam & Mackenzie, 2002; Malli et al., 2016). Parental stress has been shown to increase when children show problematic behaviors such as self-stimulation and inappropriate use of their bodies (i.e., smelling objects, rocking, twirling, and flapping; Mak & Kwok, 2010). Such perceived problematic behaviors may expose parents to courtesy stigma and become internalized as affiliate stigma (Mak & Kwok, 2010). Researchers have found caregivers of children with more severe behavioral problems experience affiliate stigma and decreased psychological well-being (Mak & Kwok, 2010). Mak and Kwok (2010) recruited 188 parents of children with ASD in Hong Kong and assessed the factors that impact parents to experience affiliate stigma. They found parents who believed that they had little to no control over their child’s problematic behaviors were more likely to experience affiliate stigma compared to parents who did believe they had higher levels of controllability regarding their child’s behaviors.

Gallagher et al. (2008) conducted a study to examine predictors of vulnerability to psychological morbidity among 32 caregivers of children with ID (i.e., DS, ASD, Cornelia de Lange, or Smith-Magenis syndrome) and 29 parents of children without disabilities. Caregivers were asked questions related to symptoms of depression, anxiety, social support, sleep quality, and caregiver burden. In addition, caregivers were asked to rate their child's behavioral problems. The researchers confirmed that caregivers for a child with ID experienced substantial symptoms of depression and anxiety compared to the control group. Consistent with previous research, more problematic behaviors exhibited by the child with ID was associated with increased psychological distress and feelings of guilt as a consequence for their child's behaviors. While Gallagher et al. (2008) did not assess if there was a correlation between caregivers' experience of affiliate stigma and perceived problematic behaviors with their child, the study reinforced the notion that children's behaviors may play a significant factor in the etiology of psychological distress. To this researcher's knowledge, there have not been any studies that evaluates whether behavioral problems have any impact on a sibling's experience of affiliate stigma or psychological functioning.

Culture

Although theorists have not yet formally adopted culture as a component of affiliate stigma, affiliate stigma may be a culturally salient factor regarding beliefs toward PWD. For instance, Chinese participants in one study were likely to keep their children with a mental illness or ID a secret and consider their children to be a disgrace to their family (Ow & Katz, 1999). In certain collectivistic cultures, the belief that one will "lose face” in society may be a prominent negative cognition among caregivers. Specifically, within some Asian cultures such as the Chinese, face concern refers to a desire to preserve a personal social image and worth among the community (Ho, 1976).

In a recent cross-sectional study of 50 caregivers from India, 56% of caregivers of children with intellectual disabilities reported facing embarrassment at least once because of their child (Adithyan et al., 2017). Furthermore, more than half of these caregivers decided not to take their child to any social functions due to fear of being ridiculed (Adithyan et al., 2017). The concern for saving face appears to exacerbate the experience of affiliate stigma and decrease well-being (Mak & Cheung, 2008). For instance, researchers surveyed 108 caregivers from Hong Kong to assess whether affiliate stigma was a mediating factor between face concern and psychological distress and found caregivers with strong face concern tended to report higher levels of affiliate stigma, which also contributed to higher levels of psychological distress (Mak & Cheung, 2008). The authors of the aforementioned studies revealed the impact culture can have on psychological well-being among caregivers in collectivistic cultures and further shed light on the importance of the contextual understanding of family members’ experiences of stigma (Adithyan et al., 2017; Mak & Cheung, 2008).

Sibling Relationship

The sibling relationship is typically the longest lasting human relationship (Cicirelli, 1982; Dunn & Kendrick, 1982). While sibling relationships are integral to one’s development, the bulk of disability-related research conducted has been related to the parent-child relationship. When there is a family member with a disability, siblings without a disability may be expected to fill specific roles such as caregiver (Burke et al., 2012; Orsmond & Seltzer, 2000), supporter (Kramer et al., 2013), and advocate (Burke et al., 2015).

Prior Research

In the past, families of individuals with disabilities were considered dysfunctional and consistently suffering (Cummings, 1976). Children were seen as the cause of maternal depression and stress, the father's neuroticism, and the sibling's reclusive behavior (Cummings, 1976; Hodapp, 2002). Historically, sisters of PWD were at a comparable risk as mothers for developing depression or other psychological symptoms due to the gendered pressure to take on adult roles such as caretaking and housekeeping duties (Boyce & Barnett, 1993; Farber & Kirk, 1960; Fowle, 1968; Lobato, 1983).

Young Siblings of PWID

Existing research concerning the overall adjustment and mental health of siblings of PWID has yielded inconsistent results. The researcher found two older longitudinal studies that were conducted with siblings of children with ID with conflicting findings. In the first study, Gath and Gumley (1978) interviewed 30 families of children with DS and 23 families without a child with DS. Each family surveyed had two children, one child diagnosed with DS and one child without a disability. Therefore, 30 siblings of individuals with DS and 30 siblings of individuals without disabilities were interviewed as well. The study was the first to compare behavioral and emotional issues among siblings of children with DS with families who did not have a child with DS. Overall, siblings who had brothers or sisters with DS were rated similarly (no significant behavioral or emotional issues) compared to the control group (Gath & Gumley, 1978). Siblings' behavioral and emotional issues were assessed through parental interviews and teacher reports. No mental health measure for the non-disabled sibling was administered. In a follow-up study conducted six years later, the researchers surveyed 19 (of the original group of 30 siblings) siblings of DS and 20 siblings from the control group (Gath & Gumley, 1984). Gath and Gumley (1984) found non-disabled siblings had more behavioral issues if their brother or sister with DS also exhibited disturbed behaviors at school or at home compared to non-disabled siblings of brothers or sisters without behavioral issues (Gath & Gumley, 1984). Similar to the previous study, the mental health and psychological functioning of the non-disabled sibling was not evaluated at the follow-up study. The authors concluded that the behavioral issues of non-disabled siblings may increase over time and the long-term psychological functioning of siblings was not able to be definitively established, particularly given the small sample size.

In the second study, Carr (1988) conducted a 21-year longitudinal investigation on children with DS and their families, all of whom consisted of multiple children. Every 10 years, 35 mothers completed self-report questionnaires to assess their concern regarding the health and behavior of the sibling without DS. While 17% of the mothers believed that their child with DS had caused difficulty for the other child, 44% expressed that the child had caused both difficulties and benefits within the sibling relationship (Carr, 1988). The other 39% of mothers believed the child had either no effect or solely brought only benefits to the sibling (Carr, 1988). Mothers reported struggling with the belief that the child without DS had been "deprived of a normal sib" (Carr, 1988, p. 419).

However, several mothers also reported their children appeared to have gained more compassion, empathy, and had a lack of embarrassment toward their sibling with DS (Carr, 1988).

Systematic reviews have shown siblings of PWID are at risk of developing a varied range of emotional and behavioral issues (Rossiter & Sharpe, 2001; Summers et al., 1994). Summers et al. (1994) conducted a meta-analysis of 13 studies of siblings' emotions and behaviors and found 25% of siblings of PWID reported overall negative effects such as aggression, anxiety, withdrawal, and dominance while 9% reported positive effects such as more compassion and empathy. Rossiter and Sharpe (2001) conducted a meta-analysis of 25 published studies from 1972 to 1999 representing approximately 1,000 children and adult siblings of PWID. The authors reported a statistically small but small negative effect for having a sibling with an intellectual disability as non-disabled siblings were more likely to exhibit depression, anxiety, and internalizing behaviors than control samples (Rossiter & Sharpe, 2001).

Other investigators have found PWID do not adversely impact a sibling's mental health compared with siblings who do not have a sibling with an ID. Dyson (1999) compared the psychosocial functioning of 37 children (ages 5–18) who had a sibling with a disability with 34 children (ages 5–18) who had a sibling without a disability. Over a 4-year period, siblings of PWID showed no difference compared to the control group on levels of self-concept, social competence, and behavioral adjustment (Dyson, 1999). Dyson's (1999) findings appear to contradict Carr's (1988) study regarding the effect on non-disabled siblings. However, a significant finding from Dyson's study may offer a possible explanation of the mixed research results. Dyson (1999) found family psychological functioning (i.e., parental stress, social support, and family environment) may be more related to the non-disabled sibling’s psychological well-being compared to the individual with the disability themselves. Hence, while non-disabled siblings may experience more distress, it is unclear if the negative psychological effects are related to the person with the disability or other variables.

Earlier studies such as Dyson’s (1999) have prompted researchers to investigate whether family factors can predict siblings’ psychosocial functioning and well-being. Giallo and Gavidia-Payne (2006) conducted a mixed methods study of 49 siblings (ages 7–16) and 49 parents of individuals with disabilities to assess if family factors were predictors of adjustment for siblings. The non-disabled sibling’s adjustment was more strongly predicted by familial and parental factors (i.e., parental stress, family resilience, support, family problem solving) compared to the non-disabled sibling’s self-reported experiences of stress and adjustment (Giallo & Gavidia-Payne, 2006). The finding highlights the relationship between parental functioning and non-disabled siblings’ experiences as well as the notion that the mere presence of a PWID may not be a contributing risk factor for non-disabled siblings.

Limitations

The research reviewed has many methodological limitations. A significant concern with the existing research is the data sources. All of the researchers of the studies reviewed in this section to this point received information from mothers regarding the siblings’ experiences rather than studying the siblings themselves. Investigators asked parents to report siblings' behaviors, psychological functioning, and their presumed stress levels (Carr, 1988; Dyson, 1999; Gath & Gumley, 1978, 1984; Giallo & Gavidia-Payne, 2006; Rossiter & Sharpe, 2001), all of which may have compromised the validity of the findings. Parental reports may not be an accurate depiction of sibling concerns as parents sometimes report greater degrees of sibling problems than siblings themselves (Sharpe & Rossiter, 2002). Speaking with parents rather than siblings may introduce a confound as results may reflect parents' concerns rather than capture siblings' experiences (Cuskelly, 1999).

Another limitation of the studies is the characteristics of the samples. Most researchers have assessed primarily White children, preventing the findings from generalizability (Carr, 1988; Dyson, 1999; Gath & Gumley, 1984; Giallo & Gavidia-Payne, 2006). In two of the studies reviewed, researchers did not differentiate between ID and other types of disabilities (Giallo & Gavidia-Payne, 2006; Summers et al., 1994). Hence, the authors were unable to determine if siblings of specific disabilities experienced greater negative outcomes compared to other siblings with a different type of disability. Determining whether these results are generalizable to siblings of individuals with ID is hindered when researchers do not examine the impact of various classifications of disabilities (Sloper & Turner, 1993).

Current Research

The existing literature on siblings of those with ID has primarily been conducted with children and adolescents. More recent researchers who study siblings have gradually started to move away from relying solely upon parental reports to better understand the siblings' experience (Hodapp et al., 2010; Orsmond, & Seltzer, 2007; Taylor et al., 2008). Furthermore, most previous researchers have focused on outcomes for young siblings between 6 and 18 years old of individuals with ID rather than examining the adult sibling relationship (Carr, 1988; Dyson, 1999; Gath & Gumley, 1984; Giallo & Gavidia-Payne, 2006; Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002; Summers et al., 1994). The adult sibling relationship is critical to explore as the sibling dyad changes over time, particularly when one person has an ID. Unlike typical sibling pairs in which neither has a disability, the non-disabled sibling begins to consider who will take on the caregiving duties for their brother or sister with ID once their aging parents can no longer take on such responsibilities (Hodapp et al., 2017). These additional caretaking duties can create ambivalent feelings toward the PWID as the non-disabled sibling attempts to balance personal life choices (i.e., career, family, romantic relationships) with their caretaking role (Hodapp et al., 2017; Hodapp et al., 2010). Due to the complexity of adult sibling relationships when an individual has an ID, it is integral to highlight the effects PWID have upon the non-disabled sibling.

Adult Siblings of PWID

Orsmond and Seltzer (2007) were the first to study the sibling relationship in adulthood when participants' brothers or sisters had an ID. They examined 154 adults (mean age of 38) who had ASD or DS regarding the frequency of sibling contact, affective involvement, sibling resources, and family background characteristics (Orsmond & Seltzer, 2007). Ninety percent of the individuals with ASD also were diagnosed with ID. The researchers stated most participants were White and did not provide any other information about participants' ethnicities. The findings were notably similar to the research on children who have a brother or sister with ASD or DS such that adult siblings of individuals with DS expressed higher levels of positive emotions and a closer relationship to their brother or sister compared to siblings of individuals with ASD.

Hodapp et al. (2010) assessed 1,166 adult siblings from 18–85 of PWD on a large-scale using a web-based survey. Participants were overwhelmingly White (90%) and female (75%). While there was a lack of racial and gender diversity, siblings of varying intellectual disabilities were included. For instance, siblings of people with DS, ASD, cerebral palsy, WS, FXS, and PWS were included. Most participants considered themselves to have a close relationship with their sibling, positive reactions toward their sibling, and overall good health and well-being (Hodapp et al., 2010).

Taylor et al. (2008) attempted to address and rectify the methodological limitations that had characterized existing research to that point that had primarily studied siblings who were the most involved emotionally and relationally with the PWID. Individuals with mild intellectual deficits were classified by having an IQ score below 85. Taylor et al. (2008) conducted a longitudinal survey based on a random sample of 268 women and men over 50 years. Follow-up surveys were conducted at three points in 1977, 1994, and 2005. Siblings of adults with mild intellectual deficits did not differ from siblings on measures of psychological well-being or distress (Taylor et al., 2008). While the results indicated no evidence of siblings to be at risk for poor psychological functioning, there were multiple limitations in the study. Only siblings of individuals with mild intellectual deficits were included, omitting the experiences of people with a sibling with moderate to severe levels of ID. Furthermore, the results were limited in their ability to generalize the findings to PWID, as some of the individuals with intellectual deficits may not have been diagnosed with an ID. All participants in the sample were White and of low socioeconomic status which may have impacted the generalizability of the findings.

Limitations

Overall, siblings of PWID have tended to exhibit empathy, compassion, responsibility, the ability to understand others' differences, and limited psychological distress or impaired well-being (Hodapp et al., 2010; Orsmond, & Seltzer, 2007; Taylor et al., 2008). Taylor et al. (2008) found siblings of PWID did not differ from the normative group (siblings of individuals without disabilities) on measures of psychological well-being or distress. However, there are multiple methodological limitations including researchers' use of primarily White samples, exclusion of siblings with certain ID, and social desirability bias (Hodapp et al., 2010; Orsmond & Seltzer, 2007; Taylor et al., 2008).

Psychological Impact on Siblings

Growing up with a sibling with an ID has both positive and negative effects (Rossiter & Sharpe, 2001). Most of the siblings of individuals with ID are psychologically well-adjusted (Cuskelly & Gunn, 2006; Levy-Wasser & Katz, 2004; Sage & Jegatheesan, 2010) and report positive feelings about their brother or sister with an ID such as warmth, increased empathy, and pride (Doody et al., 2010; Hodapp & Urbano, 2007; Hodapp et al., 2010; Skotko et al., 2011).

Alternatively, there appears to be some risk for people with a sibling with a disability of developing psychological difficulties such as depression, anxiety, low self-esteem, feelings of worthlessness, and behavior problems (Giallo et al., 2012; Petalas, et al., 2009; Rossiter & Sharpe, 2001; Shivers, 2017). These difficulties are correlated with negative emotions such as fear of the future, guilt regarding any prior mistreatment toward the PWD, loss of being able to have a typical sibling relationship, resentment due to inadequate attention by parents, and stress due to the responsibility of tasks and maintenance of the relationship (Hodapp et al., 2017; Moyson & Roeyers, 2012; Rossetti & Hall, 2015).

Recently, Shivers and McGregor (2018) surveyed 97 adolescent siblings of individuals with an ID, ASD, or without a disability. The authors aimed to compare the siblings' perceptions of their brothers and sisters with disabilities to a parent's perception of their children's feelings. Siblings of those with an ID did not report any more negative feelings about their brother or sister than did siblings of ASD. However, a notable finding was that siblings of ASD did report more overall negative feelings compared to the siblings of typically developing children. While siblings' emotions were assessed using a psychometrically reliable and valid instrument, there was no measure administered to evaluate siblings' well-being or psychological functioning. A lack of expression of negative emotions does not necessarily equate with healthy psychological functioning or adjustment (Verzeletti et al., 2016). Hence, additional studies in which investigators examine siblings' emotions, perceptions, and psychological well-being may provide a more holistic perspective of siblings' experiences.

Skotko et al. (2011) found contrary results when they surveyed 822 brothers and sisters about their sibling with DS. The researchers used multiple self-reported measures to explore the siblings' feelings, attitudes, and perceptions about their sibling. When siblings were asked about their feelings toward their sibling with DS, 96% indicated having positive feelings such as affection (Skotko et al., 2011). Fewer than 10% of the siblings felt embarrassed and less than 5% stated that they would like to trade their sibling in for someone without DS (Skotko et al., 2011). Through the use of a self-reported measure to assess attitudes and perceptions, siblings indicated negative emotions regarding the individual with DS when the parents also indicated regret of having a child with DS (Skotko et al., 2011). While the vast majority of siblings expressed positive emotions toward their siblings, there was a small minority of siblings who may be more likely to report negative feelings with the possible influence of other family members. This study is subjected to the same limitations found from the previous studies mentioned including the demographics, selection sample, and social desirability bias. All of the siblings were under 18 years of age and 85% of the siblings were White. Therefore, the data cannot be generalizable to siblings with other ID or who are people of color. Another limitation is social desirability, suggesting that participants completing a self-reported measure may present themselves more favorably. Participants may be more likely to underreport their negative feelings in order to maintain a desired image. Since Skotoko et al. (2011) did not include a social desirability measure, it is unclear whether the self-report is accurate or whether the participants answered questions in order to be viewed favorably by others. The current researcher included a social desirability measure to assess if participants are more likely to provide answers that are considered socially approved rather than answering with a sincere self-evaluation.

PWIDs' Behaviors on Siblings

Across several studies, researchers have moved beyond the impact of having a sibling with a disability to consider whether the etiology of the disability may be a factor affecting the sibling dyad. Similar to the findings from caregiving literature that state parents experience poorer psychological functioning when their child with ID displays behavioral issues (Gath & Gumley, 1984; Mak & Kwok, 2010; Werner & Shulman, 2015), sibling relationships are also negatively affected when one sibling exhibits severe behavioral problems (Hodapp et al., 2017; Shivers et al., 2013). For instance, research findings have suggested that siblings of individuals with ASD are likely to report less warmth and positive attitudes toward their sibling as well as more depressive symptoms and poorer health compared to siblings of individuals with other types of disabilities (Doody et al., 2010; Hodapp & Urbano, 2007). A possible explanation is that people in society expect family members to exert control over their child or sibling's atypical behaviors (i.e., inappropriate affective behaviors, rocking, twirling, outbursts, or lack of proper social skills), which in turn creates greater levels of stress and self-blame (Mak & Kwok, 2010; Tomanik et al., 2004). The type of ID may be an important variable that impacts psychological well-being for people with siblings with ID. For instance, higher levels of problem behaviors in PWID correlate negatively with levels of warmth from the sibling in later adulthood (Cuskelly, 2016; Orsmond & Seltzer, 2007; Shivers et al., 2013).

Studies of people with siblings with some types of ID appear to be lacking. There have been no known published studies on the psychological well-being of adult siblings of individuals with less common ID such as FXS, WS, DGS, Landau-Kleffner syndrome, angelman syndrome, cri-du-chat syndrome, or FASD. To date, there has been one published study examining the quality of life of individuals with siblings with PWS (Mazaheri et al., 2013). Mazaheri et al. (2013) administered questionnaires to a small sample size of 13 siblings. Siblings of PWS reported overall poorer quality of life compared to siblings of individuals with complex health conditions such as cancer. Participants exhibited high levels of depressive symptoms, anger, worry, and feelings of isolation (Mazaheri et al., 2013). Researchers posited that individuals with siblings who have PWS may experience negative psychological functioning due to certain maladaptive behaviors that are characteristics of PWS such as temper outbursts, stubbornness, compulsivity, and stereotyped behaviors. Due to the dearth of research on certain classes of disabilities, it is unclear if there is a consistent correlation between a PWID’s behavior problems and the non-disabled sibling’s psychological well-being. Therefore, the researcher of the current study aimed to be one of the first to include the sibling experiences of various ID and assess if problem behavior has any impact on a sibling’s psychological functioning.

Siblings and Stigma

To the best of the researcher’s knowledge, there appears to be no extant research that has explored more deeply into the nuanced experiences of adult siblings with a brother or sister with an ID. One construct that has been distinctly missing from the literature to date that may help contextualize negative reactions and experiences of having a sibling with an ID is affiliate stigma. Indeed, most of the research in this area has centered on caregivers (primarily mothers) of children with ID who experience affiliate stigma (Corrigan & Watson, 2002; dosReis et al., 2010; Link & Phelan, 2001; Mak & Cheung, 2008; Norvilitis et al., 2002; Werner & Shulman, 2015; Wong et al., 2016); however, the literature on adult siblings regarding their experiences with affiliate stigma is nonexistent.

There were 20 studies in which researchers examined courtesy or affiliate stigma among caregivers of individuals with intellectual disabilities between 1990 and 2012 (Ali et al., 2012). Of those, only three researchers explicitly studied the impact of affiliate stigma on caregivers (Mak & Cheung, 2008; Mak & Kwok, 2010; Ntswane & Van Rhyn, 2007). However, each researcher primarily focused on mothers as their sample and seemed to assume that only primary caregivers, who are typically mothers, experience stigma, further neglecting the siblings' experience. Since 2012, there have been five studies focused primarily on the impact of affiliate stigma upon caregivers of PWID. Four of the studies centered on parents of children with ASD (Chan & Lam, 2018; Werner & Shulman, 2013, 2015; Wong et al., 2016). Researchers found parents of children with ASD experience a negative correlation between affiliate stigma and psychological well-being (Chan & Lam, 2018; Werner & Shulman, 2013; Werner & Shulman, 2015; Wong et al., 2016). Yang (2015) found similar results examining caregivers of children with ID, but notably discovered that caregivers who experienced a stronger desire to save face were more likely to internalize shame leading to poorer mental health. While Yang (2015) was the only researcher to most recently examine caregivers of individuals with varying ID, there was no mention of the types of ID.

In a recent unpublished dissertation, Fleming (2015) interviewed three siblings whose brothers or sisters were diagnosed with cerebral palsy, autism and ID, and DS. Fleming (2015) identified several themes regarding how adult siblings felt about their sibling with a neurodevelopmental disability including love, pride, and admiration as well as shame, loss, and embarrassment. Two participants described feeling “embarrassed to be seen in public” with their sibling or that they felt a loss of a sense of normalcy (Fleming, 2015, p. 32). The major themes alluded to the result of internalized stigma; however, the researcher did not categorize the theme this way. Nevertheless, Fleming’s (2015) research is the first to highlight the affective component adult siblings may experience having a brother or sister with a neurodevelopmental disability. While the research was novel, it was characterized by limitations including a small sample size, limited participant age range (28–30 years old), and exclusion of other types of lesser known intellectual disabilities (i.e., FXS, WS, and PWS). An additional limitation was the lack of investigation related to stigma. Fleming (2015) noted stigma emerged as a repeated topic across siblings; however, the researcher did not explore the impact of felt stigma upon the sibling further. The researcher of the current study intends to expand upon Fleming’s (2015) research and explore whether siblings of PWID experience all three components of affiliate stigma (behavioral, affective, and cognitive), as well as the impact of the behavioral problems of the siblings with an ID, and how these impact non-disabled adult siblings’ mental health.

Rationale for the Current Study

While investigators have researched the psychological well-being of family members of PWID, the literature to date has focused primarily on parents. Research findings suggest caregivers experience high levels of depression and anxiety as well as lower psychological well-being due to internalized (affiliate) stigma (Ali et al., 2012; Dako-Gyeke, 2018; Malli et al., 2016; Norvilitis et al., 2002; Werner & Hess, 2016). As a result, caregivers of PWID often report feelings of shame and embarrassment (Mak & Cheung, 2008; Wong et al., 2016), thoughts of losing face (Adithyan et al., 2017; Ho, 1976; Mak & Cheung, 2008), and employ maladaptive behavioral strategies such as concealment and isolation (Chen et al., 2016; Grover et al., 2017; Mak & Cheung, 2008; McCann & Lubman, 2018; Liegghio, 2017; Mikami et al., 2015; Singh et al., 2016; Werner & Hess, 2016; Wong et al., 2016).

Furthermore, caregivers of children with more severe behavioral problems experience affiliate stigma and decreased psychological well-being (Mak & Kwok, 2010). The researcher of the current study aimed to extrapolate the findings from caregivers who experience affiliate stigma and explore whether affiliate stigma and behavior problems similarly impacts siblings' psychological well-being and functioning. Although siblings of PWID may have both positive and negative experiences, it is yet unknown if siblings experience affiliate stigma similarly to primary caregivers and what their unique experiences pertaining to mental health are. The current study is the first to explore whether adult siblings of PWID experience affiliate stigma as well as how stigma may impact their psychological well-being.

Of note, it is an ethical imperative for psychologists to strive to gain awareness, increase their knowledge, and learn how to assist marginalized populations (American Psychological Association [APA], 2017). Psychologists are positioned to help individuals with disabilities as well as families of individuals with disabilities through challenges and stressors (APA, 2012). Therefore, practitioners are encouraged to assess how family members are managing stress, improving their quality of life, and employing adaptive coping skills (APA, 2012). The current study adds to the literature related to the siblings' experiences with the hope that psychologists may use the research to provide support and psychoeducation to siblings of PWID.

Hypotheses

Based on the literature reviewed, the researcher proposed the following hypotheses:

1. It is hypothesized that affiliate stigma will be positively correlated with higher levels of depression among siblings of PWIDs.
2. It is hypothesized that affiliate stigma will be positively correlated with higher levels of anxiety among siblings of PWIDs.
3. It is hypothesized that affiliate stigma will be negatively correlated with psychological well-being among siblings of PWIDs.
4. It is hypothesized that affiliate stigma will partially mediate the relationship between behavior problems and psychological well-being.
5. It is hypothesized that affiliate stigma will partially mediate the relationship between behavior problems and depression.

6. It is hypothesized that affiliate stigma will partially mediate the relationship between behavior problems and anxiety.

CHAPTER III

METHODOLOGY

Participants

The researcher recruited 202 participants through social media websites, listservs associated with ID organizations, and sibling support groups to participate in the current study. Of the 202 participants who attempted to complete the study, 92 participants were removed due to duplicate cases (i.e., the same participant completed the study multiple times), invalid data (i.e., random responding), limited survey duration (i.e., took less than 2 seconds per item) and those who did not fully meet criteria (i.e., did not have a sibling with an ID). Therefore, 110 participants' data were retained for the study. Respondents who completed the study did not differ from respondents who did not complete the study. For a medium effect with an alpha level of .05 in a multiple regression with 8 predictor variables, a minimum sample size of 107 participants was necessary for a power of .80 (Cohen, 1992).

Participants ranged in age from 18 to 78 years (*M* = 30.84, *SD* = 12.51). Participants were predominantly female (77.3%) and White (90.9%). Many of the participants were employed, with 54.5% indicating that they had full-time positions. Participants were well-educated with nearly two-thirds having obtained at least a bachelor's degree. Many of the participants lived either with their sibling or within a 50-mile radius of the sibling with an ID (70%). For detailed information about participants' demographics, see Table 1.

Table 1

Demographics of Participants

Variable	**Level**	***n***	**%**
Gender	Man	24	21.8%
	Woman	85	77.3%
	Nonbinary	1	0.1%
Race	White	102	90.9%
	Hispanic/Latinx	4	3.6%
	Black	0	0%
	Native American	0	0%
	Asian	2	1.8%
	Bi-Multiracial	4	3.6%
Highest Level of Education	High school	18	16.4%
	Some post high school	15	13.6%
	2 year degree	5	4.5%
	4 year degree	44	40%
	Graduate	28	25.5%
Employment Status	Full-time	60	54.5%
	Part-time	15	13.6%
	Unemployed	8	7.3%
	Other	27	24.5%
Proximity to sibling with intellectual disability	Lives with sibling	35	31.8%
	1–10 miles	26	23.6%
	11–50 miles	16	14.5%
	51–150 miles	12	10.9%
	151–300 miles	7	6.4%
	301–500 miles	2	1.8%
	More than 500 miles	12	10.9%

Participants' disabled sibling ranged in age from 2 to 73 years (M = 28.18, SD = 12.70). Nearly half (47.3%) of the participants reported having a sibling who identified as male while 51.8% of the participants indicated that their sibling identified as female. Most participants had a biological sibling with an ID (85.5%). Nearly all participants (91.5%) indicated that they had engaged in caretaking duties for their sibling within the past year. Similarly, a vast majority of the participants (97.2%) indicated that they had engaged in caretaking duties for their sibling in the past (longer than 2 years). See Table 2 for more details of participants' siblings.

Table 2

Demographics of Participants' Sibling with Intellectual Disability

Variable	**Level**	***n***	**%**
Gender	Man/male	52	47.3%
	Woman/female	57	51.8%
	Unknown	1	0.9%
Related to Sibling	Biological	94	85.5%
	Half-sibling	12	10.9%
	Step sibling	0	0%
	Adopted	4	3.6%
Caretaking Duties Within Last Year	Daily activities	74	67.3%
	Household activities	68	61.8%
	Financial responsibilities	25	22.7%
	Healthcare	56	50.9%
	Transportation	79	71.8%
	Other	17	15.5%

Caretaking Duties Within Last 2 Years	Daily activities	89	80.9%
	Household activities	83	75.5%
	Financial responsibilities	27	24.5%
	Healthcare	71	64.5%
	Transportation	89	80.9%
	Other	12	10.9%

The majority of the participants' siblings reported having a sibling diagnosed with angelman syndrome (44.5%). Each of the intellectual disabilities were represented other than cri-du-chat (0%). See Table 3 for more details on the sibling's type of disability.

Table 3

Type of Intellectual Disability of Participants' Sibling

Variable	**Level**	***n***	**%**
Type of Disability	Down Syndrome	18	16.4%
	Williams Syndrome	13	11.8%
	Fragile X Syndrome	8	7.3%
	Prader-Willi Syndrome	7	6.4%
	Other:		
	Smith-Magenis	5	4.5%
	DiGeorge Syndrome	3	2.7%
	Fetal Alcohol Spectrum	1	0.01%
	Cri-du-Chat syndrome	0	0%
	Angelman Syndrome	49	44.5%
	Cerebral Palsy	1	0.01%
	ASD with ID	2	0.02%
	Unknown ID	3	0.03%

Procedure

Participants were primarily recruited electronically through social media websites and listservs associated with ID organizations and sibling support groups prior to the COVID-19 pandemic. These organizations included The Arc, Easter Seals, National Down Syndrome Society, Down Syndrome Partnership of North Texas, Down Syndrome Guild of Dallas, National Fragile X Foundation, National Organization for Rare Disorders, Williams Syndrome Association, Prader-Willi Syndrome Association, Smith-Magenis Syndrome Research Foundation, Angelman Syndrome Foundation, and Texas disability service agencies. The researcher also contacted support organizations specifically for siblings of PWID. The researcher asked the organizations to share information about the current study with their members on their social media pages and in their newsletters. To prevent selection bias, the researcher posted information about the current study on other sites not related to ID or siblings such as Reddit, Survey Circle, Psychological Research on the Net, and LinkedIn. Additionally, the investigator electronically distributed a flyer (see Appendix A) to local agencies and clinics with information about the study along with a link to the online survey. Due to a limited response rate from various sibling support groups and ID organizations, the researcher heavily utilized social media sources such as Facebook to post information about the current study. Since the researcher contacted various sibling support groups through social media pages, the current sample may not be representative of the greater population.

The title of the study was presented as “Experiences of Adult Siblings of Individuals with Intellectual Disabilities” to help minimize risk of demand characteristics. Participants completed an informed consent form (see Appendix B). The informed consent provided participants information regarding the purpose of the study, potential benefits, risks, sources for counseling, and the researcher and her advisor’s contact information. After indicating informed consent, participants were screened on all three criteria prior to starting the study. If participants met all criteria, they were directed to a short demographic questionnaire in addition to six online measures: Affiliate Stigma scale (AS; Mak & Cheung, 2008), Psychological Well-Being (PWB; Ryff & Keyes, 1995), Aberrant Behavior Checklist-2 (ABC; Aman et al., 1985), Center for Epidemiological Studies Depression Scale-Revised (CESD-R; Eaton & Kessler, 1981), Generalized Anxiety Disorder Scale (GAD-7; Spitzer et al., 2006), and Social Desirability Scale (SDS; Reynolds, 1982; see Appendices E-J). See Table 4 for more detailed information on the instruments. Once the assessments were completed, participants were redirected to a page with a blank textbox and had the option to answer an open-ended question, “Is there anything else that you would like the researcher to know?”

Data were collected via PsychData, a software program that provides a secure network for collecting data and ensures confidentiality of participants’ responses without identifying information. To control for order effects, the researcher counterbalanced the order of the six online measures through PsychData. Upon completion of the assessments, participants had the option to be entered into a drawing to receive one of two $25 Amazon gift cards. Participants were asked to provide an email address if they chose to enter their name for the drawing. Email addresses were not connected to participants’ responses. The researcher sent electronic gift cards to participants who were awarded the incentive.

Table 4

Means and Standard Deviations for Instruments

Measure	*M*	*SD*	Actual Range	Potential Range
AS	1.50	0.45	1.00–3.00	1.00–4.00
Affective	1.77	0.60	1.0–3.14	1.0–4.0
Cognitive	1.40	0.40	1.0–2.57	1.0–4.0
Behavioral	1.37	0.47	1.0–3.38	1.0–4.0
PWB	5.48	0.82	3.33–6.83	1.0–7.0
Autonomy	5.33	1.14	1.67–7.0	1.0–7.0
Environmental Mastery	4.92	1.20	1.50–7.0	1.0–7.0
Personal Growth	6.11	0.95	2.67–7.0	1.0–7.0
Positive Relationships	5.43	1.29	1.67–7.0	1.0–7.0
Purpose in Life	5.52	1.16	1.67–7.0	1.0–7.0
Self-Acceptance	5.57	1.23	2.0–7.0	1.0–7.0
ABC	0.59	0.45	0–1.83	0–3.0
Irritability	0.70	0.68	0–2.67	0–3.0
Social Withdrawal	0.41	0.43	0–2.17	0–3.0
Stereotypic Behavior	0.52	0.56	0–2.43	0–3.0
Hyperactive/Noncompliance	0.72	0.61	0–2.50	0–3.0
Inappropriate Speech	0.51	0.68	0–2.23	0–3.0
CESD-R	0.73	0.64	0–2.88	0–3.0
GAD-7	1.0	0.72	0–3.0	0–3.0
SDS	0.54	0.25	0–1.0	0–1.0

Note. AS = Affiliate Stigma. PWB = Psychological Well-Being. ABC = Aberrant Behavior Checklist-2. CESD-R = Center for Epidemiological Studies Depression Scale- Revised. GAD-7 = Generalized Anxiety Disorder Scale. SDS = Social Desirability Scale.

Instrumentation

General Demographic Questionnaire

Prior to being directed to the demographic questionnaire, three criterion items were asked of the participants to confirm their 1) identity as an adult (18 years of age or older), 2) having a sibling with an ID, and 3) having had recent contact with their sibling (see Appendix C). The participants who did not qualify for the study were redirected to a page that read, “Thank you for your interest in this study. The study is looking for participants over the age of 18 who have a sibling with an intellectual disability. Since you do not meet these requirements, you do not qualify for participation at this time. Thank you for your time.”

If participants qualified for the study, participants were redirected to complete a brief general demographic questionnaire (see Appendix D). The questionnaire gathered information about participants’ age, gender, ethnicity, employment status, and level of education. In addition, participants were asked questions about their sibling with an ID such as the sibling’s age, gender, relation to their sibling (i.e., full biological, half, step, or adopted sibling), the proximal living distance, as well as type of caretaking duties (if any) with which they currently or have previously assisted their sibling. The researcher analyzed all demographic variables to determine if there was a relationship with the dependent variables. The data were integrated into the primary analysis plan.

Participants were asked to indicate the specific type of ID with which their sibling has been diagnosed. Participants were provided a selection of answer choices which included DS, FXS, WS, PWS, or Other ID (e.g., Smiths-Magenis, cri-du-chat syndrome, angelman syndrome, FASD, or DiGeorge syndrome). For participants who were a sibling of a PWID with a disorder not listed as an answer choice, they had the option to specify in an empty text entry.

Affiliate Stigma Scale

The 22-item AS scale (Mak & Cheung, 2008) was adapted and used to measure siblings' internalization of stigma (see Appendix E). The investigator of the current study modified Mak and Cheung's (2008) scale. The original assessment was used primarily to study caregivers of individuals with mental illness or intellectual disabilities. Although siblings may be caregivers for PWID, not all participants may consider themselves caregivers; therefore, the current study changed the wording slightly from "family member with mental illness/intellectual disability" to "sibling with an intellectual disability." The researcher emailed and received permission from Mak and Cheung to make the slight modification to their scale.

The modified AS scale encompassed 22 items scored on a 4-point Likert scale from 1 (*strongly disagree*) to 4 (*strongly agree*). The questions were categorized into three domains: affective (seven questions), cognitive (seven questions), and behavior (eight questions). Sample items include, "I feel emotionally disturbed because I have a sibling with intellectual disability," "Having a sibling with intellectual disability makes me lose face," and "I reduce (or limit) going out with my sibling with an intellectual disability." To score the AS scale, the total score of all items were averaged. Higher scores reflected greater affiliate stigma. The scale has good internal consistency for caregivers of PWID (*α* = .95; Mak & Cheung, 2008). The current study demonstrated an alpha of .93.

Psychological Well-Being Scale

Psychological well-being was measured using a shortened version of Ryff and Keyes’ (1995) PWB measure (see Appendix F). The scale consisted of 18 items from six subscales of well-being: Self-acceptance, Positive Relations with Others, Autonomy, Environmental Mastery, Purpose in Life, and Personal Growth. Sample items consisted of, “I judge myself by what I think is important, not by what others think is important,” “The demands of everyday life often get me down,” and “I gave up trying to make big improvements or changes in my life a long time ago.” Participants were asked to respond on a Likert scale from 1 (*strongly agree*) to 7 (*strongly disagree*). All items were totaled and averaged to obtain an overall well-being score, higher scores indicating greater psychological well-being compared to lower overall scores. The subscales of the PWB demonstrates high internal consistency (*α* = .70–.89; Ryff & Keyes, 1995). The current study demonstrated an alpha of .84.

Aberrant Behavior Checklist-2

The ABC was administered to obtain information about behavioral problems adult sibling reports regarding the PWID (Aman et al., 1985; see Appendix G). The ABC was originally developed and intended for patients living in institutions; however, the measure was revised to make it more applicable to home and school settings (Aman et al., 1985). Currently the ABC is the most widely used behavior rating scale in the ID field (Rojahn et al., 2011). The ABC is a 58-item rating scale used to assess maladaptive behaviors across five subscales: Irritability, Hyperactivity, Lethargy/Withdrawal, Stereotype, and Inappropriate Speech. Participants were asked to rate the PWID's behavior over the previous 4 weeks. Each item was scored on a 4-point scale ranging from 0 (*not a problem*) to 3 (*problem is severe in degree*). Sample items consisted of participants reporting whether their sibling with ID is "restless," "disturbs others," "impulsive," "does not communicate," and "easily distracted." Higher sum of scores from the items indicated more undesirable behavior. The ABC-2 has high internal consistency for adults with intellectual disabilities (*α* = .94; de Vaan et al., 2018). The current study demonstrated an alpha of .95.

The Center for Epidemiological Studies Depression Scale-Revised

To obtain information about the participant's level of depression, the CESD-R was administered (see Appendix H). The CESD-R (Eaton & Kessler, 1981) is a 20-item self-report measure used to assess the occurrence and severity of symptoms of depression in adults. Eaton and Kessler (1981) modified Radloff's (1977) original CESD scale to more closely align with current *DSM-5* (American Psychiatric Association, 2013) diagnostic criteria for depression. The 20 items in the scale are categorized into nine groups based on depressive symptoms: suicidal ideation, agitation, fatigue, worthlessness, concentration, sleep, appetite, anhedonia, and dysphoria.

The instructions stated, "Below if a list of the ways you might have felt or behaved. Please check the boxes to tell me how often you have felt this way in the past week or so" (Eaton & Kessler, 1981, p. 33). Examples of such statements included, "I felt like a bad person," I had a lot of trouble getting to sleep," and "Nothing made me happy."

Participants were then asked to select how often they have experienced the symptom with answer choices ranging from “not at all or less than 1 day last week” to “nearly everyday for the past two weeks.” The items were scored on a 5-point ordinal scale ranging from 0 (*not at all or less than 1 day in the last week*) to 3 (*nearly every day for 2 weeks*). CESD-R scores were calculated by summing each of the single scores from the 20 items, with higher total scores indicating more severe depressive symptoms. Scores of 16 or above indicated clinical significance of depressive symptoms based on *DSM-5* (American Psychiatric Association, 2013) criteria. The CESD-R has exhibited good psychometric properties including a high internal consistency range (α = .85–.90) and high validity within the general population (Radloff, 1977). The current study demonstrated an alpha of .92.

Generalized Anxiety Disorder Scale

Anxiety symptoms were measured using the GAD-7 (Spitzer et al., 2006; see Appendix I). The GAD is a 7 item measure with each item on a 4-point Likert scale ranging from 0 (*not at all*) to 3 (*nearly every day*). Sample items included, “Feeling nervous, anxious, or on edge” and “Not being able to stop or control worrying.” Participants were asked to answer how often they have been bothered by the following problems over the last 2 weeks. The answer choices to select from consisted of not at all sure, several days, over half the days, and nearly every day. If the participant reported experiencing any of the items, they were asked if the difficulties impaired their functioning at work, home, or relationally. Items’ scores were totaled with higher scores indicating significance of anxiety symptoms. The GAD-7 has high internal consistency (α

= .89) among the general population (Löwe et al., 2008). The current study demonstrated an alpha of .88.

Social Desirability Scale

Social desirability bias was measured using the short form of the SDS (Reynolds, 1982; see Appendix J). The SDS is a 13-item measure that was adapted from the 33-item Marlowe-Crowne Social Desirability Scale (MCSDS) to measure respondents' tendency to respond to questions with honest self-evaluation (Reynolds, 1982). The shortened version was utilized as it has been shown to be a viable substitute for the original MCSDS. Participants were asked to decide whether each statement is true or false. Sample items included, "I sometimes feel resentful when I don't get my way," "No matter who I'm talking to, I'm always a good listener," and "I'm always willing to admit it when I make a mistake." Five items were reverse scored. The reverse scored items assessed a participant's tendency to overreport positive traits or underreport undesirable behaviors. Examples of items that were reverse scored included participants suggesting that they are "always courteous, even to people who are disagreeable" or that they have "never been irked when people expressed ideas very different from [my] own." The scores were totaled with each respondent receiving a social desirability score ranging from 0–13. Higher score indicated a concern with societal approval and a strong tendency to give socially desirable answers to the statements. The SDS yields an acceptable reliability (α = .76) and was correlated .93 with the original MCSDS (Reynolds, 1982). The current study demonstrated an alpha of .78.

Analytic Plan

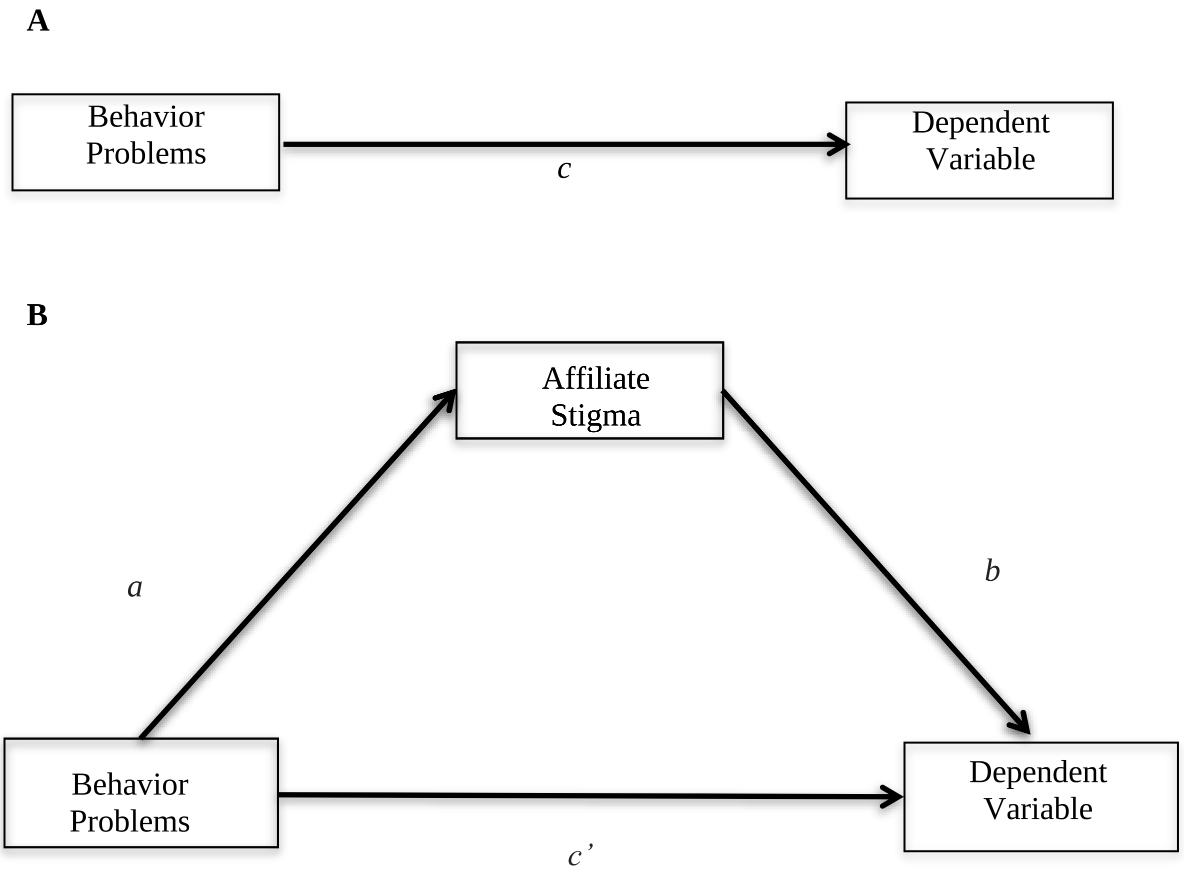
Descriptive analyses were conducted for all demographic variables. Primary variables were examined and assessed for skewness and kurtosis. All distributions met the assumption of normality. The study's hypotheses and analytical plan are listed below. Pearson's correlational analyses were conducted for Hypotheses 1, 2, and 3. Hypothesis 1, which predicted that greater affiliate stigma would predict more depressive symptoms, was tested using correlational analyses. Similarly, a correlational analysis was conducted for Hypothesis 2 which predicted that greater affiliate stigma would predict more anxiety symptoms. Hypothesis 3 posited a negative relationship would occur between psychological well-being and affiliate stigma.

For Hypotheses 4, 5, and 6, the researcher conducted a mediation analysis following the steps of Baron and Kenny (1986) and Sobel (1982) to examine the mediating role of affiliate stigma on the association between behavior problems and dependent variables (i.e., psychological well-being, depression, and anxiety). The researcher conducted a multiple regression analysis. For the first step, the primary investigator conducted a simple regression to examine whether the relationship between behavior problems and the dependent variable (i.e., psychological well-being, depression, or anxiety) was significant prior to controlling for affiliate stigma (Path *c*). Diagram A in Figure 1 represents Path *c*, representing the unmediated model. At Step 2, the researcher assessed whether behavior problems predicted more affiliate stigma (Path *a*). At Step 3, the researcher assessed the significance of affiliate stigma as a predictor of the dependent variable (i.e., sibling's psychological well-being, depression, or anxiety; Path *b*). At Step

4, the researcher assessed whether behavior problems would be significant in predicting the dependent variable after controlling for affiliate stigma (Path *c'*). Diagram B in Figure 1 represents the mediated model and depicts Path *a*, *b*, and *c'*. Lastly, a Sobel test was utilized to examine whether affiliate stigma mediated the relationship between behavior problems and the dependent variable.

Figure 1

Example of Unmediated and Mediated Model



The fourth hypothesis predicted that affiliate stigma would partially mediate the relationship between behavior problems and psychological well-being. The fifth hypothesis predicted that affiliate stigma would partially mediate the relationship between behavior problems and depression. The sixth hypothesis predicted that affiliate stigma partially mediated the relationship between behavior problems and anxiety.

To explore the presence of social desirability bias, bivariate correlations were conducted using the social desirability score and the remaining scales measuring anxiety, depression, aberrant behaviors, affiliate stigma, and psychological well-being. Positive correlations would indicate a significant level of relationship between social desirability and the subscale being assessed in which case respondents’ answers may have been skewed by impression management and would be interpreted cautiously. Negative correlations would indicate low level of relationship between social desirability and the subscale being assessed.

CHAPTER IV

RESULTS

Descriptive analyses were run for all demographic variables. Variables were assessed for skewness and kurtosis to determine whether distributions are normal or required correction. All distributions met the assumption of normality, and no corrections were made. For each hypothesis, an exploratory analysis was conducted comparing participants with siblings of differing intellectual disabilities with each other. In addition, correlational analysis and one-way Between Subjects ANOVA tests were conducted to examine if demographic variables such as age, gender, race, caretaking duties, and education impacted affiliate stigma. The findings for these exploratory analyses will be detailed following each hypothesis below.

Preliminary Analyses

Correlations Among Scales

Correlational analyses were conducted to assess intercorrelations of the various scales and subscales (see Table 5). Correlational analyses were primarily analyzed to assess if there were correlations among the five scales and each of the subscales.

Affiliate Stigma Scale

The AS scale total scale score was positively correlated with its own affect ($r = .92$, $p < .01$), behavior ($r = .91$, $p < .01$), and cognitive subscales ($r = .90$, $p < .01$). While the AS scale had a significant positive correlation with the ABC ($r = .41$, $p < .01$), the AS scale was not significant with stereotypical behaviors ($r = .17$, $p > .05$) and inappropriate speech ($r = .07$, $p > .05$) subscales of the ABC.

Table 5

Correlations

Measure	1	1a	1b	1c	2	3	4	4a	4b	4c	4d	4e	4f	5	5a	5b	5c	5d	5e
1. AS	--	.92*	.91*	.90*	.37*	.32*	-.57*	-.20**	-.52*	-.31*	-.51*	-.30*	-.49*	.41*	.42*	.30*	.17	.35*	.07
1a. Aff.	--	--	.73*	.76*	.28*	.26*	-.46*	-.05	-.47*	-.19**	-.42*	-.25**	-.41*	.37*	.34*	.25*	.15	.37*	.08
1b. Beh.	--	--	--	.75*	.33*	.29*	-.55*	-.32*	-.44*	-.32*	-.47*	-.32*	-.44*	.38*	.43*	.33*	.08	.30*	.03
1c. Cog.	--	--	--	--	.42*	.36*	-.55*	-.17	-.52*	-.35*	-.53*	-.25*	-.51*	.37*	.41*	.22**	.24**	.29*	.07
2. Dep	--	--	--	--	--	.72*	-.63*	-.25*	-.65*	-.27*	-.43*	-.43*	-.64*	.30*	.28*	.22**	.29*	.20**	.06
3. Anx	--	--	--	--	--	--	-.54*	-.28*	-.59*	-.23**	-.42*	-.24**	-.54*	.26*	.23**	.35*	.16	.11	.12
4. PWB	--	--	--	--	--	--	--	.43*	.77*	.67*	.75*	.71*	.84*	-.23**	-.22**	-.24**	-.15	-.15	.02
4a. Aut.	--	--	--	--	--	--	--	--	.26*	.19**	.15	.21**	.26*	-.12	-.19	-.08	.03	-.07	.00
4b. EM	--	--	--	--	--	--	--	--	--	.35*	.56*	.46*	.69*	-.25*	-.26*	-.21**	-.15	-.17	-.00
4c. PG	--	--	--	--	--	--	--	--	--	--	.57*	.51*	.45*	-.04	-.04	-.12	-.04	.00	.11
4d. PR	--	--	--	--	--	--	--	--	--	--	--	.41*	.56*	-.13	-.10	-.17	-.15	-.09	.04
4e. PIL	--	--	--	--	--	--	--	--	--	--	--	--	.51*	-.21**	-.15	-.27*	-.12	-.15	-.11
4f. SA	--	--	--	--	--	--	--	--	--	--	--	--	--	-.22**	-.22**	-.23**	-.20**	-.12	.03
5. PB	--	--	--	--	--	--	--	--	--	--	--	--	--	--	.89*	.67*	.69*	.88*	.36*
5a. Irr.	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	.45*	.48*	.70*	.30*
5b. SW	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	.36*	.42*	.11
5c. SB	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	.60*	.25*
5d. Hyp	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	.19**
5e. IS	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Note. 1. Affiliate Stigma, 1a. AS-Affect, 1b. AS-Behavior, 1c. AS-Cognition; 2. Depression; 3. Anxiety; 4. Psychological Well-Being, 4a. PWB-Autonomy, 4b.PWB-Environmental Mastery, 4c. PWB-Personal Growth, 4d. PWB-Positive Relationships, 4e. PWB-Purpose in Life, 4f. PWB-Self-acceptance; 5. Problem Behaviors, 5a. PB-Irritability, 5b. PB-Social Withdrawal, 5c. PB-Stereotypic Behaviors, 5d. PB-Hyperactivity, 5e. PB-Inappropriate Speech
*$p < .01$. **$p < .05$

The Psychological Well-Being Scale

The PWB was negatively correlated with AS ($r = -.57$, $p < .01$), CESD-R ($r = -.25$, $p < .01$), GAD-7 ($r = -.28$, $p < .01$), and ABC ($r = -.23$, $p < .05$). Three subscales within the ABC scale, stereotypical behaviors ($r = -.15$, $p > .05$), hyperactivity ($r = -.15$, $p > .05$), and inappropriate speech ($r = .02$, $p > .05$), were not significantly correlated with the PWB scale.

Aberrant Behavior Checklist

The ABC scale was positively correlated with AS ($r = .41$, $p < .01$), CESD-R ($r = .30$, $p < .01$), and GAD-7 ($r = .26$, $p < .01$). Conversely, ABC had a significant negative correlation with PWB ($r = -.23$, $p < .05$).

The Center for Epidemiological Studies Depression Scale-Revised

The CESD-R was positively correlated with AS ($r = .32$, $p < .01$), GAD-7 ($r = .32$, $p < .01$), and ABC ($r = .41$, $p < .01$). The CESD-R had a significant negative correlation with PWB ($r = -.57$, $p < .01$). The results indicated that the CESD-R had a significant positive correlation with all scales and subscales other than the inappropriate speech subscale of the ABC ($r = .06$, $p > .05$).

Generalized Anxiety Disorder-7 Scale

The GAD-7 scale was positively correlated with AS ($r = .32$, $p < .01$) and CESD-R ($r = .72$, $p < .01$). The GAD-7 had a significant negative relationship with PWB ($r = -.54$, $p < .01$). The GAD-7 had a significant positive correlation with the overall ABC ($r = .26$, $p <.01$).

Potential Covariates

Since previous researchers have found that demographics variables impact the experiences of affiliate stigma, further statistical analyses were conducted to determine whether affiliate stigma varies according to gender, racial-ethnic culture (individualistic versus collectivistic) and with the presence of problem behaviors among PWID.

Sex

A one-way between subjects ANOVA was conducted to determine whether the sex of the participants impacted affiliate stigma. The ANOVA was not significant ($F(2, 107) = 1.28$, $p > .05$, $\eta^2 = .02$). Therefore, no significant differences in the amount of affiliate stigma experienced were found based on the sex of the participants. This finding should be interpreted cautiously based on the disparate number of men and people of other genders compared to women who participated in the investigation.

Race-Ethnicity

A one-way between subjects ANOVA was conducted to determine whether race impacted affiliate stigma. Similarly, the ANOVA was not significant ($F(3, 106) = .02$, $p > .05$, $\eta^2 = .00$). The results suggest there is no significant difference in the amount of affiliate stigma experienced based on the racial identity of the participants. However, these results should be interpreted cautiously as there was a lack of representation of people of color within the study as most participants that completed the survey were White.

Type of Disability

A one-way between subjects ANOVA to determine whether type of disability impacted affiliate stigma. The ANOVA was not significant ($F(8, 101) = 1.50$, $p > .05$, $\eta^2 = .11$, suggesting there was no significant difference in the amount of affiliate stigma experienced based on the type of disability of the participants' sibling.

Other Demographic Variables

A one-way between subjects ANOVA was conducted to determine whether additional demographic variables impacted affiliate stigma. There was no significance between affiliate stigma and participants' employment status ($F(3, 104) = 1.49$, $p > .05$), education level ($F(4, 105) = .48$, $p > .05$), proximity to sibling with ID ($F(6, 103) = 1.48$, $p > .05$), caretaking duties within the past year ($F(6,103) = 1.69$, $p > .05$), or caretaking duties more than 2 years ago ($F(6, 103) = 1.29$, $p > .05$).

Tests of Hypotheses

Hypothesis 1

Hypothesis 1 predicted that greater levels of affiliate stigma would predict higher levels of reported depressive symptoms, such that siblings of PWIDs who experienced affiliate stigma would report increased symptoms of depression. As hypothesized, affiliate stigma was positively correlated with depressive symptoms ($r = .37$, $p < .01$). Participants who experienced affiliate stigma reported greater depressive symptoms. While the results indicated statistical significance, the correlation between affiliate stigma and depression appeared to be weak. The researcher also calculated the coefficient of determination, r^2, to determine if the proportion of variance of one variable was predictable from the other variable. Affiliate stigma had a weak effect, accounting for 15% of the variability in depressive symptoms.

A bivariate correlation was conducted to measure the level of relationship between social desirability and the scores on the affiliate stigma survey. The results suggested a low level of relationship between social desirability and the affiliate stigma subscale ($r = -.37$, $p < .01$) This finding indicates participants' answers were not skewed by impression management and that the results from Hypothesis 1 appears to be valid and reliable. Similarly, the results suggested a low level of relationship between participants' social desirability scores and the depression subscale ($r = -.40$, $p < .01$). Participants' responses were not skewed by impression management; therefore, the results appear to be valid.

Hypothesis 2

Hypothesis 2 posited that greater levels of affiliate stigma would predict increased levels of anxiety symptoms. This hypothesis suggested that siblings of PWIDs who experienced affiliate stigma would report increased symptoms of anxiety. As posited, a positive correlation was found between affiliate stigma and anxiety ($r = .32$, $p < .01$). Participants who reported higher levels of affiliate stigma also reported significantly higher levels of anxiety. While the results indicated a significant relationship between affiliate stigma and anxiety, there was a weak effect with 11% of the variability accounted for. This means that while an individual's experience of affiliate stigma may be predictive of their anxiety symptoms, affiliate stigma only accounted for 11% of the variability in anxiety symptoms. Therefore, other factors contribute to participants' anxiety symptoms.

A bivariate correlation was conducted to measure the level of relationship between social desirability and the scores on the anxiety subscale to assess if participants responses to the anxiety subscale was possibly skewed. The results suggested a low level of relationship between social desirability and the anxiety subscale ($r = -.43$, $p < .01$). The results indicate participants' answers were not skewed and that the answers on the subscales appear to be valid and reliable.

Hypothesis 3

Hypothesis 3 predicted that affiliate stigma would be negatively correlated with psychological well-being among siblings of PWIDs. As hypothesized, the results revealed that participants who reported experiencing affiliate stigma also reported lower levels of psychological well-being, ($r = -.57$, $p < .01$). While there was statistical significance at the $p = 0.01$ level, there was a moderate effect, indicating that 32% of the variability in the participants' responses can be explained by the differences between the two variables.

A bivariate correlation was conducted to measure the level of relationship between social desirability and psychological well-being. The results indicated a significant level of relationship between social desirability and the psychological well-being subscale ($r = .53$, $p < .01$, $r^2 = .28$). This finding suggests that the participants' responses may have been skewed by impression management. Therefore, the participants' responses regarding psychological well-being should be interpreted cautiously as these results may not be an accurate indicator of participants' mental health.

Mediation Analysis

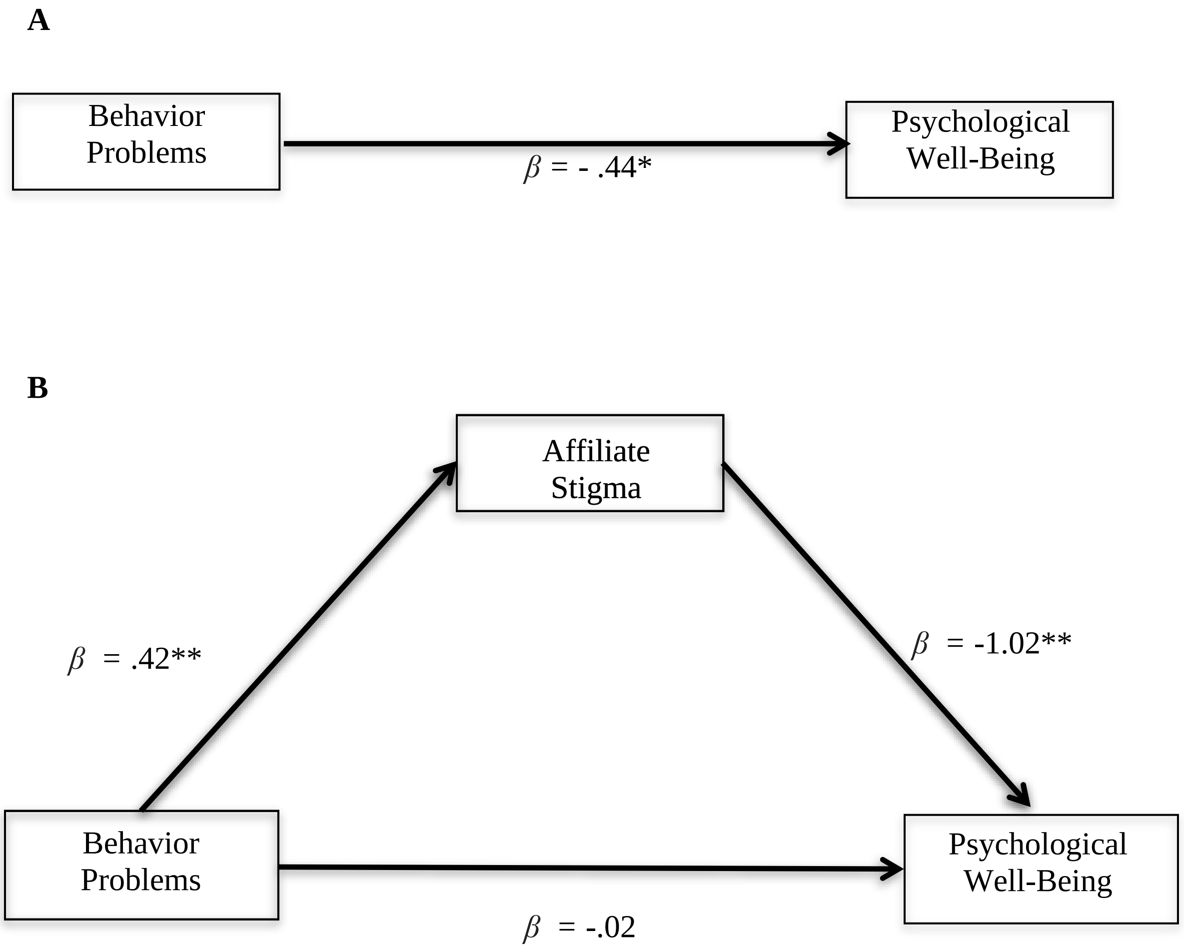
Hypothesis 4

Hypothesis 4 predicted whether affiliate stigma would partially mediate the relationship between behavioral problems and psychological well-being. Results revealed a full mediation, implying that affiliate stigma fully explained the association between behavior problems and psychological well-being. Multiple regression analyses were conducted to assess each step of the mediation model using PROCESS. The outcome variable for analysis was psychological well-being. The predictor variable for the analysis was behavior problems and the mediator variable was affiliate stigma.

In the first step, the results revealed that behavior problems were predictive of psychological well-being ($\beta = -.44$, $t(106) = -2.58$, $p < .05$) as seen in Diagram A in Figure 2. In the second step, the results revealed behavior problems of the PWID was predictive of affiliate stigma ($\beta = .42$, $t(107) = 4.74$, $p < .001$). Furthermore, affiliate stigma was negatively associated with psychological well-being ($\beta = -1.02$, $t(106) = -6.34$, $p < .001$). When affiliate stigma was controlled for, behavior problems were no longer predictive of psychological well-being ($\beta = -.02$, $t(106) = -.10$, $p = .92$), thus suggesting a full mediation. Diagram B in Figure 2 displays the results of the mediation model. A Sobel test was conducted to test for mediation. The results indicated affiliate stigma fully mediated the relation between behavior problems and psychological well-being ($z = -3.07$, $p = .002$).

Figure 2

Unmediated Model and Mediated Model for Psychological Well-Being



Note. *$p < .05$. ** $p < .001$

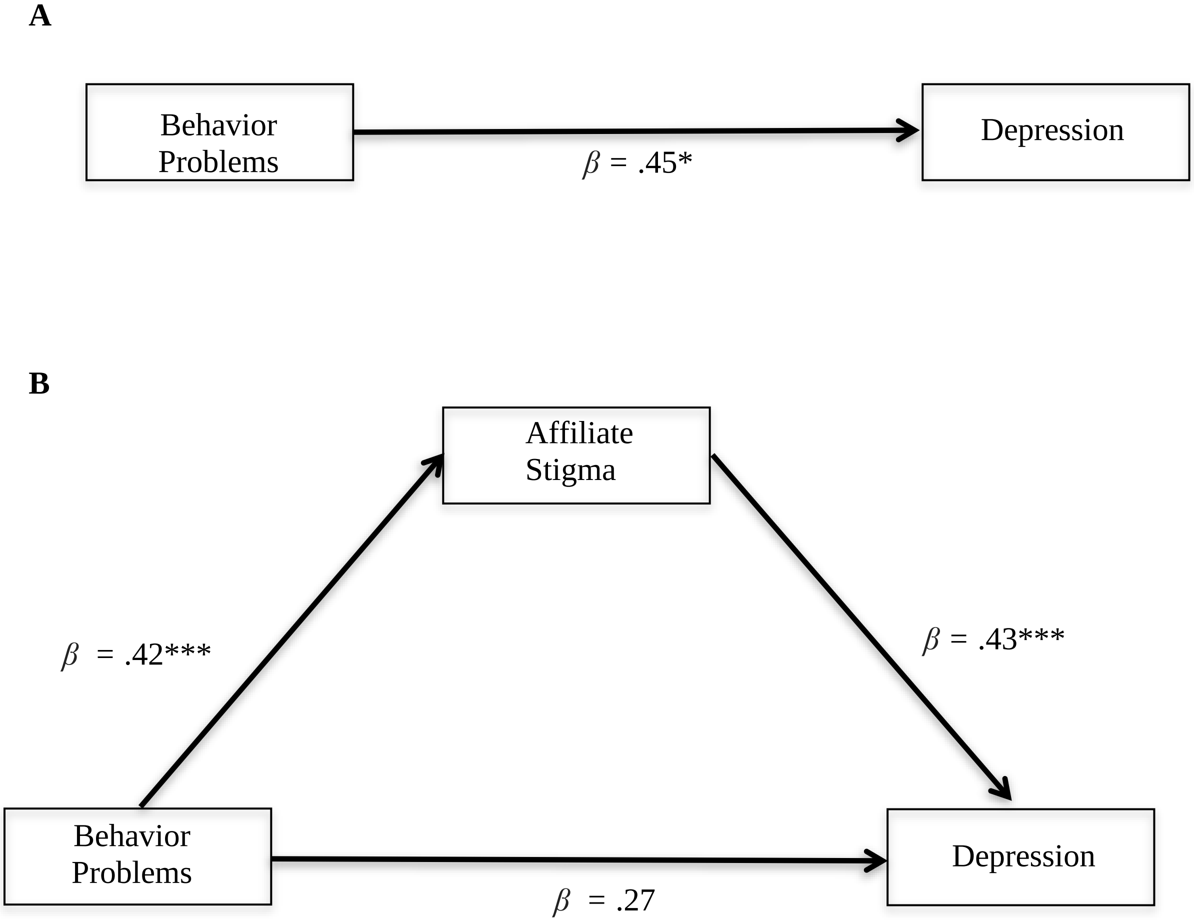
Hypothesis 5

Hypothesis 5 investigated if affiliate stigma partially mediated the relationship between behavior problems and depression. Results revealed a full mediation, implying that affiliate stigma fully explained the association between behavior problems and depression. A series of multiple regression analyses was performed using PROCESS to assess each path of the proposed mediation model. The outcome variable for analysis was depression. The predictor variable for the analysis was behavior problems and the mediator variable was affiliate stigma.

Results revealed the behavior problems of the PWID had a direct effect on a sibling's depressive symptoms (β = .45, $t(107) = 3.40$, $p < .001$; see Diagram A, Figure 3). The findings also suggested behavior problems of the PWID were predictive of affiliate stigma (β = .42, $t(107) = 4.74$, $p < .001$) within the adult sibling without the ID. The investigator also found affiliate stigma was positively correlated with depressive symptoms (β = .43, $t(107) = 3.08$, $p < .001$). Results indicated that the direct effect of behavior problems on depressive symptoms became non-significant (β = .27, $t(107) = 1.92$, $p = .06$) when controlling for affiliate stigma, thus suggesting a full mediation. Diagram B in Figure 3 displays the results of the mediation model. Since the *p* value was close to .05, the results could suggest a marginal significance. However, the results would need to be interpreted with caution due to a low statistical power and small sample size. A Sobel test was conducted to test for mediation. The results indicated that affiliate stigma fully mediated the relation between behavior problems and depression ($z = 2.35$, $p = .02$).

Figure 3

Unmediated and Mediated Model for Depression



Note. *$p < .05$. ** $p < .01$. *** $p < .001$

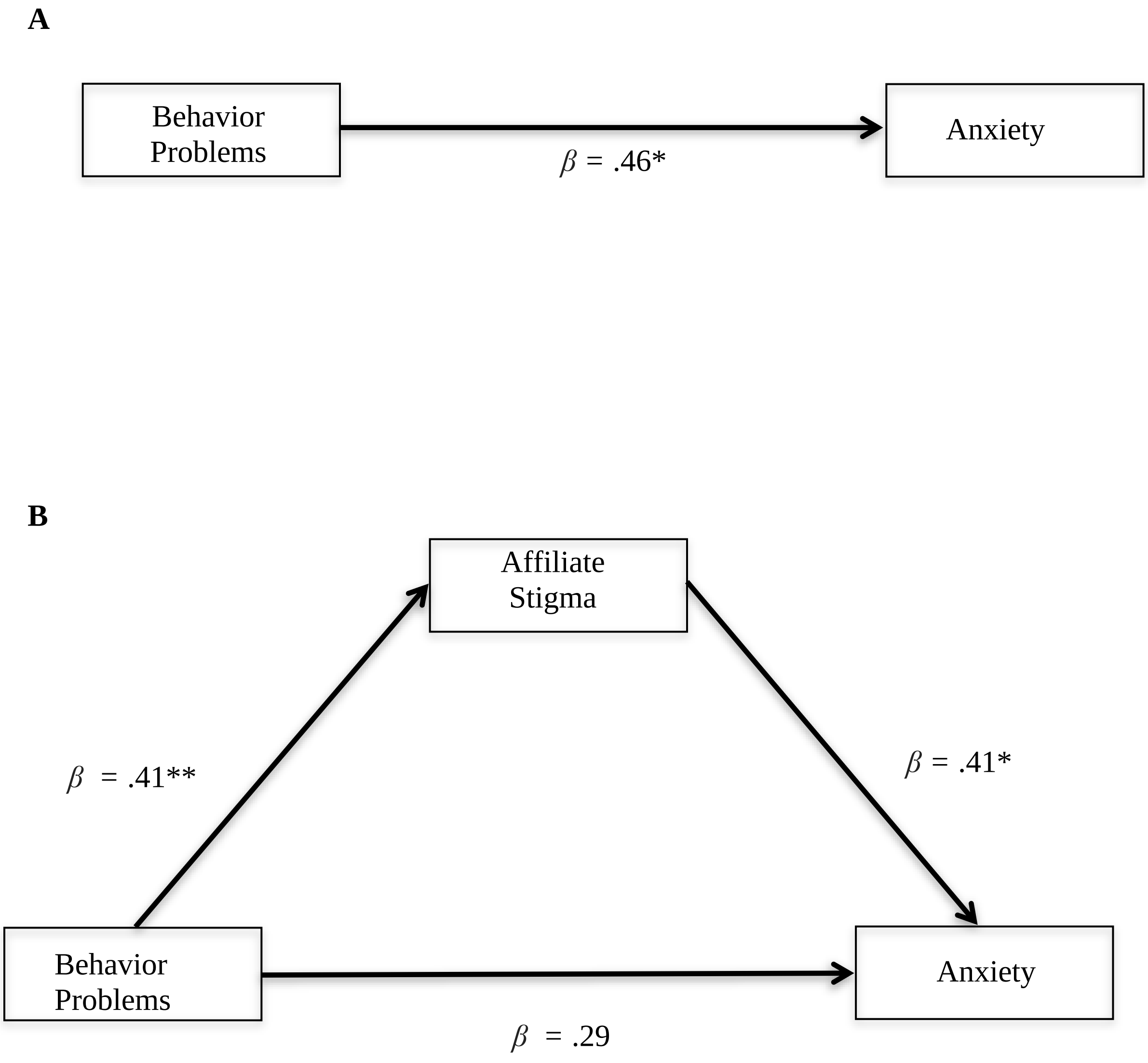
Hypothesis 6

Hypothesis 6 predicted affiliate stigma would partially mediate the relationship between behavior problems and anxiety. Results revealed a full mediation, implying that affiliate stigma fully explained the association between behavior problems and anxiety. Multiple regression analyses were conducted using PROCESS. The outcome variable for the analysis was anxiety. The predictor variable for the analysis was behavior problems, and the mediator variable was affiliate stigma.

Results revealed behavioral problems of the PWID were predictive of a sibling's anxiety symptoms (β = .46, *t*(106) = 3.01, $p < .05$) as illustrated in Diagram A of Figure 4. Behavioral problems of the PWID were also significantly predictive of affiliate stigma (β = .41, *t*(106) = 4.63, $p < .001$). Furthermore, results indicated the mediator, affiliate stigma, was positively associated with anxiety symptoms (β = .41, *t*(105) = 2.57, $p < .05$). In addition, results indicated that the direct effect of behavioral problems on anxiety symptoms became non-significant when controlling for affiliate stigma (β = .29, *t*(106) = 1.76, $p = .08$; see Diagram B, Figure 4). The results indicate affiliate stigma fully mediated the relation between behavior problems and anxiety ($z = 2.12$, $p = .03$).

Figure 4

Unmediated Model and Mediated Model for Anxiety



Note. *$p < .05$. ** $p < .001$

Open-Ended Responses

At the end of the survey, participants were offered the opportunity to provide an optional statement to the question, “Is there anything else that you would like the researcher to know?" Of the 110 participants who fully completed the study, 41 individuals provided a response, 35 of whom were women (85%) and six of whom were men (15%). Most (93%) of the participants identified as White, whereas 2% were Hispanic/Latinx, 2% were Asian, and 2% were Bi or Multiracial. Most of the participants who responded reported having a sibling with angelman syndrome (51%), 5% with WS, 5% with PWS, 7% with DS and 7% with FXS. Most of the participants who responded were young (*M* = 31.35), highly educated with either a bachelor's or graduate degree (54%) and had full or part-time employment (49%).

To analyze the qualitative responses, the researcher initially read through all the responses and then created general categories for each of the responses (i.e., emotions, personal disclosure, impact of having a sibling with an ID). Sub-categories were created thereafter to provide further richer detail. For instance, the category of emotions was grouped and tagged in either a positive, negative, or neutral sub-category. Upon review, the open-ended statements revealed similar emergent categories consistently. Categories that repetitively reappeared were clustered around positive emotions, negative emotions, career influence, clarification of responses, and self-disclosure of disability. The researcher re-read the responses and ensured that they properly fit in the categories assigned. Since the researcher did not employ a methodology from a theory drawn from qualitative research to analyze the open-ended response, the data should be interpreted with caution. While the researcher was able to link particular quotes with specific participants, the results may not be generalizable to all participants within the study since not all participants answered the open-ended question at the end of the survey.

Eight individuals shared that having a sibling with ID instilled positive emotions and made a positive impact on their life. Seven of the individuals identified as women while one identified as a man. Positive impact included having more patience, flexibility, compassion, and ability to connect with others more easily. Two of the individuals described having a sibling with ID creates a “happy and fun” environment. Among participants who believed their sibling provided a positive impact, a few individuals described how the impact has led the participant to be more active within the disability community and attempt to advocate for disability rights due personal experience. Participants who had a sibling diagnosed with PWS and DS all reported positive emotions towards their sibling with an ID.

Ten of the participants (nine women, one man) reported having negative feelings towards their sibling with ID stating that it has been an “inconvenience,” “sad to see sibling’s lifestyle,” and experience of family stigma around PWIDs. One of the recurrent negative emotions was stemmed around fear. Participants indicated fear of the future once their parents died and having to become the primary caretaker of the PWID. One participant shared how engaging in romantic or platonic relationships are difficult as they fear a future partner may not be willing to assist with shared caretaking responsibilities. Many participants disclosed having ruminative thoughts about the future, which create increased anxiety and depression. Another common theme among participants who disclosed having negative emotions about themselves and/or their sibling was courtesy and affiliate stigma. One participant noted that their sibling’s disability was a “family secret” that was hidden from all family members due to “denial” and “shame.” For many participants, it was difficult to see that “there is no cure for the disability” or felt pity for their sibling as they perceived they could not have a “meaningful life.”

While many self-reports were made of negative emotions, seven participants noted how having a sibling with ID influenced them to select a career field working with individuals with disabilities such as special education, speech-language pathology, social work, nursing, or research. Many of these participants were more likely to note positive emotions towards their sibling with ID as they perceived the experience to be more positively impactful.

Three individuals, who identified as women, personally disclosed how their own disability identity impacts their mental health. Each of the three participants disclosed the type of disability they had which consisted of a psychological disorder, intellectual disability, and chronic health issues that impaired mobility and functioning. However, there was no reference regarding if or how the PWID impacted their mental well-being.

CHAPTER V

DISCUSSION

The investigator explored the impact of affiliate stigma on siblings of PWIDs mental health and well-being. Consistent with previous literature capturing the experiences of other primary caretakers, she hypothesized that adult siblings would also experience affiliate stigma related to being a sibling of a person with an ID and therefore experience increased levels of depression and anxiety and lower psychological well-being. Because there were a few participants who self-reported having a disability (i.e., physical, psychological, or chronic health) themselves, the researcher uses “sibling” or “sibling of PWID” to refer to the sibling without an ID.

Summary of Findings

The researcher found support for the first three hypotheses. Hypothesis 1 predicted higher levels of affiliate stigma would predict higher levels of depressive symptoms. This hypothesis was supported, as individuals who reported higher levels of affiliate stigma were likely to report more depressive symptoms. Hypothesis 2 predicted higher levels of affiliate stigma would predict higher levels of anxiety symptoms. This hypothesis was supported, such that individuals who experienced affiliate stigma were more likely to also report anxiety symptoms. Hypothesis 3 predicted higher levels of affiliate stigma would predict lower levels of psychological well-being. This hypothesis was also supported, suggesting individuals who experience affiliate stigma experience reduced psychological well-being.

Hypotheses 4–6 explored whether affiliate stigma impacts the relationship between behavior problems and mental health. Hypothesis 4 predicted that affiliate stigma would mediate the relationship between behavior problems and psychological well-being. The results suggest that while there is a direct effect of behavior problems on psychological well-being, when affiliate stigma is accounted for, the results indicate the behavior problems of the PWID have an indirect effect on psychological well-being. Furthermore, the results revealed a complete mediation, rather than the initial expectation of a partial mediation, suggesting behavior problems of the PWID is no longer significant in predicting a sibling's psychological well-being in the presence of affiliate stigma. Hypothesis 5 predicted that affiliate stigma would mediate the relationship between problem behaviors and depressive symptoms. Similarly, Hypothesis 6 predicted that affiliate stigma would mediate the relationship between problem behaviors and anxiety symptoms. Hypotheses 5 and 6 suggested a full mediation, indicating behavior problems of the PWID only impacts the siblings' anxiety and depressive symptoms when experiencing affiliate stigma. In sum, the relationship between behavior problems and mental health outcomes of the sibling can only be related and explained by a sibling's experience of affiliate stigma.

Integration of Major Findings with the Existing Literature

Demographics and Impact on Mental Health

Through an exploratory analysis, the current study did not find demographics such as sex of the sibling, racial identity, and the type of the disability of the PWID had any bearing on the participant's experience of affiliate stigma or mental health concerns.

However, previous research has suggested that women (Boyce & Barnett, 1993; Farber & Kirk, 1960; Fowle, 1968; Liegghio, 2017; Lobato, 1983) and Asians (Adithyan et al., 2017; Ho, 1976; Mak & Cheung, 2008) experience lower psychological functioning and affiliate stigma, respectively. Since the prior research has been mixed and limited in regard to how the type of disability may impact the sibling's psychological well-being (De Caroli & Sagone, 2013; Doody et al., 2010; Hodapp & Urbano, 2007; Taylor et al., 2008; Werner & Shulman, 2013), the current researcher wanted to assess further if there was a correlation between a person's intellectual disability and their sibling's mental health symptoms; however, no relationship was found.

Sex of the Sibling

While previous research has found sisters of individuals with disabilities to be more likely to experience mental health concerns such as depression (Boyce & Barnett, 1993; Farber & Kirk, 1960; Fowle, 1968; Lobato, 1983) and considerably more stress than brothers of individuals with disabilities (Liegghio, 2017), the current research did not find similar results. Interestingly, the current study found that a sibling's experience of affiliate stigma and/or mental health symptoms were a considerable stressor for all siblings, regardless of their sex. There are several plausible explanations why the current study did not reveal sex differences such as limitations within the methodology as well as the increase in adoption of the caretaking role by boys and men specifically found in disability literature. While the researchers attempted to seek a representative sample of participants, the study's sample consisted primarily of women (77%), which may have made sex differences less detectable. Another explanation of not finding sex differences may be due to an increasing pressure for boys and men to take on domestic responsibilities within the household as well as take a potential caregiving role for their sibling with a disability (Mott et al., 2019). However, it is important to note that boys and men may be taking the caregiving role for their sibling due to pressure by familial members, being the eldest sibling, or being the only other sibling without a disability. Literature suggests gender differences in caretaking responsibilities continue to exist with women taking on a disproportionate amount of caretaking duties (Bureau of Labor Statistics, 2019; Giurge et al., 2020); however, there needs to be further research on how caretaking responsibilities may differ across genders when there is a sibling with an ID. Furthermore, the previous research conducted on sisters and brothers of individuals with IDs are notably dated, suggesting changes in gender roles over time may potentially impact the non-significant finding.

Race and Culture

Based on previous research, the researcher anticipated that specific racial groups such as Asians might be more likely to experience affiliate stigma. Prior literature suggested caregivers within Asian cultures were more likely to report higher levels of affiliate stigma and psychological distress due to concern for saving face within society (Adithyan et al., 2017; Ho, 1976; Mak & Cheung, 2008). However, the current research found no relationship between race, affiliate stigma, and mental health concerns, which suggests that culture may be unrelated to affiliate stigma for siblings. This finding should be considered tentatively, as the lack of representation of people of color in the current study may have precluded statistical significance. Notably, only 10 participants in the current study identified as people of color and specifically only 2 individuals identified as Asian therefore, the results of the current investigation may not accurately represent the potential impact of racial identity upon the experience of affiliate stigma.

Type of Disability

Previous researchers have found mixed results regarding how the severity of one’s intellectual disability may impact the sibling relationship as well as the sibling’s mood and mental health. While some researchers have found siblings of adults with varying IDs to have few negative psychological effects as adults (Taylor et al., 2008), other researchers have found contrasting results, suggesting siblings of individuals diagnosed with specific intellectual disabilities such as ASD may be more likely to experience more depressive symptoms compared to siblings of individuals with other disabilities (De Caroli & Sagone, 2013; Doody et al., 2010; Hodapp & Urbano, 2007; Werner & Shulman, 2013). The researcher of the current study found no relationship between a sibling’s type of ID and the sibling’s psychological functioning, suggesting that type of ID may not be an important variable that impacts siblings’ psychological well-being.

There are a few possible explanations for this finding. Since the current study focused on examining siblings of individuals with rarer IDs, the researcher did not examine the impact of siblings of individuals with ASD. While there were two participants who identified as being a sibling of an individual with ASD, the inadequate sample size was not sufficient to yield valid results. Furthermore, while prior researchers have compared siblings of people with ASD with other IDs, the literature has not clearly delineated which other IDs have been researched. Therefore, it is unknown if type of ID may not be a factor in siblings well-being or if siblings of individuals with ASD are uniquely impacted.

Another possible explanation for this finding is that past literature solely looked to see if an interaction between affiliate stigma and a child's disability diagnosis was significant, rather than looking at characteristics of specific disabilities. For instance, in a study conducted by Werner and Shulman (2013), caregivers of individuals with ASD were more likely to report greater affiliate stigma than caregivers of individuals with other developmental disabilities. The researchers postulated that the caregivers of individuals with ASD were more likely to internalize stigma than other disabilities based off the diagnosis, therefore attributing a person's disability as the issue for a caregiver. Other studies have revealed that siblings of individuals with ASD were at a higher risk of internalizing problems or negative psychological well-being (Hastings, 2016; Petalas et al., 2009); however, these studies did not indicate the reason behind these findings. Of note, this type of generalization can be harmful to both the PWD as well as the caregiver. The researcher of the current study believed it was important to explore whether other factors such as affiliate stigma may better explain the role problem behaviors (i.e., lack of social reciprocity, minimal social skills, and stereotyped behaviors) seen in PWID impact the non-disabled sibling's mental health.

Affiliate Stigma and Mental Health Issues

To date, there has been accumulating evidence to suggest experiences of affiliate stigma contribute to increased depression and anxiety, as well as higher levels of psychological morbidity among caregivers of individuals with ADHD (Mikami et al., 2015) and mental illness (Chen et al., 2016; Grover et al., 2017; Mak & Cheung, 2012; Singh et al., 2016). There have been relatively fewer studies that have examined the association between affiliate stigma and psychological morbidity, and most researchers have studied parents rather than siblings. However, the results have shown a negative interaction between affiliate stigma and the caregiver's well-being, suggesting that caregivers who experience greater affiliate stigma may also report lower levels of psychological well-being (Werner & Shulman, 2013) and higher levels of depression and anxiety (Chan & Lam, 2018; Mak & Cheung, 2008, 2012; Yang, 2015).

As previously discussed, there has been little literature on the impact affiliate stigma has upon the mental health among siblings who have a sibling with an ID. While there have been few researchers who found siblings of PWID are at a higher risk of developing emotional issues such as anxiety and depression (Giallo et al., 2012; Petalas et al., 2009; Rossiter & Sharpe, 2001; Shivers, 2017), others have found contrasting results, suggesting having a sibling with an ID does not adversely impact the mental health of the sibling without the ID (Dyson, 1999; Hodapp et al., 2010; Orsmond & Seltzer, 2007; Taylor et al., 2008). However, most previous researchers assessed the siblings' report of feelings and thoughts about their sibling with an ID, rather than examining, as in the case of the current study, whether mental health issues were related to the sibling's experience of internalized stigma rather than the PWID.

The current research found similar results to previous research conducted on caregivers of individuals with IDs (Chan & Lam, 2018; Mak & Cheung, 2008, 2012;

Yang, 2015; Werner & Shulman, 2013), suggesting siblings of PWID are likely to experience affiliate stigma and that the internalization of negative thoughts, feelings, and behaviors is associated with lower psychological well-being. This finding points to the significance that siblings, similar to parents of PWID, are likely to exhibit depressive and anxiety symptoms when they experience negative cognitions, such as thoughts of others discriminating against them due to their affiliation with the PWID, emotions such as helplessness or shame, and/or avoidance of contact with the PWID or isolating themselves from others. This finding also disproves the myth that the PWID themselves cause the distress or mental health concerns for the sibling without an ID (Hastings, 2016). Rather, the results suggest the sibling without the ID may report experiencing affiliate stigma due to the stigma attached to being associated with a PWID. Research has shown families of individuals with ID are more likely to experience affiliate stigma when they witness or experience the person with the disability to be criticized, judged, or disgraced by others (Lam & Mackenzie, 2002). Similarly, the current study's findings may have similar implications, indicating the PWID may experience stigmatizing responses from society, which in turn may impact the sibling. However, the current research did not examine or assess the experiences of the PWID; future researchers may want to examine if there is a direct correlation between the sibling and PWID's experiences of stigma and how that may impact the sibling's mental health issues.

Affiliate Stigma and Behavior Problems

The current researcher found behavioral problems of the PWID does not directly impact the sibling's mental health. In fact, the behavior problems only have a direct effect on mental health outcomes if a sibling experiences affiliate stigma. These findings are contrary with some of the literature that have suggested siblings of individuals with ID exhibit high levels of depression, anxiety, and poorer overall health (Doody et al., 2010; Hodapp et al., 2017; Hodapp & Urbano, 2007; Shivers, et al., 2013). Furthermore, prior researchers have made the claim that the PWID's behavioral problems is the integral source of psychological distress among caregivers (Baker et al., 2003; Blacher & McIntyre, 2006; Dunn et al., 2001). The current research found the contrary from previous findings suggesting that the PWID's behavioral problems do not solely cause decreased psychological well-being or poor mental health symptoms upon the sibling. Rather, the PWID's behavioral problems only impact a sibling's mental health when affiliate stigma is present.

The current findings appear to be congruent with some of the prior literature on affiliate stigma suggesting individuals who perceive the PWID to have behavioral problems may be more aware and sensitive of public attitudes and prejudices towards people with IDs, which may be in turn increase their susceptibility to self-stigmatization (Mak & Cheung, 2008; Mak & Kwok, 2010; Mikami et al., 2015). Consistent with other studies, the results of the current study suggest that participants' affiliate stigma was significantly associated with mood disorder symptoms (Gallagher et al., 2008; Mak & Cheung, 2008). Siblings with greater degrees of affiliate stigma may be at risk for experiencing more depressive and anxiety symptoms as well as lower psychological well-being. Prior research has found similar results, suggesting caregivers of individuals with ASD may experience more stigma when the PWID displays problematic behaviors

(Werner & Shulman, 2013). The problematic behaviors can vary from aggression to being excessively active or impulsive, repeating questions or words, or displaying repetitive body movements such as rocking back and forth (Rojahn et al., 2011; Werner & Shulman, 2013). Caregivers are likely to experience prejudice and discrimination from other family, friends, and community members (similar to the stigmatized individual), which is associated with negative psychological effects, such as depressive and anxiety symptoms (Mak & Cheung, 2008). Similarly, the current findings suggest that experiences of affiliate stigma appear to be similar among siblings as they have been among parents serving as caregivers.

While the current findings indicate that affiliate stigma fully explains the relationship between behavioral problems of the PWID and the sibling's mental health, there was a slight marginal significance between behavior problems and siblings' depressive symptoms when controlling for affiliate stigma. The results suggest there may be other mechanisms fundamental to the development of affiliate stigma that impacts a sibling's depressive symptoms. For instance, further analysis of factors such as caregiver burden or familism could provide additional insight about correlates of stigma. Prior researchers looking at the sibling relationship found family factors such as parental stress, family resilience, support, and family problem solving could play an important role in the degree to which a sibling experiences stress (Dyson, 1999; Giallo & Gavidia-Payne, 2006). For instance, a strong familial support could act as a buffer against high levels of affiliate stigma and caregiver stress for siblings of PWID. The messages a sibling receives in their family system, the parents' perception of a disability, and the parents' potential internalizing behaviors may play a mediating role between an adult sibling's experience of affiliate stigma and mental health concerns. For instance, if a sibling learned from their parent that the PWID has problematic behaviors, causes distress within the family system, or if the parent themselves experiences affiliate stigma, the sibling may be more likely to internalize similar messages as an adult, which could impact their perception of the sibling relationship as well as their own mental health.

Implications for Theory

Goffman (1963) and Jones (1984) posited that individuals experience a stigmatized response if society has deemed specific attributes or behaviors as negative and against societal norms. Page (1984) also suggested society attributes varying degrees of blame on the stigmatized person. For instance, individuals with conduct stigma, those who engage in behaviors that are not deemed socially appropriate by conventional societal standards (i.e., flapping hands, flailing, interrupting others), are generally judged as having deficiencies. It is commonly believed that individuals who experience conduct stigma, such as PWID, are thought to have chosen to behave in socially unacceptable ways and therefore deemed as blameworthy for their actions (Page, 1984; Recio et al., 2020). Additional literature has found blame and judgment do not merely impact the person with an ID; stigmatization may also be felt by those in close association of the stigmatized individual such as caregivers, friends, and siblings (Banga & Ghosh, 2017; Chiu et al., 2013; Recio et al., 2020). For instance, caregivers who witness their child with a disability experiencing discrimination may also experience similar stigmatized reaction and affiliate stigma such as loneliness, feelings of rejection, and fear (Recio et al., 2020). The current findings generalize, in the same manner as previous literature and consistent with Goffman (1963) and Page's (1984) theories, that siblings also internalize the public stigma experienced by the PWID (i.e., feeling uncomfortable regarding their sibling's behaviors or disability). The current findings revealed an association between problem behaviors and affiliate stigma, suggesting higher levels of problem behaviors exhibited by the PWID was related to higher levels of stigma experienced by the participant.

Link and Phelan (2001) further conceptualized stigma by describing the components of stigmatization and the consequences. Link and Phelan (2001) discussed how individuals tend to use the technique of labeling to point out similarities and differences in others which lead to stereotyping, discrimination, loss of status, and separating. Prior research examined the public's attitudes on PWID and found four main stereotypes people generally have: friendly, in need, unintelligent, and a nuisance (Pelleboer-Gunnink et al., 2021). Individuals who reported experiencing stereotypes of being a nuisance or unintelligent experienced higher levels of discrimination in the form of less support and higher social avoidance from others than individuals who reported experiencing the stereotype of friendly and in need (Pelleboer-Gunnink et al., 2021). The literature on labeling, stereotyping and discrimination demonstrates the negative consequences of stigmatization. The psychological effects of stigmatization experienced by the targeted individual also appear to impact the persons in association with the stigmatized individual. The current findings suggest siblings of PWID experience consequences such as feeling inferior, helpless, discrimination, prejudicial attitudes, restricted social network, and lack of support. The stigmatization consequences experienced by a sibling of a PWID may be analogous to the stigmatized response of a PWID.

Implications for Training

Training Programs

The current findings have implications for psychologists generally and for counseling psychology training programs specifically. While psychology trainees may be exposed to discussions and training around diversity variables such as ability status, psychologists have historically reported lacking the competence and experience working with clients who have disabilities (Man et al., 2018; Strike et al., 2004). Trainees in APA-accredited training programs report receiving minimal exposure to ID research and inadequate training on how to serve prospective clients with IDs (Graesser, 2014). Trainees' perceptions of competence with an ID population appears to be limited and may inhibit them from providing competent care.

There is currently little research on psychology trainees' competence or level of training on sibling relationships and specifically the influences of a person with an ID on the sibling without a disability. However, it may be important for a trainee's personal and professional growth that there are further discussions and information presented in training programs to facilitate awareness and competence when working with adult clients who are a sibling of a PWID.

Psychology training programs that offer any formal coursework on topics related to sibling research may be situated in developmental, child, or school psychology.

However, it may be beneficial for counseling psychology programs to begin to integrate training and research on adult siblings of PWDs. Training programs may facilitate discussions on topics related to experiences of adult siblings, financial concerns, desire for advocacy, caregiving issues, fear of the future when parents die, the impact of stigma on mental health, concerns of siblings of PWID, benefits of being a sibling of a PWID, and the impact of family structure on the sibling. An important point to note is that while there may be attention to disability within individual and cultural diversity coursework within counseling and clinical psychology programs as mandated by the standards of accreditation, trainees may not receive education on topics related to siblings as many counseling psychology programs across the nation do not require coursework in family psychology as part of the degree requirement. Therefore, topics related to family cycle or caregiving responsibilities faced by siblings may only be covered in training programs that offer family psychology curriculum.

Furthermore, training programs should expose students to research on siblings with cultural and subcultural issues as most sibling studies have focused on White, middle-class families. For instance, it may be important to discuss how siblings may be expected to be the primary caregiver of the PWID once the parents die in collectivist cultures. Similarly, siblings with a PWID may be more likely to live at home with the entire family as adults in Latinx families compared to White families (Blacher, 2001). Discussions around culture, beliefs, expectations, and cultural norms may be critical exploration topics for trainees to be aware of and discuss within their respective programs.

APA Guidelines

In addition to further discussion around PWID and their family system within trainee's respective psychology programs, current and future psychologists should become familiar with the APA Task Force on *Guidelines for Assessment and Treatment of Persons with Disabilities*, particularly given the results of the current investigation. To date, although there is not a specific set of Practice Guidelines for working with families of persons with disabilities, the *Guidelines of Assessment of and Intervention with Persons with Disabilities* pinpoints the importance of psychologists considering the social and cultural context of a person with a disability. Guideline 8 encourages the use of a systems approach to understand the client through family, peer, and schools (APA, 2012). Psychologists are encouraged to work with family members, such as asking about siblings' lived experiences of the client with the disability as well as an exploration of the family system. While the APA Guidelines do not specify the inclusion of siblings of persons with disabilities, it may be beneficial for psychologists to take an integrative approach by emphasizing the need to speak to siblings in addition to parents and other caregivers when working with individuals with disabilities. As most of the prior and current research has focused on reports from parental figures and/or primary caregivers, siblings' voices have not been centralized, which has prevented psychologists from understanding siblings' needs and experiences, and is a unique contribution of the current study's findings.

Guideline 10 focuses on the importance of psychologists acknowledging that families of PWD face struggles and strengths (APA, 2012). Family members may struggle with family stressors such as financial issues (Atkin & Tozer, 2014; Davys et al., 2016), caregiving burden (Arnold et al., 2012; Heller & Kramer, 2009; Seltzer et al., 1991), societal attitudes and biases (Ali et al., 2012; Burke, 2010), and social isolation (Chen et al., 2016; Grover et al., 2017; Mak & Cheung, 2008; McCann & Lubman, 2018; Mazaheri et al., 2013; Werner & Hess, 2016; Wong et al., 2016), which can impact psychological well-being (Giallo et al., 2012; Hodapp & Urbano, 2007; Mazaheri et al., 2013; Piven et al., 1990; Tomeny et al., 2017; Rossiter & Sharpe, 2001). It is important for psychologists to be aware of such challenges and how these stressors may impact their ability to fully participate within their family structure and community.

Furthermore, the resiliency model of family stress, adjustment, and adaptation may be a particularly useful approach when conceptualizing family stressors and challenges as it explores how families confront major stressors such as when a member has a disability and manages the life event through functional, healthy coping skills (Kosciulek et al., 1993). Understanding the resiliency model may be critically important for mental health practitioners when working with a sibling of a PWID, as siblings may report stigma, fear, or depressive symptoms that may stem from concern about their future of becoming a guardian once their parents die, caregiving issues, or social isolation from peers (Davys et al., 2016; Fleming, 2015; Mazaheri et al., 2013; Roper et al., 2014; Taggart et al., 2012). Psychologists may be able to help siblings explore healthy coping strategies they have used in the past to foster resiliency while utilizing a strengths-based approach to focus on benefits they have gained from their experience as a sibling of a PWID.

Implications for Practice

The findings from the current research have several implications for psychologists as well as community organizations. A greater understanding of siblings' experiences can impact how practitioners conceptualize their work, apply appropriate interventions, and advocate on for those who are more likely to experience stigma and mental health concerns.

It is evident from the results of the study that feelings of affiliate stigma are related to overall psychological well-being and mental health concerns. Affiliate stigma is a direct result of stigma internalized by families (Mak & Kwok, 2010), and practitioners can assist clients by trying to reduce the stigma by acknowledging the influence of stigmatization upon the siblings and by providing appropriate support and resources. Professionals who work with families and/or within disability services are ideally suited to inquire about family members such as siblings who may be experiencing mental health concerns. There is an integral need to encourage professionals to be more mindful and aware of the mental health concerns siblings of PWID may face and for clinicians to strengthen their ability to assess and respond to siblings' specific needs.

Awareness of Culture

Inadequate professional training in work related to intellectual disabilities and families of individuals with IDs impedes access to quality mental health services. Therefore, it is imperative for professionals to be encouraging and supportive when families and/or siblings of PWID seek out professional services. Previous researchers have found that families of individuals with intellectual disabilities may be reluctant to seek therapy services primarily due to the belief that they should be able to manage their problems and mental health concerns without professional help (Burke, 2010). For instance, Asian Americans are less likely to seek assistance from practitioners as it is an indicator that the family is unable to provide adequate support to the family member which can be a sign of disrespect (Jones et al., 2011). Therefore, clients may be more likely to be resistant to seek services or potentially feel additional shame for utilizing community resources. Although the current study's sample size was generally racially homogenous, the researcher stresses it is important for professionals to acknowledge the client's cultural context, explore how cultural and familial values may be impacting the client's mental health, and assist with destigmatizing help-seeking behaviors.

Therapy

Practitioners can serve their clients by encouraging exploration and understanding of the siblings' experiences within their family system. Prior research has found feelings of loss and shame are common among siblings of individuals living with a PWID (Fleming, 2015). These feelings could be attributed to grieving the loss of a sense of normalcy or additional burden of responsibility (Fleming, 2015; Werner & Shulman, 2013). Therefore, the researcher encourages mental health practitioners to explore the potential feelings of loss and shame, attitudes towards the PWID, and the perceived expectations placed upon the sibling.

The results of the current research found how cognitive, behavioral, and the affective domains may contribute to a sibling's experience of affiliate stigma. For instance, if a sibling experiences fear or anxiety regarding the future, it may be critical for the mental health practitioner to assess if these feelings may be related to the potential fear of being assigned as a primary caregiver when their parents are no longer able to provide care for the PWID. Practitioners may want to explore how a sibling's emotional responses could be impacted by their experiences and role as a sibling within their family system.

Similarly, practitioners may want to assess how a sibling's behavioral response such as isolation and disconnection from others could be related to their prior and current experiences. For instance, individuals with stronger feelings of affiliate stigma may be less likely to seek assistance or support from others as they may have had less time to spend with others or experienced less support by their peers in the past (Werner & Shulman, 2013; Yoong & Koritsas, 2012). As prior studies have found social support acts as a buffer for caregivers of children with intellectual disabilities (Chen & Tang, 1997; Dyson, 1999; Lovell et al., 2012; Mak et al., 2007; White & Hastings, 2004), it may be equally important for practitioners to provide support inside the therapy room as well as help increase a sibling's social support outside of therapy.

The role a sibling plays within a family system and with the PWID should not be undervalued; their contribution should be recognized and respected. It is equally important to note that not all siblings may experience feelings of isolation, shame, or burden. While not all concerns the sibling presents may be related to experiences of stigma, it still may be important for the practitioner to explore messages, assess mental health concerns, and employ a strengths-based approach to note siblings' character strengths. While this study did not fully explore the sibling's positive outcomes of having a sibling with an ID, the responses from the open-ended question revealed several themes of character strengths and resiliency from life experiences. The result was similar to research findings that have noted individuals who have siblings with disabilities are more likely to show increased levels of specific personal strengths such as ability to be open-minded about varying perspectives, accepting of differences, and ability to reflect upon their purpose in life (Dykens, 2005).

Sibling Support Services

While the current study did not research or explore how social support can impact feelings of affiliate stigma and overall psychological well-being, social inclusion has been found to be a significant factor in other studies to reduce stigma and increase overall mental health issues (Chen & Tang, 1997; Dyson, 1999; Lovell et al., 2012; Mak et al., 2007; Werner & Shulman, 2013; White & Hastings, 2004). Knowledge regarding appropriate referrals for siblings is integral in helping to promote and support the well-being of siblings. Practitioners could encourage siblings to build relationships with other siblings of PWID through national organizations, groups on social media, books, and workshops. For instance, the Sibling Leadership Network is a national organization that provides siblings of individuals with disabilities the ability to connect with others who may have a shared experience as well as enable them to act as change agents for themselves, families, and others within the community. Similarly, there are other organizations for people with specific IDs that provide blogs, support groups, and research for families, such as The Arc, Sibling Support Project, Angelman Syndrome Foundation, and the National Down Syndrome Congress. While some of these national organizations are not solely for siblings, it can be nonetheless beneficial for siblings to be aware of available resources to decrease feelings of social isolation that may come from experiences of affiliate stigma. Thus, professionals should be aware of the resources available in order to refer siblings for education, training, and support purposes.

Implications for Research

The current research has several implications for future studies. To date, there have been only a limited number of studies examining the well-being and psychological distress of siblings of adults with disabilities (Giallo et al., 2012; Petalas et al., 2009; Rosseti & Hall, 2015). Only a handful of studies have examined the well-being of siblings of adults with intellectual disabilities (Hodapp et al., 2010; Hodapp et al., 2017; Orsmond & Seltzer, 2007; Rossiter & Sharpe, 2001; Shivers & McGregor, 2018; Skotko et al., 2011; Taylor et al., 2008). Furthermore, there is no study to date examining siblings' report of their mental health and experiences of having a sibling with a rare ID.

While the current researcher attempted to recruit a wide range of participants, the sample primarily consisted of those siblings who were highly involved with their siblings with ID, which is similar to other sibling studies in the past (Heller & Kramer, 2009; Hodapp et al., 2005; Hodapp et al., 2010). When samples are comprised of participants who are highly involved, the research can become skewed and fail to represent the general experience of all siblings, such as those who may be inaccessible due to a lack of resources, have negative experiences, or decline to participate for various reasons. Therefore, future researchers may want to consider recruiting samples with varied experiences to help provide additional support for siblings. Furthermore, future researchers may consider employing qualitative methods to gain richer information regarding the siblings' experiences. The current study primarily used quantitative methods using formal assessments to gather data; however, there was an open-ended question near the end of the questionnaire for the participant to add any further information, comments, or feedback regarding their responses or experiences. The open-ended question generated unique varied responses that would not have been garnered from the quantitative measures solely. Future researchers may consider a mixed-methods or qualitative methodology for capturing richer data.

It is important to note that the nature and results of the study do not imply that the adult with the ID is the cause of the sibling's mental health symptoms or reduced psychological well-being. There are likely various other factors that influence the account for siblings' report of their mental health and experiences of affiliate stigma. As prior studies have found, it may be likely that other personal, relational, and family issues could contribute to participants' experiences of affiliate stigma and mental health concerns (Dyson, 1999; Giallo & Gavidia-Payne, 2006). Factors such as coping skills, availability of resources, family dynamics, and social support were not explored in the current study. Therefore, future research may want to explore how personal, family, relational, and social context may impact siblings' mental health outcomes.

The results from the study expand the stigma research by suggesting affiliate stigma experienced by siblings may be a predictor of lower psychological well-being in families of PWIDs. An area that may be extended for further research is the potential effect upon the sibling relationship. Future researchers could examine in what ways the sibling relationship may be impacted if a sibling experiences affiliate stigma. Prior literature has found conflicting results on sibling relationships. On one hand, there has been research indicating siblings of individuals with mild intellectual disabilities are more likely to feel an obligatory type of relationship where there is increased physical interaction (i.e., living the same town, calling, or visiting the PWID quite frequently for check-ins) but less emotional attachment (Taylor et al., 2008). However, other studies have found quite contrasting evidence to suggest siblings of persons with disabilities report close relationships, spend quality time with their sibling without obligatory motive, and describe positive psychological benefits such as fewer depressive symptoms (Hodapp et al., 2010). While these former studies did not assess if siblings experienced any affiliate stigma, it is important to further extend the literature to further examine how affiliate stigma may predict the relationship quality between siblings.

Protective Factors/Coping Skills

The current study explored if affiliate stigma experienced by siblings of PWID may be associated with higher levels of psychological distress. An area not examined within this study but that may be critical is to explore potential protective factors that can moderate the association between affiliate stigma and mental health concerns. Studies conducted on parents of children with disabilities have found family, friend, and professional support are associated with better psychological well-being, with family support the most significant predictor of psychological distress (Benson, 2012; Davis & Gavidia-Paynes, 2009; Wong et al., 2016). In addition, self-compassion has been found to be a powerful protective factor beyond support services, specifically for parents of children with intellectual disabilities (Wong et al., 2016). Future researchers may want to extend this literature to siblings of PWID as it has been found that siblings do experience levels of affiliate stigma similar to parents of PWID.

Practice

The current study has several implications for further research on interventions and strategies that may be useful to assist clients who struggle with stigmatizing beliefs. Given that siblings of PWID may experience affiliate stigma and mental health concerns, researchers may want to explore stigma-coping strategies that could be incorporated in practice who may be more likely to experience self-stigma and its associated psychological distress. Prior research has found primary caregivers who receive psychoeducation, stigma coping skills training, employ mindfulness strategies, employ self-compassion within their daily, and attend support groups are more likely to reduce affiliate stigma (Chan & Lam, 2018; Chen et al., 2016; Wong et al., 2016). While the research has primarily focused on parents of children with a disability, it may be beneficial to be extended to explore if siblings of PWID may show similar effective reduction in internalized stigma through various interventions.

Strengths of the Study

Although prior studies have explored issues related to affiliate stigma, this study was one of the first to capture siblings' experiences, as most of the previous studies have focused on parents of children with disabilities (Chen et al., 2016; Mak & Cheung, 2012; Mikami et al., 2015; Werner & Shulman, 2015; Wong et al., 2016). One strength of the study is the inclusion of siblings, an underrepresented population within the research.

Moreover, there has been almost no research on the mental health and well-being of siblings of individuals with these rare intellectual disabilities. Therefore, this study is the first to begin the discussion on the importance of understanding the mental health of siblings of PWID.

The current study found that siblings of PWID do experience affiliate stigma similar to parents (Mak & Cheung, 2008, 2012). Furthermore, the current study found that the experience of affiliate stigma may be a contributing factor to mental health issues such as depression, anxiety, and overall lower psychological well-being. The finding sheds light on the impact of stigma upon all individuals within the family system such as the PWID, parents, and siblings. In addition, the results highlight the importance of stigma in understanding siblings' experience. Practitioners may want to explore the sibling's family of origin, the relationship between sibling without and with the ID, and stigmatized experiences of the PWID and how that may impact the sibling's overall well-being.

Another strength of the study is the diversity within the sample as individuals of varying ages and being a sibling of varying types of IDs were represented. The current study is the first to examine the experiences of siblings with rare IDs. While there is a growing amount of literature on more common known intellectual disabilities such as DS and ASD, there is far less research conducted on rarer IDs such as angelman syndrome, DiGeorge syndrome, Smith-Magenis, and PWS. Moreover, while there have been few studies that have examined the siblings' experiences, they have primarily focused on the parents' perception of the sibling rather than the sibling themselves. Furthermore, the studies that do report the adult siblings' experiences are primarily focused on having a sibling with ASD or DS rather than rarer intellectual disabilities. This is the first study to examine adult siblings to explore the experiences of people with siblings of individuals with diverse intellectual disabilities.

Limitations

Due to various limitations of the current study, some cautions apply regarding the generalizability of the study. The demographics of the study were skewed in relation to gender, race, and education level. The current sample identified as primarily White, well-educated women, limiting the applicability of the present findings to a larger general population.

One significant limitation of the study was the small sample size. Because only 110 individuals participated, the analyses may have lacked the statistical power to detect an effect of significant importance. While the mediation analyses found a full mediation across all three models, the results need to be interpreted with caution as a larger sample size may have supported the initial hypotheses and found a partial mediation. As Baron and Kenny (1986) suggested, partial mediation may be more of a rational expectation to find in social sciences compared to a full mediation since there may be multiple causes or mediators that significantly impact the relationship between the independent and dependent variables. Therefore, future studies may want to replicate the study by increasing the sample size to determine if a full mediation continues to be present.

The sample was drawn from participants who had access to the internet and specifically recruited through social media sites, organizational listservs, and sibling support groups. Therefore, the participants who chose to complete the survey may have differed from individuals who did not participate. For instance, the recruitment method for the current study assumes that siblings of individuals with IDs are actively participating in sibling support groups and/or on ID organizational sites. Furthermore, there may be a sizable population of individuals who may not be seeking services, resources, or support from others and accordingly would not have learned about the study from the recruitment sites. Moreover, most of the participants were well-educated with a bachelor’s degree or an advanced degree, indicating that individuals with less education were not equally represented within the current study. These individuals may not have been able to access the internet.

The participants who participated in the study may have had more interest in the topic than those who did not participate which may have influenced the responses on the instruments. For instance, a significant percentage (44.5%) of participants who completed the study identified as having a sibling diagnosed with angelman syndrome. The participants may have been more likely to complete the study due to more recruiting efforts made by the angelman syndrome organizations to spread awareness of the current study on their newsletter, social media, and website. Since the current study was not posted on other national organization websites other than the angelman syndrome site, this may have been the reason why many more participants with a sibling diagnosed with angelman syndrome were recruited in comparison to other varying IDs. It was difficult to recruit siblings of varying IDs due to lack of responsiveness from the organizational sites and limited number of members on the social media pages. Furthermore, many of the support groups were focused on primary caretakers such as parents rather than siblings of individuals with IDs. Therefore, the current study was seen primarily by parents of PWID and then asked to distribute to their child without the ID. While this method may have employed more participants, it may also influence the results of the study as some participants may have felt compelled to complete the questionnaires due to parental influence.

Another limitation of the current study was the time required to participate, as many of the participants did not finish the study in its entirety. The length of time may have been a source of fatigue for participants. Furthermore, many of the respondents who did not complete the study stopped while taking the ABC, which had 58 items. While the ABC assessment is a valid and reliable tool to assess an individual’s behavior problems, future researchers may want to utilize a shorter and equally reliable instrument such as the Developmental Behavior Checklist-short form (Taffe et al., 2007). Furthermore, while most of the participants were recruited prior to the COVID-19 pandemic, there were a few participants that completed the study during the midst of the pandemic, which could have impacted the results of the study as well as individuals’ desire to participate in the research. The current researcher did not examine differences between pre COVID and during the pandemic, however, it is important to note familial situations and mental health outcomes could have impacted participants’ responses on the surveys. While it is unknown whether the results from the study were impacted by the COVID-19 pandemic, further research replicating the study after the pandemic could be conducted to compare the results.

Another limitation for the current study is social desirability. While a social desirability measure was used to assess if participants were more likely to answer more positively or negatively to their experience, the face validity of some of the assessments may have impacted the social desirability responses. For instance, participants responded to the PWB assessment in a more positive light compared to the CESD-R and GAD-7 scales. Ryff (1989) suggested that the assessment may need to be provided to others or observational data may need to be conducted in order to obtain a more complete understanding of participants' psychological well-being. Therefore, the utilization of the assessment may not be an accurate predictor of a respondent's true psychological well-being. It should also be noted that self-reported measures, while customary in psychological research, can be impacted by both social desirability, and the interpretation of questions, response bias, and the use of restrictive rating scales. Furthermore, participants are more likely to have difficulty recalling their experiences, inaccurately perceive their affective responses, and may rely on current mood to evaluate how they feel about life overall (Lucas, 2018). Therefore, further data and information may need to be gathered to accurately assess a participant's well-being.

Conclusion

Siblings of people with IDs experience internal stigma similar to parents of PWID. Siblings of PWID in the current study reported experiencing high levels of affiliate stigma, which is associated with depressive, anxiety symptoms, and lower psychological well-being. Further research is integral to provide replication of the current study's findings, explore if other factors may contribute to siblings' experience of affiliate stigma, and identify how protective factors may serve as a buffer to the experience of internalized stigma. The current research is the first known study to examine whether siblings experience affiliate stigma similarly to primary caregivers of individuals with IDs, as well as how affiliate stigma may impact siblings' psychological well-being.

REFERENCES

Abbeduto, L., & Murphy, M. M. (2004). Language, social cognition, maladaptive behavior, and communication in Down syndrome and fragile X syndrome. In M. L. Rice & S. F. Warren (Eds.), *Developmental language disorders: From phenotypes to etiologies* (pp. 77–96). Lawrence Erlbaum Associates. https://doi.org/10.4324/9781410610881

Adithyan, G. S., Sivakami, M., & Jacob, J. (2017). Positive and negative impacts on caregivers of children with intellectual disability in India. *Disability, CBR & Inclusive Development*, *28,* 74–94. https://doi.org/10.5463/dcid.v28i2.595

Al-Dababneh, K. A., & Al-Zboon, E. K. (2018). Parents' attitudes towards their children with cerebral palsy. *Early Child Development and Care*, *188*, 731–747. https://doi.org/10.1080/03004430.2016.1230737

Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities*, *33*, 2122–2140. https://doi.org/10.1016/j.ridd.2012.06.013

Aman, M. G., Singh, N. N., Stewart, A. W., & Field, C. J. (1985). The aberrant behavior checklist: A behavior rating scale for the assessment of treatment effects. *American Journal of Mental Deficiency*, *89*, 485–491. http://psycnet.apa.org/record/1985-19035-001

Amaresha, A. C., Kalmady, S. V., Joseph, B., Agarwal, S. M., Narayanaswamy, J. C., Venkatasubramanian, G., Muralidhar, D., & Subbakrishna, D. K. (2018). Short term effects of brief need based psychoeducation on knowledge, self-stigma, and burden among siblings of persons with schizophrenia: A prospective controlled trial. *Asian Journal of Psychiatry*, *32,* 59–66. https://doi.org/10.1016/j.ajp.2017.11.030

American Association on Intellectual and Developmental Disabilities. (2002). *Definition of intellectual disability*. https://aaidd.org/intellectual-disability/definition

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). American Psychiatric Publishing.

American Psychological Association. (2012). Guidelines for assessment of and intervention with persons with disabilities. *American Psychologist*, *67,* 43–62. https://doi.org/10.1037/a0025892

American Psychological Association. (2017). *Multicultural guidelines: An ecological approach to context, identity, and intersectionality*. http://www.apa.org/about/policy/multicultural-guidelines.pdf

Americans With Disabilities Act of 1990, Pub. L. No. 101-336, § 12102, 104 Stat. 328 (1990). https://www.ada.gov/pubs/adastatute08.htm#12102

Arnold, C. K., Heller, T., & Kramer, J. (2012). Support needs of siblings of people with developmental disabilities. *Intellectual Developmental Disabilities*, *50,* 373–382. https://doi.org/10.1352/1934-9556-50.5.373

Atkin, K., & Tozer, R. (2014). Personalisation, family relationships, and autism: Conceptualising the role of adult siblings. *Journal of Social Work*, *14,* 225–242. https://doi.org/10.1177/1468017313476453

Bailey, D. B., Hatton, D. D., Skinner, M., & Mesibov, G. (2001). Autistic behavior, FMR1 protein, and developmental trajectories in young males with fragile X syndrome. *Journal of Autism and Developmental Disorders*, *31*, 165–174. https://doi.org/10.1023/A:1010747131386

Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: Behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research*, *47*, 217–230. https://doi.org/10.1046/j.1365-2788.2003.00484.x

Bambauer, K. Z., & Prigerson, H. G. (2006). The stigma receptivity scale and its association with mental health service use among bereaved older adults. *Journal of Nervous and Mental Disease*, *194*, 139–141. http://doi.org/10.1097/01.nmd.0000198200.20936.03

Banga, G., & Ghosh, S. (2017). The impact of affiliate stigma on the psychological well-being of mothers of children with specific learning disabilities in India: The mediating role of subjective burden. *Journal of Applied Research in Intellectual Disabilities*, *30*, 958–969. https://doi.org/10.1111/jar.12311

Baron, R. M., & Kenny, D. A. (1986). The moderator–mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, *51*, 1173–1182. http://psycnet.apa.org/buy/1987-13085-001

Baxter, C., & Cummins, R. A. (1992). Community integration and parental coping. *International Journal of Rehabilitation Research*, *15*, 289–300.

Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities*, *18*, 47–56. https://doi.org/10.1111/j.1468-3148.2004.00218.x

Benson, P. R. (2012). Network characteristics, perceived social support, and psychological adjustment in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *42*, 2597–2610. https://doi.org/10.1007/s10803-012-1517-9

Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture. *American Journal on Mental Retardation*, *106*, 173–188. https://doi.org/10.1352/0895-8017(2001)1062.0.CO;2

Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research*, *50*, 184–198. https://doi.org/10.1111/j.1365-2788.2005.00768.x

Bouras, N., & Jacobson, J. (2002). Mental health care for people with mental retardation: A global perspective. *World Psychiatry*, *1*, 162–165.

Boyce, G. C., & Barnett, W. S. (1993). Siblings of persons with mental retardation: A historical perspective and recent findings. In Z. Stoneman, & P.W. Berman (Eds.), *The effects of mental retardation, disability, and illness on sibling relationships: Research issues and challenges* (pp. 145–184). Paul H. Brookes Publishing.

Broomhead, K. E. (2016). ‘They think that if you're a teacher here … you're not clever enough to be a proper teacher:’ The courtesy stigma experienced by teachers employed at schools for pupils with behavioural, emotional and social difficulties (BESD). *Journal of Research in Special Educational Needs*, *16*, 57–64. https://doi.org/10.1111/1471-3802.12056

Brown, W.T. (2002). The molecular biology of the fragile X mutation. In R. J. Hagerman & P. J. Hagerman (Eds.), *Fragile X syndrome: Diagnosis, treatment and research* (pp. 110–135). Johns Hopkins University Press.

Buljevac, M., Majdak, M., & Leutar, Z. (2012). The stigma of disability: Croatian experiences. *Disability and rehabilitation*, *34*, 725–732. https://doi.org/10.3109/09638288.2011.616570

Bureau of Labor Statistics. (2019). *Percent of the population engaging in selected household activities, averages per day by sex.* https://www.bls.gov/charts/american-time-use/activity-by-hldp.htm

Burke, P. (2010). Brothers and sisters of disabled children: The experience of disability by association. *The British Journal of Social Work*, *40*, 1681–1699. https://doi.org/10.1093/bjsw/bcp088

Burke, M. M., Arnold, C. K., & Owen, A. L. (2015). Sibling advocacy: Perspectives about advocacy from siblings of individuals with intellectual and developmental disabilities. *Inclusion*, *3*, 162–175. https://doi.org/10.1352/2326-6988-3.3.162

Burke, M. M., Taylor, J. L., Urbano, R., & Hodapp, R. M. (2012). Predictors of future caregiving by adult siblings of individuals with intellectual and developmental disabilities. *American Journal on Intellectual and Developmental Disabilities*, *117*, 33–47. https://doi.org/10.1352/1944-7558-117.1.33

Buscaglia, L. (1983). *The disabled and their parents: A counseling challenge*. Charles B. Slack.

Butler, R. C., & Gillis, J. M. (2011). The impact of labels and behaviors on the stigmatization of adults with Asperger's disorder. *Journal of Autism and Developmental Disorders*, *41*, 741–749. https://doi.org/10.1007/s10803-010-1093-9

Carr, J. (1988). Six weeks to twenty-one years old: A longitudinal study of children with Down's syndrome and their families. *Child Psychology & Psychiatry & Allied Disciplines*, *29*, 407–431. https://doi.org/10.1111/j.1469-7610.1988.tb00734.x

Chan, K. K. S., & Lam, C. B. (2018). Self-stigma among parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *48*, 44–52. https://doi.org/10.1016/j.rasd.2018.01.001

Chang, C. C., Su, J. A., & Lin, C. Y. (2016). Using the affiliate stigma scale with caregivers of people with dementia: Psychometric evaluation. *Alzheimer's Research & Therapy*, *8*(45), 1–8. https://doi.org/10.1186/s13195-016-0213-y

Channell, M. M., Phillips, B. A., Loveall, S. J., Conners, F. A., Bussanich, P. M., & Klinger, L. G. (2015). Patterns of autism spectrum symptomatology in individuals with Down syndrome without comorbid autism spectrum disorder. *Journal of Neurodevelopmental Disorders*, *7*(5), 1–9. https://doi.org/10.1186/1866-1955-7-5

Chapman, R. S., & Hesketh, L. J. (2000). Behavioral phenotype of individuals with Down syndrome. *Mental Retardation and Developmental Disabilities Research Reviews*, *6*, 84–95. https://doi.org/10.1002/1098-2779(2000)6:2<84::AID-MRDD2>3.0.CO;2-P

Chen, E. S., Chang, W. C., Hui, C. L., Chan, S. K., Lee, E. H. M., & Chen, E. Y. (2016). Self-stigma and affiliate stigma in first-episode psychosis patients and their caregivers. *Social Psychiatry and Psychiatric Epidemiology*, *51*, 1225–1231. https://doi.org/10.1007/s00127-016-1221-8

Chen, T. Y. K., & Tang, C. S. K. (1997). Stress appraisal and social support of Chinese mothers of adult children with mental retardation. *American Journal of Mental Retardation: AJMR*, *101*, 473–482. https://europepmc.org/abstract/med/9083604

Chiu, M.Y.L., Yang, X., Wong, F.H.T., Li, J.H., & Li, J. (2013). Caregiving of children with intellectual disabilities in China- An examination of affiliate stigma and the cultural thesis. *Journal of Intellectual Disability Research*, *57*, 1117–1129. https://doi.org/10.1111/j.1365-2788.2012.01624.x

Choruma T. (2006). *The forgotten tribe: People with disabilities in Zimbabwe*. Progressio.

Chou, Y. C., Pu, C. Y., Lee, Y. C., Lin, L. C., & Kröger, T. (2009). Effect of perceived stigmatisation on the quality of life among ageing female family carers: A comparison of carers of adults with intellectual disability and carers of adults with mental illness. *Journal of Intellectual Disability Research*, *53*, 654–664. https://doi.org/10.1111/j.1365-2788.2009.01173.x

Chromik, L. C., Quintin, E. M., Lepage, J. F., Hustyi, K. M., Lightbody, A. A., & Reiss, A. L. (2015). The influence of hyperactivity, impulsivity, and attention problems on social functioning in adolescents and young adults with fragile X syndrome. *Journal of Attention Disorders*, *1*, 1–9. https://doi.org/10.1177/1087054715571739

Churchill, J. D., Grossman, A. W., Irwin, S. A., Galvez, R., Klintsova, A. Y., Weiler, I. J., & Greenough, W. T. (2002). A converging−methods approach to fragile X syndrome. *Developmental Psychobiology: The Journal of the International Society for Developmental Psychobiology*, *40*, 323–338. https://doi.org/10.1002/dev.10036

Cicirelli, V. G. (1982). Sibling influence throughout the lifespan. In M. E. Lamb & B. Sutton-Smith (Eds.), *Sibling relationships: Their nature and significance across the lifespan* (pp. 267–284). Lawrence Erlbaum Associates.

Clayton-Smith, J., & Laan, L. A. E. M. (2003). Angelman syndrome: A review of the clinical and genetic aspects. *Journal of Medical Genetics*, *40*, 87–95. https://doi.org/10.1136/jmg.40.2.87

Cohen, J. (1992). A power primer. *Psychological Bulletin*, *112*, 155–159. http://doi.org/10.1037//0033-2909.112.1.155

Cooney, G., Jahoda, A., Gumley, A., & Knott, F. (2006). Young people with intellectual disabilities attending mainstream and segregated schooling: Perceived stigma, social comparison and future aspirations. *Journal of Intellectual Disability Research*, *50*, 432–444. https://doi.org/10.1111/j.1365-2788.2006.00789.x

Constantino, J. N. (2011). The quantitative nature of autistic social impairment. *Pediatric Research*, *69*, 55R–62R. http://doi.org/10.1203/PDR.0b013e318212ec6e

Corrigan, P. W. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical Psychology: Science and Practice*, *7*, 48–67. https://doi.org/10.1093/clipsy.7.1.48

Corrigan, P. W. (2004). How stigma interferes with mental health care. *American Psychologist*, *59*, 614–625. https://doi.org/ 10.1037/0003-066X.59.7.614

Corrigan, P. W., Edwards, A. B., Green, A., Diwan, S. L., & Penn, D. L. (2001). Prejudice, social distance, and familiarity with mental illness. *Schizophrenia Bulletin*, *27*, 219–225. https://doi.org/10.1093/oxfordjournals.schbul.a006868

Corrigan, P. W., Green, A., Lundin, R., Kubiak, M. A., & Penn, D. L. (2001). Familiarity with and social distance from people who have serious mental illness. *Psychiatric Services*, *52*, 953–958. https://www.ncbi.nlm.nih.gov/pubmed/11433114

Corrigan, P., Markowitz, F. E., Watson, A., Rowan, D., & Kubiak, M. A. (2003). An attribution model of public discrimination towards persons with mental illness.

Journal of Health and Social Behavior, *44*, 162–179. http://doi.org/10.2307/1519806

Corrigan, P. W., Roe, D., & Tsang, H. W. (2011). *Challenging the stigma of mental illness: Lessons for therapists and advocates*. John Wiley & Sons.

Corrigan, P. W., & Shapiro, J. R. (2010). Measuring the impact of programs that challenge the public stigma of mental illness. *Clinical Psychology Review*, *30*, 907–922. https://doi.org/10.1016/j.cpr.2010.06.004

Corrigan, P. W., & Watson, A. C. (2002). The paradox of self‐stigma and mental illness. *Clinical Psychology: Science and Practice*, *9*, 35–53. https://doi.org/10.1093/clipsy.9.1.35

Crawford, D. C., Acuña, J. M., & Sherman, S. L. (2001). FMR1 and the fragile X syndrome: Human genome epidemiology review. *Genetics in Medicine*, *3*, 359–371. https://doi.org/10.1097/00125817-200109000-00006

Cummings, S. T. (1976). The impact of the child's deficiency on the father: A study of fathers of mentally retarded and of chronically III children. *American Journal of Orthopsychiatry*, *46*, 246–255. http://dx.doi.org/10.1111/j.1939-0025.1976.tb00925.x

Cuskelly, M. (1999). Adjustment of siblings of children with a disability: Methodological issues. *International Journal for the Advancement of Counselling*, *21*, 111–124. https://doi.org/10.1023/A:1005331700993

Cuskelly, M. (2016). Contributors to adult sibling relationships and intention to care of siblings of individuals with Down syndrome. *American Journal on Intellectual* *and Developmental Disabilities*, *121*, 204–218. https://doi.org/10.1352/1944-7558-121.3.204

Cuskelly, M., & Gunn, P. (2006). Adjustment of children who have a sibling with Down syndrome: Perspectives of mothers, fathers and children. *Journal of Intellectual Disability Research*, *50*, 917–925. https://doi.org/10.1111/j.1365-2788.2006.00922.x

Dagnan, D., & Waring, M. (2004). Linking stigma to psychological distress: Testing a social–cognitive model of the experience of people with intellectual disabilities. *Clinical Psychology & Psychotherapy: An International Journal of Theory & Practice*, *11*, 247–254. https://doi.org/10.1002/cpp.413

Dako-Gyeke, M. (2018). Courtesy stigma: A concealed consternation among caregivers of people affected by leprosy. *Social Science & Medicine*, *196*, 190–196. https://doi.org/10.1016/j.socscimed.2017.11.030

Daunhauer, L. A., & Fidler, D. J. (2011). The Down syndrome behavioral phenotype: Implications for practice and research in occupational therapy. *Occupational Therapy in Health Care*, *25*, 7–25. https://doi.org/10.3109/07380577.2010.535601

Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities. *Journal of Intellectual & Developmental Disability*, *34*, 153–162. https://doi.org/10.1080/13668250902874608

Davys, D., Mitchell, D., & Haigh, C. (2016). Adult siblings consider the future: Emergent themes. *Journal of Applied Research in Intellectual Disabilities*, *29*, 220–230. https://doi.org/10.1111/jar.12172

De Caroli, M. E., & Sagone, E. (2013). Siblings and disability: A study on social attitudes toward disabled brothers and sisters. *Procedia-Social and Behavioral Sciences*, *93*, 1217–1223. https://doi.org/10.1016/j.sbspro.2013.10.018

DeLoach, C., & Greer, B. G. (1981). *Adjustment to severe physical disability: A metamorphosis*. McGraw-Hill Companies.

de Vaan, G., Vervloed, M., Peters-Scheffer, N. C., van Gent, T., Knoors, H., & Verhoeven, L. (2018). Assessing autism spectrum disorder in people with sensory impairments combined with intellectual disabilities. *Journal of Developmental and Physical Disabilities*, *30*, 471–487. https://doi.org/10.1007/s10882-018-9597-x

Doody, M. A., Hastings, R. P., O'Neill, S., & Grey, I. M. (2010). Sibling relationships in adults who have siblings with or without intellectual disabilities. *Research in Developmental Disabilities*, *31*, 224–231. https://doi.org/10.1016/j.ridd.2009.09.007

dosReis, S., Barksdale, C. L., Sherman, A., Maloney, K., & Charach, A. (2010). Stigmatizing experiences of parents of children with a new diagnosis of ADHD. *Psychiatric Services*, *61*, 811–816. https://ps.psychiatryonline.org/doi/full/10.1176/ps.2010.61.8.811

Driscoll, D. J., Miller, J. L., Schwartz, S., & Cassidy, S. B. (2017). Prader-Willi syndrome. In *GeneReviews [Internet]*. University of Washington. https://www.ncbi.nlm.nih.gov/books/NBK1330/?report=reader

Dudley, J. R. (2000). Confronting stigma within the services system. *Social Work*, *45*, 449–455. https://search.proquest.com/openview/40c6dc44d5716eb09623a0898f598a02/1?pq-origsite=gscholar&cbl=40730

Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community mental health journal*, *37*, 39–52. https://doi.org/10.1023/A:1026592305436

Dunn, J., & Kendrick, C. (1982). *Siblings: Love, envy, and understanding.* Harvard University Press.

Dykens E. M. (2005). Happiness, well-being, and character strengths: Outcomes for families and siblings of persons with mental retardation. *Mental retardation*, *43*(5), 360–364. https://doi.org/10.1352/0047-6765(2005)43[360:HWACSO]2.0.CO;2

Dyson, L. L. (1999). The psychosocial functioning of school-age children who have siblings with developmental disabilities: Change and stability over time. *Journal of Applied Developmental Psychology*, *20*, 253–271. https://doi.org/10.1016/S0193-3973(99)00016-7

Eaton, W., & Kessler, L. G. (1981). Rates of symptoms of depression in a national sample. *American Journal of Epidemiology*, *114*, 528–538. https://doi.org/10.1093/oxfordjournals.aje.a113218

Eddy, C. M., & Cavanna, A. E. (2013). On being your own worst enemy: An investigation of socially inappropriate symptoms in Tourette syndrome. *Journal of Psychiatric Research*, *47*, 1259–1263. https://doi.org/10.1016/j.jpsychires.2013.05.019

Edelbrock, C., & Costello, A. J. (1988). Convergence between statistically derived behavior problem syndromes and child psychiatric diagnoses. *Journal of Abnormal Child Psychology*, *16*, 219–231. https://doi.org/10.1007/BF00913597

Edgin, J. O., Pennington, B. F., & Mervis, C. B. (2010). Neuropsychological components of intellectual disability: The contributions of immediate, working, and associative memory. *Journal of Intellectual Disability Research*, *54*, 406–417. https://doi.org/10.1111/j.1365-2788.2010.01278.x

Eisenhower, A. S., Baker, B. L., & Blacher, J. (2005). Preschool children with intellectual disability: Syndrome specificity, behaviour problems, and maternal well−being. *Journal of Intellectual Disability Research*, *49*(9), 657–671. https://doi.org/10.1111/j.1365-2788.2005.00699.x

Farber, B., & Kirk, S. A. (1960). Family organization and crisis: Maintenance of integration in families with a severely mentally retarded child. *Monographs of the Society for Research in Child Development*, *25*, 1–95. https://doi.org/ 10.2307/1165524

Ferri, B. A., & Connor, D. J. (2005). In the shadow of Brown: Special education and overrepresentation of students of color. *Remedial and Special Education, 26,* 93–100. https://doi.org/10.1177%2F07419325050260020401

Fidler, D. J., Philofsky, A., Hepburn, S. L., & Rogers, S. J. (2005). Nonverbal requesting and problem-solving by toddlers with Down syndrome. *American Journal on Mental Retardation*, *110,* 312–322. https://doi.org/10.1352/0895-8017(2005)110[312:NRAPBT]2.0.CO;2

Fife, B. L., & Wright, E. R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior, 41*, 50–67. https://doi.org/10.2307/2676360

Fingerman, K. L., & Bermann, E. (2000). Applications of family systems theory to the study of adulthood. *International Journal of Aging and Human Development*, *51*, 5–29. https://doi.org/10.2190%2F7TF8-WB3F-TMWG-TT3K

Fiske, S. T. (2012). Warmth and competence: Stereotype content issues for clinicians and researchers. *Canadian Psychology = Psychologie Canadienne, 53*, 14–20. https://doi.org/10.1037/a0026054

Fleming, A. P. (2015). *Adult retrospective: Life with a sibling with a developmental disorder*. [Unpublished doctoral dissertation]. Alliant International University

Fowle, A. M. (1968). Atypical leukocyte pattern of schizophrenic children. *Archives of General Psychiatry*, *18,* 666–680. https://doi.org/10.1001/archpsyc.1968.01740060026004

Freidson, E. (1965). Disability as social deviance. In M.B. Sussman (Ed.), *Sociology and rehabilitation* (pp. 71–99). American Sociological Association.

Gallagher, S., Phillips, A. C., Oliver, C., & Carroll, D. (2008). Predictors of psychological morbidity in parents of children with intellectual disabilities. *Journal of Pediatric Psychology*, *33*, 1129–1136. https://doi.org/10.1093/jpepsy/jsn040

Gath, A., & Gumley, D. (1978). *Down's syndrome and the family: The early years*. Academic Press.

Gath, A., & Gumley, D. (1984). Down's syndrome and the family: Follow−up of children first seen in infancy. *Developmental Medicine & Child Neurology, 26*, 500–508. https://doi.org/10.1111/j.1469-8749.1984.tb04478.x

Giallo, R., & Gavidia-Payne, S. (2006). Child, parent and family factors as predictors of adjustment for siblings of children with a disability. *Journal of Intellectual Disability Research*, *50*, 937–948. https://doi.org/10.1111/j.1365-2788.2006.00928.x

Giallo, R., Gavidia-Payne, D., Minett, B., & Kapoor, A. (2012). Sibling voices: The self−reported mental health of siblings of children with a disability. *Clinical Psychologist*, *16*, 36–43. https://doi.org/10.1111/j.1742-9552.2011.00035.x

Gill, J., & Liamputtong, P. (2011) Being the mother of a child with Asperger's Syndrome: Women's experiences of stigma. *Health Care Women International, 32*, 708–722. https://doi.org/10.1080/07399332.2011.555830

Giurge, L.M., Whillans, A.V., & Yemiscigil, A. (2021). A multicountry perspective on gender differences in time use during COVID-19. *Proceedings of the National Academy of Sciences, 118*, 1–7. https://doi.org/10.1073/pnas.2018494118

Goffman, E. (1963). *Stigma: Notes on a spoiled identity*. Simon & Schuster, Inc.

Gona, J. K., Mung'ala-Odera, V., Newton, C. R., & Hartley, S. (2011). Caring for children with disabilities in Kilifi, Kenya: What is the carer's experience? *Child*, *37*, 175–183. https://doi.org/10.1111/j.1365-2214.2010.01124.x

Goodey, C. F. (2005). Blockheads, roundheads, pointy heads: Intellectual disability and the brain before modern medicine. *Journal of the History of the Behavioral Sciences*, *41*, 165–183. https://doi.org/10.1002/jhbs.20081

Gosch, A., & Pankau, R. (1997). Personality characteristics and behaviour problems in individuals of different ages with Williams syndrome. *Developmental Medicine & Child Neurology*, *39*, 527–533. https://doi.org/10.1111/j.1469-8749.1997.tb07481.x

Graesser, E. (2014). *Serving clients with intellectual disabilities: Clinical psychology training in APA-Accredited doctoral programs*. [Unpublished doctoral dissertation]. Antioch University.

Gray, D. E. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health & Illness*, *15*, 102–120. https://doi.org/10.1111/1467-9566.ep11343802

Gray, D. E. (2002). ‘Everybody just freezes. Everybody is just embarrassed’: Felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness, 24*, 734–749. https://doi.org/10.1111/1467-9566.00316

Green, S. E. (2003). “What do you mean ‘what's wrong with her?’”: Stigma and the lives of families of children with disabilities. *Social Science & Medicine*, *57,* 1361–1374. https://doi.org/10.1016/S0277-9536(02)00511-7

Green, S. E. (2004). The impact of stigma on maternal attitudes toward placement of children with disabilities in residential care facilities. *Social Science & Medicine, 59*, 799–812. https://doi.org/10.1016/j.socscimed.2003.11.023

Greenberg, J., Schimel, J., & Martens, A. (2002). Ageism: Denying the face of the future. In T. D. Nelson (Ed.), *Ageism: Stereotyping and prejudice against older persons* (pp. 27–48). MIT Press.

Greenberg, J. S., Seltzer, M. M., Orsmond, G. I., & Krauss, M. W. (1999). Siblings of adults with mental illness or mental retardation: Current involvement and expectation of future caregiving. *Psychiatric Services*, *50*, 1214–1219. https://doi.org/10.1176/ps.50.9.1214

Grossman, H. J. (Ed.). (1983). *Classification in mental retardation* (Rev. ed.). American Association on Mental Deficiency.

Grover, S., Avasthi, A., Singh, A., Dan, A., Neogi, R., Kaur, D., Lakdawala, B., Rozatkar, A. R., Nebhinani, N., Patra, S., Sivashankar, P., Subramanyam, A.A., Tripathi, A., Gania, A. M., Singh, G. P., & Behere, P. (2017). Stigma experienced by caregivers of patients with severe mental disorders: A nationwide multicentric study. *International Journal of Social Psychiatry*, *63*, 407–417. https://doi.org/10.1177/0020764017709484

Hanks, J. R., & Hanks, L. M. (1948). The physically handicapped in certain non-occidental societies. *Journal of Social Issues*, *4*(4), 11–20. https://doi.org/10.1111/j.1540-4560.1948.tb01514.x

Hastings, R.P. (2016). Do children with intellectual and developmental disabilities have a negative impact on other family members? The case for rejecting a negative narrative. In R. M. Hodapp & D. J. Fidler (Eds.), *International Review of Research in Developmental Disabilities* (pp. 165–190). Academic Press.

Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *43*, 629–642. https://doi.org/10.1007/s10803-012-1604-y

Hebl, M. R., Tickle, J., & Heatherton, T. F. (2000). Awkward moments in interactions between nonstigmatized and stigmatized individuals. In T. F. Heatherton, R. E. Kleck, M. R. Hebl, & J. G. Hull (Eds.), *The social psychology of stigma* (pp. 275–306). Guilford Press.

Heller, T., & Kramer, J. (2009). Involvement of adult siblings of persons with developmental disabilities in future planning. *Intellectual Developmental Disabilities*, *47*, 208–219. https://doi.org/10.1352/1934-9556-47.3.208

Hinshaw, S. P. (2007). *The mark of shame: Stigma of mental illness and an agenda for change.* Oxford University Press.

Ho, D. Y. F. (1976). On the concept of face. *American Journal of Sociology, 81*, 867–884. https://doi.org/10.1086/226145

Hobbs, M.C. (1973). *The future of children categories and their consequences*. Jossey Bass.

Hodapp, R. M. (2002). Parenting children with mental retardation. In M. H. Bornstein (Ed.), *Handbook of parenting: Children and parenting* (pp. 355–381). Lawrence Erlbaum Associates Publishers.

Hodapp, R. M., Glidden, L. M., & Kaiser, A. P. (2005). Siblings of persons with disabilities: Towards a research agenda. *Intellectual and Developmental Disabilities, 43*, 334–338. https://doi.org/10.1352/0047-6765(2005)43[334:SSOSEB]2.0.CO;2

Hodapp, R. M., Sanderson, K. A., Meskis, S. A., & Casale, E. G. (2017). Adult siblings of persons with intellectual disabilities: Past, present, and future. In R. M. Hodapp & D. J. Fidler (Eds.), *International review of research in developmental disabilities* (Vol. 53, pp. 163–202). Elsevier.

Hodapp, R. M., & Urbano, R. C. (2007). Adult siblings of individuals with Down syndrome versus with autism: Findings from a large-scale US survey. *Journal of Intellectual Disability Research, 51*, 1018–1029. https://doi.org/10.1111/j.1365-2788.2007.00994.x

Hodapp, R. M., Urbano, R. C., & Burke, M. M. (2010). Adult female and male siblings of persons with disabilities: Findings from a national survey. *Intellectual and*

Developmental Disabilities, *48*, 52–62. https://doi.org/10.1352/1934-9556-48.1.52

Jahoda, A., Cattermole, M., & Markova, I. (1989). Day services for people with mental handicaps: A purpose in life? *Journal of the British Institute of Mental Handicap (APEX)*, *17*, 136–139. https://doi.org/10.1111/j.1468-3156.1989.tb00545.x

Jones, E. E. (1984). *Social stigma: The psychology of marked relationships*. WH Freeman.

Jones, P. S., Winslow, B. W., Lee, J. W., Burns, M., & Zhang, X. E. (2011). Development of a caregiver empowerment model to promote positive outcomes. *Journal of Family Nursing*, *17*, 11–28. https://doi.org/10.1177/1074840710394854

Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. *Journal of Autism and Developmental Disorders*, *46*, 942–953. https://doi.org/10.1007/s10803-015-2637-9

Klein-Tasman, B. P., Li-Barber, K. T., & Magargee, E. T. (2011). Honing in on the social phenotype in Williams syndrome using multiple measures and multiple raters. *Journal of Autism and Developmental Disorders*, *41*, 341–351. https://doi.org/10.1007/s10803-010-1060-5

Korenberg, J. R., Chen, X. N., Schipper, R., Sun, Z., Gonsky, R., Gerwehr, S., Carpenter, N., Daumer, C., Dignan, P., & Disteche, C. (1994). Down syndrome phenotypes:

The consequences of chromosomal imbalance. *Proceedings of the National Academy of Sciences, 91*, 4997–5001. https://doi.org/10.1073/pnas.91.11.4997

Kosciulek, J. F., McCubbin, M. A., & McCubbin, H. I. (1993). A theoretical framework for family adaptation to head injury. *Journal of Rehabilitation*, *59*, 40–45. https://search.proquest.com/openview/083966abfb999d636129d0c4eb507f61/1?pq-origsite=gscholar&cbl=1819158

Kramer, J., Hall, A., & Heller, T. (2013). Reciprocity and social capital in sibling relationships of people with disabilities. *Mental Retardation*, *51*, 482–495. https://doi.org/10.1352/1934-9556-51.6.48

Kraus, L. (2017). *2016 Disability Statistics Annual Report*. University of New Hampshire. https://disabilitycompendium.org/sites/default/files/user-uploads/2016_AnnualReport.pdf

Kraus, C., Vanicek, T., Weidenauer, A., Khanaqa, T., Stamenkovic, M., Lanzenberger, R., ... & Kasper, S. (2018). DiGeorge syndrome. *Wiener klinische Wochenschrift*, *130*, 283–287. https://doi.org/10.1007/s00508-018-1335-y

Lakhan, R., & Sharma, M. (2010). A study of knowledge, attitudes and practices (KAP) survey of families toward their children with intellectual disability in Barwani, India. *Asia Pacific Disability Rehabilitation Journal*, *21*, 101–117. http://english.aifo.it/disability/apdrj/apdrj210/kap_barwani.pdf

Lam, L. W., & Mackenzie, A. E. (2002). Coping with a child with Down syndrome: The experiences of mothers in Hong Kong. *Qualitative Health Research, 12,* 223–237. https://doi.org/10.1177/104973202129119856

Larson, J. E., & Corrigan, P. (2008). The stigma of families with mental illness. *Academic psychiatry*, *32*, 87–91. https://doi.org/10.1176/appi.ap.32.2.87

Lebowitz, M. S., Rosenthal, J. E., & Ahn, W. K. (2016). Effects of biological versus psychosocial explanations on stigmatization of children with ADHD. *Journal of Attention Disorders*, *20*, 240–250. https://doi.org/10.1177/1087054712469255

Lee, J. (2013). Maternal stress, well-being, and impaired sleep in mothers of children with developmental disabilities: A literature review. *Research in Developmental Disabilities*, *34*, 4255–4273. https://doi.org/10.1016/j.ridd.2013.09.008

Leffert, J. S., & Siperstein, G. N. (2002). Social cognition: A key to understanding adaptive behavior in individuals with mild mental retardation. In L. M. Glidden (Ed.), *International review of research in mental retardation* (Vol. 25, pp. 135–181). Elsevier.

Leiter, R. G. (2018). *Behind the stigma: stereotypes and reactions towards children and adults with down syndrome*. [Unpublished thesis]. Whitman College.

Levy-Wasser, N., & Katz, S. (2004). The relationship between attachment style, birth order, and adjustment in children who grow up with a sibling with mental retardation. *The British Journal of Development Disabilities*, *50*, 89–98. https://doi.org/10.1179/096979504799103921

Liegghio, M. (2017). ‘Not a good person:’ Family stigma of mental illness from the perspectives of young siblings. *Child & Family Social Work*, *22*, 1237–1245. https://doi.org/10.1111/cfs.12340

Lim, F., Downs, J., Li, J., Bao, X. H., & Leonard, H. (2013). Caring for a child with severe intellectual disability in China: The example of Rett syndrome. *Disability and Rehabilitation*, *35*, 343–351. https://espace.curtin.edu.au/bitstream/handle/20.500.11937/12411/189278_189278.pdf?sequence=2&isAllowed=y

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, *27*, 363–385. https://doi.org/10.1146/annurev.soc.27.1.363

Link, B. G., Struening, E. L., Rahav, M., Phelan, J. C., & Nuttbrock, L. (1997). On stigma and its consequences: Evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *Journal of Health and Social Behavior*, *38*, 177–190. https://doi.org/ 0.2307/2955424

Linton, S. (1998). Disability studies/not disability studies. *Disability & Society*, *13*, 525–539. https://doi.org/10.1080/09687599826588

Lobato, D. (1983). Siblings of handicapped children: A review. *Journal of Intellectual and Developmental Disorders*, *13*, 347–364. https://doi.org/10.1007/BF01531585

Lovell, B., Moss, M., & Wetherell, M. A. (2012). With a little help from my friends: Psychological, endocrine and health corollaries of social support in parental caregivers of children with autism or ADHD. *Research in Developmental Disabilities*, *33*, 682–687. https://doi.org/10.1016/j.ridd.2011.11.014

Löwe, B., Decker, O., Müller, S., Brähler, E., Schellberg, D., Herzog, W., & Herzberg, P. Y. (2008). Validation and standardization of the Generalized Anxiety Disorder

Screener (GAD-7) in the general population. *Medical Care*, *46*, 266–274. https://www.jstor.org/stable/40221654

Lucas, R. E. (2018). Reevaluating the strengths and weaknesses of self-report measures of subjective well-being. In E. Diener, S. Oishi, & L. Tay (Eds.), *Handbook of well-being* (pp. 1–12). DEF Publishers.

Mainardi, P. C. (2006). Cri du Chat syndrome. *Orphanet Journal of Rare Diseases, 1*(33), 1–9. https://doi.org/10.1186/1750-1172-1-33

Mak, W. W., & Cheung, R. Y. (2008). Affiliate stigma among caregivers of people with intellectual disability or mental illness. *Journal of Applied Research in Intellectual Disabilities*, *21*, 532–545. https://doi.org/10.1111/j.1468-3148.2008.00426.x

Mak, W. W., & Cheung, R. Y. (2012). Psychological distress and subjective burden of caregivers of people with mental illness: The role of affiliate stigma and face concern. *Community Mental Health Journal*, *48*, 270–274. https://doi.org/10.1007/s10597-011-9422-9

Mak, W. W., Cheung, R. Y., Law, R. W., Woo, J., Li, P. C., & Chung, R. W. (2007). Examining attribution model of self-stigma on social support and psychological well-being among people with HIV+/AIDS. *Social Science & Medicine, 64*, 1549–1559. https://doi.org/10.1016/j.socscimed.2006.12.003

Mak, W. W., & Kwok, Y. T. (2010). Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong. *Social Science & Medicine, 70*, 2045–2051. https://doi.org/10.1016/j.socscimed.2010.02.023

Malli, M. A., Forrester-Jones, R., & Murphy, G. (2016). Stigma in youth with Tourette's syndrome: A systematic review and synthesis. *European child & adolescent psychiatry*, *25*, 127–139. https://doi.org/10.1007/s00787-015-0761-x

Man, J., Kangas, M., Trollor, J., & Sweller, N. (2018). Clinical practices and barriers to best practice implementation of psychologists working with adults with intellectual disability and comorbid mental ill health. *Journal of Policy and Practice in Intellectual Disabilities*, *15*, 256–266. https://doi.org/10.1111/jppi.12256

Matson, J. L., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*, *30*, 1107–1114. https://doi.org/10.1016/j.ridd.2009.06.003

Mazaheri, M. M., Rae-Seebach, R. D., Preston, H. E., Schmidt, M., Kountz-Edwards, S., Field, N., Cassidy, S., & Packman, W. (2013). The impact of Prader-Willi syndrome on the family's quality of life and caregiving, and the unaffected siblings' psychosocial adjustment. *Journal of Intellectual Disability Research*, *57*, 861–873. https://doi.org/10.1111/j.1365-2788.2012.01634.x

McCann, T. V., & Lubman, D. I. (2018). Stigma experience of families supporting an adult member with substance misuse. *International Journal of Mental Health Nursing*, *27*, 693–701. https://doi.org/10.1111/inm.12355

McDaniel, W. (1969). *Physical disability and human behavior*. Pergamon.

McDuffie, A., & Abbeduto, L. (2009). Language disorders in children with mental retardation of genetic origin: Down syndrome, fragile X syndrome, and Williams syndrome. In R.G. Schwartz (Ed.). *Handbook of child language disorders* (pp. 44–66). Psychology Press.

McDuffie, A., Kover, S., Abbeduto, L., Lewis, P., & Brown, T. (2012). Profiles of receptive and expressive language abilities in boys with comorbid fragile X syndrome and autism. *American Journal on Intellectual and Developmental Disabilities*, *117*, 18–32. https://doi.org/10.1352/1944-7558-117.1.18

Melendez, M. S., Lichtenstein, B., & Dolliver, M. J. (2016). Mothers of mass murderers: Exploring public blame for the mothers of school shooters through an application of courtesy stigma to the Columbine and Newtown tragedies. *Deviant Behavior, 37,* 525–536. https://doi.org/10.1080/01639625.2015.1060754

Meng, H. (1938). Zur sozialpsychologie der Kar perbeschiidigten: Ein beitrag zum problem der prak tisch en psychohygiene [On the social psychology of carers: A contribution to the problem of practical psycho-hygiene] *Schweizer Archives fiir Neurologie und Psychiatrie, 40,* 328–344. https://doi.org/10.4414/sanp.1999.01110

Mercer J. R. (1992) The impact of changing paradigms of disability on mental retardation in the year 2000. In L. Rowitz (Ed.), *Mental retardation in the year 2000: Disorders of human learning, behavior, and communication* (pp. 15–38). Springer.

Mervis, C. B., & John, A. E. (2008). Vocabulary abilities of children with Williams syndrome: Strengths, weaknesses, and relation to visuospatial construction ability.

Journal of Speech, Language, and Hearing Research, *51*, 967–982. https://doi.org/ 10.1044/1092-4388

Mervis, C. B., & Morris, C. A. (2007). Williams syndrome. In M. M. Mazzocco & J. L. Ross (Eds.), *Neurogenetic developmental disorders: Variation of manifestation in childhood* (pp. 199–262). MIT Press.

Mervis, C. B., Morris, C. A., Klein-Tasman, B. P., Bertrand, J., Kwitny, S., Appelbaum, L. G., & Rice, C. E. (2003). Attentional characteristics of infants and toddlers with Williams syndrome during triadic interactions. *Developmental Neuropsychology*, *23*, 243–268. https://doi.org/10.1080/87565641.2003.9651894

Meyer-Lindenberg, A., Kohn, P., Mervis, C. B., Kippenhan, J. S., Olsen, R. K., Morris, C. A., & Berman, K. F. (2004). Neural basis of genetically determined visuospatial construction deficit in Williams syndrome. *Neuron*, *43*, 623–631. https://doi.org/10.1016/j.neuron.2004.08.014

Mikami, A. Y., Chong, G. K., Saporito, J. M., & Na, J. J. (2015). Implications of parental affiliate stigma in families of children with ADHD. *Journal of Clinical Child & Adolescent Psychology*, *44*, 595–603. https://doi.org/10.1080/15374416.2014.888665

Milačić-Vidojević, I., Gligorović, M., & Dragojević, N. (2014). Tendency towards stigmatization of families of a person with autistic spectrum disorders. *International Journal of Social Psychiatry*, *60*, 63–70. https://doi.org/ 10.1177/0020764012463298

Miller, A. B., & Keys, C. B. (1996). Awareness, action, and collaboration: How the self-advocacy movement is empowering for persons with developmental disabilities. *Mental Retardation*, *34,* 312–319. https://search.proquest.com/openview/a7aa75eb0ed2680bc32e8d955833cd22/1?pq-origsite=gscholar&cbl=1976608

Mott, J., Schmidt, B., & MacWilliams, B. (2019). Male caregivers: Shifting roles among family caregivers. *Clinical Journal of Oncology Nursing, 23,* 17–24. https://doi.org/10.118/19.CJON.E17-E24

Moyson, T., & Roeyers, H. (2012). 'The overall quality of my life as a sibling is all right, but of course, it could always be better.' Quality of life of siblings of children with intellectual disability: The siblings' perspectives. *Journal of Intellectual Disability Research*, *56,* 87–101. https://doi.org/10.1111/j.1365-2788.2011.01393.x

Muderedzi, J., Eide, A. H., Braathen, S. H., & Stray-Pedersen, B. (2017). Perceptions and treatment of children with cerebral palsy among the Tonga of Binga in Zimbabwe. *Cogent Social Sciences*, *3*, 1–14. https://doi.org/ 10.1080/23311886.2017.1418144

Munyi, C. W. (2012). Past and present perceptions towards disability: A historical perspective. *Disability Studies Quarterly*, *32*, 1–10. http://doi.org/10.18061/dsq.v32i2.3197

Mutton, D., Alberman, E., & Hook, E. B. (1996). Cytogenetic and epidemiological findings in Down syndrome, England and Wales 1989 to 1993. National Down syndrome cytogenetic register and the association of clinical cytogeneticists. *Journal of Medical Genetics*, *33*, 387–394. http://doi.org/10.1136/jmg.33.5.387

National Library of Medicine. (2018a). *Angelman syndrome.* https://ghr.nlm.nih.gov/condition/angelman-syndrome

National Library of Medicine. (2018b). *Prader-Willi syndrome.* https://ghr.nlm.nih.gov/condition/prader-willi-syndrome#statistics

Norris, C., & Lloyd, G. (2000). Parents, professionals and ADHD: What the papers say. *European Journal of Special Needs Education*, *15*, 123–137. https://doi.org/10.1080/088562500361565

Norvilitis, J. M., Scime, M., & Lee, J. S. (2002). Courtesy stigma in mothers of children with attention-deficit/hyperactivity disorder: A preliminary investigation. *Journal of Attention Disorders*, *6*, 61–68. https://doi.org/10.1177/108705470200600202

Ntswane, A. M., & Van Rhyn, L. (2007). The life-world of mothers who care for mentally retarded children: The Katutura township experience. *Curationis*, *30*, 85–96. https://doi.org/10.4102/curationis.v30i1.1060

Olaniyan, O., Garriett, V., Mychailyszyn, M. P., Anixt, J., Rowe, P. C., & Cheng, T. L. (2007). Community perspectives of childhood behavioral problems and ADHD among African American parents. *Ambulatory Pediatrics*, *7*, 226–231. https://doi.org/10.1016/j.ambp.2007.02.002

Orsmond, G. I., & Seltzer, M. M. (2000). Brothers and sisters of adults with mental retardation: Gendered nature of the sibling relationship. *American Journal on*

Mental Retardation, *105,* 486–507. https://www.ncbi.nlm.nih.gov/pubmed/11958202

Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism or Down syndrome: Effects on adult lives. *Journal of Intellectual Disability Research*, *51*, 682–696. https://doi.org/10.1111/j.1365-2788.2007.00954.x

Osborne, L. (1974). Beyond stigma theory: A literary approach. *Issues Criminology*, *9*, 71–90. https://www.jstor.org/stable/42909696?seq=1#page_scan_tab_contents

Östman, M., & Kjellin, L. (2002). Stigma by association: Psychological factors in relatives of people with mental illness. *The British Journal of Psychiatry*, *181*, 494–498. https://doi.org/10.1192/bjp.181.6.494

Ow, R., & Katz, D. (1999). Family secrets and the disclosure of distressful information in Chinese families. *Families in Society: The Journal of Contemporary Social Services*, *80*, 620–628. http://psycnet.apa.org/record/2000-15917-008

Page, R. (1984). *Stigma (Concepts in social policy)*. Routledge & Kegan Paul.

Parker, S. E., Mai, C. T., Canfield, M. A., Rickard, R., Wang, Y., Meyer, R. E., Anderson, P., Mason, C. A., Collins, J. S., Kirby, R. S., Correa, A., National Birth Defects Prevention Network. (2010). Updated national birth prevalence estimates for selected birth defects in the United States, 2004–2006. *Birth Defects Research Part A: Clinical and Molecular Teratology*, *88*, 1008–1016. https://doi.org/10.1002/bdra.20735

Paterson, L., McKenzie, K., & Lindsay, B. (2012). Stigma, social comparison and self–esteem in adults with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 25*, 166–176. https://doi.org/10.1111/j.1468-3148.2011.00651.x

Pelleboer-Gunnink, H. A., Van Oorsouw, W. M. W. J., Van Weeghel, J., & Embregts, P. J. C. M. (2017). Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: A systematic review. *Journal of Intellectual Disability Research*, *61*, 411–434. https://doi.org/10.1111/jir.12353

Pelleboer-Gunnink, H.A., van Weeghel, J. & Embregts, P.J.C.M. (2021) Public stigmatisation of people with intellectual disabilities: A mixed-method population survey into stereotypes and their relationship with familiarity and discrimination. *Disability and Rehabilitation*, *43*, 489–497. https://doi.org/10.1080/09638288.2019.1630678

Petalas, M. A., Hastings, R. P., Nash, S., Lloyd, T., & Dowey, A. (2009). Emotional and behavioural adjustment in siblings of children with intellectual disability with and without autism. *Autism*, *13*, 471–483. https://doi.org/10.1177/1362361309335721

Phillip, N., & Bassett, A. (2011). Cognitive, behavioural and psychiatric phenotype in 22q11.2 Deletion Syndrome. *Behavior Genetics*, *41*, 403–412. https://doi.org/10.1007/s10519-011-9468-z

Piven, J., Gayle, J., Chase, G. A., Fink, B., Landa, R., Wzorek, M. M., & Folstein, S. E. (1990). A family history study of neuropsychiatric disorders in the adult siblings of autistic individuals. *Journal of the American Academy of Child & Adolescent Psychiatry*, *29*, 177–183. https://doi.org/10.1097/00004583-199003000-00004

Plato (1943). *The republic*. (B. Jowett, Trans.) Anchor. (Original work published ca. 375 B.C.E).

Poisson, A., Nicolas, A., Cochat, P., Sanlaville, D., Rigard, C., de Leersnyder, H., Rigard, C., Franco, P., des Portes, V., Edery, P., & Demily, C. (2015). Behavioral disturbance and treatment strategies in Smith-Magenis syndrome. *Orphanet Journal of Rare Diseases*, *10*, 1–9. https://doi.org/10.1186/s13023-015-0330-x

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied psychological measurement, 1*, 385–401. https://doi.org/10.1177/014662167700100306

Recio, P., Molero, F., García-Ael, C., & Pérez-Garín, D. (2020). Perceived discrimination and self-esteem among family caregivers of children with autism spectrum disorders (ASD) and children with intellectual disabilities (ID) in Spain: The mediational role of affiliate stigma and social support. *Research in Developmental Disabilities*, *105*, 103737. https://doi.org/10.1016/j.ridd.2020.103737

Reynolds, W. M. (1982). Development of reliable and valid short forms of the Marlowe-Crowne Social Desirability Scale. *Journal of Clinical Psychology*, *38*, 119–125.https://doi.org/10.1002/1097-4679(198201)38:1<119::AID-JCLP2270380118>3.0.CO;2-I

Rojahn, J., Rowe, E. W., Kasdan, S., Moore, L., & van Ingen, D. J. (2011). Psychometric properties of the Aberrant Behavior Checklist, the Anxiety, Depression and Mood Scale, the Assessment of Dual Diagnosis and the Social Performance Survey Schedule in adults with intellectual disabilities. *Research in Developmental Disabilities, 32*, 2309–2320. https://doi.org/10.1016/j.ridd.2011.07.035

Roper, S.O., Allred, D. W., Mandleco, B., Freeborn, D., & Dyches, D. (2014). Caregiver burden and sibling relationships in families raising children with disabilities and typically developing children. *Families, Systems & Health: The Journal of Collaborative Family Healthcare, 32*, 241–246. https://doi.org/10.1037/fsh0000047

Rossetti, Z., & Hall, S. (2015). Adult sibling relationships with brothers and sisters with severe disabilities. *Research and Practice for Persons with Severe Disabilities, 40*, 120–137. https://doi.org/10.1177%2F1540796915592829

Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies, 10*, 65–84. https://doi.org/10.1023/A:1016629500708

Rüsch, N., Angermeyer, M. C., & Corrigan, P. W. (2005). Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *European Psychiatry, 20*, 529–539. https://doi.org/10.1016/j.eurpsy.2005.04.004

Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, *57*, 1069–1081. https://doi.org/10.1037/0022-3514.57.6.1069

Ryff, C. D., & Keyes, C. L. M. (1995). The structure of psychological well-being revisited. *Journal of Personality and Social Psychology*, *69*, 719–727. https://doi.org/10.1037/0022-3514.69.4.719

Safilios-Rothschild, C. (1968). Prejudice against the disabled and some means to combat it. *The International Rehabilitation Review*, *19*, 8–10. https://doi.org/10.1177/136346156900600122

Sage, K. D., & Jegatheesan, B. (2010). Perceptions of siblings with autism and relationships with them: European American and Asian American siblings draw and tell. *Journal of Intellectual and Developmental Disability*, *35*, 92–103. https://doi.org/10.3109/13668251003712788

Schalock, R. L., Luckasson, R. A., & Shogren, K. A. (2007). The renaming of mental retardation: Understanding the change to the term intellectual disability. *Intellectual and Developmental Disabilities*, *45*, 116–124. https://doi.org/10.1352/1934-9556(2007)45[116:TROMRU]2.0.CO;2

Seguin, E. (1907). *Idiocy: And its treatment by the physiological method*. W. Wood & Company.

Seltzer, G. B., Begun, A., Seltzer, M. M., & Krauss, M. W. (1991). Adults with mental retardation and their aging mothers: Impacts of siblings. *Family Relations: An Interdisciplinary Journal of Applied Family Studies*, *40*, 310–317. https://doi.org/10.2307/585017

Seltzer, M. M., Greenberg, J. S., Orsmond, G. I., & Lounds, J. (2005). Life course studies of siblings of individuals with developmental disabilities. *Mental Retardation*, *43*, 354–359. http://www2.waisman.wisc.edu/family/pubs/AgingDD/34%20-%20MR_2005_life_course_studies.pdf

Shin, J., Nhan, N. V., Crittenden, K. S., Hong, H. T. D., Flory, M., & Ladinsky, J. (2006). Parenting stress of mothers and fathers of young children with cognitive delays in Vietnam. *Journal of Intellectual Disability Research*, *50*, 748–760. https://doi.org/10.1111/j.1365-2788.2006.00840.x

Shivers, C. (2017). The sibling experience: More than my brother's keeper. In B. S. N. Goffman & N. P. Springer (Eds.), *Intellectual and developmental disabilities* (pp. 116-128). Routledge.

Shivers, C. M., Deisenroth, L. K., & Taylor, J. L. (2013). Patterns and predictors of anxiety among siblings of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *43*, 1336–1346. https://doi.org/10.1007/s10803-012-1685-7

Shivers, C. M., & McGregor, C. M. (2018). Brief report: Sibling feelings toward their brother or sister with or without autism or intellectual disability. *Journal of Autism and Developmental Disorders*, *1*, 1–6. https://doi.org/10.1007/s10803-018-3694-7

Shontz, F. C. (1975). *The psychological aspects of physical illness and disability*. Macmillan.

Siller, J., & Chipman, A. (1964). Factorial structure and correlates of the attitudes toward disabled persons scale. *Educational and Psychological Measurement*, *24*, 831–840. https://doi.org/10.1177/001316446402400410

Singh, A., Mattoo, S. K., & Grover, S. (2016). Stigma associated with mental illness: Conceptual issues and focus on stigma perceived by the patients with schizophrenia and their caregivers. *Indian Journal of Social Psychiatry*, *32*, 134–142. http://www.indjsp.org/text.asp?2016/32/2/134/181095

Skotko, B. G., Levine, S. P., & Goldstein, R. (2011). Having a brother or sister with Down syndrome: Perspectives from siblings. *American Journal of Medical Genetics Part A*, *155*, 2348–2359. https://doi.org/10.1002/ajmg.a.34228

Sloper, P., & Turner, S. (1993). Determinants of parental satisfaction with disclosure of disability. *Developmental Medicine & Child Neurology*, *35*, 816–825. https://doi.org/10.1111/j.1469-8749.1993.tb11733.x

Sobel, M. E. (1982). Asymptotic confidence intervals for indirect effects in structural equation models. *Sociological methodology*, *13*, 290–312. https://doi.org/10.2307/270723

Sontag, J. C. (1996). Toward a comprehensive theoretical framework for disability research: Bronfenbrenner revisited. *The Journal of Special Education*, *30*, 319–344. https://doi.org/10.1177/002246699603000306

Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: The GAD-7. *Archives of Internal Medicine*, *166*, 1092–1097. https://doi.org/10.1001/archinte.166.10.1092

Stainton, T. (2001). Reason and value: The thought of Plato and Aristotle and the construction of intellectual disability. *Mental retardation*, *39*, 452–460. https://doi.org/10.1352/0047-6765(2001)039<0452:RAVTTO>2.0.CO;2

Staniland, J. J., & Byrne, M. K. (2013). The effects of a multi-component higher-functioning autism anti-stigma program on adolescent boys. *Journal of Autism and Developmental Disorders*, *43,* 2816–2829. https://doi.org/10.1007/s10803-013-1829-4

Stojanovik, V. (2006). Social interaction deficits and conversational inadequacy in Williams syndrome. *Journal of Neurolinguistics*, *19*, 157–173. https://doi.org/10.1016/j.jneuroling.2005.11.005

Strike, D. L., Skovholt, T. M., & Hummel, T. J. (2004). Mental health professionals' disability competence: Measuring self-awareness, perceived knowledge, and perceived skills. *Rehabilitation Psychology*, *49*, 321–327. https://doi.org/10.1037/0090-5550.49.4.321

Strømme, P., Bjømstad, P. G., & Ramstad, K. (2002). Prevalence estimation of Williams syndrome. *Journal of Child Neurology*, *17,* 269–271.https://doi.org/10.1177/088307380201700406

Summers, C. R., White, K. R., & Summers, M. (1994). Siblings of children with a disability: A review and analysis of the empirical literature. *Journal of Social Behavior and Personality, 9,* 169–184. https://psycnet.apa.org/record/1996-20000- 001

Szivos-Bach, S. E. (1993). Social comparisons, stigma and mainstreaming: The self-esteem of young adults with a mild mental handicap. *Mental Handicap Research*, *6*, 217–236. https://doi.org/10.1111/j.1468-3148.1993.tb00054.x

Taffe, J. R., Gray, K. M., Einfeld, S. L., Dekker, M. C., Koot, H. M., Emerson, E., Koskentausta, T., & Tonge, B. J. (2007). Short form of the developmental behaviour checklist. *American Journal of Mental Retardation, 112,* 31–39. https://doi.org/10.1352/0895-8017(2007)112[31:SFOTDB]2.0.CO;2

Taggart, L., Truesdale-Kennedy, M., Ryan, A., & McConkey, R. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities*, *16*, 217–234. https://doi.org/10.1177/1744629512456465

Tait, K., Fung, F., Hu, A., Sweller, N., & Wang, W. (2016). Understanding Hong Kong Chinese families' experiences of an autism/ASD diagnosis. *Journal of Autism and Developmental Disorders*, *46*, 1164–1183. https://doi.org/10.1007/s10803-015-2650-z

Taylor, J. L., Greenberg, J. S., Seltzer, M. M., & Floyd, F. J. (2008). Siblings of adults with mild intellectual deficits or mental illness: Differential life course outcomes. *Journal of Family Psychology*, *22*, 905. https://doi.org/10.1037/a0012603

Thomas, D.H. (1957). A survey of mental deficiency problems in the United States of America. *Journal of Intellectual Disability Research*, *1*, 33–52. https://doi.org/10.1111/j.1365-2788.1957.tb00279.x

Thompson, T. L. (1982). Disclosure as a disability−management strategy: A review and conclusions. *Communication Quarterly*, *30*, 196–202. https://doi.org/10.1080/01463378209369449

Tint, A., & Weiss, J. A. (2016). Family wellbeing of individuals with autism spectrum disorder: A scoping review. *Autism*, *20*, 262–275. https://doi.org/10.1177/1362361315580442

Tomanik, S., Harris, G. E., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability*, *29*, 16–26. https://doi.org/10.1080/13668250410001662892

Tomeny, T., Ellis, B. M., Rankin, J., & Barry, T.D. (2017). Sibling relationship quality and psychosocial outcomes among adult siblings of individuals with autism spectrum disorder and individuals with intellectual disability without autism. *Research in Developmental Disabilities*, *62*, 104–114. https://doi.org/ 10.1016/j.ridd.2017.01.008

Trent J. W., Jr. (1994). *Inventing the feeble mind: A history of mental retardation in the United States* (Vol. 6). University of California Press.

U.S. Census Bureau. (2015, March 19). *Desire to Move and Residential Mobility: 2010–2011* (Report No. P70–140). http://www.census.gov/library/publications/2015/demo/p70-140.html

Usitalo, A. M. (2002). *Perceptions of stigmatization, attributional style and adjustment in adolescents with craniofacial conditions* [Unpublished doctoral dissertation]. University of Florida. https://archive.org/stream/perceptionsofsti00usit/perceptionsofsti00usit_djvu.txt van der Sanden, R. L., Pryor, J. B., Stutterheim, S. E., Kok, G., & Bos, A. E. (2016). Stigma by association and family burden among family members of people with mental illness: The mediating role of coping. *Social Psychiatry and Psychiatric Epidemiology, 51*, 1233–1245. https://doi.org/10.1007/s00127-016-1256-x

Verzeletti, C., Zammuner, V. L., Galli, C., & Agnoli, S. (2016). Emotion regulation strategies and psychosocial well-being in adolescence. *Cogent Psychology, 3,* 1–15. https://doi.org/10.1080/23311908.2016.1199294

Warren, S. F., & Brady, N. C. (2007). The role of maternal responsivity in the development of children with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13,* 330–338. https://doi.org/10.1002/mrdd.20177

Weiner, B. (1995). *Judgments of responsibility: A foundation for a theory of social conduct.* Guilford.

Weiner, B., Perry, R.P., & Magnusson, J. (1988). An attributional analysis of reaction to stigma. *Journal of Social Issues, 35,* 120–155. https://www.ncbi.nlm.nih.gov/pubmed/2974883

Weinstein, S., Sersen, E. A., Fisher, L., & Vetter, R. J. (1964). Preferences for bodily parts as a function of sex, age, and socio-economic status. *The American Journal of Psychology, 77*, 291–294. https://doi.org/10.2307/1420138

Weise, A., Mrasek, K., Klein, E., Mulatinho, M., Llerena, J. C., Hardekopf, D., Pekova, S., Bhatt, S., Kosyakova, N., Liehr, T. (2012). Microdeletion and microduplication syndromes. *The Journal of Histochemistry and Cytochemistry:*

Official Journal of the Histochemistry Society, *60*, 346–58. https://doi.org/10.1369/0022155412440001

Werner, P., & Hess, A. (2016). Examining courtesy stigma among foreign health care workers caring for persons with Alzheimer's disease: A focus group study. *Home Health Care Services Quarterly, 35*, 69–85. https://doi.org/10.1080/01621424.2016.1227011

Werner, S., & Shulman, C. (2013). Subjective well-being among family caregivers of individuals with developmental disabilities: The role of affiliate stigma and psychosocial moderating variables. *Research in Developmental Disabilities, 34*, 4103–4114. https://doi.org/10.1016/j.ridd.2013.08.029

Werner, S., & Shulman, C. (2015). Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability? *Journal of Intellectual Disability Research*, *59*, 272–283. https://doi.org/10.1111/jir.12136

White, N., & Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*, 181–190. https://doi.org/10.1111/j.1468-3148.2004.00197.x

Williams, J. F., Smith, V. C., & Committee on Substance Abuse. (2015). Fetal alcohol spectrum disorders. *Pediatrics, 136*, 1395–1406. https://doi.org/ 10.1542/peds.2015-3113

Wilson, M. C., & Scior, K. (2015). Implicit attitudes toward people with intellectual disabilities: Their relationship with explicit attitudes, social distance, emotions and contact. *PloS one*, *10*(9), 1–19. https://doi.org/10.1371/journal.pone.0137902

Won, J. C., Jun, M. H., & Jung, S. H. (2017). Exploratory research on the death and survival of neonates with congenital disorders in North Korea. *Children and Youth Services Review*, *82*, 162–168. https://doi.org/10.1016/j.childyouth.2017.09.013

Wong, C. C., Mak, W. W., & Liao, K. Y. H. (2016). Self-compassion: A potential buffer against affiliate stigma experienced by parents of children with autism spectrum disorders. *Mindfulness*, *7*, 1385–1395. https://doi.org/10.1007/s12671-016-0580-2

Wright, D., & Digby, A. (Eds.). (1996). *From idiocy to mental deficiency*. Routledge.

Yamamoto, K. (1971). To be different. *Rehabilitation Counseling Bulletin*, *14*, 180–188. https://eric.ed.gov/?id=EJ035983

Yang, X. (2015). No matter how I think, it already hurts: Self-stigmatized feelings and face concern of Chinese caregivers of people with intellectual disabilities. *Journal of Intellectual Disabilities*, *19*, 367–380. https://doi.org/10.1177/1744629515577909

Yildirim, T.M., & Eslen-Ziya, H. (2020). The differential impact of COVID-19 on the work conditions of women and men academics during the lockdown. *Gender, Work, and Organization*, *28*, 243–249. https://doi.org/10.1111/gwao.12529

Yip, K. S. (2003). Traditional Confucian concepts of mental health: Its implications to social work practice with Chinese communities. *Asia Pacific Journal of Social Work and Development*, *13*, 65–89. https://doi.org/10.1080/21650993.2003.9755929

Yoong, A., & Koritsas, S. (2012). The impact of caring for adults with intellectual disability on the quality of life of parents. *Journal of Intellectual Disability Research*, *56*, 609–619. https://doi.org/10.1111/j.1365-2788.2011.01501

APPENDIX A

Flyer

Experience of Adult Siblings of Individuals with Intellectual Disabilities Study

Are you 18 years of age or older?
Are you a sibling of an individual with an intellectual disability (i.e., Down syndrome, Fetal Alcohol Syndrome, Williams syndrome, etc.?)

If you answered YES to these questions, you may be eligible to participate in a psychology research study.

The purpose of this research study is to understand the experience of adult siblings of individuals with intellectual disabilities. The study is conducted primarily online and will take 30-45 minutes to complete. After completing the study, participants can choose to be entered into a drawing to receive one of two Amazon gift cards worth $25 each.

This study is being conducted through Texas Woman’s University. If you are interested in participating or would like more information, please contact the primary investigator, Natasha Shukla at NShukla1@twu.edu.

APPENDIX B

Informed Consent

TEXAS WOMAN'S UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

Title: Experiences of Adult Siblings of Individuals with Intellectual Disabilities

Investigator: Natasha Shukla, M.S.	NShukla1@twu.edu	972-838-6845
Advisor: Debra Mollen, Ph.D.	DMollen@twu.edu	940-898-2317

Summary and Key Information about the Study

You are being asked to participate in a research study for Ms. Natasha Shukla, a student at Texas Woman's University, as part of her dissertation. The purpose of this research is to explore the experiences of adult siblings of individuals with intellectual disabilities in the United States. This study will ask you about your experience being an adult sibling of an individual with an intellectual disability, general demographic information, and questions related to your sibling's behaviors, stigmatization of being a sibling of an individual with a disability, and your psychological well-being. You have been asked to participate in this study because you are over the age of 18 and identify as a sibling of an individual with an intellectual disability. The total time commitment for this study will be about 30-45 minutes. Following completion of the study you can be entered into a drawing to win one of two $25 Amazon gift cards for your participation. The greatest risks of this study include potential loss of confidentiality and emotional discomfort. We will discuss these risks and the rest of the study procedures in greater detail below.

Participation is entirely voluntary and you are free to withdraw at any time without penalty. If you are interested in learning more about this study, please review this consent form carefully and take your time deciding whether or not you want to participate. Please feel free to ask the researcher any questions you have about the study at any time.

Description of Procedures

As a participant in this study you will be asked to spend approximately 30-45 minutes of your time completing six surveys and a short demographic questionnaire online. In order to be a participant in this study, you must be at least 18 years of age or older and identify as being a sibling with an intellectual disability.

Potential Risks

The surveys will ask questions relating to your experience as being a sibling, the behaviors of your sibling with an intellectual disability, as well as your psychological health. Answering survey questions related to physical and mental health and to one's experiences as being a sibling with an intellectual disability may become uncomfortable for some participants. You are free to take breaks if you become fatigued or withdraw at any point of the study without penalty. If you experience any emotional discomfort while completing the survey, you are encouraged to visit APA's Psychologist Locator, http://locator.apa.org, to find a mental health professional from whom you may choose to seek services.

Another risk in this study is loss of confidentiality. Confidentiality will be protected to the extent that is allowed by law. Your personal identifying data will not be collected with the survey. Data collected through PsychData will be stored in a password protected electronic file. Should you choose to participate, you will be given an option to provide your contact information if you would like to have the results of the study sent to you and if you would like to be entered into a drawing for a gift card. Please be informed that this information will not be linked to survey responses, and will be in a separate electronic file that is password protected. The results of the study may be reported in scientific magazines or journals but your name or any other identifying information will not be included. There is a potential risk of loss of confidentiality in all email, downloading, and internet transactions.

There is also a risk for loss of anonymity in this study if you provide your e-mail address to request the results of the study or to enter the drawing for a gift card. If you are a gift card winner and provide your home address and contact information, you are also at risk for loss of anonymity. To minimize this risk, the researchers will collect e-mail addresses/contact information in a secure, password protected database, which will be maintained separately from survey responses. E-mail addresses and contact information will be entirely deleted from the database one year after the completion of the study, and no paper copies will be printed.

Any personal information collected for this study will not be used or distributed for future research even after the researchers remove your personal or identifiable information (e.g. your name, contact information, home address).

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participation and Benefits

Your involvement in this study is completely voluntary and you may withdraw from the study at any time. Following the completion of the study, you will be provided with the option to be entered into a raffle to receive one of two $25 Amazon gift cards in appreciation for your participation. Not all who enter will win, and each participant is eligible to win one of the gift cards. If you would like to know the results of this study, we will be email them to you. Please be advised that although your contact information will be stored separately from survey responses, anonymity cannot be guaranteed.

Questions Regarding the Study

You may choose to print a copy of this consent form for your records. If you have any questions about the research study, please feel free to contact the researchers; their phone numbers are located at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at IRB@twu.edu.

If you have read and agree to the above statements, please click on the "Yes" button below to indicate your consent to participate.

Yes No

*If you would like to know the results of this study tell us where you want them to be sent:

Email: ______________________or Home Address: ____________________________

APPENDIX C

Criterion Confirmation

1. Are you 18 years of age or older?

   ___Yes
   ___No

2. Are you a sibling of a brother or sister with a formal diagnosis of an intellectual disability (i.e., Down syndrome, Fragile X syndrome, Williams syndrome, Prader-Willi syndrome, Smith-Magenis syndrome, Cri-du-Chat syndrome, Angelman syndrome, Fetal Alcohol Spectrum Disorder, or DiGeorge syndrome)?

   ___Yes
   ___No

3. Have you had recent contact with your sibling with an intellectual disability? Recent contact indicates within the past 4 weeks and would include speaking over the phone, interacting over the internet, and/or meeting face-to-face.

   ___Yes
   ___No

APPENDIX D

General Demographic Questionnaire

Please answer the following items.

1. **Age: _______**

2. **Gender**

___Man
___Woman
___Transgender (Assigned Male at Birth and identify as another gender)
___Transgender (Assigned Female at Birth and identify as a another gender)
___Non-binary

3. **Race/ethnicity**

___White/European American
___Hispanic/Latino(a)/Latinx
___Black/African/African American
___Native American
___Asian/Asian American/Pacific Islander
___Bi- or Multiracial/Ethnic (Specify all): ______________
___Other; Specify: ______________

4. **Employment status**

___Employed full-time (> 20 hours)
___Employed part-time (1-19 hours)
___Unemployed
___Other (student; seasonally employed)

5. **Highest level of education completed**

___High school
___Some post-high school education
___Two-year (Associate's) degree
___Four-year (Bachelor's) degree
___Graduate (Masters, Ph.D., M.D.) degree

6. **Indicate your proximity from your sibling with intellectual disability**

___Currently lives with my sibling
___1-10 miles
___1-50 miles
___51-150 miles
___151-300 miles
___301-500 miles
___Above 500 miles

7. **With what types of caretaking duties (if any) have you assisted your sibling with recently (in the last year)? (Select as many answer choices that fit with your answer)**

___ Daily activities (Bathing, dressing, feeding, meal preparation)
___ Household activities (cleaning, laundry, dishes, vacuuming)
___ Financial responsibilities (budgeting, paying bills)
___ Health care (medication monitoring, taking vital signs, scheduling doctor visits)
___ Transportation
___Other (specify: ________________)

8. **With what types of caretaking duties (if any) have you assisted your sibling with in the past (more than 2 years ago)? (Select as many answer choices that fit with your answer)**

___ Daily activities (Bathing, dressing, feeding, meal preparation)
___ Household activities (cleaning, laundry, dishes, vacuuming)
___ Financial responsibilities (budgeting, paying bills)
___ Health care (medication monitoring, taking vital signs, scheduling doctor visits)
___ Transportation
___Other (specify: ________________)

9. How are you related to your sibling with an intellectual disability?

___ Full biological sibling (we have the same parents)
___ Halfsibling (we have one common biological parent)
___ Stepsibling (we are not related biologically but through our parents' marriage/cohabitation)
___ Adopted sibling (we are not related biologically)

10. **How old is your sibling with an intellectual disability? ______**

11. What is the gender of your sibling with an intellectual disability?

___ Man
___ Woman
___ Transgender (Assigned Male at birth and identifies with another gender)
___Transgender (Assigned Female at birth and identifies with another gender)
___Non-binary

12. Please select the specific type(s) of intellectual disability your sibling has:

___ Down syndrome
___ Fragile X syndrome
___ Williams syndrome
___ Prader-Willi syndrome

___ Other intellectual disability (Smiths-Magenis, Cri-du-Chat syndrome, Angelman syndrome, Fetal Alcohol Spectrum Disorder, DiGeorge syndrome).
Specify:________

___ If not listed, please specify: ________________________

___Not sure

APPENDIX E

Affiliate Stigma Scale

Below are some sentences related to your life as a sibling of a person with an intellectual disability. There are no right or wrong answers. Please read each sentence and choose the option which best represents your opinion.

Strongly Disagree Disagree Agree Strongly Agree
1………….………..2…….……….…....….3………..………..4

1. I feel inferior because I have a sibling with an intellectual disability.
2. I avoid communicating with my sibling with an intellectual disability.
3. Other people would discriminate against me if I am with my sibling with an intellectual disability.
4. I feel emotionally disturbed because I have a sibling with an intellectual disability.
5. I dare not tell others that I have a sibling with an intellectual disability.
6. My reputation is damaged because I have a sibling with an intellectual disability.
7. The behavior of my sibling with an intellectual disability makes me feel embarrassed.
8. I reduce (or limit) going out with my sibling with an intellectual disability.
9. People’s attitude towards me turns bad when I am together with my sibling with an intellectual disability.
10. I feel helpless for having a sibling with an intellectual disability.
11. Given that I have a sibling with an intellectual disability, I reduce contact with my friends and relatives.
12. Having a sibling with an intellectual disability imposes a negative impact on me.
13. I feel sad because I have a sibling with an intellectual disability.
14. When I am with my sibling with an intellectual disability, I would keep a relatively low profile.
15. Having a sibling with an intellectual disability makes me think that I am incompetent compared to other people.
16. I worry that other people would know I have a sibling with an intellectual disability.
17. I reduce interacting with my sibling with an intellectual disability.
18. Having a sibling with an intellectual disability makes me think that I am lesser to others.
19. I feel that I am under great pressure because I have a sibling with an intellectual disability.
20. I dare not participate in activities related to intellectual disability lest other people would suspect I have a sibling with an intellectual disability.
21. Having a sibling with an intellectual disability makes me lose face (or lose respect).
22. Given that I have a sibling with an intellectual disability, I reduce contact with the neighbors.

APPENDIX F

Psychological Well-Being Scale

Please indicate your degree of agreement (using a score ranging from 1-7) to the following sentences:

1= Strongly Agree
2 = Somewhat Agree
3 = A little Agree
4 = Neither Agree or Disagree
5 = A Little Disagree
6 = Somewhat Disagree
7 = Strongly Disagree

1. I like most parts of my personality.
2. When I look at the story of my life, I am pleased with how things have turned out so far.
3. Some people wander aimlessly through life, but I am not one of them.
4. The demands of everyday life often get me down.
5. In many ways I feel disappointed about my achievements in life.
6. Maintaining close relationships has been difficult and frustrating for me.
7. I live life one day at a time and don't really think about the future.
8. In general, I feel I am in charge of the situation in which I live.
9. I am good at managing the responsibilities of daily life.
10. I sometimes feel as if I've done all there is to do in life.
11. For me, life has been a continuous process of learning, changing, and growth.
12. I think it is important to have new experiences that challenge how I think about myself and the world.
13. People would describe me as a giving person, willing to share my time with others.
14. I gave up trying to make big improvements or changes in my life a long time ago.
15. I tend to be influenced by people with strong opinions.
16. I have not experienced many warm and trusting relationsips with others.
17. I have confidence in my own opinions, even if they are different from the way most other people think.
18. I judge myself by what I think is important, not by the values of what others think is important.

APPENDIX G

Aberrant Behavior Checklist-2

Please rate your sibling's behavior for the last four weeks. For each item, decide whether the behavior is a problem and circle the appropriate number:

0 = not at all a problem
1 = the behavior is a problem but slight in degree
2 = the problem is moderately serious
3 = the problem is severe in degree

When judging your sibling's behavior, please keep the following points in mind:

(a) Take relative frequency into account or each behavior specified. That is, consider this person with respect to others of similar age and sex, in general. For example, if your sibling averages more temper outbursts than most other people you know of similar age and sex or most others in his/her class, it is probably moderately serious (2) or severe (3) even if these occur only once or twice a week. Other behaviors, such as noncompliance, would probably have to occur more frequently to merit a high rating.

(b) If you have access to this information, consider the experiences of other caregivers with your sibling. If your sibling has problems with others but not with you, try to take the whole picture into account.

(c) Try to consider whether a given behavior interferes with his/her development, functioning or relationships. For example, body rocking or social withdrawal may not disrupt other children or adults, but it almost certainly hinders individual development or functioning.

Do not spend too much time on each item - your first reaction is usually the right one.

1. Excessively active at home, school, work, or elsewhere
2. Injures self on purpose
3. Listless, sluggish, inactive
4. Aggressive to other children or adults (verbally or physically)
5. Seeks isolation from others
6. Meaningless, recurring body movements
7. Boisterous (inappropriately noisy and rough)
8. Screams inappropriately
9. Talks excessively
10. Temper tantrums/outbursts
11. Stereotype behaviors; abnormal, repetitive movements
12. Preoccupied; stares into space
13. Impulsive (acts without thinking)
14. Irritable and whiny
15. Restless, unable to sit still
16. Withdrawn; prefers solitary activities

17. Odd, bizarre in behavior
18. Disobedient; difficult to control
19. Yells at inappropriate times
20. Fixed facial expression; lacks emotional responsiveness
21. Disturbs others
22. Repetitive speech
23. Does nothing but sit and watch others
24. Uncooperative
25. Depressed mood
26. Resists any form of physical contact
27. Moves or rolls head back and forth repetitively
28. Does not pay attention to instructions
29. Demands must be met immediately
30. Isolates himself/herself from other children or adults
31. Disrupts group activities
32. Sits or stands in one position for a long time
33. Talks to self loudly
34. Cries over minor annoyances and hurts
35. Repetitive hand, body, or head movements
36. Mood changes quickly
37. Unresponsive to structured activities (does not react)
38. Does not stay in seat (e.g. during lesson or learning periods, meals, etc.)
39. Will not sit still for any length of time
40. Is difficult to reach, contact, or get through to
41. Cries and screams inappropriately
42. Prefers to be alone
43. Does not try to be communicate by words or gestures
44. Easily distractible
45. Waves or shakes the extremities repeatedly
46. Repeats a word or phrase over and over
47. Stamps feet or bangs objects or slams doors
48. Constantly runs or jumps around the room
49. Rocks body back and forth repeatedly
50. Deliberately hurts himself/herself
51. Pays no attention when spoken to
52. Does physical violence to self
53. Inactive, never moves spontaneously
54. Tends to be excessively active
55. Responds negatively to affection
56. Deliberately ignores directions
57. Has temper outbursts or tantrums when he/she does not get own way
58. Shows few social reactions to others

APPENDIX H

Social Desirability Scale

Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide whether the statement is True or False as it pertains to you personally.

Note: Response options of True and False should be provided for each statement

1. It is sometimes hard for me to go on with my work if I am not encouraged.
2. I sometimes feel resentful when I don't get my way.
3. On a few occasions, I have given up doing something because I thought too little of my ability.
4. There have been times when I felt like rebelling against people in authority even though I knew they were right.
5. No matter who I'm talking to, I'm always a good listener.
6. There have been occasions when I took advantage of someone.
7. I'm always willing to admit it when I make a mistake.
8. I sometimes try to get even rather than forgive and forget.
9. I am always courteous, even to people who are disagreeable.
10. I have never been irked when people expressed ideas very different from my own.
11. There have been times when I was quite jealous of the good fortune of others.
12. I am sometimes irritated by people who ask favors of me.
13. I have never deliberately said something that hurt someone's feelings.

APPENDIX I

Generalized Anxiety Disorder Scale

Over the last 2 weeks, how often have you been bothered by the following problems?

Not at all	Several days	Over half the days	Nearly everyday
0	1	2	3

1. Feeling nervous, anxious, or on edge
2. Not being able to stop or control worrying
3. Worrying too much about different things
4. Trouble relaxing
5. Being so restless that it's hard to sit still
6. Becoming easily annoyed or irritable
7. Feeling afraid as if something awful might happen

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all ___________
Somewhat difficult__________
Very difficult ______________
Extremely difficult __________

APPENDIX J

Center for Epidemiological Depression Scale-Revised

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

0	1	2	3	4
Not at all or less than one day	1-2 days	3-4 days	5-7 days	Nearly everyday

1. My appetite was poor.
2. I could not shake off the blues.
3. I had trouble keeping my mind on what I was doing.
4. I felt depressed.
5. My sleep was restless.
6. I felt sad.
7. I could not get going.
8. Nothing made me happy.
9. I felt like a bad person.
10. I lost interest in my usual activities.
11. I slept much more than usual.
12. I felt like I was moving too slowly.
13. I felt fidgety.
14. I wished I were dead.
15. I wanted to hurt myself.
16. I was tired all the time.
17. I did not like myself.
18. I lost a lot of weight without trying to.
19. I have a lot of trouble getting to sleep.
20. I could not focus on the important things.