

**IMPACT OF DIFFERENTIATION OF SELF AND RACIAL/ETHNIC  
IDENTITY ON INTERNALIZED STIGMA IN PARENTAL CAREGIVERS  
OF CHILDREN WITH AUTISM SPECTRUM DISORDER**

by

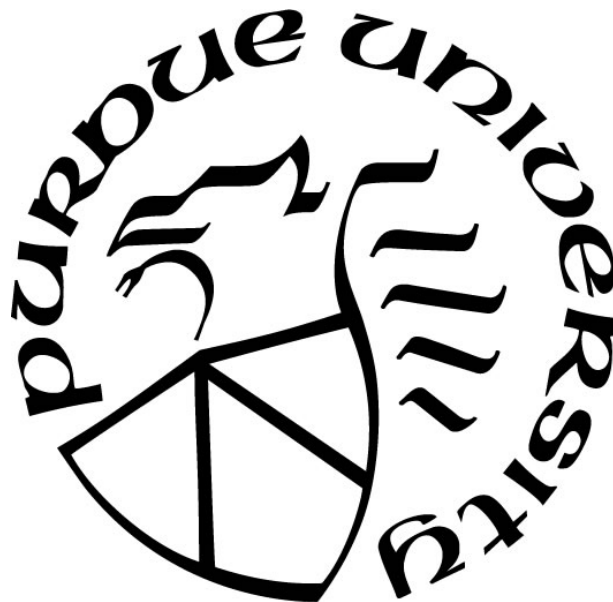
**Jessica McGuire**

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**STATEMENT OF COMMITTEE APPROVAL**

**Dr. Anne Edwards, Chair**

Department of Behavioral Sciences

**Dr. Kevin Hynes**

Department of Behavioral Sciences

**Dr. Brie Turns**

Department of Marriage and Family Therapy, Fuller Theological Seminary

**Approved by:**

Dr. Megan Murphy

*This work is dedicated to Levi & Reilly – who embody the passion and tenacity from which this was written.*

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## **ABSTRACT**

Due to the unique experiences and needs of parents with children diagnosed with Autism Spectrum Disorder (ASD), (i.e., child's limited functional ability; increased duration and extent of caretaking), parents of children with ASD often experience affiliate stigma. Affiliate stigma is the internalized cognitive, affective, and behavioral impact of association with marginalized populations, in this case individuals diagnosed with a mental illness or a developmental disability such as ASD (Mak & Cheung, 2008). Outside of differences in provider-caregiver interactions (Mandell & Novak, 2005; Palmer et al., 2010), little research has explored the impact of racial and ethnic identity on ASD caregiving experiences. Research exploring differentiation of self in parental caregivers is also sparse. Differentiation is conceptualized as the way individuals think about themselves in relation to others. Optimal differentiation is characterized by emotional interdependence with others -- that is maintaining a state of connectedness without emotional over-involvement (Kerr & Bowen, 1988). To address these gaps in the literature, a self-report survey measuring affiliate stigma, differentiation of self and racial/ethnic identity was completed by 147 parents of children diagnosed with ASD. Participants identifying as a racial/ethnic minority made up 36.7% of this study's sample. Results from a hierarchical regression analysis suggests that higher differentiation of self predicts greater affiliate stigma. Identity as a racial or ethnic minority had no significant impact on experiencing affiliate stigma.



## **CHAPTER 1: STATEMENT OF THE PROBLEM**

### **Autism Spectrum Disorder**

Autism spectrum disorder (ASD) is a developmental disability characterized by atypical social communication and preference for repetitive patterns of behavior (APA, 2013). Within the United States approximately 1.5 million children aged 3-18 are diagnosed with ASD (Kogan et al., 2018). ASD is characterized by atypical patterns of social interactions and preference for routine and/or repetitive stimulation (APA, 2013). Sensory sensitivities are common for individuals with ASD (APA, 2013; DeBoth & Reynolds, 2017). ASD is considered a developmental disability because symptoms are first apparent during the developmental stages of young childhood, particularly between 12 and 24 months of age (APA, 2013). Diagnostic rates for ASD have increased to 1.7% of children between ages 3-18 from a previous rate of 1.5% in 2013 (Knopf, 2018). The average age of diagnosis has also decreased, from 59.3 months (nearly 5 years old) in 2004 (Mandell et al., 2010) to 50 months (just over 4 years old) in 2012 (Christensen et al., 2018). These changes in trends have occurred in part due to increased public awareness of behaviors associated with ASD (Knopf, 2018).

### **Ethnic and Racial Disparities**

Racial minorities are disproportionately under-diagnosed with ASD (Durkin et al., 2017). African-American children exhibiting symptoms of ASD are diagnosed on average 18 months later than White children exhibiting the same symptoms (Mandell et al., 2002). When compared to their White peers, children identifying as Hispanic are less than half as likely to receive a diagnosis at all (Palmer et al., 2010). These disparities appear to persist even when access to medical care and other socioeconomic factors are controlled (Durkin et al., 2017; Palmer et al., 2010). Researchers believe this may be because families identifying as a racial minority neither voiced, nor were asked about developmental concerns from the attending physician (Mandell et al., 2002). Further, early ASD indicators related to poor social skills may be misattributed to race or ethnicity-related stereotypes (i.e., childhood defiance), rather than an ASD diagnosis (Begeer et al., 2009; Mendell & Novak, 2005). Such discrimination indicates potential racial/ethnic

differences in the experiences of those impacted by ASD. Due to the sparse research on this topic, the ways in which ethnic and racial identity influences the experiences of those with ASD and their parental caregivers remain largely unknown.

### **ASD and Parental Caregiving**

Children diagnosed with ASD often need assistance in completing daily living skills such as personal hygiene, food preparation, and handling finances (Bal et al., 2015). While all children need caregiving to some extent, the compromised functional abilities of those with ASD results in a higher degree of care for most families. This higher level of care often impacts the availability of parental caregivers to work outside of the home. For example, mothers are 9% less and fathers are 2.6% less likely to obtain employment when compared to families with no disability diagnosis (McCall & Starr, 2018). For those who are employed, both mothers and fathers of children with ASD tend to work fewer hours than parents of typically developing children (McCall & Starr, 2018).

### **Psychological Impact**

Relative to parents of typically developing children, parents of children with ASD report greater symptoms of depression, anxiety and caregiver stress (Hodge et al., 2011; Lai et al., 2015). Evidence suggests each of these psychological experiences are associated with experiencing internalized stigma in parents of children with ASD (Chan & Lam, 2017; Dehnavi et al., 2011; Mak & Cheung, 2008). While stigma refers to negative evaluation of others based on their physical appearance, perceived character, or cultural identity (Goffman, 1963), internalized stigma occurs when one anticipates stigmatization from others and begins to believe these assumptions about oneself (Livingston & Boyd, 2010). Internalized stigma experienced by those who are commonly associated with individuals with a mental or neurological disorder, such as ASD, is specifically referred to as affiliate stigma (Mak & Cheung, 2008).

## **Therapeutic Considerations**

Clinicians treating the psychosocial impact of stigmatization within a family context may consider utilizing Bowen's Family Systems approach (Kerr & Bowen, 1988) to promote the differentiation of self within parental caregivers. By increasing differentiation of self, parental caregivers will be better prepared to tackle the behavioral concerns common in providing care to a child with ASD (Perez, 2019). Ghoreishi and colleagues (2018) explored the impact of differentiation of self on parental stress in parents raising a child with ASD. In this study, high parental self-differentiation was negatively correlated with parental stress. Therefore, differentiation within relationships may buffer against stress associated with parenting a child with ASD (Ghoreishi et al., 2018). Outside of this study, empirical research exploring differentiation within families affected by ASD appears nonexistent. To fill this gap in the literature, this study investigates the role of differentiation of self in affiliate stigma in parental caregivers of children with ASD. To extend the minimal existing research on the intersections of racial identity and ASD experiences, this study will evaluate whether racial differences exist in terms of reported levels of internalized stigma.

## **CHAPTER 2: SIGNIFICANCE OF THE PROBLEM**

### **ASD and Parental Caregiving**

An ASD diagnosis impacts far more than just the individual who is diagnosed. Research regarding parents of individuals with ASD suggest parental experiences are complex, comprising both responsibilities and rewards associated with parenting (Boshoff et al., 2016). Extensive rehabilitative therapy and medical appointments often place additional financial burdens and time-constraints on families (Jackson, 2019). Children with ASD also depend on their parents to advocate for these services on their behalf, and this advocacy often extends beyond age 18 (Boshoff et al., 2016). Despite these significant challenges, a number of positive aspects related to the development of one's sense of self in relation to others often accompanies a child's ASD diagnosis, such as personal fulfillment from ASD advocacy (Markoulakis et al., 2012) and an increase in resilience (Byrne et al., 2018).

### **Racial/Ethnic Minority Populations**

Racial and ethnic minorities are consistently underrepresented in research studies involving parents of children with ASD. Therefore, recent calls to the fields of family therapy and counseling psychology encourage greater study of the intersectionality between racial/ethnic identity and disability status (Goff Nelson, 2019; Nieweglowski & Sheehan, 2017; Shin et al., 2017). The use of intersectionality as an academic theory is rooted within the feminist and critical race literatures (Crenshaw, 1991; Collins, 2002), with a number of studies exploring the intersecting experiences of gender and race or ethnicity (Settles, 2006; Gabbidon et al., 2011; Davis et al., 2018). Findings from these studies suggest the experiences of Black women are not equivalent to adding the lived experience of being Black to experiences of being a female. Instead, living as a Black woman creates experiences unique from that of either Black men or White women (Guittar & Guittar, 2015). Likewise, the experiences of families with racial and ethnic minority backgrounds cannot be generalized by adding common experiences within families affected by developmental disabilities to typical experiences of racial minorities. To increase rates of participants identifying as a racial minority, Zamora and colleagues (2016)

recommend cultivating a relationship with existing organizations devoted to providing support and education to racial minority families affected by ASD.

Studies exploring the intersection of race and ASD often merge the study of ethnicity and racial identity (Azmi et al., 1997; Magaña et al., 2017; Stahmer et al., 2019). These overlapping constructs have nuanced distinctions. Ethnic identity refers to cultural values and practices, while racial identity is related to the perceptions of collective racial groups (Cokley, 2007). Literature suggests the experiences of parental caregivers of children with ASD is related to both self- and societal perceptions (racial identity) and cultural norms and values (ethnic identity) (Burkett et al., 2015; Durkin et al., 2017; Ferguson & Vigil, 2019; Stahmer et al., 2019).

Mandell & Novak (2005) suggest ethnic differences in cultural beliefs shape the way families give meaning to an ASD diagnosis, which in turn impacts decision making towards seeking services. Some Hispanic families report attributing their child's diagnosis to self-blaming explanations such as poor parenting or punishment from God rather than strictly biological roots (Ferguson & Vigil, 2019). Likewise, some African American families report accusations from others attributing ASD to poor parenting (Stahmer et al., 2019). Therefore, intervention and support programs neglecting to attend to cultural beliefs may not reach this underserved and double marginalized group.

Several studies have examined the effectiveness of cultural adaptations made to programs for families affected by ASD, though these are mainly aimed at reducing the behavioral symptoms of ASD (Buzhardt et al., 2016; Kuhn et al., 2019). One such program titled *Parents Taking Action* was developed in Spanish for Hispanic families. This program used culturally-sensitive considerations including in-home visits of promotoras, or peer health educators, within the community. While this program provided structured psychoeducation to family caregivers, exploration of the cultural meaning of an ASD diagnosis was not apparent. Participation in this program increased parental knowledge in terms of their child's educational rights and overall knowledge of ASD, but participation in this program did not impact caregiver burden, caregiver efficacy, or depressive symptoms (Magaña, et al., 2017).

Existing empirical evidence surrounding the intersection of racial/ethnic identity and ASD primarily explore disparities in diagnosis and treatment of ASD (e.g. Durkin et al., 2017; Mandell & Novak, 2005). As previously mentioned, individuals identifying as a racial or ethnic minority tend to be diagnosed at later ages and at lower rates (Durkin et al., 2017; Mandell et al.,

2002; Palmer et al., 2010). Disparities in access to services also exist. Even controlling for income, families identifying as a racial minority tend to have lower access to ASD services, relative to those who identify as White (Bhasin & Schendel, 2007). While some theorize these disparities are mainly connected to economic and language barriers (Begeer et al., 2009; Shattuck & Grosse, 2007), others believe racial and ethnic disparities in ASD diagnosis are related to implicit biases (Bhasin & Schendel, 2007; Burkett et al., 2015; Mandell & Novak, 2005).

Despite robust research on racial and ethnic disparities in ASD case ascertainment and treatment, specific ways in which one's racial and/or ethnic identity intersects with providing parental care are rarely explored in detail within this population. Mandell and Salzer's (2007) study explored ethnic differences in support group attendance for parents of children with ASD. Greater rates of attendance were reported for White parents, relative to parents identifying as an ethnic minority (Mandell & Salzer, 2007). One explanation for this finding is parents identifying as an ethnic minority may be deterred from participation due to concerns that traditional support groups will not address their specific needs (Mandell & Salzer, 2007). Likewise, researchers suggest anticipated stigma from health care professionals and their community at large as additional deterrents of seeking ASD services within Black communities (Burkett et al., 2015). These studies highlight the role of stigma- in terms of biases of others and the internalized affiliate stigma of parents themselves - in accessing ASD services.

### **Internalized Stigma**

Stigma refers to negative perceptions commonly associated with socially marginalized attributes (Goffman, 1963). Stigma toward the disability community has been documented over time (Grue, 2016; Susman, 1994). Internalized stigma is the acceptance and eventual belief in these negative evaluations toward oneself (Livingston & Boyd, 2010). Within the body of literature exploring social stigma, the term "internalized stigma," is often used interchangeably with related terms including felt stigma and self-stigma (Livingston & Boyd, 2010). Each of these constructs all occur at the micro-level; however, each is nuanced in the theoretical pathway in which they are experienced. Felt stigma, also known as courtesy stigma (Gray, 1993; Mak & Kwok, 2010), is the experience of anticipating the negative evaluation of others (Boyle, 2018).

As exposure to felt stigma from others continues over time, these negative evaluations often become incorporated into one's sense of self, resulting in self-stigma (Livingston & Boyd, 2010; Corrigan et al., 2006).

Self-stigma as it relates to the association with individuals with neurodevelopmental conditions, including ASD, is referred to as affiliate stigma (Mak & Cheung, 2008). While operational definitions exist for the purposes of research, the lines between these theoretical definitions become less distinct in the way stigma is experienced and internalized in the daily lives of parents providing care to their children with ASD (Gray, 2002; Mitter, 2019).

### **Affiliate Stigma**

Affiliate stigma is defined as the “internalization of stigma among associates of targeted [or marginalized] individuals, specifically caregivers of individuals with intellectual disability or mental illness” (Mak & Cheung, 2008, p. 532). Affiliate stigma is comprised of three aspects: (a) cognitive - the way individuals think about their relationship to the individual to which they are providing care, (b) affective - the emotional reactions associated with their relationship to this individual, and (c) behavioral- the specific actions individuals engage in or avoid as it relates to their relationship to this individual. Affiliate stigma has been explored in families in a variety of contexts including mental illness (Farzand & Baysen, 2018; Shi et al., 2018), learning disabilities (Banga & Ghosh, 2017), and developmental disabilities (Mikami et al., 2015; Werner, & Shulman, 2013; Wong et al., 2016). A growing body of research has investigated affiliate stigma specifically within parental caregivers of children with ASD (Liao et al., 2019). Within this literature, affiliate stigma is negatively associated with the psychological wellbeing of parental caregivers (Chan & Lam, 2017; Dehnavi et al., 2011). Affiliate stigma has also been shown to impact parental decision making related to the care of their children with ASD, including hesitation to include them in public outings (Ryan, 2010) and considering placement in long-term residential care (Green, 2004).

Qualitative research examines interactions with the general public as the main context in which family caregivers experience affiliate stigma (Gray, 2002; Ryan, 2010). Parental caregivers have long reported instances of hostile comments and negative nonverbal cues from strangers when individuals with ASD experience behavioral difficulties in public spaces (Gray,

1993; Chiaraluce, 2018). For example, parents report the anticipation of frequent meltdowns during otherwise typical shopping trips, followed by stares from onlookers (Gray, 2002; Neely-Barnes et al., 2011; Ryan, 2010). At times these incidents illicit comments alluding to, or explicitly referring to, poor parenting (Byrne et al., 2018). This felt stigma experienced in public often leads to self-doubt over competency, further facilitating internalized stigma (Eaton et al., 2016).

To a lesser extent, affiliate stigma is reported to occur within the contexts of casual friendships and extended family (Broady et al., 2017; Chiaraluce, 2018). For example, parental caregivers often report feeling rejected when requests for accommodations (i.e., enhanced safety measures; sensory-friendly environment) are ignored by extended family (Broady et al., 2017; Neely-Barnes et al., 2011). Rejection from loved ones within this context may reinforce feelings of inferiority and dejection, facilitating the internalized process of affiliate stigma. Consequently, caregivers report increased social isolation related to their child's ASD diagnosis, in part related to avoiding stigma experienced in public (Byrne et al., 2018). Kinnear and colleagues (2016) quantitatively measured these sentiments, finding 40.4% of family caregivers have avoided spending time with family or friends due to adverse reactions of others in response to behaviors associated with ASD. Researchers hypothesize affiliate stigma may be less apparent in these contexts because family caregivers can limit the extent to which they discuss their family member with ASD and/or avoid interactions with those who illicit feelings of felt stigma. In this way, parental caregivers can engage in a form of impression management by highlighting identities other than caregiving, thereby reducing feelings of affiliate stigma (Gray, 2002; Voysey, 1972).

Previous research has indicated several demographic correlates with affiliate stigma. Women, relative to men, and unemployed, relative to employed, caregivers are more likely to experience affiliate stigma (Farzand & Baysen, 2018). One explanation for these differences is the influence of self-identity on experiencing affiliate stigma (Chiaraluce, 2018). Women are often socialized to form identities grounded in the care they provide for others (Gilligan, 1982). This is especially evident in mothers (Lemkau & Landau, 1986) and is exacerbated when a lifelong disability, such as ASD, is diagnosed in a child (Eaton et al., 2016; Gray, 2002). Therefore, the process of internalizing affiliate stigma tends to be more pronounced for mothers relative to fathers (Farzand & Baysen, 2018; Gray, 2002). Likewise, those who participate in



employment may have an expanded sense of social identity (e.g., caregiver and employee) (Caroll et al., 2019). Caregivers who do not work outside of the home have reported feeling as though they have lost their individual sense of self and have replaced it with a solitary identity: one of a caregiver (Chiaraluce, 2018). Studies evaluating a potential correlation between affiliate stigma and age appear to be mixed, as some results indicate a relationship exists (Mak & Cheung, 2008) while others do not (Werner & Shulman, 2015). Researchers have speculated affiliate stigma may decrease with age, possibly because parents become less sensitive to the remarks of others over time (Gray 1993; Ryan, 2010).

Affiliate stigma is especially pervasive for caregivers of ASD, relative to other diagnoses (Werner & Shulman, 2015). Researchers attribute this difference to the fact that ASD is an “invisible” diagnosis, which is marked primarily by behavioral symptoms rather than physical characteristics (Chiaraluce, 2018; Gray, 2002; Neely-Barnes, 2011). Without an obvious diagnostic explanation for the individual’s behavior, public spectators attribute the problematic behavior to a lack of discipline rather than symptoms of an ASD diagnosis (Broady et al., 2017).

It is unclear whether parental affiliate stigma is directly related to the extent of traits related to ASD in their children, as some studies have indicated a positive relationship between these two variables (Kinnear et al., 2016), while others have not (Dehnavi et al., 2011). The prevalence and extent of affiliate stigma in families affected by high-functioning ASD complicates this relationship (Broady et al., 2017; Gray, 2002). Initial studies using the affiliate stigma scale indicate no correlation to a child’s functional ability, as measured by Mahoney & Barthel’s (1965) Barthel index (Ma & Mak, 2016; Mak & Kwok, 2010). Researchers have found no statistically significant relationship between extent of autistic traits in children diagnosed with ASD and parenting stress (Costa et al., 2017; Factor et al., 2018).

### **Internalized Stigma in Racial/Ethnic Minority Populations**

In addition to internalized stigma as it relates to mental illness and developmental disabilities, researchers have explored its appearance in LGBTQ+ populations, known as internalized homophobia (Malyon, 1982; Sophie, 1987), and racial minorities, known as internalized racism (Speight, 2007; Watts-Jones, 2002). Campbell (2008) proposed theoretical parallels between internalized stigma as it relates to disability and race. Like affiliate stigma,

internalized racism is preceded by ongoing experiences of stigmatization and discriminatory behavior from others (Campbell, 2008; Kinnear et al., 2016; Speight, 2007). Both constructs are also maintained at the systemic level through societal messages associating inferiority with the marginalized identity (Chiaraluce, 2018; Speight, 2007).

Belonging to more than one marginalized group is traditionally thought to compound the psychological impact associated with stigma (Nabors et al., 2001). Results from empirical studies suggest individuals belonging to multiple minority groups experience internalized stigma differently than those with a single marginalized identity (Molina et al., 2014; Szymanski & Gupta, 2009). However, racial disparities in terms of internalized stigma are not straightforward. Molina and colleagues (2014) found reports of internalized homophobia differed by race, though internalized sexism did not. Therefore, internalized stigma in multiple marginalized populations may not be additive, but dependent on the context of the marginalized identity.

Those who identify with multiple marginalized identities are forced to integrate these aspects into a singular self-concept (Nabors et al., 2001). The way in which these integrations are made may vary wildly, depending on the intersections of each identity and the larger societal context (Guittar & Guittar, 2015). Like diagnostic and treatment disparities, literature suggests internalized stigma related to the intersection of ASD and racial/ethnic identity is rooted in both cultural beliefs and differences in lived experiences. For example, evidence suggests cultural beliefs related to disability within Korean communities contribute to especially salient internalized stigma in ASD families. This is thought to be due to the cultural belief that disabilities, including ASD, are attributed to neglect by the mother during the prenatal stage (Kang-Yi et al., 2013). Stahmer et al. (2019), compared racial and ethnic differences in experiences of caring for family members with ASD using a semi-structured interview. In this study, caregivers identifying as Hispanic or Black reported accusations from others attributing ASD to poor parenting, while caregivers identifying as White did not (Stahmer et al., 2019). These findings suggest experiences tied to racial and/or ethnic identity may influence affiliate stigma in families affected by ASD.

Little is known about how identification with other marginalized minority groups impacts experiences of internalized stigma for individuals within the disability community, much less about that of affiliate stigma specifically. In their meta-analysis of studies investigating internalized stigma, Livingston & Boyd (2010) suggest the incorporation of an intersectional

approach in future research to fill this gap within the literature. The purpose of this study is to explore the relationship between affiliate stigma and differentiation in a sample of parental caregivers of children with ASD. Further, this study will explore whether identifying as a racial/ethnic minority impacts reported levels of affiliate stigma.

## **Theoretical Framework**

### **Neurodiversity**

A growing trend within the field of developmental disability research is a lens of neurodiversity. This framework avoids pathologizing diagnoses and instead presumes individuals diagnosed with neurological conditions have different, but not lesser, capabilities (Armstrong, 2010). For example, an individual with ASD may be atypical compared to peers in terms of social interactions and hypersensitivity to sensory stimulation. Neurodiversity theory acknowledges these tendencies while simultaneously recognizing strengths such as greater orientation to details and systematic classification (Baron-Cohen et al., 2009).

Neurodiversity theory stands in contrast to a medical model of examining developmental disabilities. Research grounded in the medical model has explored the impact of sleep patterns on maladaptive social behavior in those diagnosed with a developmental disability (Cohen et al., 2018; Pallathra et al., 2018). Rather than emphasizing deficits in functional ability, neurodiversity places greater concern on the contextual factors inherent in neurodivergent experiences within a neurotypical world (Robertson, 2009). For example, researchers using this theoretical framework have explored the subjectively positive experiences of families raising children with ASD (Bayat, 2007; Chiaraluce, 2018; Leedham, Thompson, & Freeth, 2020).

Collecting data related to the severity of ASD traits in a neutral, non-stigmatizing way poses a challenge in quantitative studies. Instruments measuring ASD symptomology often ask questions centering on deficits. For example, the Autism Behavior Checklist (Krug et al., 1980) uses items such as *Gets involved in complicated “rituals” such as lining things up, ect. and is very destructive; toys and household items are soon broken.* While the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000) and Childhood Autism Rating Scale (CARS) (Schopler et al., 1980) are commonly used in modern social science research, they require a

diagnostic interview completed by a qualified clinician, and therefore considered outside of the scope of this study. One measure used in studies centered around neurodiversity is Baron-Cohen and colleagues' (2001) autism-spectrum quotient (Kapp et al., 2013). The autism-spectrum quotient uses non-pathologizing wording, with a focus on typical actions and interactions rather than functional deficits, thus making it more palatable for respondents.

### **Bowen's Family System Theory**

A primary assumption of Bowen's family system theory is the use of differentiation of self as an indicator of healthy psychological functioning (Kerr & Bowen, 1988). Differentiation is achieved by maintaining a distinct sense of self without sacrificing connection within relationships, but undifferentiation is characterized by unclear emotional boundaries in relationships (Brown, 1999). Differentiation of self consists of four components: emotional reactivity, I-position, fusion with others, and emotional cutoff (Kerr & Bowen, 1988). Bowen hypothesized differentiation of self acts as a buffer against psychological distress (Kerr & Bowen, 1988). Results from a number of studies support this hypothesis (Elieson & Rubin, 2001; Murdock & Gore, 2004; Peleg-Popko, 2002; Skowron & Friedlander, 1998). For example, high levels of differentiation of self are related to lower perceived stress (Murdock & Gore, 2004). High levels of differentiation of self have also been found to buffer against depression (Elieson & Rubin, 2001) and anxiety (Skowron & Friedlander, 1998).

Bowen theorized levels of differentiation of self influence interactions with others, including how one perceives those interactions (Kerr & Bowen, 1988). Peleg-Popko (2002) investigated the role of differentiation of self in social anxiety using a sample of college students. Results from this study indicate a negative correlation between each of the four components of differentiation of self (i.e., emotional reactivity, I-position, fusion with others, and emotional cutoff) and social anxiety. Differentiation of self is particularly associated with fear of negative evaluation from others (Peleg-Popko, 2002). As noted earlier, a precursor to internalized stigma is the anticipation of negative evaluation from others because of one's physical appearance or association (Livingston & Boyd, 2010). Differentiation of self has also found to be negatively associated with engaging in external experiential avoidance (Ross et al., 2016). Therefore, low levels of differentiation of self may facilitate apprehension to include family members with ASD

in public outings, as previously discussed (Byrne et al., 2018; Kinnear et al., 2016). Taken together, these results support Bowen's theoretical assumption of low differentiation contributing to high dependence on others for approval (Kerr & Bowen, 1988).

Bowen contends measures of differentiation of self transcends racial differences (Kerr & Bowen, 1988). Studies have found moderate support for this assumption (Gushue, et al., 2013; Skowron, 2004). For example, higher differentiation of self is correlated with progressing toward racial identity development. This finding was consistent regardless of racial identity (i.e., White or racial minority) (Gushue et al., 2013). In a separate study, differentiation of self scores of a solely Filipino sample were statistically comparable to a fairly homogeneous U.S. sample (Tuason & Friedlander, 2000). Some researchers have questioned whether Bowen's concept of differentiation of self adequately takes into account the beliefs and experiences of racial and ethnic minorities (Erdem & Safi, 2018; Gushue et al., 2013). For example, the concept of fusion may have significant overlap with non-pathological collectivistic values (Gushue et al., 2013). Evidence suggests psychometric validity of the differentiation of self-revised version (DSI-R), particularly for the fusion with others subscale, is poor when administered to Asian-American bicultural adults (Lee & Johnson, 2017). Despite these criticisms, the original DSI instrument has shown adequate internal consistency and construct validity in samples composed of individuals identifying as a racial/ethnic minority (Gushue et al., 2013; Skowron, 2004).

Use of Bowen's natural family systems approach with families affected by ASD uniquely provides a lens for parents to examine how their own emotional reactions impact their family as a whole (Perez, 2019). As reviewed above, several qualitative studies have explored concepts related to differentiation of self, such as emotional reactivity to the comments of others (Broady et al., 2017; Chiaraluce, 2018; Ryan, 2010) and emotional cutoff from extended family (Broady et al., 2017; Byrne et al., 2018; Green, 2004). Few empirical research studies have specifically explored differentiation of self in caregivers of developmental disabilities. Negash et al. (2015) examined potential relationships between differentiation of self and intimate relationship satisfaction in couples raising at least one child with special needs. Results of this study include an inverse relationship between emotional reactivity and overall relationship satisfaction. Researchers theorized mutual emotional strain related to caregiving may exacerbate the influence of emotional reactivity within the couple's relationship. Contrary to studies exploring general

populations (Schnarch & Regas, 2012), no subscales of differentiation of self were correlated with sexual satisfaction within this study (Negash et al., 2015).

Studies have not yet explored whether the age and functional ability of children with ASD is associated with a caregiver's differentiation of self. Despite this gap in the literature, it is feasible to predict providing care children, relative to adults, with ASD may contribute to lower sense of differentiation of self. Similarly, providing care to individuals with greater difficulties in daily living skills (i.e., feeding, personal care) may negatively impact one's levels of differentiation of self. Aside from studies exploring differentiation of self in the context of romantic relationships (Ghoreishi et al., 2018; Negash et al., 2015), research related to differentiation of self in family caregivers for individuals with ASD is sparse.

## **Research Questions and Hypotheses**

### **Research Question 1**

Is there a relationship between differentiation of self and affiliate stigma in parental caregivers of children diagnosed with ASD?

### **Hypothesis 1**

Differentiation of self will have a negative association with affiliate stigma in parental caregivers of children diagnosed with ASD.

### **Research Question 2**

Is racial/ethnic minority status associated with the amount of affiliate stigma in parental caregivers of children diagnosed with ASD?

### **Hypothesis 2**

Parental caregivers of children diagnosed with ASD who identify as a racial/ethnic minority will experience greater affiliate stigma relative to parental caregivers who identify as White.

## **CHAPTER 3: METHODOLOGY**

### **Participants and Procedure**

Studies exploring the psychosocial impact of ASD on parents often utilize convenience samples (Broady et al., 2017; Chiaraluce, 2018; Eaton et al., 2016). Use of social media or virtual support groups are widely used avenues of data collection (Chiaraluce et al., 2018; Cox et al., 2015; Negash et al., 2015; Ryan, 2010). Given the nature of social media support groups and informational pages, some difficulty exists in obtaining complete responses in a timely manner (Dworkin et al., 2016; Negash et al., 2015). Therefore, use of data collection services such as Amazon Mechanical Turk (MTurk) are increasingly being combined with social media outreach for participation recruitment (Clauser et al., 2020; Cox et al., 2015; Yu et al., 2018). MTurk is an online data collection service which provides subjects with financial compensation in return for research participation (Buhrmester et al., 2016). Data collected using MTurk is reliable and tends to provide more a diverse sample than using either social media or List serves alone (Dworkin et al., 2016).

Participants for this study were recruited using both social media (i.e., Reddit, Facebook) and MTurk. Social media responses (n=54) were completed between December 14, 2020 and February 17, 2021. MTurk responses (n=94) were completed between February 16, 2021 and February 19, 2021. Studies involving parental caregivers tend to include a disproportionately high number of participants reporting the following demographics: female, married, White, and upper socioeconomic status (Goff Nelson, 2019). To prepare for this potential sampling bias, oversampling was achieved by recruiting using social media groups targeting racial minority audiences (i.e., Autistic BIPOC; Black Autism Moms).

Participants wishing to complete this survey were required to meet the following inclusion criteria: age of 18 or older; parent of a child between ages 6-22 who has been formally diagnosed with ASD; and provide at least 2 hours of care weekly for this child. To obtain a medium effect size with an alpha of .05, a minimum of 97 participants are recommended in order to complete data analysis, with at least 64 participants identifying as a racial/ethnic minority (Cohen, 1992). It was therefore hoped that 150 eligible participants would complete this study, with approximately half identifying as a racial/ethnic minority. To achieve enough participants to

reach statistical power, researchers anticipated at least 300 subjects would initiate participation in this survey. Informed consent and survey data was collected from participants anonymously using Qualtrics. Participants recruited via social media were compensated with a chance to win 1 of 6 \$50 Amazon cards. Contact information collected for this purpose was kept confidential by using a separate link external to the study survey itself. All study procedures were approved by Purdue University's Institutional Review Board.

## **Instrumentation**

### **Demographic Information**

Demographic information collected for this study included participant age, current age of child, child's age at diagnosis, relationship status, and gender identity of participant and child. Following recommendations for comprehensive and inclusive data collection, data related to racial and ethnic identity was collected with one question, allowing identification with as many or as few racial and/or ethnic identities as the participant deemed appropriate (Fernandez et al., 2016). Questions inquiring about the nature of the relationship to an individual with ASD (e.g., biological child, step-child, adopted child), aspects of care provided (e.g., meal preparation, transportation), and the average time spent providing care weekly were also included.

### **Affiliate Stigma**

Affiliate stigma was measured using the *Affiliate Stigma Scale* (Mak & Cheung, 2008). Each of the instrument's 22 questions is measured on a 4-point Likert scale: Participants may select from the following responses: (1) *strongly disagree*, (2) *agree*, (3) *disagree*, or (4) *strongly disagree*. Diagnostic terms such as "mental illness" and "intellectual disability" used within the original published survey was replaced with the term "autism spectrum disorder" to promote coherence throughout survey for subjects. Three domains of affiliate stigma are measured using this scale: cognitive, affective, and behavioral. For the purpose of this study, the scale's total score will be used. Sample statements from this measure include "My reputation is damaged because I have a child with autism at home" and "I am under great pressure as I have a child with autism." Previous studies indicate a high internal consistency within a sample of caregivers of



persons with intellectual disabilities, (Cronbach's  $\alpha = 0.95$ ) (Mak & Cheung, 2008). Prior studies show similar internal consistency of this measure in Persian, Ghanaian, Chinese, and Latinx samples (Bonsu et al., 2020; Mak et al., 2018; Mercado et al., 2020; Saffari et al., 2019). Item-total correlations between items on this measure ranged between .38 and .75, which is considered acceptable (Mak & Cheung, 2008). Follow-up psychometric analyses also suggest adequate concurrent validity due to moderate correlation between the affiliate stigma scale and both the Rosenberg Self-Esteem Scale ( $r^2 = .52$ ) and the Beck Anxiety Inventory ( $r^2 = .32$ ) (Chang et al., 2015).

### **Differentiation of Self**

Participants completed the *Differentiation of Self Inventory* (Skowron & Friedlander, 1998) to measure differentiation between themselves and others. This scale is comprised of 4 subscales: emotional reactivity, I-position, emotional cutoff, and fusion of others. Each of the instrument's 43 statements is measured on a 6-point Likert scale from (1) *not at all true of me* to (6) *very true of me*. Higher scores represent a greater degree of differentiation of self (i.e., less emotional reactivity/less fusion with others). Sample statements include "If someone is upset with me, I can't seem to let it go easily," and "Whenever there is a problem in my relationship, I'm anxious to get it settled right away." Initial validation for the full Differentiation of Self Inventory yielded acceptable results (Cronbach's  $\alpha = .88$ ). In Gushue et al.'s (2013) study, internal consistency was similar between White and racial/ethnic minority samples (Cronbach's  $\alpha = .81, .83$ , respectively).

### **ASD Characteristics**

Participants completed the 50-item *Autism-Spectrum Quotient* (AQ; Baron-Cohen et al., 2006; Auyeung et al., 2008) to measure their child's extent of ASD characteristics. The AQ is adequate for use in research, rather than a clinical diagnostic tool, and is tailored specifically for parental report (Baron-Cohen, 2006). This measure is commonly used to control for extent of autistic traits in children (Costa et al., 2017; Dehnavi et al., 2011; MacMullin et al., 2010; Weiss et al., 2015). The AQ is comprised of 5 subscales (social skills; attention switching; attention to detail; communication; imagination). Only the total sum was used for the purpose of this study.

Three versions of this measure exist: for adults aged 16 and older (Baron-Cohen et al., 2001); for adolescents ages 9 – 16 (Baron-Cohen et al., 2006); and children age 4 – 11 (Auyeung et al., 2008). Items do not differ significantly between each of these versions; however, differences in scoring and clinically significant cut-off for each version exist (Auyeung et al., 2008). This study used scoring methods from the children’s version. The children’s version scores items using a Likert scale, where *Definitely Agree* = 1 and *Definitely Disagree* = 4. Scores are totaled for maximum score of 150. Sample statements from this measure include “S/he finds it hard to make new friends” and “S/he notices patterns in things all the time.” In this study the term “S/he” was replaced with “my child” for all items to avoid perpetuating the construct of a gender binary. Internal consistency is considered good for this measure (Cronbach’s  $\alpha = .97$ ). Initial validation of the AQ used a sample of children residing in the United Kingdom and yielded a fairly high internal consistency (Cronbach’s  $\alpha = .97$ ; Auyeung et al., 2008). Results from follow-up, cross-cultural studies suggest lower internal consistency in Indian, Malaysian, Italian, and Chinese populations (Cronbach’s  $\alpha = .66, .58, .76$ , and  $.63$ , respectively; Freeth et al., 2013; Ruta et al., 2012; Ward et al., 2021).

## **Racial Identity**

Following the direction purposed by Fernandez and colleagues (2016), participants self-selected racial/ethnic identities from the following terms: American Indian or Alaska Native; Asian; Black or African American; Native Hawaiian or Other Pacific Islander; Middle Eastern or North African; Hispanic, Latino, or Spanish origin; White. Participants were permitted to select multiple responses.

In addition to self-selecting racial/ethnic identity, participants completed the *Multigroup Ethnic Identity Measure- Revised* (MEIM-R; Phinney & Ong, 2007). This 6-item instrument quantifies strength of ethnic identity membership using two subscales: exploration and commitment. Each statement is rated along a 5-point Likert scale from (1) *Strongly Disagree* to (5) *Strongly Agree*. A sample statement from the exploration subscale is “I have a strong sense of belonging to my own ethnic group.” A sample statement from the commitment subscale is “I have spent time trying to find out more about my ethnic group, such as its history, traditions and customs.” Internal consistency is considered good for this measure (Cronbach’s  $\alpha = .81$ ).

Researchers evaluating the MEIM-R by racial/ethnic differences found higher consistency for the commitment subscale in a sample of Ethnic minority participants relative to a non-Hispanic White sample (Cronbach's  $\alpha = .94, .82$ , respectively). However, consistency was higher for non-Hispanic White participants, relative to Ethnic minority participants in terms of exploration (Cronbach's  $\alpha = .71, .52$ , respectively; Mills & Murray, 2017).

### **Data Analysis**

Select items on the Differentiation of Self Inventory and AQ were reverse coded according to scoring instructions (Skowron & Friedlander, 1998; Auyeung et al., 2008). Items on the AQ were transformed from scores ranging from 1-4 to scores of 0-3, per the instructions of the AQ-child (Auyeung et al., 2008). Racial/ethnic identity, gender identity, and employment status were recoded as dichotomous dummy variables. Participants indicating full-time or part-time employment or academic involvement were recoded as employed and those indicating furlough, seeking employment, or not seeking employment were recoded as unemployed. Participants were permitted to select multiple options for racial/ethnic and gender identity. Participant's racial/ethnic identity was recoded as White or racial/ethnic minority. Participants identifying two or more racial identities were coded as multiracial, and were categorized as a racial/ethnic minority for the purpose of this study. Gender identity was recoded as female and male, with participants selecting trans-male or trans-female coded as male and female, respectively.

To answer the first and second research questions, a hierarchical multiple regression analysis was performed using differentiation of self and ethnic/racial identity as independent variables. Age, gender, employment status and extent of child's ASD characteristics (measured by AQ) served as control variables. Affiliate stigma was the dependent variable. In block one, control variables (age, gender, employment status, AQ) were entered. In block two, differentiation and racial/ethnic identity were entered. These variables were regressed on the dependent variable, affiliate stigma. T-scores, F-scores, r-square values, and p-values derived from this analysis are used to answer both research questions.

## **CHAPTER 4: RESULTS**

### **Data Screening**

All data screening and analysis were completed using IBM's Statistical Package for the Social Sciences (SPSS). A total of 381 participants initiated this survey, 106 via social media and 275 via Mturk. Prior to data analysis, data was screened to identify missing data, ineligible participants, outliers, and unmet assumptions. One-hundred eighty-one responses (42 from social media; 139 from MTurk) were removed from analysis due to early drop-out (i.e., discontinuing survey prior to autism quotient instrumentation), likely related to survey fatigue. Four additional participants were removed from analysis due to excessive missing data from one or more instruments. Of the remaining 196 participants, 34 participants were excluded from final analysis due to not meeting eligibility requirements (i.e., child was under the age of 6 and/or non-parental relationship to a relative with ASD). One participant was dropped from analysis due to exclusively selecting nonbinary gender identity. Responses completed in 5 minutes or less (n=19) were visually inspected for anomalies in responses. Of these, 10 were excluded from analysis due to suspected respondent bias. After inspecting for influence and leverage, 2 additional cases were removed as outliers. While no variables had significant kurtosis, two had skewed data, AQ and differentiation of self. There were no other apparent reasons to discard data, therefore data was retained. This resulted in a total of 147 participants (54 from social media and 94 from MTurk) used for this study's final analyses.

### **Demographics**

In terms of racial/ethnic identity, 63.3% of the final sample selected White as their only identity and 36.7% selected at least one racial/ethnic minority in which they identified. As reported in table 1, 95.3% of participants selected a single racial identity, as follows: American Indian or Alaska Native 0.7%, Asian 7.5%, Black or African American 13.6%, Native Hawaiian or Other Pacific Islander 0.7%, Middle Eastern or North African 1.4%, Hispanic, Latino, or Spanish Origin 8.1%, White 63.3%. Participants identifying with 2 or more racial identities totaled 4.7% of this sample.

Table 1. Racial/Ethnic Identity

Racial Identity (n=147)	Frequency	Percentage
American Indian or Alaska Native	1	0.7%
Asian	11	7.5%
Black or African American	20	13.6%
Native Hawaiian or Other Pacific Islander	1	0.7%
Middle Eastern or North African	2	1.4%
Hispanic, Latino, or Spanish origin	12	8.1%
White	93	63.3%
Multiracial	7	4.7%

Participant's age ranged from 20 - 57, with a mean age of 36.02 ( $SD = 8.11$ ). Participants identifying as a racial/ethnic minority tended to be slightly younger in this sample ( $M = 33.80$ ;  $SD = 7.46$ ), relative to White participants ( $M = 37.31$ ;  $SD = 8.22$ ). The final sample for this study was evenly distributed in terms of participant's gender identity (49.7% male; 50.3% female). The racial/ethnic minority subsample had a greater proportion of female participants (59.3%), while the White subsample had a greater proportion of male participants (54.8%). Employed participants (i.e., full- or part-time employee or student) comprised 85.7% of this sample. The majority of both the racial/ethnic minority and White subsamples selected full-time employment as their employment status (59.3%, 73.1%, respectively). The majority of participants selected married as their relationship status (75.5%). This is true for both racial minority (70.4%) and White (78.8%) participants. A small number of participants indicated they were separated or divorced within this sample (10.2%). Table 3 illustrates descriptive statistics for specific relationships and employment statuses.

Participants reported a mean age of 10.25 ( $SD = 3.95$ ) for their child with ASD. Average age of child's diagnosis was 5.96 ( $SD = 3.46$ ). Current age of child was comparable between both subsamples. Contrary to larger studies, the mean age of diagnosis for White participants ( $M = 6.20$ ) was slightly higher than that of participants identifying as a racial/ethnic minority ( $M = 5.56$ ). In the total sample, 68.7% of participants reported male gender identity for their child. A

slightly larger proportion of participants identifying as White indicated male gender identity for their child (72%), relative to participants identifying as a racial/ethnic minority (63%).

Table 2. Age

Demographic	Racial/Ethnic Minority			White			Total Sample		
	Min	Max	M (SD)	Min	Max	M (SD)	Min	Max	M (SD)
Participant's Age (n=147)	21	57	33.80 (7.464)	20	57	37.31 (8.222)	20	57	36.02 (8.107)
Child's Age – Current (n=144)	6	22	10.47 (3.993)	6	22	10.12 (3.932)	6	22	10.25 (3.945)
Child's Age – At Dx (n=146)	1	15	5.56 (3.295)	2	17	6.20 (3.545)	1	17	5.96 (3.457)

Table 3. Participant Demographics

Measure	Category	Racial/Ethnic Minority		White		Total Sample	
		Freq.	%	Freq.	%	Freq.	%
Gender Identity - Participant (n=147)	Male	22	40.7%	50	53.8%	72	49.0%
	Female	32	59.3%	43	46.2%	75	51%
Gender Identity – Child (n=147)	Male	34	63.0%	67	72.0%	101	68.7%
	Female	20	37.0%	26	30.0%	46	31.3%
Employment Status (n=147)	Unemployed, not actively looking for work	2	3.7%	8	8.6%	10	6.8%
	Unemployed, actively seeking work	7	13%	4	4.3%	4	2.7%
	Temporarily unemployed/furloughed/laid off	1	1.9%	0	0%	7	4.8%
	Student, part-time	8	14.8%	0	0%	1	0.7%
	Student, full-time	1	1.9%	1	1.1%	2	1.4%
	Employed, part-time	8	14.8%	5	5.4%	13	8.8%
	Employed, full-time	32	59.3%	68	73.1%	100	68.0%
	Self-employed	3	5.6%	7	7.5%	10	6.8%
Relationship Status (n=147)	Married	38	70.4%	73	78.8%	111	75.5 %
	Living together or domestic partnership	6	11.1%	5	5.4%	11	7.5%
	Separated	1	1.9%	3	3.2%	4	2.7%
	Divorced	5	9.3%	6	6.5%	11	7.5 %
	Widowed	0	0%	1	1.1%	1	0.7%
	Never married	4	7.4%	5	5.4%	9	6.1%

## Instrumentation

Three instruments were used in the final analysis of this study: *Affiliate Stigma Scale* (Mak & Cheung, 2008), *Differentiation of Self* (Skowron & Friedlander, 1998), and the *Autism Quotient* (AQ; Auyeung et al., 2008). The *Multigroup Ethnic Identity Measure- Revised* (MEIM-R; Phinney & Ong, 2007) and each of its subscales (exploration and commitment) were used in correlational analysis. This measure is comprised of two subscales: exploration and commitment. Table 4 details the number of items, theoretical and observed range, descriptive statistics, and reported and observed Cronbach's  $\alpha$  of each scale.



Table 4. Instruments and Descriptive Statistics

Scale	Racial /Ethnic Identity	# of items	Possible Range	Observed Range	N	M (SD)	Cron. $\alpha$	Cron. $\alpha$ (in this study)
Affiliate Stigma Scale	Minority	22	1-4	1.05-3.95	54	2.66 (.718)	.94	.96
	White	22	1-4	1-4	93	2.79 (.737)	.93	.96
	Total Sample	22	1-4	1-4	147	2.70 (.730)	.95	.96
Differentiation of Self	Minority	43	1-6	1.58-4.53	54	2.86 (.712)	.83	.88
	White	43	1-6	1.44-4.81	93	2.92 (.748)	.81	.83
	Total sample	43	1-6	1.44-4.81	147	2.90 (.733)	.88	.89
Autism Quotient	Minority	50	1-6	52-134	54	78.59 (14.408)	.58-.66	.83
	White	50	1-6	61-126	93	84.48 (16.780)	.79	.87
	Total Sample	50	0-150	52-134	147	82.32 (16.153)	.97	.87
Total MEIM-R	Minority	6	1-5	2.17-5	54	3.66 (.782)	.91	.83
	White	6	1-5	1.5-4.83	93	3.43 (.779)	.82	.83
	Total Sample	6	1-5	1.5-5	147	3.51 (.785)	.81	.83
MEIM-R: Commitment	Minority	3	1-5	1.67-5	54	3.71 (.942)	.91	.86
	White	3	1-5	1.33-5	93	3.53 (.839)	.82	.79
	Total Sample	3	1-5	1.33-5	147	3.60 (.879)	.78	.82
MEIM-R: Exploration	Minority	3	1-5	1-5	54	3.61 (.854)	.52	.69
	White	3	1-5	1-5	93	3.33 (.945)	.71	.80
	Total Sample	3	1-5	1-5	147	3.43 (.919)	.76	.77

## Correlations

Relationships between continuous variables of interest were investigated via Pearson correlation analysis. Within the total sample, affiliate stigma and differentiation of self had a moderate, positive correlation ( $r = .543, p < .01$ ), AQ ( $r = .295, p < .01$ ). Weak, yet statistically significant, positive correlations between affiliate stigma and both participant's age ( $r = .229, p < .01$ ), and total MEIM-R ( $r = -.254, p < .01$ ) were found. A weak, negative correlation between the exploration subscale of the MEIM-R and affiliate stigma was found in the total sample ( $r = -.311, p < .01$ ), though a significant correlation between the commitment subscale and affiliate stigma did not emerge. Both the exploration and commitment subscales of the MEIM-R were negatively associated with differentiation of self in the total sample ( $r = -.437, p < .01$ ;  $r = -.285, p < .01$ , respectively). Weak, positive correlations between differentiation of self and both AQ ( $r = .357, p < .01$ ) and participant age ( $r = .213, p < .01$ ) were found at a statistically significant level. A weak, positive correlation was found between AQ and participant age at a statistically significant level ( $r = .270, p < .05$ ). All significant correlations were replicated within the White subsample. Within the racial/ethnic minority subsample, correlations only reached significance between differentiation of self and the following variables: affiliate stigma ( $r = .496, p < .01$ ), AQ ( $r = .375, p < .01$ ), and MEIM-R exploration ( $r = -.302, p < .05$ ). See table 5 below for a visual representation of all correlations.

Table 5. Correlations

Scale	Racial/Ethnic Identity	1	2	3	4	5	6	7
1. Affiliate Stigma Scale	Minority	-	.496**	.118	.120	-.045	.235	.103
	White	-	.567**	.366**	-.451**	-.434**	-.349**	.275**
	Total Sample	-	.543**	.295**	-.254**	-.311**	-.131	.229**
2. Differentiation of Self	Minority	-	-	.375**	-.247	-.302*	-.139	.149
	White	-	-	.349**	-.507**	-.503**	-.373**	.241*
	Total Sample	-	-	.357**	-.415**	-.437**	-.285**	.213**
3. Autism Quotient	Minority	-	-	-	-.244	-.197	-.228	.223
	White	-	-	-	-.310**	-.309**	-.231*	.251*
	Total Sample	-	-	-	-.305**	-.293**	-.240**	.270**
4. Total MEIM-R	Minority	-	-	-	-	.858**	.884**	-.601
	White	-	-	-	-	.886**	.857**	-.289**
	Total Sample	-	-	-	-	.878**	.867**	-.233**
5. MEIM-R Exploration	Minority	-	-	-	-	-	.518**	-.082
	White	-	-	-	-	-	.521**	-.242*
	Total Sample	-	-	-	-	-	.523**	-.215**
6. MEIM-R Commitment	Minority	-	-	-	-	-	-	-.027
	White	-	-	-	-	-	-	-.268**
	Total Sample	-	-	-	-	-	-	-.193*
7. Participant Age	Minority	-	-	-	-	-	-	-
	White	-	-	-	-	-	-	-
	Total Sample	-	-	-	-	-	-	-

\*\*Denotes significance at  $p < .01$  (2 tailed)\*Denotes significance at  $p < .05$  (2 tailed)

## Analysis of Research Questions

A hierarchical multiple regression was used to answer both research questions in this study. Control variables in block one included participant's age, gender, employment status, and composite AQ score. Independent variables in block two included differentiation of self and racial/ethnic identity. These variables were regressed on the dependent variable, affiliate stigma.

The first step of the regression model was significant,  $F(4, 142) = 5.618, p < .001, R^2 = .137$ , and adjusted  $R^2 = .112$ . Therefore, the following control variables account for 11.2% of affiliate stigma: age, employment status, and extent of child's characteristics of ASD.

The second step of the regression model was significant,  $F(1, 141) = 4.522, p = .001, R^2 = .138$ , and adjusted  $R^2 = .108$ . This suggests the following control variables account for 10.8% of variance in affiliate stigma: age, employment status, and extent of child's characteristics of ASD, racial/ethnic minority status. Given a decrease in adjusted  $R^2$  values from step 1 to step 2 ( $-.004$ ), not only does racial/ethnic minority identity status not significantly predict affiliate stigma, but its addition to this regression yields a slightly smaller prediction of affiliate stigma, compared to using only age, employment status and extent of ASD characteristics.

The final step of the regression model was significant,  $F(1, 140) = 12.166, p < .001, R^2 = .343$ , and adjusted  $R^2 = .315$ . This suggests differentiation of self, along with all control variables accounts for 31.5% of affiliate stigma. When age, employment status, extent of child's ASD characteristics and racial/ethnic minority status are held constant, differentiation of self uniquely accounts for 20.7% of variance in affiliate stigma.

Table 6. Regression on Affiliate Stigma

Predictors	B	Std Error	Beta	T
Step 1				
(Constant)	1.606	.445		3.605***
Age	.014	.007	.150	1.812
Gender Identity	-.222	.122	-.153	-1.816
Employment	-.056	.183	-.027	-.304
Autism Quotient	.010	.004	.217	2.593*
Step 2				
(Constant)	1.696	.481		3.526**
Age	.013	.008	.142	1.672
Gender	-.231	.124	-.159	-1.863
Employment	-.065	.185	-.031	-.353
Autism Quotient	.009	.004	.210	2.459*
Racial/Ethnic Identity	-.063	0.124	-.042	-.505
Step 3				
(Constant)	1.149	.430		2.673**
Age	.007	.007	.073	.972
Gender Identity	-.213	.109	-.146	-1.962
Employment	-.099	.162	-.048	-.613
Autism Quotient	.002	.004	.047	.593
Racial/Ethnic Identity	-.101	.109	-.067	-.922
Differentiation of Self	.487	.074	.489	6.600***

\*  $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

### Hypothesis One

Hypothesis one stated differentiation of self negatively impacts affiliate stigma in parental caregivers of children diagnosed with ASD. While differentiation of self was associated with affiliate stigma at a statistically significant level ( $t=6.6$ ,  $p < .001$ ), this relationship was positive rather than negative. This suggests greater differentiation of self contributes to greater affiliate stigma for parental caregivers. Therefore, the hypothesis is not supported.

## **Hypothesis Two**

Hypothesis two stated identity as a racial/ethnic minority is a contributing factor to experiencing affiliate stigma. This hypothesis was not supported by the data in this study ( $t=-.505$ ,  $p=.614$ ). This suggests status as a racial/ethnic minority does not predict affiliate stigma at a statistically significant level.

## **Conclusion**

This study used a hierarchical regression analysis to examine the impact of racial/ethnic identity and differentiation of self on affiliate stigma, controlling for age, employment status, and AQ. Neither hypothesis one nor hypothesis two were supported by the results of this study. While the direction of hypothesis one was not supported, the overall regression model was statistically significant at each step. Results from step two indicate identity as a racial/ethnic minority is not a statistically significant factor in experiencing affiliate stigma. Results from the final step in this model indicate a statistically significant, positive relationship between differentiation of self and affiliate stigma. This suggests participants with a greater sense of differentiation of self tend to experience greater affiliate stigma as it relates to caring for their child with ASD. These findings provide empirical support for a relationship between a parental caregiver's view of their relationships with others and their perception of experiencing stigma.

## **CHAPTER 5: DISCUSSION**

Affiliate stigma is a relatively new concept within research exploring psychosocial implications of disability. While much qualitative research exists on this topic (Broady et al., 2017; Byrne et al., 2018; Chiaraluce, 2018; Green, 2004; Ryan, 2010) little empirical research has explored what factors contribute to experiencing affiliate stigma. This study adds to this body of literature by examining the impact of racial/ethnic identity and differentiation of self on affiliate stigma in parental caregivers of children diagnosed with ASD.

The overall model used in this study was significant. Though negative relationships were hypothesized, positive relationships between affiliate stigma and both participant age and differentiation of self were found. Employment and female gender identity were also thought to predict higher levels of affiliate stigma; however, these variables did not reach statistical significance within the model used in this study. Contrary to hypothesis two, there was no significant relationship between status as a racial/ethnic minority and affiliate stigma. While no hypothesis was made on the relationship between differentiation of self and AQ, a significant correlation appears to exist (correlation coefficient: .357).

### **Hypothesis One**

Hypothesis one was not supported by the results of this study. While differentiation of self did predict experiences of affiliate stigma for parental caregivers, this relationship was positive rather than negative. Much research suggests high levels of differentiation of self acts as a buffer against negative psychosocial implications including stress (Murdock & Gore, 2004), depression (Eileson & Rubin, 2001), and anxiety (Skowron & Friedlander, 1998). It could be affiliate stigma is different from these psychosocial experiences, and related to self-concept rather than a transient state.

By definition, parents with low differentiation of self fuse their own identity with the identity of others (Kerr & Bowen, 1988). Qualitative studies often cite changes in self-concept for parental caregivers in reaction to learning about their child's diagnosis of ASD (Bayat, 2007; Chiaraluce, 2018; Eaton et al., 2016). These changes could include any or all of the following: failure to meet the standard of a good parent (Eaton et al., 2016), primary role as an advocate

(Byrne et al., 2018), or embodying compassion towards others (Neely-Barnes et al., 2011). Such changes in identity as it relates to their child's ASD diagnosis may be in response to emotional reactivity and overidentification with their child, and thus low differentiation of self. Studies suggesting parental advocacy serves as a coping mechanism against psychological distress provide support this argument (Boshoff et al., 2016; Broady et al., 2017). Further, Altier & von Kluge (2009) suggest such advocacy work may be grounded in a drive for acceptance from others within the autism community. Undifferentiated parents may be aware of societal prejudices toward their child, but consider looks or stares in public to be directed toward their child or the fused parent-child unit, rather than internalize this as stigma themselves.

Conversely, parental caregivers with high differentiation of self may resist changes to their identity as it relates to an ASD diagnosis. Rather than thinking of themselves as an "autism parent," they may consider their child's diagnosis to be a medical fact unrelated to their own self-concept. This conceptualization embodies the emotional non-reactivity inherent in differentiation of self. By distancing their identity from their child's diagnosis, highly differentiated parents may become more acutely aware of well-documented public judgement toward parents of children with ASD (Gray, 2002; Ryan, 2010), leading to greater affiliate stigma. In this way, taking on the identity of their child's diagnosis may serve as a defense mechanism buffering against internalized shame and stigma as it relates to providing care to a child with ASD.

## **Hypothesis Two**

Hypothesis two was not supported by the results of this study. It was hypothesized identifying as a racial/ethnic minority would be a contributing factor for affiliate stigma. Instead, this variable did not approach statistical significance. Moreover, the mean for affiliate stigma within the White sample ( $M = 2.92$ ) was slightly larger than that of the racial/ethnic minority sample ( $M = 2.86$ ). These results support previous studies suggesting internalized racism may not interact with stigma related to other marginalized identities (i.e., affiliate stigma) in an additive manner (Guittar & Guittar, 2015).

In a previous study, unstructured interviews were conducted with a small sample of participants ( $n=21$ ), all diagnosed with an intellectual disability, identifying as South Asian, and



living in the United Kingdom (Azmi et al., 1997). Among other experiences related to their intellectual disability (i.e., satisfaction with individualized services; experiences in recreation and friendship), participants described their identity as it relates to disability, race, and ethnicity. Nearly all participants (n=20) indicated they more strongly identified with their race and ethnicity compared to their disability status. Additionally, 63% of participants reported incidents of racism and 57% reported discrimination related to their disability (Azmi et al., 1997). While this is a narrow margin and small sample, such qualitative accounts may speak to the intersectional nature of race, ethnicity, and disability.

In the present study, affiliate stigma was slightly larger for participants identifying as White relative to those identifying as a racial/ethnic minority. Though this result was not statistically significant, it is unclear if a larger and more robust sample would illustrate a difference in affiliate stigma by racial identity. If so, racism (both internalized and observed) could be more salient for parental caregivers relative to stigma related to their child's disability status.

### **Additional Findings**

Previous research results showed inconsistencies in the relationship between affiliate stigma and parent-reported AQ (Dehnavi et al., 2011; Kinnear et al., 2016). In this sample, a positive relationship between these variables was found, consistent with one other study (Kinnear et al., 2016). Researchers have suggested this relationship may be more pronounced when the child with ASD is considered high-functioning, as their diagnosis is often not obvious to others in public settings (Broady et al., 2017; Gray, 2002). The relatively low mean of AQ in this study ( $M = 82.32$ ) may provide further support for this explanation.

A positive relationship between AQ and differentiation of self was also found ( $r=.357$ ,  $p<.001$ ). It is possible highly differentiated parents are more likely to provide higher AQ scores for their child, due to their ability to be emotionally unreactive and separate their own conception of self from their child's score. Additionally, participants with low differentiation of self may have dropped out, due to emotional difficulty in answering such questions about one's child- and because of fusion of their and their child's identities – about oneself. Alternatively, parents may

adopt more highly differentiated conceptualizations of themselves as a defense mechanism against internalized stigma surrounding their child's diagnosis.

This study utilized data collected in the midst of a global health crisis (COVID-19 pandemic). It is unclear the extent to which social distancing practices may have impacted reported scores. The aggregated mean ( $M = 2.70$ ) and standard deviation ( $SD = .730$ ) of affiliate stigma scores in this study were higher relative to those of earlier studies, (Mak & Cheung 2008; Werner & Shulman, 2013; Wong et al., 2016). This may be related to a national increase in virtual education and employment during the COVID-19 pandemic, accompanied by reported difficulties in balancing work with parental responsibilities (Weaver & Swank, 2021). As video conferencing from home increases, so does visibility of family life within the professional setting. This may partially explain the inflated rates of affiliate stigma scores within this study. Questions related to whether participants were engaging in work or academic study from home were not asked, therefore this rationale is purely speculative.

Statistical observations related to MEIM-R were made that were not reflected in research questions. MEIM-R was administered to gain information about the engagement and affirmation of participant's racial/ethnic identity. Using the regression analysis, the binary categorization of racial/ethnic identity (white; racial/ethnic minority) did not yield significant differences in affiliate stigma. However, significant negative correlations were found between total MEIM-R and each of its subscales and all variables of interest within the total and White subsample. With the exception of a weak, negative relationship between differentiation of self and the exploration subscale of MEIM-R, these results did not reach significance within the racial/ethnic minority subsample. It is unclear if a relationship was not observed in this subsample due to low number of participants ( $n=54$ ).

A negative relationship also exists between MEIM-R and affiliate stigma in the White subsample of this study ( $r=-.451$ ,  $p<.001$ ). This is true for both the exploration subscale ( $r=-.434$ ,  $p<.01$ ) and the commitment subscale ( $r=-.349$ ,  $p<.01$ ). This suggests greater exploration and commitment of White culture is associated with less affiliate stigma. Like with reporting extent of ASD traits, White participants with greater exploration of their racial and ethnic identity may be more likely to engage in a social model of disability, considering traits of autism as differences rather than deficits, and therefore less likely to internalize stigma related to their parent-child relationship. The relationship between commitment to racial/ethnic identity and

affiliate stigma may also be related to the westernized origins of the medical model of disability (Veatch, 1973). It is possible parents who subscribe to the medical model of health attribute overt discrimination from others to the medical diagnosis of ASD rather than internalizing these experiences as affiliate stigma.

### **Clinical Implications**

Bowen claimed his concept of differentiation of self is a universal standard to aspire to, though much criticism of this claim exists (Miller et al., 2004). Other constructs within Bowen Family System Therapy including triangulation, sibling position, and multigenerational transmission, have little empirical support (Miller et al., 2004). Despite overall theoretical criticisms, the relationship between differentiation of self and psychological distress has appeared to have garnered the most support (Frost, 2020). Within a family context, a Bowenian approach has been found effective in increasing self-regulation in children (Skowron et al., 2013) and in promoting weight loss, vis-à-vis a reduction in anxiety (Havstad & Sheffield, 2018). The results of this study, however, suggest treating affiliate stigma by improving differentiation of self is contraindicated.

When working with this -or any- population, clinicians should remain intentional in targeting the presenting problem in order to create a coherent treatment, regardless of model used (Sprenkle et al., 2009). While a treatment approach grounded in Bowen family systems appears uncondusive to treating parental affiliate stigma, this approach may be more aligned with improving behavioral outcomes for children with ASD. For example, the clinician may assist a parent in increasing their differentiation of self in terms of emotional reactivity, thereby empowering the client to become consistent in enforcing boundaries and communicating expectations with their child.

The results of this study should serve as a reminder to marriage and family therapists of the value of evidence-based treatment in clinical practice. Despite a strong rationale for the use of a Bowenian lens when working with parental caregivers expressing concerns to affiliate stigma, using this approach to increase differentiation of self may exasperate symptoms. When used in combination with therapeutic common factors (i.e., building relationship with the client, fostering a sense of hope for change), the use of an evidenced-based treatment is considered best

practice (Sprenkle et al., 2009). In terms of evidence-based practices for treating affiliate stigma in parental caregivers, limited research suggests mindfulness and self-compassion within psychotherapy as possible treatment approaches. Wong et al., (2016) identified self-compassion as a moderating factor between affiliate stigma and psychological distress. Cachia et al. (2015) reviewed a number of studies exploring the use of mindfulness in reducing stress in parents of children with ASD. While these studies did not examine affiliate stigma specifically, it could be suggested mindfulness-based treatment may be clinically appropriate in increasing self-compassion and thereby decreasing affiliate stigma. No other treatment modalities have been studied for this specific presenting problem at this time.

Few studies have provided clinical guidelines and recommendations for working with families impacted by ASD or other developmental disabilities (Kurz, 2018; Ramisch, 2012). Recommendations have remained broad in nature rather than providing guidelines for treating specific presenting problems. Further, no studies to date have explored specific guidelines for working with parental caregivers who have marginalized racial or ethnic identities. While the results of this study indicate no significant differences in terms of racial/ethnic identity, best practices in providing therapeutic treatment assert the importance of mindful consideration for the intersectional impact of a client's multiple identities – for example racial or ethnic identity and their child's disability status (Shin et al., 2017).

Two community based participatory research studies have identified considerations to increasing overall mental health in this population. Within these studies, parental caregivers were asked to provide qualitative feedback on the development of community based mental health support groups (Lock et al., 2013) and resources (Gilson et al., 2018). Participants discussed the role of both support groups and individual counseling in meeting their mental health needs (Gilson et al., 2018; Lock et al., 2013). In Lock et al.'s (2013) qualitative study, participants reported appreciation for psychoeducation and access to support from others as key aspects of parental support groups. Parental caregivers recognized the importance of safe spaces to acknowledge and discuss strong emotions – both positive and negative (Gilson et al., 2018). Parents also acknowledged the importance of engaging in regular self-care, including engaging in respite and self-reflection (Gilson et al., 2018).

## Strengths and Limitations

Despite an attempt to oversample participants identifying as a racial/ethnic minority, this largely diverse population was only represented in 36.7% of participants for this study's sample. The small scope of this study also necessitated the use of a dichotomous categorization of individuals by racial/ethnic identity, rather than exploration of individual racial and ethnic identities. Like previous research related to parental caregivers of children with ASD, the majority of participants in this study were married, employed, and White (Goff Nelson, 2019). Therefore, readers should avoid overgeneralizing the results of this study to all parental caregivers. Other than employment status, no questions were asked regarding socio-economic status. Without inquiring about income, education, or occupation, it is unclear whether the socio-economic status of this sample is representative of White or racial/ethnic minority populations at large. Likewise, caution should be made against using racial or ethnic identity alone as a proxy for socio-economic status (Manuel et al., 2012). Questions surrounding race and ethnicity were asked only of participants and not of their children. Therefore, we cannot know the racial or ethnic demographics of the children with ASD represented in this parental study. While results suggested an insignificant difference, this study explored the impact of racial and ethnic identity, which is an under-researched variable in psychosocial experiences of parental caregivers for developmental disabilities (Shin et al., 2017). Further studies exploring the role of a child's ethnic identity on parental affiliate stigma, as well impact of racial presentation and racism towards parental caregivers would expand extant knowledge on this subject.

Though many studies within ASD literature use disproportionately female samples (Goff Nelson, 2019), the sample of this study was evenly distributed in terms of gender identity.

This is likely due to the use of multiple recruitment avenues (social media and MTurk). Despite previous results suggesting a significant relationship (Farzand & Baysen, 2018), the relationship between gender identity and affiliate stigma merely approached significance in this study ( $p=.052$ ). This could be due to uneven distribution of participants by gender for each of these recruitment avenues. MTurk yielded a greater number of males relative to females ( $n= 57, 35$ , respectively), while social media yielded a greater number of females relative to males ( $n=40, 15$ , respectively). Statistical analyses comparing avenues of participation were not made, therefore this explanation is speculative.

This study used the AQ as a proxy for functional ability of children with ASD. This measure was created to measure stereotypical traits of ASD, which may not fully map onto functional ability (Gregory & Plaisted-Grant, 2016). Researchers have also expressed criticism for AQ's Eurocentric biases (Teufel-Prida & Prida, 2017). Cross-cultural studies yielded significantly lower internal consistency relative to initial validation studies (Cronbach's  $\alpha = .58-.76, .88$ , respectively; Auyeung et al., 2008; Freeth et al., 2013; Ruta et al., 2012; Ward et al., 2021).

Using convenience samples may have also led to a self-selection bias. This is especially relevant given the topic of differentiation of self, as less differentiated participants may have been more likely to engage in a topic related to their child's diagnosis. The use of a hierarchical regression analysis was used to evaluate impact of variables of interest on the dependent variable, affiliate stigma. Though the resulting model was significant at all steps, we cannot infer causation between differentiation of self or any control variables and affiliate stigma without use of a controlled experiment.

This study adds to a limited, yet quickly expanding, knowledge base of affiliate stigma (Liao et al., 2019). Confirming previous work (Kinnear et al., 2016), results from this study suggest a positive relationship between affiliate stigma and AQ ( $r = .295$ ). Though previous work identified gender, age, and employment as correlates of affiliate stigma (Farzand & Baysen, 2018), none of these control values reached significance in the final step of the model. Qualitative studies have merged topics of stigma and differentiation (Broady et al., 2017; Byrne et al., 2018; Ryan, 2010), yet this is the first to quantitatively evaluate their relationship. A significant correlation between these two constructs appears to exist ( $r = .543$ ). Though not specified within the research questions, results also indicated a positive correlation between differentiation of self and AQ ( $r = .357$ ). Given the few quantitative studies of differentiation of self within families affected by ASD (Ghoreishi et al., 2018; Negash et al., 2015), results from this study highlight the need for more work integrating these two bodies of research.

Debate surrounding the use of identity-first or person-first language in research related to ASD continues to evolve (Bottema-Beutel et al., 2020; Dunn & Andrews, 2015). Recent updates to the APA publication manual (7<sup>th</sup> edition) suggest reviewing the preferences of participants themselves when conducting research related to disability (APA, 2020). According to a recent content analysis of social media support groups, the majority of self-advocacy groups for autistic

adults used identity-first language, while groups targeting parental caregivers tend to use person-first language (Abel et al., 2019). In an effort to respect the diverse preferences of parents for whom this project studied, person-first language (i.e., “child with ASD”) was used throughout the survey material and this manuscript. Any offense to autistic self-advocates or their allies is unintentional, yet would be a significant limitation of this study.

### **Further Research**

The results of this study provide caution against using a Bowenian lens rooted in differentiation of self when treating affiliate stigma; however, further study may identify contexts in which this treatment model is clinically appropriate for this population. For example, Perez (2019) suggested increasing parental differentiation may contribute to greater ability to assist their child in mitigating challenges often associated with ASD. Behavioral-focused family systems researchers should consider evaluating the impact of parental differentiation of self on behavioral outcomes in children diagnosed with ASD.

Applied research yielding specific guidelines on working with parental caregivers with a range of presenting problems is also recommended. Marriage and family therapy researchers are uniquely qualified to lead this research, due to the understanding of multidirectional influences on which family systems theory was founded (Kerr & Bowen, 1988). Using this framework, researchers can center the impact of a child’s ASD diagnosis on various experiences of parental caregivers. Guidelines should provide specific recommendations for evidenced-based treatment of common presenting problems within this population including affiliate stigma, behavioral and affective outcomes for children, and family relationship satisfaction. Previous researchers have also noted the absence of empirical research related to helping families affected by ASD to strengthen their family unit (Lock et al., 2013).

Finally, further research exploring the use of specific modalities in treating affiliate stigma is recommended. Specifically, studies should examine the effectiveness of support groups and treatments grounded in self-compassion. Novel basic research identifying correlates of affiliate stigma may further indicate appropriate treatment for affiliate stigma in parental caregivers.

## **Conclusion**

This study used a hierarchical regression analysis to evaluate the impact of differentiation of self and racial/ethnic identity on affiliate stigma in parental caregivers of children with ASD. Results supported a positive relationship between differentiation of self and affiliate stigma. The relationship between racial/ethnic identity and affiliate stigma was not statistically significant in this study. Further study on affiliate stigma and its relationship with differentiation of self and other psychosocial constructs are necessary. This body of research will inform and innovate therapeutic treatment tailored to this prevalent need within the ASD community.



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6

## **APPENDIX A. INFORMED CONSENT**

### **RESEARCH PARTICIPANT INFORMATION SHEET**

Differentiation of Self and Affiliate Stigma in Families affected by Autism Spectrum Disorder

Dr. Anne Edwards and Jessica McGuire  
Department of Behavioral Sciences  
Purdue University

#### **Key Information**

Please take time to review this information carefully. This is a research study. Your participation in this study is voluntary which means that you may choose not to participate at any time without penalty or loss of benefits to which you are otherwise entitled. You may ask questions to the researchers about the study whenever you would like. If you decide to take part in the study, you will be asked to sign this form, be sure you understand what you will do and any possible risks or benefits.

#### **What is the purpose of this study?**

You are being asked to participate in a study designed by Dr. Anne Edwards and Jessica McGuire of Purdue University. We want to better understand the experiences of caregivers and the way caregivers see themselves. We would like to enroll 300 people in this study.

#### **What will I do if I choose to be in this study?**

If you choose to participate, you acknowledge that you are 18 years of age or older, have a child diagnosed with Autism Spectrum Disorder (ASD) and provide a minimum of 2 hours of care for this individual. You will be asked to complete an online survey about the interactions between you and others, your family caregiving experiences, and demographic questions, such as age, gender, and employment status. You are free to not respond to any questions that make you uncomfortable. You are free to withdraw your participation at any time.

#### **How long will I be in the study?**

Participation in the survey is expected to last between 15 – 20 minutes.

#### **What are the possible risks or discomforts?**

Breach of confidentiality is always a risk with data, but we will take precautions to minimize this risk as described in the confidentiality section. To minimize this risk, only researchers listed above will access the data from this study, and no personally identifying information will be collected during the study. If any questions within this survey cause you emotional distress, you can visit <http://www.psychologytoday.com> to find someone to speak to about any distress that may come to participating in this survey. For additional resources related to providing care to a child with autism, visit <http://www.nationalautismassociation.org>.

**Are there any potential benefits?**

You will not directly benefit from this study. You will have a chance to take part in research, and your participation may, thus, contribute to the scientific understanding of the experiences of caregivers.

**Will I receive payment or other incentive?**

By participating in this survey, you will be compensated with \$0.75.

**Are there costs to me for participation?**

There are no anticipated costs to participate in this research.

**Will information about me and my participation be kept confidential?**

The project's research records may be reviewed by departments at Purdue University responsible for regulatory and research oversight. The researchers will not have access to your IP address, and, therefore, cannot connect your answers to any identifying information. Data will be kept in a data file that is password protected, and only the Principal Investigator and the second researcher indicated at the top of this form will have access to any data.

**What are my rights if I take part in this study?** You do not have to participate in this research project. If you agree to participate, you may withdraw your participation at any time without penalty.

**Who can I contact if I have questions about the study?**

If you have questions, comments or concerns about this research project, you can talk to one of the researchers. Please contact Dr. Anne Edwards via email at [abedward@pnw.edu](mailto:abedward@pnw.edu) or by phone at 219-989-8439.

To report anonymously via Purdue's Hotline see [www.purdue.edu/hotline](http://www.purdue.edu/hotline)

If you have questions about your rights while taking part in the study or have concerns about the treatment of research participants, please call the Human Research Protection Program at (765) 494-5942, email ([irb@purdue.edu](mailto:irb@purdue.edu)) or write to:

Human Research Protection Program - Purdue University

Ernest C. Young Hall, Room 1032

155 S. Grant St.

West Lafayette, IN 47907-2114

**Documentation of Informed Consent**

I have had the opportunity to read this consent form and have the research study explained. I have had the opportunity to ask questions about the research study, and my questions have been answered. I am prepared to participate in the research study described above.

## APPENDIX B. SURVEY

Q1 What is your age?

---

Q2 What is your sex assigned at birth?

- ☐ Female
- ☐ Male
- ☐ Prefer not to answer

Q3 How do you describe your gender identity? (select all that apply)

- ☐ Female
- ☐ Male
- ☐ Trans female
- ☐ Trans male
- ☐ Nonbinary
- ☐ Prefer not to answer
- ☐ Different identity (explain below)

---

Q4 What is your current employment status?

- ☐ Unemployed, not looking for work
  - ☐ Unemployed, actively seeking work
  - ☐ Temporally unemployed / furloughed / laid off
  - ☐ Student, part-time
  - ☐ Student, full-time
  - ☐ Employed, part-time
  - ☐ Employed, full-time
  - ☐ Self-employed
  - ☐ Prefer not to answer
- 

Q5 How do you describe your current relationship status?

- ☐ Married
  - ☐ Living together/Domestic partnership
  - ☐ Separated
  - ☐ Divorced
  - ☐ Widowed
  - ☐ Never Married
  - ☐ Prefer not to answer
-

Q6 With which ethnic and racial group(s) do you identify? (select all that apply)

- ☐ American Indian or Alaska Native
  - ☐ Asian
  - ☐ Black or African American
  - ☐ Native Hawaiian or Other Pacific Islander
  - ☐ Middle Eastern or North African
  - ☐ Hispanic, Latino, or Spanish origin
  - ☐ White
  - ☐ Prefer not to answer
  - ☐ Other (explain below)
- 

End of Block: Initial Demographics

---

Start of Block: MEIM

Q7 In this country, people come from a lot of different cultures and there are many different words to describe the different backgrounds or ethnic groups that people come from. Some examples of the names of ethnic groups are Mexican-American, Hispanic, Black, Asian-American, American Indian, Anglo-American, and White. Every person is born into an ethnic group, or sometimes two groups, but people differ on how important their ethnicity is to them, how they feel about it, and how much their behaviors is affected by it. These questions are about your ethnicity group and how you feel about it or react to it.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I have spent time trying to find out more about my ethnic group, such as its history, traditions, and customs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a strong sense of belonging to my own ethnic group.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I understand pretty well what my ethnic group membership means to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have often done things that will help me understand my ethnic background better.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have often talked to other people in order to learn more about my ethnic group.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel a strong attachment toward my own ethnic group.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

End of Block: MEIM

Start of Block: Inclusion Criteria

Q13 Are you a parent to a child formally diagnosed with autism spectrum disorder (otherwise known as autism, autistic disorder, or Asperger's syndrome).

- ☐ Yes
- ☐ No
- ☐ Unsure
- ☐ Prefer not to answer

*Skip To: End of Survey If Are you a parent to a child formally diagnosed with autism spectrum disorder (otherwise known as... != Yes*

---

Q14 How are you related to your family member with autism? (If you have more than one relative with autism, please select one family member for the purpose of this survey.)

- ☐ This person is my biological child
  - ☐ This person is my step-child
  - ☐ This person is my adopted child
  - ☐ Other (please explain below) \_\_\_\_\_
  - ☐ Prefer not to answer
-



Q15 What aspects of care do you provide for this individual? (select all that apply)

- ☐ Preparing meals and/or feeding
- ☐ Personal care or hygienic assistance (i.e., bathing, toileting)
- ☐ Transportation and/or attendance at medical or therapeutic appointments
- ☐ Participation in social skill development
- ☐ Participation in educational development
- ☐ Monitoring and/or ensuring general safety
- ☐ None of the above
- ☐ Prefer not to answer

Q16 On average, how much time do you spend providing care to this individual weekly?

- ☐ 30 minutes or less
- ☐ 30 minutes - 2 hours
- ☐ 2 hours - 8 hours
- ☐ 8 hours - 40 hours
- ☐ 40 hours - 80 hours
- ☐ I provide care approximately half of the time
- ☐ I provide care all of the time, or nearly all of the time
- ☐ Prefer not to answer

*Skip To: End of Survey If On average, how much time do you spend providing care to this individual weekly? = 30 minutes or less*

*Skip To: End of Survey If On average, how much time do you spend providing care to this individual weekly? = 30 minutes - 2 hours*

End of Block: Inclusion Criteria

---

Start of Block: Family Demographics

Q17 What is the gender identity of your child with autism? (Select all that apply)

- ☐ Female
  - ☐ Male
  - ☐ Trans female
  - ☐ Trans male
  - ☐ Nonbinary
  - ☐ Prefer not to answer
  - ☐ Different Identity (explain below)
- 

Q18 What is the current age of your child with autism?

---

*Skip To: End of Survey If Condition: What is the current age of ... Is Greater Than 22. Skip To: End of Survey.*

---

Q19 How old was your child at their age of diagnosis?

---

Q20 Does your family member have any other known diagnoses?

- ☐ Yes (please list) \_\_\_\_\_
- ☐ Not to my knowledge
- ☐ Prefer not to answer

End of Block: Family Demographics

---

Start of Block: DSI

Q21 These are questions concerning your thoughts and feelings about yourself and relationship with others. Please read each statement carefully and decide how much the statement is *generally true* of you on a 1 (*not at all*) to a 6 (*very*) scale. If you believe that an item does not pertain to you (e.g., you are not currently in a committed relationship), please answer the item according to your best guess about what your thoughts and feelings would be in that situation. Be sure to answer every item and try to be as honest and accurate as possible in your responses.

	Not at all true of me 1	2	3	4	5	6	Very true of me 7
People have remarked that I'm overly emotional.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have difficulty expressing my feelings to people I care for.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I often feel inhibited around my family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tend to remain pretty calm even under stress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm likely to smooth over or settle conflicts between two people whom I care about.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When someone close to me disappoints me, I withdraw from him or her for a time.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

No matter  
what  
happens in  
my life, I  
know that  
I'll never  
lose my  
sense of  
who I am.

☐☐☐☐☐☐☐

I tend to  
distance  
myself  
when  
people get  
to close  
to me.

☐☐☐☐☐☐☐

It has been  
said (or  
could be  
said) of me  
that I am  
still very  
attached  
to my  
parent(s).

☐☐☐☐☐☐☐

I wish that  
I weren't  
so  
emotional.

☐☐☐☐☐☐☐

Q50 These are questions concerning your thoughts and feelings about yourself and relationship with others. Please read each statement carefully and decide how much the statement is *generally* true of you on a 1 (*not at all*) to a 6 (*very*) scale. If you believe that an item does not pertain to you (e.g., you are not currently in a committed relationship), please answer the item according to your best guess about what your thoughts and feelings would be in that situation. Be sure to answer every item and try to be as honest and accurate as possible in your responses.

	Not at all true of me 1	2	3	4	5	6	Very true of me 7
I usually do not change my behavior simply to please another person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My spouse or partner could not tolerate it if I were to express to him or her my true feelings about somethings.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whenever there is a problem in my relationship, I'm anxious to get it settled right away.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
At times my feelings get the best of me and I have trouble thinking clearly.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am having an argument with someone, I can separate my thoughts about the issue from my feelings about the person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I'm often uncomfortable when people get too close to me.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

It's important for me to keep in touch with my parents regularly.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

At times, I feel as if I'm riding an emotional roller coaster.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

There's no point in getting upset about things I cannot change.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

I'm concerned about losing my independence in intimate relationships.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

I'm overly sensitive to criticism.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

When my spouse or partner is away for too long, I feel like I am missing a part of me.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

I'm fairly self-accepting.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

I often feel  
that my  
spouse or  
partner wants  
too much  
from me.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

I try to live up  
to my parents'  
expectation.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

If I have had  
an argument  
with my  
spouse or  
partner, I tend  
to think about  
it all day.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

I am able to  
say no to  
others even  
when I feel  
pressured by  
them.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

When one of  
my  
relationships  
becomes very  
intense, I feel  
the urge to  
run away from  
it.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

Arguments  
with my  
parent(s) or  
sibling(s) can  
still make me  
feel awful.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------

I would never  
consider  
turning to any  
of my family  
members for  
emotional  
support.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------	-----------------------



Q50 These are questions concerning your thoughts and feelings about yourself and relationship with others. Please read each statement carefully and decide how much the statement is *generally true* of you on a 1 (*not at all*) to a 6 (*very*) scale. If you believe that an item does not pertain to you (e.g., you are not currently in a committed relationship), please answer the item according to your best guess about what your thoughts and feelings would be in that situation. Be sure to answer every item and try to be as honest and accurate as possible in your responses.

	Not at all true of me 1	2	3	4	5	6	Very true of me 7
If someone is upset with me, I can't seem to let it go easily.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm less concerned that others approve of me than I am about doing what I think is right.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I find myself thinking a lot about my relationship with my spouse or partner.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I'm very sensitive to being hurt by others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My self-esteem really depends on how others think of me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

When I'm  
with my  
spouse or  
partner, I  
often feel  
smothered.

☐☐☐☐☐☐☐

I worry  
about  
people  
close to me  
getting sick,  
hurt, or  
upset.

☐☐☐☐☐☐☐

I often  
wonder  
about the  
kind of  
impression  
I create.

☐☐☐☐☐☐☐

When  
things go  
wrong,  
talking  
about them  
usually  
makes it  
worse.

☐☐☐☐☐☐☐

I feel things  
more  
intensely  
than others  
do.

☐☐☐☐☐☐☐

I usually do  
what I  
believe is  
right  
regardless  
of what  
others say.

☐☐☐☐☐☐☐

Our relationship might be better if my spouse or partner would give me the space I need.

☐☐☐☐☐☐☐

I tend to feel pretty stable under stress.

☐☐☐☐☐☐☐

End of Block: DSI

Start of Block: Affiliate Scale

Q63 I feel inferior because my child has autism.

- ☐ Strongly Agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly Disagree

Q64 I feel emotionally disturbed because of my child with autism.

- ☐ Strongly Agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly Disagree

Q65 The behavior of my child with autism makes me feel embarrassed.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q66 I feel helpless for having a child with autism.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q67 I feel sad because I have a child with autism.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q68 I worry if other people would know I have a child with autism.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
-

Q69 I am under great pressure as I have a child with autism.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q70 Other people would discriminate against me if I am with my child with autism.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q71 My reputation is damaged because I have a child with autism.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q72 People's attitude towards me turns sour when I am with my child with autism.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
-

Q92 Having a child with autism imposes a negative impact on me.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q73 Having a child with autism makes me think that I am incompetent compared to other people.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q74 Having a child with autism makes me think that I am lesser to others.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
-

Q75 Having a child with autism makes me lose face.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q76 I avoid communicating with my child with autism.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q77 I dare not to tell others that I have a child with autism.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q78 I reduce going out with my child with autism.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
-



Q79 Given that I have a child with autism, I've cut down contact with my friends and relatives.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q80 When I am with my child with autism, I would keep an especially low profile.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q81 I've cut down the contact with my child with autism.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
-

Q82 I dare not to participate in activities related to autism lest other people would suspect that I have a child with autism.

- ☐ Strongly Agree
  - ☐ Agree
  - ☐ Disagree
  - ☐ Strongly Disagree
- 

Q83 Given that I have a child with autism, I've cut down contact with my neighbors.

- ☐ Strongly Agree
- ☐ Agree
- ☐ Disagree
- ☐ Strongly Disagree

End of Block: Affiliate Scale

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Start of Block: AQ

Q84 My child prefers to do things with others rather than on their own.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-

Q85 My child is drawn more strongly to people than to things.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q86 My child finds social situations easy.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q87 My child would rather go to a library than a birthday party.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q88 My child finds it hard to make new friends.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-

Q89 My child finds it easy to work out what someone is thinking or feeling just by looking at their face.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q90 My child enjoys social occasions.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q91 My child finds it difficult to work out people's intentions.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-

Q92 My child enjoys meeting new people.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q93 My child is good at taking care not to hurt other people's feelings.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q94 My child has difficulty understanding rules for polite behavior.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q95 My child enjoys social chit-chat.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-

Q96 When my child talks, it is not always easy for others to get a word in edgewise.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q97 My child does not know how to keep a conversation going with peers.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q98 My child finds it easy to "read between the lines" when someone is talking to them.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q99 My child knows how to tell if someone listening to them is getting bored.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-

Q100 When my child talks on the phone, they are not sure when it is their turn to speak.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q101 My child is often the last to understand the point of a joke.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q102 My child is good at social chit-chat.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q103 People often tell my child that they keep going on and on about the same thing.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-

Q104 My child prefers to do things the same way over and over again.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q105 My child frequently gets so strongly absorbed in one thing that they lose sight of other things.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q106 In a social group, my child can easily keep track of several different people's conversations.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-



Q107 My child tends to have very strong interests, which they get upset about if they cannot pursue.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q108 It does not upset my child if their daily routine is disturbed.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q109 My child finds it easy to go back and forth between different activities.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-

Q110 My child enjoys doing things spontaneously.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q111 If there is an interruption, my child can switch back to what they were doing very quickly.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q112 My child likes to plan any activities they participate in carefully.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q113 New situations make my child anxious.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-

Q114 If my child tries to imagine something, they find it very easy to create a picture in their mind.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q115 When my child is reading a story, they can easily imagine what the characters might look like.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q116 My child finds making up stories easy.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-

Q117 When my child is reading a story, they find it difficult to work out the characters' intentions or feelings.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q118 My child does not particularly enjoy fictional stories.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q119 My child would rather go to the cinema than a museum.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-

Q120 When my child was in preschool, they used to enjoy playing games involving pretend with other children.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q121 My child likes to collect information about categories of things (e.g., types of car, types of bird, types of train, types of plant, etc.)

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q122 My child finds it difficult to imagine what it would be like to be someone else.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-

Q123 My child finds it very easy to play games with children that involve pretending.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q124 My child often notices small sounds when others do not.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q125 My child usually notices house numbers or similar strings of information.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q126 My child is fascinated by dates.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-

Q127 My child tends to notice details that others do not.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q128 My child is fascinated by numbers.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q129 My child notices patterns in things all the time.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q130 My child usually concentrates more on the whole picture, rather than the small details.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
-

Q131 My child is not very good at remembering phone numbers.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q132 My child does not usually notice small changes in a situation, or a person's appearance.

- ☐ Definitely Agree
  - ☐ Slightly Agree
  - ☐ Slightly Disagree
  - ☐ Definitely Disagree
- 

Q133 My child is not very good at remembering people's date of birth.

- ☐ Definitely Agree
- ☐ Slightly Agree
- ☐ Slightly Disagree
- ☐ Definitely Disagree

End of Block: AQ