STIGMATISM INTERNALIZED BY PARENTS OF CHILDREN WITH AUTISM AND COPING MECHANISMS TO COMBAT ITS EFFECTS

A Project

Presented to the faculty of the Division of Social Work

California State University, Sacramento

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SOCIAL WORK

by

Deidre Sudderth

SPRING
2015
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S. Torres, Jr. Date

Division of Social Work
Abstract

of

STIGMATISM INTERNALIZED BY PARENTS OF CHILDREN WITH AUTISM
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by

Deidre Sudderth

Autism is a disorder that impairs a child’s communication and social interaction, and causes the development of stereotypic or repetitive behaviors or interests. As autism increases in prevalence, it becomes significantly more important to focus research on how this disorder impacts children and their families. As parents play a key role in a child’s development, it is necessary to investigate the unique challenges faced by parents of children with autism, and of additional concern is whether the parents face stigmatization as a result of bearing and raising their child with autism. This study primarily explored the experience of parenting a child with autism, and specifically investigated the internalization of stigma on families because of their child's diagnosis. Secondly, the author identified recent and different coping styles that have been helpful to families with children with autism compared to studies completed more than 10 years ago. Additionally, theory has been applied to the particular experiences of the participants in this study. Next, integration of qualitative data from participant surveys into a broad conceptualization of the manifestation of stigma in parents of children with autism was completed. Finally, the author provided recommendations for professionals working with
the population of autism, and acted as an impetus for future research. Autism certainly is stigmatized amongst parents and families of children with autism. One of the main findings of this study was the variation in the perceptions of stigma among parents. Parents were noted to feel depressed, misunderstood, guilty, and even isolated. Additionally, families including children with and without autism specified that the siblings of a child with autism were helpful, kind, embarrassed, and sometimes neglectful. While some parents (47%) felt stigmatized by their child's condition and experienced negative emotionality because of it, 52% contrastingly denied internalizing stigma. However, parents who have utilized coping strategies such as meditation, research on autism, and prayer experienced less negative emotions. Overall, parenting a child with autism or being associated with a child with autism, as a family member, can lead to “associated stigma” which causes negative emotionality if internalized.

_______________________, Committee Chair
Kisun Nam Ph.D., MSSW

_______________________
Date
ACKNOWLEDGEMENTS

Prima facie, I am grateful to God for the good health and wellbeing that were necessary to complete this project.

I wish to express my sincere thanks to Dr. Kisun Nam, my project advisor, who expertise, understanding, and patience, added considerably to my final year in graduate school. I appreciate his vast knowledge and skill in many areas and assistance with my writing and limited skills in SPSS. Additionally, I am thankful for him allowing me to be very independent during the completion of my project. Most importantly I thank him for accepting me as his advisee at my most vulnerable moment. I would like to thank the research review committee, Dr. Jude Antonyappan, Dr. Teiahsha Bankhead, Dr. Maria Dinis, Dr. Serge Lee, and Dr. Francis Yuen for accepting my IRB application. Finally, I express gratitude to Dr. Santos Torres, Jr. for signing off on my project.

I take this opportunity to express gratitude to the entire Division of Social Work faculty members for their help and support. Many thanks to the Office of Graduate Studies for their availability during the closing of my graduate studies career. I also thank my family, friends, colleagues, and supervisors for the unceasing encouragement, support, and attention.

I am most grateful to Lori Ann Dotson, Dr. Elizabeth Hughes, Gary W. LaVigna, Sonia Venegas, and all of those involved at the Institute for Applied Behavior Analysis, who directly or indirectly, has lent their hand in this venture. I am appreciative of their availability, cooperation, persistence, and support during my project. I greatly
appreciative their acceptance of my project and their allowing me to recruit and utilize their clientele as my research participants.

Most notably, I am overwhelmingly thankful for the participants in this study. I thank each parent for their role in this study and taking out the time, and energy, to contribute to the betterment of knowledge surrounding children with autism. Without them this study would be impossible!

Exceedingly grateful,

Deidre Sudderth
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Chapter 1

Introduction

Dilshad D. Ali (2013), a parent of a child with autism, once said the following:

I am the mother of three children, the oldest being Daanish, who is 10 years old and has moderate to severe autism. Daanish is nonverbal and sometimes aggressive. He can't read or tell me why he can get suddenly sad or angry, but his receptive skills (how he understands and follows directions) are remarkable. He also has a real connection to close loved ones. Raising a child with autism is a constant challenge, and being his mother is an exhausting, exhilarating, and lonely roller coaster ride.

Autism spectrum disorders (ASDs) are a group of developmental conditions that involve delayed or impaired communication and social skills, behaviors, and cognitive skills. Symptoms of ASDs range from mild to severe. As a result, each child, and family, coping with autism has a unique set of challenges. The above quote is a perfect description of how the stigma of autism can affect the parent of a child with autism. Stigma here refers to a mark of disgrace associated with a particular circumstance, quality, or person; while stigmatization refers to the unjust or prejudicial treatment with a particular circumstance, quality, or person.

A child’s autism diagnosis affects every member of the family in different ways. Parents/caregivers shift their primary focus on helping their child with ASD, which may put stress on their marriage, other children, work, finances, and personal relationships and responsibilities. Parents now have to modify much of their resources of time and money
towards providing treatment and interventions for their child, to the exclusion of other priorities. The needs of a child with ASD can greatly complicate familial relationships.

Again, stigma is a mark of disgrace that sets a person apart from others. When an individual is labeled by their condition they are seen as part of a stereotyped group. Stigma brings experiences and feelings of shame, blame, hopelessness, distress, misrepresentation in the media, and reluctance to seek and/or accept necessary help. Raising a child with autism places extraordinary demands and stress on parents as individuals, and on the family as a whole. Prime among these demands is the lack of enough hours in the day to do all one’s wishes. Among the biggest stress producers is the stigma applied to and internalized by families of children with autism. Specifically, these stressors may be identified as embarrassment among peers, frustration, and guilt (Gary, 1993). It is essential to analyze the stigmatized field of autism as it identifies the different types of stigma that are placed on parents, and families, of children that have been diagnosed. Stigma has become gravely entwined with the label of autism, yet it seems there is no agreement on definitions of what exactly the label means.

Indeed, families of a child with autism have been shown to experience significant stigmatization from the community in the form of blame for the onset of autism or its deterioration, social avoidance, pity, and contamination. An excellent review on the effects of stigma on population health inequalities states that stigma thwarts, undermines, or exacerbates several processes (i.e., availability of resources, social relationships, psychological and behavioral responses, stress) that ultimately lead to adverse health outcomes (Hatzenbuehler, Phelan, & Link, 2013). It is even more necessary to examine
how this stigma affects the parent, because as the primary caretakers of children with autism, parents directly impact the development of the child. As autism grows in prevalence, it becomes increasingly important to understand how the diagnosis impacts the primary caretakers of children with autism.

**Background of the Problem**

Autism is a developmental disorder diagnosed on the basis of an early onset of social and communication impairments and rigid and repetitive patterns of behavior and interests (http://www.autismspeaks.org/what-autism). It is among the most heritable of developmental disorders: siblings of those with autism have a fifty times higher risk of ASD than the general population, and identical twins show a 60–90% concordance, compared to 0–5% in fraternal twins (Frith & Happé, 2005).

There are many different effects of autism that impact the child. This pervasive developmental disorder impairs a child’s communication and social interaction, and causes the development of stereotypical and repetitive behaviors or interest. As autism grows more prevalent among today’s children, information and research in this area has really grown. Previous researchers suggest that stigmatizing attitudes about the symptoms of a child with autism has an equally damaging effect on social functioning among the parents, because it brings about public embarrassment and sometimes ridicule (Corrigan & Penn, 1998; Fisher, 1994; Link, Cullen, Struening, et al., 1989; Penn et al., 1994). Also, it has been suggested that mothers of children with autism experience high levels of stress (Holroyd & McArthur, 1976; Kasari & Sigman, 1997). Loneliness has been identified amongst parents of children with autism due to society not always accepting
their child and their condition. This may then turn into anger and protection of their child and family. Embarrassment is the most common affect of internalized stigma as a result of the way the child may act while in public. Thus, this causes the parent to explain their child’s behavior to surrounding inquirers. Amongst the limited amounts of research studies, some have found that parents of children with autism actually are stigmatized more often than not, and they internalize it resulting in higher degrees of negative emotionality. Internalization in this paper refers to the process of accepting a set of norms and values established by people or groups, which are influential to the individual through the process of socialization. When internalizing stigma, parents then begin believing the negative things they hear.

Studies seeking to understand parental influences have concluded that parents often face considerable dilemmas when making decisions relating to their children’s behavioral difficulties (Hansen & Hansen, 2006). Educational professionals recognize stresses experienced by parents as they struggle with the connection of their children’s special educational needs (Norwich, 2008). The basic problem for these parents is whether to suffer potential disadvantages such as stigma, depression and rejection, or risk losing resources and opportunities that might be released by a formal identification. Hodge (2005) found evidence that parents feel forced into accepting an ASD diagnosis in order to access services. Such parental predicaments reflect constant differing discussions between biomedical and sociological scholars concerning ASD.

Statement of the Research Problem

Despite the prevalent research on autism, few studies have investigated the effect
of this disorder on the child’s parents thus resulting in stigmatization going unnoticed. Autism can make close familial relationships extremely difficult to develop. It is a disorder that naturally changes the parent-child relationship; communication is hindered or even impossible, intimacy can be challenging, and a child’s self-injurious behaviors may make a parent, or other family members, feel frightened and helpless. Stress levels in parents of children with autism have been shown to be higher than those in other parents (Hastings et al., 2005). Stress in parents is understandable given the fact that their children face the stigma of autism and children with autism pose unique challenges. Stigmatization, as defined by the author of this paper, signifies the situation in which an individual is devalued or does not receive full social acceptance because of some trait or condition that is marked undesirable by societal norms, which can certainly have negative effects on the individual involved. Children with autism are marginalized by society, may have difficulty obtaining necessary services and benefits, and suffer overall psychological strain (Major, 2006).

**Study Purpose**

This study primarily seeks to explore the experience of parenting a child with autism, and specifically to investigate the internalization of stigma on families because of their child's diagnosis. The secondary purpose is to identify recent and different coping styles that have been helpful to families with children with autism compared to studies completed more than 10 years ago. Examining traditional theories of stigma in the literature review of this project will lay a framework with which to evaluate the experience of the population of interest. Secondly, this project will seek to apply theory
to the particular experiences of parents of children with autism. Finally, the study will integrate qualitative data from participant surveys into a broad conceptualization of the manifestation of stigma in parents of children with autism, which will be recorded later in the results section.

**Theoretical Framework**

Though there is a great deal of literature on autism, including diagnosis, related causes and treatments, and the impacts it has on families (such as marital and sibling impairments), society rarely discusses how to prevent families from being stigmatized and in return feeling isolated, lacking support (Stuart, Koller, & Miley, 2008). In exploring the possible application theories to explain the stigmatism internalized by parents of children with autism, the writer identified the stigma theory as the most applicable. Social stigma is a mark of severe social disapproval that results from an individual's deviation from social norms. Social stigma is so profound that it overpowers positive social feedback regarding the way in which the same individual adheres to other social norms (Boundless, 2014). Stigma plays a primary role in sociological theory. Émile Durkheim, one of the founders of the social sciences, began to address the social marking of deviance in the late nineteenth century. Erving Goffman, an American sociologist, is responsible for bringing the term and theory of stigma into the main social theoretical fold. In his work, Goffman presented the fundamentals of stigma as a social theory, including his interpretation of stigma as a means of spoiling identity (Boundless, 2014). By this, he referred to the stigmatized trait's ability to "spoil" recognition of the individual's adherence to social norms in other facets of self. Goffman identified three
main types of stigma: (1) stigma associated with mental illness; (2) stigma associated with physical deformation; and (3) stigma attached to identification with a particular race, ethnicity, religion, ideology, etc. (Boundless, 2014).

While Goffman is responsible for the seminal texts in stigma theory, stigmatization is still a popular theme in contemporary sociological research. In Conceptualizing Stigma, sociologists Jo Phelan and Bruce Link (2001) interpret stigma as the convergence of four different factors: (1) differentiation and labeling of various segments of society; (2) linking the labeling of different social demographics to prejudices about these individuals; (3) the development of an us-versus-them ethic; and (4) disadvantaging the people who are labeled and placed in the "them" category. Given that stigmas arise from social relationships, the theory places emphasis, not on the existence of deviant traits, but on the perception and marking of certain traits as deviant by a second party. For example, theorists of stigma do not care much about whether parents have children with autism, but rather how the parent’s perceive or internalize their child’s diagnosis and how society treats them differently.

**Definition of Terms**

To provide clarification, when stated in this study: (1) stigma refers to a mark of disgrace associated with a particular circumstance, quality, or person; (2) stigmatization denotes the unjust or prejudicial treatment with a particular circumstance, quality, or person; (3) coping strategies signify the specific efforts, both behavioral and psychological, that people employ to master, tolerate, reduce, or minimize stressful events; and (4) internalization refers to the process of accepting a set of norms and values
established by people or groups which are influential to the individual through the process of socialization. Additionally, parental perception is used in this study to refer to the parents of children with autism’s observation, internalization, and understanding of their child’s condition and their emotionality towards stigmatization.

Autism spectrum disorder (ASD) and autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. With the May 2013 publication of the DSM-5 diagnostic manual, all autism disorders were merged into one umbrella diagnosis of ASD. ASD can be associated with intellectual disability, difficulties in motor coordination and attention, and physical health issues such as sleep and gastrointestinal disturbances.

Assumptions

This study is conducted based off the following assumptions: (1) the majority of adults parenting children with autism experience hardships, (2) having a sibling with autism can cause stress, and (3) stigma is prevalently experienced among parents of children with autism in today’s society.

Social Work Research Justification

This study brings about a direct insight to families and parents of children with autism. It identifies issues and stigmas that may go unnoticed, which is essential for treatment of children with autism and the relationship with the parents. Being that the social work profession looks to provide resources and treatment to those in need, it is necessary for background information to be identified to better assist clientele. In this
case, the parental internalization of stigma due to parenting a child with autism will benefit the social work profession as it brings an understanding of the services needed for the child as well as the services needed for the family. This study will identify what parents and siblings of children with autism experience on a daily basis internally and externally. Thereby providing (1) society with knowledge on what these families are experiencing and, (2) the social work profession awareness of what services are needed and what services may be effective for other families.

To investigate the stigma that may be associated with parenting a child with autism, this paper will first define and evaluate traditional conceptualizations of stigmatization to understand how it can apply to a particular population. The author will explore the implications of being a stigmatized individual and then discuss the concept of secondary stigma, or stigma by association. This paper will then apply theory to the population of interest (parents of children with autism) using qualitative case analyses to support or refute research findings. Finally, this paper will offer suggestions of how to begin to mitigate the stigma, if present, and recommendations for social work professionals in working with parents of children with autism.
Chapter 2

Review of the Literature

The following is a review of the pertinent literature associated with stigmatization of parents and families raising children with autism and the coping skills that have been utilized in these families. The first section explains the meaning of mental illness and extends a thorough exploration of the diagnostic criteria for the Autism Spectrum Disorder according to the DSM-5. The following three sections discuss the internalized stigma of parents with children with autism, the experience of parenting a child with autism, and the idea that parents are stigmatized because of their child’s diagnosis. The fourth and final section studies the use of coping mechanisms amongst families with children with autism and concludes with suggestions for further research.

Neurodevelopmental Disorders

Neurodevelopmental Disorders (NDDs) are disorders of brain function that affect emotion, learning, and memory. These disorders develop over time and are associated with a wide variation of mental, emotional, behavioral, and physical features. Commonly known NDDs include autism spectrum disorders, cerebral palsy, attention deficit/hyperactivity disorder (ADHD), communication, speech, and language disorders, and genetic disorders such as fragile X syndrome (FXS) and Down syndrome (Reynolds & Goldstein, 1999). These various disorders, at symptom level, seem to share similar behavioral symptoms and diagnostic criteria. This is a significant limitation in the current diagnostic criteria, as symptoms frequently overlap and best practice treatment suggestions may differ depending on one’s presentation.
According to the National Institute of Neurological Disorders and Stroke (2014), autism spectrum disorder (ASD) consist of a range of complex neurodevelopmental disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior. Autism is the most severe form of ASD, while other conditions along the spectrum include a milder form of autism, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS). Although ASD varies significantly in character and severity, it occurs in all ethnic and socioeconomic groups and effects every age group. Experts estimate that 1 out of 88 children starting at age 8 will have an autism spectrum disorder (Centers for Disease Control and Prevention, 2012). Additionally, males are four times more likely to have an ASD than females.

**DSM-5 (2013) - Autism**

This section will present a well-described format explaining the required criteria needed for an individual to be diagnosed with autism. Furthermore, in this section, the author will interpret the important facts and description of autism.

**Autism Spectrum Disorder According to the DSM-5**

One of the most important changes in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) is to autism spectrum disorder (ASD). The revised diagnosis represents a new, more accurate, and medically and scientifically useful way of diagnosing individuals with autism-related disorders. As previously mentioned, using DSM-IV, patients could be diagnosed with four separate disorders: autistic disorder, Asperger’s disorder, childhood disintegrative disorder, or the catch-all
diagnosis of pervasive developmental disorder not otherwise specified. Researchers found that these separate diagnoses were not consistently applied across different clinics and treatment centers. Additionally, studies have shown that parents of children with ASD notice a developmental problem before their child's first birthday. Concerns about vision and hearing were more often reported in the first year, and differences in social, communication, and fine motor skills were evident from 6 months of age.

People with ASD tend to have communication deficits, such as responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty building friendships appropriate to their age. In addition, people with ASD may be overly dependent on routines, highly sensitive to changes in their environment, or intensely focused on inappropriate items. Again, the symptoms of ASD fall on a continuum, with some individuals showing mild symptoms and others having much more severe symptoms.

Under the DSM-5 criteria, individuals with ASD must show symptoms from early childhood, even if those symptoms are not recognized until later. This criteria change (in the DSM-5) encourages earlier diagnoses of ASD but also allows those whose symptoms may not be fully recognized, until social demands exceed their capacity, to receive the diagnosis. It is an important change from DSM-IV criteria, which was focused on identifying school-aged children with autism-related disorders, and was not as useful in diagnosing younger children.

The DSM-5 criterion has been tested in realistic clinical settings as part of DSM-5 field trials, and analysis from that testing indicated that there would be no significant
changes in the prevalence of the disorder. More recently, the largest and most up-to-date study, published by Huerta, et al., in the October 2012 issue of American Journal of Psychiatry, provided the most comprehensive assessment of the DSM-5 criteria for ASD based on symptom extraction from previously collected data. The study found that DSM-5 criteria identified 91 percent of children with clinical DSM-IV PDD diagnoses, suggesting that most children with DSM-IV PDD diagnoses will retain their diagnosis of ASD using the new criteria. Several other studies, using various methodologies, have been inconsistent in their findings.

**Parenting a Child with Autism**

Many studies investigating the impact of parenting a child with autism found that having an autism diagnosis for a child affects every member of the family in different ways. Parents and caregivers must restructure their focus on helping the child with ASD, which may increase stress on the marriage, siblings of the child, work, finances, personal relationships, and responsibilities. Most parents move their resources of time and money toward providing treatment and interventions for their child, to the exclusion of other priorities. The needs of a child with ASD complicate familial relationships, especially with siblings. For parents of children with ASDs, there are many lifestyle and attitude adjustments to make.

Nurturing a child with autism demands a significant amount of care, often more than thirty hours per week, which causes some mothers to sacrifice their careers to support their child. This then leads to financial pressure on the family and exposes them to an additional stressful situation. During these times parents may begin to resent their
lifestyle as they begin to make many changes for the sake of their child’s well-being, which may not be consistent with the sacrifices of other parents. Additionally, if a child has severe autism and shies away from a parent’s touch or is unable to communicate with “mom” or “dad”, it can be heartbreaking. Commonly, parents experience difficulty adjusting their expectations and desires for their child for now and the future. Most parents have anxiety for their child’s future. Initially they have high hopes that their child will develop the necessary skills to live life almost independently. However, because children do not recover from autism these hopes have declined, as parent’s original vision of their child living independently has not come to pass.

Moreover, parenting a child with autism increases the strain of never knowing what to expect from your child in terms of behavior or mood, which can make day-to-day living challenging and going to new places or attending extended family get-togethers even more so. “Jack had dark periods where he was despondent and I didn’t know why,” says Ursitti. “That’s excruciating as a mother -- to know that your child is sad and suffering and to not know why. I couldn’t begin to guess what was going on with him because he experiences the world in such a different way. That’s one of the toughest parts of having a child with autism” (Autism Spectrum Disorders, 2015).

Green, Davis, Karshmer, Marsh, and Straight (2005), examined the direct and secondhand impact of the social processes of felt and enacted stigma and their impact on the lives on individuals with autism and their families. It has been identified that the challenges of living a stigmatized life brings about: (1) labeling; (2) stereotyping; (3) separation; (4) status loss; and (5) discrimination within the context of power differential
Autism is said to be an invisible condition, however when “negative” characteristics are displayed, labeling and stereotyping come as a result. The majority of people in the community relate behaviors of autism, such as tantrums, yelling, and meltdowns, to bad parenting or raising an uncontrollable child. When in actuality, parents are doing their best by taking their child out and letting them explore instead of leaving them isolated at home. In sum, the literature contains the main idea that parents of children with autism display a variety of psychological symptoms including depression, anxiety, and pessimism as a result of the stigmatizing eye in the community.

**Parental Internalization of Stigma**

The term of stigma firstly had been used by Greeks and referred to the bodily signs referred to a person's bad and unusual moral manner. Goffman (1963) proposes two kinds of stigma: self and affiliate stigma, which appears amongst parents of children with autism. Affiliate stigmatization happens afterward, in the way that people simply having a relation to a stigmatized person are at the exposure of negative behaviors from society. To be connected with a stigmatized being, a caregiver, family member, or friend might be exposed to the most common stigma in society called curtsy stigma. Suffering from affiliate stigma, can cause feelings of sadness and helplessness due to having relations with a stigmatized person. Based on these cognitive and emotional effects of affiliate stigma, relatives may react to show they have no relation with a stigmatized person through several behaviors such as concealing a stigma situation, not attending social occasions, or even separating the stigmatized person from themselves to show there is no relation between them. Because parents and children have genetic connection,
transferring stigma from children to parents is inevitable. Parents will perceive that stigma is attached to them, even with the diagnosis not being visible, which would lead to an increase in both stress and depression (Mak and Kwok, 2010). Being parents of a stigmatized child causes secondary stigma and specific complications, which will be discussed further in this section.

Studies have identified that when internalizing stigma, parents and families experience negative emotionality. Gray (2002) noted that internalizing stigma led to the highest damage amongst psychological well-being. It was due to the fact that mothers compared to fathers experience more negative emotions. Mothers strongly feel guilty and depressed about their children; and in less cases when mothers encounter stroke or physical illness, they believe that this problem is related to the child's autism. There are mothers who mostly experience emotional distress and career disruptions due to their main role in the child's referral treatment process and the relationship with educational problems. Mothers also are considered to be responsible for the child's behavior by their husbands and other people outside the home (Gray, 2002). Fathers actually did not feel stigmatized in most cases. Instead, they found it easy to deal with their child, as opposed to mothers who spend a large amount of their time with the child, and then feel guilty. In most cases, mothers felt despondent when their lives significance revolve around taking care of their relatives. A main factor for the explanation of this is perceived or internalized stigma

Dalky (2012) emphasizes that autism contributes significantly to a families’ perception of stigma. In his study, Arab families associated the experience of caring for a
mentally ill family member with feelings of fear, loss, embarrassment, and disgrace of family reputations. Furthermore, feelings of secrecy, isolation, despair, and helplessness were reported the most common among family groups in the Arab area of Jordan and Morocco. Some parent’s perception focused on how raising a child with autism changes the environment and function of the family. The parents emphasized how hard it is to take care of their child humbly when they are continuously judged in public. The parents experience the majority of stigma by virtue of their child. Mak, Cheung, & Rebecca (2008) discovered that the components of stigma (thoughts, feelings, and actions of caregivers or mothers) could be interlocked where parents feeling ashamed and act on those feelings by shutting out peers and family members who may stigmatize their child. Consequently, parents with high levels of affiliate stigma are most likely to have a sense of shame and inferiority as a result of their association with the child.

In a research by Sedigheh, Mokhtar, Salar, et al. (2011), it was revealed that parents of children with autism frequently face harsh and insensitive reactions from people, especially when the children behave “improperly” in public. The parents then internalize this public stigma by applying negative self-evaluations in controlling behaviors of their children, and perceiving the responsibility of the children’s behavior and then choosing isolation and avoidance from attending any social activities. Wnoroski (2008) also pinpoints how autism can invite undeserved blame on the parents. He states that autism is perceived as a stigma against both children and parents. Parents in the study mentioned feeling lonely, blamed for being a bad parent, misunderstood, stressed, and isolated. The author goes on to share that parents have experienced rude comments and
harsh treatment from strangers, based on assumptions about their parenting style being exhibited in their child’s behavior. These comments damage parent’s self-perception and increase their feelings of guilt by reinforcing the stigma that parent’s are the ones responsible for the child’s disorder. In regards to personal isolation, the parents of these children felt alone without any support.

Autism has different stigmatizing effects due to the extreme unsettling characteristics of autistic symptoms, the average physical appearance of children with autism, and the lack of public knowledge and understanding regarding the nature of autism. Gary (1993) suggested that there is a direct correspondence between others' perception of the child’s identity and the child’s subjective and reflexive perception of his or her identity. Most parents of children with autism perceived themselves to be stigmatized by their child’s disorder. Not only was this found in America but also it was similarly discovered in Australia. There was a common tendency for mothers to feel more stigmatized than fathers; and children who were under the age of twelve were more likely to perceive themselves as being stigmatized further. Majority of parents perceived either themselves, or other members of their family, as being stigmatized by their child’s conditions. Specifically, parents were concerned with the other children in the household. Positively, siblings were helpful with the child with autism; but, negatively, they were defamed and could not live as they would like. Many parents began stigmatizing themselves and believing that their child’s autistic diagnosis was due to something genetic. In connection to this internalization, Gary (1993) mentions grandparents were the least supportive in regards to the child with autism and made comments to their
offspring (the parent of the child) such as “that did not come from our side of the family” (p. 115).

In the one of the recent studies, Mak and Kwok (2010) investigated the effects of perceived stigma on the parents' of children with autism based on the attribution theory to propose a model to explain internalization stigma in this group. The results indicated that parents directly internalized the enacted stigma through controllability, perceived responsibility, and self-blaming. The direct relationship between stigma and parents' stigma in society was due to the spread of negative attitudes about disabled people in society. These parents accepted easily the negative attitudes about themselves and their children. Some of them accepted the responsibility and blame about their child's situation; therefore, internalizing the current stigma of society. In more details, those parents who believed that they have low control over their children's autism and their coinciding behaviors experienced internalized stigma more.

As mentioned previously, autism can effect the whole family of a child, creating feelings of social isolation, depression, shame (in parents), and initial complaints and shame in siblings (Dababnah and Parish, 2013). This eventually leads to a sense of responsibility for the care of the child. Negative family and community attitudes are the main source of stress, shame, and blame for parents. Also, there are many financial, psychological, and caregiving worries leading parents to feel confined to their homes, embarrassed about their child’s condition, and desperate for answers. Caring of the child with autism is very demanding and can produce a huge amount of stress for parents. Overall, the internalization of stigma among parents of children who suffer from autism
was severe. It has been indicated that most parents are led into negative thinking by incorporating the stigma placed on them. This negative thinking then impacts their lives undesirably with depression, stress, anxiety, and fear. Lastly, both parents experienced stigma, but the mothers internalized it more as a result of their maternal connection to the child.

Coping Mechanisms

In order to manage a healthy lifestyle, it is always recommended in the social work field to utilize coping mechanisms. In this section, the author will identify coping mechanisms utilized by parents of children with autism that combat the effects of stigma. Farrugia’s (2009) indicates that a child’s diagnosis of autism is critical for parents to resist stigmatization. It was found that biological and genetic explanations for disorders are strategically organized by parents of children diagnosed with ASD to resist stigmatization. It has been highlighted in the literature that parents frequently resist personal experiences of stigma by speaking out on the prejudices that were placed on them by the society in which they reside. Additionally, parents experienced considerable enacted stigma, but successfully resisted felt stigma by using medical knowledge to articulate their conditions. Resistance to stigma is successful to the degree that others, particularly those in power within institutions, accepted medical constructions of abnormality organized by parents.

To avoid prejudice and discrimination, some parents withdraw from social circles and conceal their status from others. Dababnah and Parish (2013) identify coping mechanisms utilized by most families such as: (1) active avoidance and denial of the
diagnosis; (2) acceptance and religion; (3) social interaction and support: (4) spousal support; and (5) information seeking. Most importantly, positive parental perceptions were identified as the most powerful coping skill used when adjusting to stressors.

It is clear that stigma is compounded with multiple unique stressors that can make the parental experience difficult. Nonetheless, it was reported by Winoroski (2008) that parents found diverse and creative ways to resist and actively counter the negative effects of stigma in their lives. Mothers of children with autism reported having to educate people they encounter, about the condition of their child, in order to dissolve the social awkwardness. It has been further indicated that parents use screening activities, which can be identified as a coping mechanism. Screening activities (actions that shelter’s unwanted feelings) allot parents to the confinement of their family and other families with children with autism. These activities enabled the family to block negativity before it could damage them. Additionally, some parents report that support from family and friends, prayer, exercise, relaxation exercises, journaling, advocacy, and counseling assists them as they attempt to cope with the daily impact of stigma (Marcus, et al, 1997).

Lazarus (1996) describes that the problems of parenting a child with autism, and the means of coping have changed over time. The total number of coping strategies reported by parents has declined and there has been a general shift away from problem-focused towards emotion-focused means of coping. In particular, the reliance on service providers has declined and the relative importance of religion and other coping strategies such as an appreciation of their child’s good qualities has increased. The reasons for these
changes may reflect both the changing problems of the children and the services currently available for their treatment.

In the context of a number of literatures, it is evident that parents of children with autism have experienced stigma due to society’s idea of what autism is. These studies have shown that this then leads parents to internalize the stigma being placed upon themselves and their children. Some parents believe the different perceptions and opinions others have of them, and others begin to think all society have the same views on autism and families with children that have autism. Parents have testified to experiencing shame, guilt, depression, sadness, confusion, and anger because of the conversations, interactions, and ideas of the everyday person. It is hypothesized from these studies, that parents do in fact experience negative emotionality due to the internalization of stigma as a result of their child’s autism diagnosis.
Chapter 3

Methods

This research is a qualitative cross-sectional study of the experiences of parenting a child with autism, and specifically the internalization of stigma on families because of their child's diagnosis. The research method for the study was based on ethnographic methods that emphasized in-depth survey/questionnaires.

Study Objectives

This study primarily explored the experience of parenting a child with autism, and specifically investigated the internalization of stigma on families because of their child's diagnosis. The author identified recent and different coping styles that have been helpful to families with children with autism compared to studies completed more than 10 years ago. These objectives were discovered through the research question: Do parents experience negative emotionality due to the internalization of stigma as a result of their child’s autism? And, what coping mechanisms are utilized to combat stigma’s effects? It was hypothesized that parents will experience emotions such as shame, guilt, and embarrassment as they internalize the stigma of society.

Study Design

This cross-sectional study surveyed a sample of parents of children with autism in the Los Angeles area of California. The survey was administered online through Survey Monkey and took each parent approximately 20 minutes to complete. Questions on the survey were adopted from the Parental Changes Scale adapted from Life Management Survey (Scorgie & Sobsey, 2000). (See Appendix C for the survey questions). The
California State University, Sacramento Division of Social Work Research Review Committee approved this study. (Please see response letter in Appendix A).

**Sampling Procedures**

Potential parent participants were identified through information about their child with autism, contained within an agency, Institute for Applied Behavior Analysis (IABA). This agency was sent an initial invitation to participate in the current study. IABA approved an IRB application and agreed to participate. The agency was then sent a recruitment letter (see Appendix D) to be sent to the clientele of IABA, consisting of 75 parents and families. These families consist of children with autism from ages 4 to 11 years old. Staff of the agency privately indicated the contact information for those children and parents that were eligible for this study, and mailed them the recruitment email. Per the recruitment email, potential participants found a link to the online survey through Survey Monkey. The consent from participants was implied if the participants chose to take the online survey (see Appendix E). Participation was expected to take no more than 15-20 minutes to complete. Once the survey was complete, the data was entered into SPSS for analysis and destroyed after the study’s results were discovered.

**Data Collection Procedures**

The online tool used in this study was Survey Monkey. Through this online database, the participant’s answers were saved online momentarily, until the study concluded. After each parent completed their survey and the data collection period has ended, the data from the surveys was inserted into SPSS and analyzed. A total of 75 parents were contacted in efforts of having them participate in this study. A total of 17
parents completed the survey between the recruitment times of December 2014 to March 2015. Of those 17 parents, 15 answered every question on the survey. Thus, the full participation rate for the study was 88%.

**Measurements**

The survey used in this study is composed of 18 questions formed from the author and 18 questions adopted from the Life Management Survey Part III-Parental Changes Subscale (Parental Changes; Scorgie & Sobsey, 2000). This subscale includes items, which examine themes related to the positive parental transformations associated with personal changes (e.g., “My reputation is damaged because I have a child with autism at home.”), relational changes (e.g., “Has stigma effected your ability to make or keep friends?”), and changes in perspective (e.g., “Having a child with autism forces a negative impact on me.”). Each item was rated on a 5-point Likert scale ranging from 1 (Strongly Disagree) to 5 (Strongly Agree). There have been no measures of reliability completed for Life Management Survey to date, although it is considered to have good content validity based on high levels of disagreement with a contrast item. Additionally, there have been multiple studies utilizing this scale for data analysis.

The survey questionnaire consisted of four parts. The first part asked parents to provide information about family life including how many biological children the parent had, how many of those children have autism, how the parent’s family responded to learning that their child(ren) had autism, whether those interactions between family members changed, if the parent’s had children without autism and how they related to the child with autism, and whether the family has events without the child with autism. The
second part focused on the experiences of stigma and consisted of 6 multiple choice questions with the options of Never to Always, 3 questions specific to emotionality, 3 Yes, No, or Not sure questions, and 1 Likert scale ranging from 1 to 10. The third section was composed of 9 questions directed towards the internalization of stigma ranging from Strongly disagree to Strongly agree. The final section, entitled coping mechanisms, contained 5 yes or no questions, 1 question asking the parent to identify specific coping mechanisms that were helpful to them, and the final question was open-ended allowing parents to freely state anything additional that they would like the author to know.

Data Analysis

The design that was used for this study was a survey/questionnaire method. The independent variable in the analysis was the characteristics of the sample (parents of autistic child). The dependent variable included the: (1) internalization of the parents after experiencing stigma, whether it produced negative or positive emotionality, and (2) coping strategies. The results of the study have been entered into the SPSS database system, which produced a feasible analysis of the resulting data among participants. The statistical test that was used in this study was a correlational analysis. The online tool used to form and archive the participant’s surveys was Survey Monkey.

Protection of Human Subjects

The application for the protection of human subjects was prepared and submitted to the Division of Social Work Institutional Review Board (IRB) for review and was approved. Human Subjects Protocol #: 14-15-031.
Chapter 4

Study Findings and Interpretations

It was hypothesized that parents do in fact experience negative emotionality due to the internalization of stigma as a result of their child’s autism. Specifically, parents have experienced emotions such as shame, guilt, and embarrassment as they internalized the stigma of society.

Overall Findings

The total sample size consisted of 17 parents, but descriptive data for all respondents and their children were not available resulting in missing data for some categories. The participants in this study consisted of parents with one to three biological children. 17% of parents had 1 child in their home, 35% of parents had 2 children in their home, 24% had 3 children, 1% had 4 children, and another 1% had 5 children in their home. Of these children, 11 parents had one child with autism, 3 parents had 2 children with autism, and 1 parent had 3 children with autism. Almost all parents had additional children in the home without autism, except for 7 out of 17 parents. Amongst the 10 families that included siblings without autism, the siblings were noted to respond kindly, confused/questioning, helpful, angry, and embarrassed. Specifically, 57% reacted kindly, 57% reacted confused/questioning, 35% reacted helpfully, 13% reacted with anger, and 1% were embarrassed. However, surprisingly, only two parents indicated that there were events their child was excluded from. For example, one parent explained that their child does not normally eat dinner with them.
Amongst, the siblings and parents of a child with autism, this author examined the initial effect (from the family) when learning that a child has autism. Most families responded with sadness (47%) as opposed to neglectful (0%), shocked (35%), judgmental (17%), and supportive (41%). When examining the experiences of stigma among parents, the responses were very different. Most agreed that “sometimes” the average person is afraid of someone with autism and “often”, children have been stigmatized due to their diagnosis of autism. More importantly, parents reported frequently feeling stigmatized due to their child’s condition. When expressing the emotions that evolved due to stigmatization, 29% of parents were angry, 16% were shocked, 18% were embarrassed, 59% felt guilty, 29% were saddened, and 1% reported feeling misunderstood.

Parents described their family members to be stigmatized on fewer occasions, hardly ever, or never compared to their experiences as parents. These family members experienced the emotions of mainly anger, shock, and embarrassment. The impact of stigma on the parent and families resulted in arguments (35%), confusion (47%), separation (24%), growing relationships (12%), depression (47%), and embarrassment (29%).

Overwhelmingly, 7/17 parents believed stigma affected their family’s ability to make and/or keep friends (Figure 1); 10/17 parents identified stigma having an impact on the ability to interact with other relatives (Figure 2); and 8/17 parents believed the experience of stigma effected their quality of life (Figure 3). Overall, stigma does not effect self-esteem as significantly as noted in previous studies. Most parents were neutral at a 4 on a 10-point scale.
Figure 1. Ability to make friends. This graph shows the ability to make friends by parents of children with autism.

Figure 2. Ability to interact with others. Depicted in this graph are the effects of stigma on the ability to interact with others in society.
Figure 3. Stigma affecting family’s quality of life. This figure illustrates parent’s perception on whether stigma has effected the family’s quality of life.

About the same amount of parents were involved in support groups and their religious community. Parents were creative in their coping mechanisms. All parents noted a coping mechanism that has worked for them, insinuating that parents are able to manage life with a child with autism. When assessing the emotions related to stigmatization as a parent of a child with autism, very few parents were shocked or embarrassed. This indicated that parents have been stigmatized before to where the experience is less startling, and unfortunately more expected. As a family member of a child that has autism, it was discovered that family member experience less stigma and internalization of stigma compared to the parent. This can be interpreted under the maximum and limited amount of association with the child. As parents are with their child on a daily basis, they are bound to experience more stigma than a family member who is visible with the child on special occasions or less frequently. Furthermore, when
comparing the emotionality experienced by parents and family members, parents reported feeling guilty, angry, and saddened while families were angry, shocked, and embarrassed. The impact on families caused mainly negative effects instead of positive effects (for example, growing relationships).

The most significant finding, was the correlation between parents who had more than one child with autism in relation their self-esteem level. Parents with more than one child with autism rated the effect of stigma on their self-esteem as a medium-high or the highest amount. These parents may have had a decreased self-esteem due to their creation of more than one child with autism. Society has a preconceived notion of children with autism, and for a family to be composed of multiple children with autism, it is proposed that those families may experience a higher amount of stigma resulting in a higher effect on self-esteem.

Specific Findings

*Figure 4. Experiences of stigma. Depicted above is the frequency and magnitude of parental experiences of stigma.*
The average age of parents experiencing stigma was resulted in high amounts \((M = 11, \text{SD} = 5)\). The experience of stigma of 15/17 parents ranged from 5-20. The peak interval of experiences was between 5 and 10. The distribution of the experiences of stigma was positively skewed, with most of the responses on the lower ranges.

![Bar Chart](image)

*Figure 5.* Effect of stigma on self-esteem. This graph illustrates the frequency of stigma in relation to the self-esteem of parents of children with autism.

The above bar chart shows the effects of stigma on self-esteem on parents. Two students reported the smallest effect of stigma on self-esteem; 4 parents reported a mild effect of stigma on self-esteem; 3 parents reported a medium effect of stigma; 5 parents experienced medium-high effects; and 1 parent experienced the highest amount of stigma.
Table 1 below lists the descriptives of the sample utilized in this study. In this group of participants, the mean score was 11 (standard deviation = 5.00. The range was 17, with the highest score = 19, and the lowest score = 2.

Table 1

Descriptives

<table>
<thead>
<tr>
<th>Experiences of Stigma</th>
<th>Statistic</th>
<th>Std. Error</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>11.0</td>
<td>1.3</td>
</tr>
<tr>
<td>95% Confidence Interval for Mean</td>
<td>Lower Bound 8.23</td>
<td>Upper Bound 13.77</td>
</tr>
<tr>
<td>5% Trimmed Mean</td>
<td>11.06</td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>10.00</td>
<td></td>
</tr>
<tr>
<td>Variance</td>
<td>25.00</td>
<td></td>
</tr>
<tr>
<td>Std. Deviation</td>
<td>5.00</td>
<td></td>
</tr>
<tr>
<td>Minimum</td>
<td>2.00</td>
<td></td>
</tr>
<tr>
<td>Maximum</td>
<td>19.00</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>17.00</td>
<td></td>
</tr>
<tr>
<td>Interquartile Range</td>
<td>9.00</td>
<td></td>
</tr>
<tr>
<td>Skewness</td>
<td>-.028</td>
<td>.580</td>
</tr>
<tr>
<td>Kurtosis</td>
<td>-.735</td>
<td>1.12</td>
</tr>
</tbody>
</table>

Table 2 shows that there is a significant difference between the degrading of families with a child with autism in terms of the negative impact of stigma (chi square = 17.357, p=.043). The same results can also be interpreted to mean that there was a significant difference between the impacts of stigma of which the judgments of others caused. In this case, phi = 1.076, which is a positive relationship between the two variables. Notice that this correlation is flagged as significant, with the same p-value that was give for the chi square test.
Table 2

*Chi-Square Test*

<table>
<thead>
<tr>
<th></th>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>17.357a</td>
<td>9</td>
<td>.043</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>17.991</td>
<td>9</td>
<td>.035</td>
</tr>
<tr>
<td>Linear-by-Linear Association</td>
<td>2.795</td>
<td>1</td>
<td>.095</td>
</tr>
</tbody>
</table>

Number of Valid Cases 15

*Note.* a = 16 cells (100.0%) have expected count less than 5. The minimum expected count is .13.

Displayed below is Table 3, which focuses on the amount of responses for the relationship between families being judged and the negative impact judgment caused for parents. There were two cases that had missing values for “Judging family” and the “Negative impact on parent”.

Table 3

*Case Processing Summary*

<table>
<thead>
<tr>
<th></th>
<th>Valid</th>
<th>Cases Missing</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>15</td>
<td>2</td>
<td>17</td>
</tr>
<tr>
<td>%</td>
<td>88.2%</td>
<td>11.8%</td>
<td>100%</td>
</tr>
</tbody>
</table>

*Note.* N = the number of respondents

In Table 4, notice the negative impact on parents is on the column and judging families is on the row of the cross tabulation assigned. Three parents strongly disagreed that the judging views of society caused a negative impact on them, three parents disagreed, seven parents agreed that the judging views of society caused a negative impact, and two strongly agreed. In this case, the largest difference in the column percentages for survey respondents in the categories of "negative impact on parent" when
compared across "judging family" was that of “strongly Disagree”, which was 75 % (=75-0). The other differences were “disagree” which was 60% (=100-40) and “agree” which was 15% (=80-40-25). Thus there was relationship between families being judged, with the result being negatively impacted parents.

Table 4

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Count Strongly disagree</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Expected Count</td>
<td>.8</td>
<td>1.0</td>
<td>1.0</td>
<td>.2</td>
<td>3.0</td>
</tr>
<tr>
<td>%</td>
<td>75%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
<td>20%</td>
</tr>
<tr>
<td>Count Disagree</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Expected Count</td>
<td>.8</td>
<td>1.0</td>
<td>1.0</td>
<td>.2</td>
<td>3.0</td>
</tr>
<tr>
<td>%</td>
<td>0%</td>
<td>40%</td>
<td>0%</td>
<td>100%</td>
<td>20%</td>
</tr>
<tr>
<td>Count Agree</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Expected Count</td>
<td>1.9</td>
<td>2.3</td>
<td>2.3</td>
<td>.5</td>
<td>7.0</td>
</tr>
<tr>
<td>%</td>
<td>25%</td>
<td>40%</td>
<td>80%</td>
<td>0%</td>
<td>47%</td>
</tr>
<tr>
<td>Count Strongly agree</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Expected Count</td>
<td>.5</td>
<td>.7</td>
<td>.7</td>
<td>.1</td>
<td>2.0</td>
</tr>
<tr>
<td>%</td>
<td>0%</td>
<td>20%</td>
<td>20%</td>
<td>0%</td>
<td>13%</td>
</tr>
<tr>
<td>Count Total</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>1</td>
<td>15</td>
</tr>
<tr>
<td>Expected Count</td>
<td>4.0</td>
<td>5.0</td>
<td>5.0</td>
<td>1.0</td>
<td>15.0</td>
</tr>
<tr>
<td>%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

Note. Parents rated being judged as families from strongly disagree to strongly agree, which is found in the far left column.
Table 5

Effect of Stigma on Self-Esteem vs. Parental Support Groups (Crosstab.)

<table>
<thead>
<tr>
<th>Count</th>
<th>No</th>
<th>Yes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Expected Count</td>
<td>1.2</td>
<td>.8</td>
<td>2.0</td>
</tr>
<tr>
<td>%</td>
<td>22.2%</td>
<td>0.0%</td>
<td>13.3%</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Expected Count</td>
<td>2.4</td>
<td>1.6</td>
<td>4.0</td>
</tr>
<tr>
<td>%</td>
<td>22.2%</td>
<td>33.3%</td>
<td>26.7%</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Expected Count</td>
<td>1.2</td>
<td>.8</td>
<td>2.0</td>
</tr>
<tr>
<td>%</td>
<td>22.2%</td>
<td>0.0%</td>
<td>13.3%</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Expected Count</td>
<td>.6</td>
<td>.4</td>
<td>1.0</td>
</tr>
<tr>
<td>%</td>
<td>11.1%</td>
<td>0.0%</td>
<td>6.7%</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Expected Count</td>
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</table>

Note. In the left column, 1 = the lowest amount of self-esteem and 9 = the highest amount of self-esteem.

Table 5 depicts the relationship between utilizing coping mechanisms (for this example the author used “parental support groups” and “effect of stigma on self-esteem”). There is an evident relationship between the rated levels of self-esteem (1 for the lowest and 10 for the highest). Each level of self-esteem resulted in 10% or higher due to the differences of 10% or more in the categories of the dependent variable, “effect
of stigma on self-esteem". Specifically parents rated their self-esteem as 1 (11%), 4 (10%), 5 (22%), 6 (11%), 7 (22%), 8 (33%), and 9 (11%). It is evident from this table that parents who rated their self-esteem to be 8/10, a high amount of self-esteem, were involved in using a coping mechanism which successfully combated the effects of stigma experienced.

Table 6

<table>
<thead>
<tr>
<th>Parent Stigmatized vs. Biological Children with Autism (Crosstab.)</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>Total</th>
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<tr>
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<td></td>
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<tr>
<td>Count</td>
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<tr>
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<td>%</td>
<td>9%</td>
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<td>0%</td>
<td>7%</td>
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<tr>
<td>%</td>
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<td>.3</td>
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<td>%</td>
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<tr>
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<td>%</td>
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<td>100%</td>
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</tbody>
</table>

*Note.* Parents rated being stigmatized from never to always, which is found in the far left column.

When examining the relationship of the participants with multiple children with autism and their experiences of stigma, the biggest significant relationship was between
parents with three children with autism who reported they experienced stigma often (100%). So, parents with more than one child with autism are prone to experience stigma more often.

Summary

It is evident that children with autism, their parents, siblings, an families’ have been stigmatized. Parents, being more attached to the child, experience more stigmatization and thus negative emotions than other family members. Due to these emotions, parents have an idea of how society perceives them and furthermore, this knowledge negatively impacts the parents leading them to the internalization of stigma. However, a strong relationship was discovered between parents using coping mechanisms and successfully combating the effects of stigma experienced, as their self-esteem was rated higher than other parents. It was hypothesized that parents are prone to experience negative emotionality due to the internalization of stigma as a result of having a child with autism. This study has proven this hypothesis to be true, as participants have expressed feelings of, guilt, sadness, and depression because of their association with their child. Those parents with more than one child with autism reported experiencing stigma more often and thus experienced more negative emotionality. Largely, the data analysis demonstrated that the internalization of stigma is severe as noted by the strong relationship between (1) families being judged and the negative impact of stigma; (2) parental support groups and the effect of stigma on self-esteem; and (3) parents stigmatized and the number of biological children with autism.
Chapter 5

Conclusion, Summary, and Recommendations

There are a number of important implications from this study. First, after connecting theory of stigma, its dimensions and implications, and its impact on those directly connected to the individual with the stigmatized identity to the unique experiences of parents of children with autism, it is clear that there can be a stigma attached to parenting these children. Additionally, it is clear that this stigma is compounded with multiple unique stressors that can make the parenting experience rather difficult. It is also evident that there is little to be done to eradicate the age-old phenomenon of stigmatization, thus many parents and families have experienced stigma.

Secondly, stigma experienced by parents and families of children with autism has multiplied, causing families to internalize stigma. This then brings changes in the home, familial relationships, siblings’ interaction, and parental perception. Stigma can initiate feelings of embarrassment, guilt, anger, sadness, and confusion. With these feelings and emotions, families begin to change their idea of how society perceives them. This is when internalization of stigma takes place. This has brought about a shift in parental self-esteem.

Finally, parents have discovered how to overcome stigma by developing and personalizing coping mechanisms. Being the parent of an individual with a stigmatized identity can result in the parent also being stigmatized, which comes with its own challenges. Parents utilize prayer, exercising, meditation, and counseling, research on autism, support groups, and journaling as a way to manage the negative emotionality
caused by stigma. Nonetheless, these coping mechanisms have shown to improve the lives and self-esteem of parents with children with autism.

Implications for Social Work

It is clear that there is little to be done to remove the ancient phenomenon of stigmatization. But, eliminating the stigma of autism would involve challenging deep-rooted and unconscious perceptions of social value and deviance. There are strategies and adjustments the social work profession can make to improve the parental experience. The first step social workers must take in micro practice is respecting parents for their vital role in the lives of their child. Along with accepting them as individuals, social workers can collaborate with the parent(s) to ensure success for the child. Parents and professionals should build mutually beneficial relationships centered on the child. Changing or eliminating the assumptions that are commonly made about parents can eliminate some of the condescension that exists between parents and outsiders.

The family will need to be encouraged to be an open system. That is, a system open to growth and change instead of remaining closed, one that maintains the status quo and avoids change. Families should be able to learn to change by reaching out to social work agencies that provide support, resources, and strategies for families with a child with autism. Additionally, social workers should provide counseling or treatment so that families can indulge in the process of: (1) exchanging ideas and (2) openly discussing the stressors in relation to living with a child that has autism. Social workers will then increase communication between family members and introduce a safe space to exchange ideas and express feelings.
Lastly, social workers can advocate for parents and families of children with autism as well as advocate for the child that has autism. This can be accomplished through many aspects, one being verbalizing and combating any stigma towards the autistic population. In regards to policy, education of children with autism can be applicable since school is the first place most children with autism will experience the effects of stigma. An important factor for educators to remember is the educational planning process. This experience has been said to have a significant impact on parental perceptions of the educational system as a whole. Parental roles in educational planning should be clearly defined to support success. Parents should also be valued in the process as equal contributors, and appreciated for what they can offer to the team. Accordingly, policies should be established to allow parents the opportunity to play a part in their child’s day at school.

**Recommendations**

To date, only one previous study has applied a scale to measure stigma in families of those with autism (Mak & Cheung, 2008). The findings of the current study mainly recommend Parent Changes scale (Scorgie & Sobsey, 2000), to be used when analyzing the internalization of stigma. Given that this study aimed to discover the positive (coping mechanisms) and negative experiences (internalization of stigma) of parents of children with autism, further development of the stigma scales should be undertaken and re-tested amongst the same population of interest, along with an exploration of a more suitable scale to capture the parents’ positive experiences. Subgroups of parents differ
significantly in terms of certain stigma experiences, so future studies should further explore characteristics of parents that may influence experiences of stigma.

In addition, there should be an equal focus on the way both parents internalize and perceive stigma as opposed to only focusing on the mother. This would help in understanding how both parents, different or same genders, in different roles identify and treat internalized stigma. Future research should seek to explore stigmatization of the family further and discover how it affects the psychological and developmental welfare of siblings of children with autism.

**Limitations**

The current study was limited in the demographics. There was no detailed information about the child or parent, their age, condition and functioning level, socioeconomic details, gender, or race in order to keep confidentiality of the respondents. Without this information, the studies demographics were limited in determining if there was any significance of the way a male or female parent would interpret stigma, or whether the race of the child was an added stigma. Additionally, the amount of participants was very limited due to the author solely receiving participants from an agency instead of the public. This limited the amount of participants who consisted of parents whose children receive services from an agency focused on autism. With these services, their child may be improving more than a child with autism who does not receive services. Thus, stigma may be more prominent amongst children without behavior intervention compared to those with behavior intervention.
Due to the indirect method of recruitment, the author did not connect with the participants in this study. But the agency sent a direct email to their clients. There was no possibility of follow-up by this author, which resulted in a substantial amount of item non-response and lesser participants. There were also limitations to the evaluation of the survey. Only 15 out of a total of 17 parents responded to all items within this survey indicating a minute item non-response. With such a low sample, the slightest deficit is impactful to the study. With parents not responding to all questions, or participants not relating to certain questions, question 4 was deleted. Additionally some of the options under questions 3 and 15 were deleted due to a lack of responses.

**Conclusion**

Many behavioral peculiarities in the form of self-stimulation and inappropriate use of the children with autism’s bodies through flapping, smelling and mouthing objects, and rocking as well as improper forms of social interactions are usually stereotyped. Common prejudice in society is the start of a stigmatized society, which becomes isolated and discrimination against this population follows (Penn, 1998). Moreover, Gray (1993) believed that co-occurring of strong anti-social destructive behavior with children’s normal appearance and low knowledge about autism leads to the increase of stigmatization in these children and essentially their parents. Anti-social and destructive behaviors, which are clearly observable, are considered as impolite and disobedient behavior. People attribute these behaviors to the parent’s way of nurturing, not to the nature of the child’s condition. Although public knowledge about ASD has improved more than other forms of childhood disorders, the general public has little knowledge
about autism. Therefore, parents with children with autism frequently encounter harsh or insensitive reactions from people, especially when their children behave “improperly”. Many parents internalize public stigma in the society by applying negative self-evaluation in their parenting role as well as perceiving the responsibility of the children's behavior and then frequently choosing isolation and avoidance from attending social activity (Mak and Kwok, 2010).

This paper has presented the results of a study of stigma internalized among a sample of parents of children with autism. One of the main findings of the study was the variation in the perceptions of stigma among parents. While the majority of parents have feel stigmatized by their child's disorder, a substantial percentage did not believe they or their families’ internalized stigma and thus there was no occurrence of negative emotionality. There were several issues raised by this research that cannot be resolved by the present data. Perhaps the most important of these is the difference in stigma internalized by parents with more than one child with autism and those with one child with autism. This suggests possible directions for future research concerning internalization of stigma among the parents of children with autism.
Appendix A

Response Letter from the Division of Social Work

To: Deidre Sudderth  
From: Research Review Committee  
Date: November 7, 2014

RE: HUMAN SUBJECTS APPLICATION

Your Human Subjects application for your proposed study, “Stigmatism Internalized by Parents of Children with autism and Coping Mechanisms to Combat its Effects “, is Approved, Exempt, with Recommendation(s). Please review the recommendations below and discuss with your project/project Advisor. You do not need to resubmit your Human Subjects Application to the Research Review Committee.

Your Human Subjects application Protocol # is: 14-15-031. Please use this number in all official correspondence and written materials relative to your study. Your approval expires one year from this date. Approval carries with it that you will inform the Committee promptly should an adverse reaction occur, and that you will make no modification in the protocol without prior approval of the Committee.

Recommendation(s)

Recommendation 1: Include some demographic questions

Recommendation 2: The committee wishes you the best in your research.

Research Review Committee Professors: Jude Antonyappan, Teiahsha Bankhead, Maria Dinis, Serge Lee, Kisun Nam, Francis Yuen
Appendix B

Autism Spectrum Disorder Diagnostic Criteria

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive, see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

Specify if there is severity of symptoms, based on social communication impairments and restricted repetitive patterns of behavior.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g.,
simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify if there is severity of symptoms, based on social communication impairments and restricted, repetitive patterns of behavior.

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism
spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.
Appendix C

Survey Questions

Family Life

1. How many biological children do you have?
   - One
   - Two
   - Three
   - Four
   - Five
   - Other __________________________

2. How many biological children do you have with an Autistic Disorder?
   - One
   - Two
   - Three
   - Four
   - Five
   - Other __________________________

3. How did your family respond to learning that your child(ren) has autism? (Check all that apply)
   - Shocked
   - Judgmental
   - Supportive
   - Neglectful
   - Saddened
   - Other __________________________

4. Have the patterns of relating (or interactions) between family members changed? If so, please state below. If not, please move to question #5. ________________

5. Do you have any children without an autistic diagnosis? If yes, please check ‘yes’ then move forward to question #6. If no, please check ‘no’ and skip to question #7.
   - Yes
   - No

6. How have your children (without autism) reacted to having a sibling with autism? (Check all that apply)
   - Kindly
   - Confused/Questioning
   - Helpful
7. Do you have family events (i.e. dinner, movies, sport games, etc.) without your child with autism? If so, please state below. If not, please move to question #8.  
_______________________________________________________________

Experiences of Stigma

8. Do you believe people think less of those with autism?
   - Never
   - Rarely
   - Sometimes
   - Often
   - Always

9. Do you think that people think less of you or your family because of your autistic child(ren)?
   - Never
   - Rarely
   - Sometimes
   - Often
   - Always

10. Do you think that the average person is afraid of someone with autism?
    - Never
    - Rarely
    - Sometimes
    - Often
    - Always

11. Has your child(ren) been stigmatized because of his/her autistic diagnosis?
    - Never
    - Rarely
    - Sometimes
    - Often
    - Always

12. Have you felt stigmatized because of your child’s condition?
    - Never
    - Rarely
    - Sometimes
    - Often
    - Always
13. If you answered ‘sometimes’, ‘often’, or ‘always’ to question #12, what emotions came about due to the stigmatism? (Check all that apply). If you answered ‘never’ or ‘rarely’ please skip to question #14.
   - Angry
   - Shocked
   - Embarrassed
   - Guilty
   - Saddened
   - Other __________________________

14. Have other members of your family been stigmatized because of your child(ren) with autism?
   - Never
   - Rarely
   - Sometimes
   - Often
   - Always

15. If you answered ‘sometimes’, ‘often’, or ‘always’ to question #14, what emotions came about as a result of being stigmatized? If you answered ‘never’ or ‘rarely’ please skip to question #16.
   - Angry
   - Shocked
   - Embarrassed
   - Guilty
   - Saddened
   - Other __________________________

16. What impact has stigma had on you and your family? (Check all that apply)
   - Arguments
   - Confusion
   - Separation
   - Growing relationships
   - Depression
   - Embarrassment
   - Other __________________________

17. Has stigma affected your family’s ability to make or keep friends?
   - Yes
   - Not sure
   - No

18. Has stigma affected your ability to interact with other relatives?
   - Yes
   - Not sure
   - No

19. Have your experiences with stigma affected your family’s quality of life?
   - Yes
20. On a ten-point scale with one being the lowest possible amount and ten being the greatest possible amount, how much has stigma affected your self-esteem? Please state the number that best quantifies this impact. __________

Internalization of Stigma

21. Most people believe that parents of children with autism are just as responsible and caring as other parents.
   - Strongly disagree
   - Disagree
   - Agree
   - Strongly agree

22. Most people look down on families that have a member who is autistic living with them.
   - Strongly disagree
   - Disagree
   - Agree
   - Strongly agree

23. Most people believe their friends would not visit them as often if a member of their family were receiving behavior intervention for autism.
   - Strongly disagree
   - Disagree
   - Agree
   - Strongly agree

24. Most people treat families with an autistic child in the same way they treat other families.
   - Strongly disagree
   - Disagree
   - Agree
   - Strongly agree

25. Most people do not blame parents for the condition of their children.
   - Strongly disagree
   - Disagree
   - Agree
   - Strongly agree

26. My reputation is damaged because I have a child with autism at home.
   - Strongly disagree
   - Disagree
   - Agree
   - Strongly agree

27. People’s attitudes towards me turn sour when I am with my child.
28. Having a child with autism forces a negative impact on me.
   - Strongly disagree
   - Disagree
   - Agree
   - Strongly agree

29. Having a child with autism makes me think I am less important to others.
   - Strongly disagree
   - Disagree
   - Agree
   - Strongly agree

Coping Mechanisms

30. As a coping strategy, do you try to avoid situations that may be stigmatizing to your family?
   - Yes
   - Not sure
   - No

31. Are you involved in any parental support groups?
   - Yes
   - No

32. If you answered you ‘yes’ to question #31, are the support groups beneficial to coping with the learned stigma? If you answered ‘no’, please skip to question #33.
   - Yes
   - No

33. Are you involved in a religious community?
   - Yes
   - No

34. If you answered ‘yes’ to question #33, has your religion helped you manage any negative emotions? If you answered ‘no’, please skip to question #35.
   - Yes
   - No

35. What has been helpful for you to face the stigmatism of having a child with autism? (Check all that apply)
   - Reading
   - Journaling
   - Exercising
   - Cooking
   - Research on Autism
☐ Counseling
☐ Meditation
☐ Prayer
☐ Music
☐ Other _________________________

36. Is there anything else you would like the researcher to know about your emotional experiences as a parent of a child with autism that has not been asked?

__________________________________________________________________
__________________________________________________________________
________________________
Appendix D

Recruitment Letter

Hello Parents,

I am writing to tell you about a study that aims to investigate stigma experienced by parents of children with autism and coping skills. This study is meant to expand upon previous research, which is more than a decade old. The specific purposes of this research study are to explore the experience of parenting a child with autism, including experienced stigma and coping skills that have been helpful to families with children with autism. Deidre Sudderth, at the California State University at Sacramento, is conducting this study.

There will be an anonymous survey issued through the Internet, consisting of 36 questions in total. The information requested covers (1) family life; (2) experiences of stigma; (3) internalization of stigma; and (4) coping mechanisms. The survey is expected to take no more than 15-20 minutes to complete.

You may be eligible for this study if you: (1) have a biological child with autism that is between the ages of 4-11 years old and (2) are English speaking. If any of these screening conditions are not met, please do not take the survey.

It is important to know that this letter is not to require you to join this study. It is your decision. Your participation is voluntary. Whether or not you participate in this study will have no effect on your relationship with the Institute for Applied Behavior Analysis (IABA) as a client. In fact, IABA will not know whether you participate in this survey or not.

If you would like to participate in this study, please enter this link (https://www.surveymonkey.com/s/F5JN8MM) on your web browser.

If you would like to talk to the researcher directly, please contact Deidre Sudderth at (707) XXX-XXXX.

Thank you for your consideration!
Appendix E

Implied Consent

**Study Topic:** Stigmatism Internalized by Parents of Children with Autism and Coping Mechanisms to Combat its Effects

**Researcher:** Deidre Sudderth, Masters student, MSW Program in Social Work, California State University, Sacramento

**Purpose Of The Research:** This study primarily seeks to explore the experience of parenting a child with autism, and specifically to investigate the internalization of stigma on families because of their child's diagnosis. The secondary purpose is to identify recent and/or different coping styles that have been helpful to families with children with autism compared to studies completed more than 10 years ago.

**What You Will Be Asked To Do In The Research:** The survey consists of 36 questions in total. The information requested includes (1) family life; (2) experiences of stigma; (3) internalization of stigma; and (4) coping mechanisms. The survey is expected to take no more than 15-20 minutes to complete.

**Risks And Discomforts:** There are no foreseen risks or discomfort from your participation in the research. There is a possibility that the questions being asked in the researcher’s survey could result in uncomfortable emotions. If this occurs, please be advised that you can always choose not to answer any questions and/or decide to withdrawal from the study. Participating in the study has no relation with receiving service from the Institute for Applied Behavior Analysis (IABA) and there is no harm from participating or not participating in the study.

**Benefits Of The Research And Benefits To You:** It is expected participants will experience general feeling of reward for: (1) participating in the study, and (2) advancing the cause of better knowledge and insight into autism and it’s impact on families. There are no anticipated risks to the subjects. Respondents will not be compensated in any way.

**Voluntary Participation:** Your participation in the study is completely voluntary and you may refuse to answer any question or choose to stop participating in the study at any time. Your decision not to volunteer will not influence the treatment you may receive or the nature of your relationship with California State University, Sacramento or the Institute for Applied Behavior Analysis either now, or in the future.

**Withdrawal From The Study:** You can stop participating in the study at any time, for any reason. Your decision to stop participating, or to refuse to answer particular questions,
will not affect your relationship with the researcher, California State University, Sacramento, or IABA. Should you decide to withdraw from the study, all data generated from your participation will be destroyed.

**Confidentiality:** All information you supply during the research will be held in confidence. Your data will be safely stored in a locked facility and only the researcher and advisor will have access to this information.

**Questions About The Research:** If you have questions about the research in general or about your role in the study, please feel free to contact the researcher, Deidre Sudderth at (707) XXX-XXXX, or deidresudderth@csus.edu or the researcher’s project advisor, Dr. Kisun Nam at (916) 278-7069 or knam@saclink.csus.edu.

**Consent:** I have understood the nature of this project and consent to participate by clicking 'next' below.
References


