Uncovering the Stigma in Parents of Children with Autism

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by

Allison Kady Wnoroski

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ABSTRACT

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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 thesis seeks to explore the experience of parenting a child with autism, and specifically the possibility that parents are stigmatized because of their child’s diagnosis. Examining traditional theories of stigma in the first part of this work will lay a framework with which to evaluate the experience of the population of interest. Part two will seek to apply theory to the particular experience of parents of children with autism. Finally, part three will integrate qualitative data from personal interviews into a broad conceptualization of the manifestation of stigma in parents of children with autism.

As an often invisible disability, and one that can incur unwarranted blame on the parents, it appears that autism certainly is stigmatized against in both children and parents. This research will begin to provide recommendations for professionals working with this population, and act as an impetus for future research.
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by Allison Wnoroski

Approved by:

___________________________, Advisor
Dr. Kathy McMahon-Klosterman

___________________________, Reader
Dr. Julie S. Rubin

___________________________, Reader
Dr. Paul Flasphohler

Accepted by:

___________________________, Director,
University Honors Program
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Introduction

Autism is a neurological disorder affecting an estimated one in every 150 children (Rice, 2007). This pervasive developmental disorder impairs a child’s communication and social interaction, and causes the development of stereotypic or repetitive behaviors or interests. It is clear that this devastating diagnosis can impact a child in every realm of their existence. As autism grows more prevalent among today’s children, information and research in this area have exploded.

Despite the prevalent research on autism, few studies have investigated the effect of this disorder on the child’s parents. Autism, at its very core, makes intimate familial relationships extremely difficult to develop. It is a disorder that inherently changes the parent-child relationship: communication is impeded or even impossible; intimacy can be a challenge, and a child’s self-injurious behaviors may make a parent 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. But of additional concern is whether the parents face stigmatization as a result of bearing and raising a child with autism.

Stigmatization, or 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, can certainly have negative effects on the individual involved. They are marginalized by society, may have difficulty obtaining necessary services and benefits, and suffer overall psychological strain (Major, 2006).

Some may argue that a child with autism does not in itself directly affect the identity of the parent. However, simply being the parent of a child with autism can greatly influence or
shape one’s identity. Do parents feel a sense of shame or experience stigmatization as a result of their child’s autism? As an often invisible disability, and one that can incur unwarranted blame on the parents, it appears that autism certainly is stigmatized against in both children and parents. It is 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 disorder impacts the primary caretakers of children with autism.

To investigate the stigma that may be associated with parenting a child with autism, I will first evaluate traditional conceptualizations of stigmatization to understand how it can apply to a particular population. I will explore the implications of being a stigmatized identity and then discuss the concept of secondary stigma, or stigma by association. I will then apply this theory to the population of interest (parents of children with autism) using qualitative case analyses to support or refute research findings. Finally, I will offer suggestions of how to begin to mitigate the stigma, if present, and recommendations for educators and school professionals in working with parents of children with autism.
Chapter 1: Stigma

Definitions

The term *stigma* was originated by the Greeks, referring to “bodily signs designed to expose something unusual and bad about the moral status” of the individual in question—attributes meant to expose disgrace or personal failure (Goffman, 1963, p. 1). The concept of the marked or blemished identity, therefore, is by no means contemporary. Humans have a natural tendency to categorize and marginalize deviance (Dovidio, Major & Crocker, 2000). Unfortunately, such marginalization can have negative implications for the stigmatized individual and those associated with them. Before discussing these implications, I will more closely examine the concept of stigmatization.

Goffman (1963), in his early discussion of stigma, broadly describes the situation in which an individual does not receive full social acceptance. The stigmatizing condition can be a physical mark or moral blemish that signals the individual is to be devalued. More recently, the term has “tended to be associated almost exclusively with ‘inferior’ forms of physical appearance, conduct or ethnicity” (Page, 1984, p. 2). Inferior attributes are ones that clearly violate common and widely held social norms, again signaling that the person’s identity has been, in a sense, spoiled.

Dovidio, Major and Crocker (2000) defined stigma as a social construction with two primary components: first, the recognition of difference based on some distinctive trait, and then, the ensuing devaluation of the person. Additionally, they note the more contemporary trend to focus on the “contextual and dynamic nature of stigma” (p. 3), with the basic idea that stigma is in the eye of the beholder, or dependent upon its social context. Stigma involves the relationship...
between what is perceived about an individual and how this perception compares with socially acceptable traits or attributes for that population. Ultimately, Kando (as cited in Page, 1984) sums up the concept of stigma quite nicely: “In its most sociological sense, the term stigma can be used to refer to any attribute that is deeply discrediting and *incongruous with our stereotype of what a given type of individual should be*” (p. 1, emphasis added).

So why do we stigmatize? What function does it serve? Social stigma is a phenomenon observed in nearly every generation, every culture, and every society. As such, it would be reasonable to explore the possibility that it serves some function for the observer. In fact, stigmatization can serve several, including “self-esteem enhancement, control enhancement, and anxiety buffering” (Dovidio, Major & Crocker, 2000, p. 7).

One process people use to perceive the self is that of social comparison (Wills, 1981). Downward social comparison processes can serve to enhance one’s self-esteem by way of comparison to those less fortunate. This comparison boosts the individual’s general sense of well-being and good fortune, and this process can certainly be achieved through the act of stigmatization.

Additionally, stigmatization can enhance an individual’s feelings of control. Stigmatizing conditions inherently cause anxiety and perceived threat in observers, so it makes sense that discriminating or marginalizing carriers of such conditions would help to ease the anxiety and thus reinforce feelings of control. Additionally, using broad stereotypes to categorize individuals allows the observer to make inferences about their character and predict their behavior beyond what they could using only the available information, again adding to the observer’s perceived control of the situation (Dovidio, Major & Crocker, 2000).
Finally, stigmatization can serve to alleviate or reduce anxiety. Rejecting difference is a means of reinforcing one’s own world view and social context, buffering some of the anxiety the difference aroused in the first place (Dovidio, Major & Crocker, 2000). It is widely held that the initial function of stigma formation is avoiding threat to self (Stangor & Crandall, 2000). As threat, of course, induces anxiety, the ensuing stigmatization should serve to relieve it.

**Dimensions of stigma**

Jones et al. (1984) describe six chief dimensions impacting the manifestation of stigmatization in everyday interactions: concealability, course, disruptiveness, aesthetic qualities, origin and peril (p. 24). The first dimension, concealability, refers to the visibility of the condition, as well as how controllable the visibility is. This is a fundamental aspect impacting the degree to which a individual is stigmatized. Course, the second dimension, refers to the pattern of the condition over time. Some stigmatizing conditions may fade over time, while others are constant. The disruptiveness of a stigmatizing condition is self-explanatory—the degree to which the condition disrupts social interaction. The aesthetics of a stigmatizing condition reference how attractive (or unattractive) the mark appears. Origin indicates how the mark came to be, and lends itself to questions of the victim’s responsibility in producing the mark. Peril, the final dimension, focuses on the threat of danger posed by the stigmatized individual (Jones et al., 1984). These dimensions are extremely useful in distinguishing how and why we stigmatize others, and to what degree.

Similarly, Katz (1981) identified visibility, threat, and perceived responsibility as significant factors in predicting how observers will react to typically stigmatized individuals. There are several visibility considerations of stigmas. There is obviously the physical visibility
of a condition—can it be seen? Goffman (as sited in Katz, 1981) also identifies the “known-aboutness” (p. 3) of the condition, which can vary depending on a person’s knowledge of or experience with the stigmatized individual. The next feature he identifies is “that of obtrusiveness—the extent to which a stigma interferes with the flow of interaction” (p. 3), citing the example of a blind man’s cane. The cane can be clearly seen but not attended to, while the absence of eye contact in conversation is an unavoidable disruption in interaction (Katz, 1981, p. 3). Finally, the focus of the stigma is a feature of visibility referring to in what context the stigma has salience, or is most focused. All of these features accumulate to form a person’s perception and awareness of the stigmatizing condition, and thus impact how they will treat the possessors.

Threat is an element of stigma that varies widely, but is nearly always present. Behavioral deviants tend to elicit the most fear of “physical harm and social disorder,” (p. 3) because they challenge fundamental societal expectations. Perceived responsibility, the third significant factor defined by Katz, has considerable influence on the way the individual possessing the stigmatizing condition will be treated. Katz states:

There may…be a relatively primitive, unconscious tendency to assign more blame to handicapped individuals when the disorder is genetically determined than when it is the result of an accident, since the former type of causation may be perceived as more closely associated with the person. (p. 4-5)

This tendency, albeit primitive and unconscious, will prove to have extreme significance when handling the secondary stigma experienced by parents of individuals with a stigmatized identity. Katz highlights the fundamental error humans tend to make in attributing causality and in turn, blame.
The concept of correspondence bias found in social psychological attribution theories may begin to answer an enduring question: why do we blame individuals for the condition that stigmatizes them? Attribution theory attempts to explain how humans attribute causality to the behavior of others, and the correspondence bias refers to our tendency to underestimate the impact of the situation and overestimate dispositional factors in explaining others’ behavior (Gilbert, 1995). The correspondence bias, also known as the Fundamental Attribution Error, is basically a misattribution of behavior to one’s personality when the situation is actually to blame. This idea can be connected to Katz’s ‘perceived responsibility’ dimension of stigma. We are more apt to assign responsibility to the individual than to assign responsibility to the situation the individual is in, which can eventually result in stigmatizing circumstances or conditions that do not warrant stigmatization.

Both Jones’ and Katz’s theories present very important considerations to evaluate when trying to understand stigmatization. Visibility and perceived responsibility are two of the most significant, if not the most significant, variables to identify. I will discuss these factors with reference to their particular significance when dealing with parents of children with autism in further detail in Chapter Two of this work.

Implications

Being an individual with a stigmatized identity does not come without its costs. There can be many cognitive, affective and behavioral implications. At the organizational level, discriminatory treatment can make obtaining certain resources or benefits difficult (Major, 2006). Such treatment can jeopardize the health and general well-being of the stigmatized. “The stigmatized are also ignored, excluded, patronized, and targeted by physical violence” (Major,
which can damage their psychological and social health. Additionally, it is not uncommon for the victims of stigmatization to have elevated anxiety and stress as a result of all the negativity that surrounds their condition or even their identity (Major, 2006).

Several theories of the effects of stigmatization have also identified a phenomenon in which stigma “becomes internalized into chronic feelings of inferiority” (Major, 2006, p. 194). Although this effect has certainly not been demonstrated by conclusive evidence, it seems intuitive, and as Allport (1954) aptly commented, “One’s reputation, whether false or true, cannot be hammered, hammered, hammered into one’s head without doing something to one’s character” (p. 142).

Finally, stigma is presumed to have a significant impact on the self-esteem of the stigmatized. Crocker and Quinn (2000) use a contemporary view of self-esteem as a construct of the context or situation (rather than a fixed or stable aspect of the personality), and thus approach the self-esteem of the stigmatized individual as a product of their situation. If or when a lack of self-worth emerges, it is because the situation has social significance to the individual. As such, when an individual approaches a socially significant situation in which they are discriminated against and marginalized, their self-esteem will certainly suffer (Crocker & Quinn, 2000).

Stigmatized individuals may engage in a variety of coping strategies in response to negative treatment and their own internal suffering. Miller and Major (2000) site a coping inventory (the COPE scale; Carver et al., 1989, as cited in Miller & Major, 2000) that distinguishes 13 different ways that people say they can cope with a stressful situation, “including avoidance, denial, mental disengagement, behavioral disengagement, acceptance, positive reframing, venting negative emotions, seeking emotional support, seeking instrumental social support, religious coping, suppressing activities, active coping, and planful coping” (p.
Presuming stigmatization to be a stressor, any of these strategies can be used to manage the ramifications. A chief goal of coping with stigma is believed to be the reduction of stressful emotions initiated by the stigmatization, and this can be done through emotion-focused coping (Miller & Major, 2000). “Examples of emotion-focused efforts to cope with stigma include attributing a failure to external factors rather than to one’s own limitations, devaluing the importance of a domain in which one has experienced a failure, or engaging in…social comparisons” (Miller & Major, 2000, p. 251). Social comparisons can either be restricted to individuals with a similar stigmatized identity to protect the individual from the emotional strain of comparison with non-stigmatized observers; or can be downward social comparisons that alleviate some of their own negative emotions (Miller & Major, 2000). These coping strategies can be observed in the behaviors of parents of children with autism, discussed in Chapter Three of this work.

Research has consistently shown that possessors of a stigmatizing condition face certain challenges that are unique to their experience. There are also, however, unique challenges for those who simply associate with the stigmatized. Being the parent of an individual with a stigmatized identity can result in ‘secondary’ stigma, with its own implications and challenges.

Secondary stigma

The individual with a stigmatizing condition is not isolated in the experience of stigmatization. Unfortunately, any individual who is “related through the social structure to a stigmatized individual” (Goffman, 1963, p. 30) may be treated similarly. Neuberg, Smith, Hoffman and Russell (1994) posit balance processes as determinant of the result of these interactions. To restore balance between the incompatible nature of the marked and normal
individuals, the observer can either de-stigmatize the marked individual or stigmatize the normal individual, depending on the strength of their initial perceptions. Stigma by association occurs in the latter situation, when a typical individual experiences negative treatment because of their connection to the stigmatized individual.

Parents of stigmatized children experience myriad ramifications in response to their child’s diagnosis or condition. A genetic connection to a stigmatized individual is one that is impossible to escape, rendering stigma by association inevitable for parents. Additionally, the birth of a child with a disability may significantly restrict the parents’ activities and social lives, bringing about change across every domain of life (Jones et al., 1984). Being associated with a stigmatized individual in this way, then, often leads to experiencing the stigma directly. Given the particular population of parents of children with autism, I will identify how this stigma manifests itself due to the unique nature of autism as a pervasive developmental disorder.
Chapter 2: Applying Stigma Theory to a Population of Interest

Autism

Kanner first recognized the group of symptoms (now identified as autism) as a disorder distinct from any other in the 1940’s. He noted common characteristics among a group of children that did not fit in any established diagnosis, such as isolation and self-direction in activities. Kanner initially differentiated the diagnosis of autistic disorder, and this diagnosis is currently defined in the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition: Text Revision (2000) of the American Psychiatric Association (Scott, Clark & Brady, 2000).

There are three primary aspects of functioning that are impaired by autism. The first is communication. Communication does not just involve speech and language; it is the means by which people share and exchange ideas. Autism can impair any aspect of one’s ability to communicate effectively. This impairment is necessary for a diagnosis of autism, but the degree of impairment can range from completely nonverbal to advanced vocabulary skills (Scott, Clark & Brady, 2000).

The second aspect of functioning greatly impacted by autism is in the social domain. “A deficit in social relatedness is essential to the diagnosis of autism” (Scott, Clark & Brady, 2000, p. 16). Often, children with autism appear aloof, have little or no regard for their peers, and do not understand social reciprocity. These qualities can make them seem emotionally cold and resistant to social relationships. The absence of social responsiveness is “one factor that makes autism particularly stressful for parents” (Glasberg, Martins & Harris, 2006, p. 280). Typically developing children tend to express affection for their parents, which in turn reinforces the parent for their behavior in light of the general stressors involved in raising a child. However, this
tendency can be absent or considerably lacking in individuals with autism, thereby increasing the intensity of parental stressors (Glasberg, Martins & Harris, 2006).

Finally, behavioral aspects of autism complete the triad of deficit. The behavioral attributes are often the easiest to identify and the most obvious indication of difference. Similar to all other aspects of autism, stereotypic or inappropriate behaviors manifest themselves in a spectrum; there is a wide range of “behavioral symptoms, including hyperactivity, short attention span, impulsivity, aggressiveness, self-injurious behavior, and temper tantrums” (Scott, Clark & Brady, 2000, p. 23). These difficulties are generally classified as excesses or deficits.

It is apparent from this brief discussion of the characteristics and hallmark behaviors of autism that it can be exceedingly difficult for parents and family members to cope with. Intimate relationships are difficult to develop due to the very nature of the disorder, completely changing the experience and role of the parent. The questionable etiology of autism is of additional concern. Unfortunately, “the problem of what causes autism is not yet solved” (Hewetson, 2002, p. 119). Although significant amounts of research have investigated brain abnormalities, genetic and neurochemical abnormalities, infections, and diet, among many other things, there has been little conclusive evidence pointing to any one, identifiable cause in the majority of cases. This absence of an identifiable antecedent in most cases may result in a serious misattribution of blame in the direction of the parents, which I will discuss later.

*Applying Katz’s Dimensions of Stigma*

As previously discussed, several chief dimensions of stigmatization have been identified by numerous researchers. It appears that certain dimensions have greater salience in this
population of parents of children with autism, and those are Katz’s dimensions of visibility and perceived responsibility (blame).

Visibility

Very little research addresses the stigmatization of the parent raising a child with autism. Literature most often addresses causes, the incurred stress, and coping strategies associated with having a child with autism, and this information can be helpful in determining how the primary factors of this stigma interact to build a parent’s experience.

A concealed stigma refers to a “stigmatized identity that is not immediately knowable in a social interaction” (Quinn, 2006, p. 84). Autism can be just that—it is very often a hidden identity. There are no visible markers and no necessary physical ailments or features. Some might consider this a positive feature—if nobody knows a child has a problem, how can they stigmatize or judge them? This may be true on some level. However, when a child is misbehaving in public, and they have no physical marker to act as an ‘excuse,’ they may in fact be judged more harshly. The average American feels a certain degree of pity for a person with a disability; in a 1991 Harris poll, an impressive 77% of the public said they felt “pity” for disabled people (Harris, 1991). Pity may be unwelcome, but it involves an element of compassion and sympathy. Without any sign to indicate the disability of the child with autism and trigger pity, their behavior problems elicit negative treatment, especially towards parents. Although pity may have a negative connotation in society, it can at least provide some relief to a parent. Parents of children with autism often report more stress than parents of children without disabilities or parents of children with other disabilities, such as Down’s syndrome (Hastings et al., 2005). This added stress could very well be attributed to the lack of sympathy and support parents receive from out-group members who simply can’t see the child’s ailment.
Stigmatization very likely increases as a function of visibility: as the condition becomes less visible, it becomes more stigmatizing because there exists no element of pity.

On the other end of the spectrum, some parents may choose to hide their child’s diagnosis to avoid stigmatization. However, research illustrates that the act of hiding a stigma can itself be psychologically damaging. Smart and Wegner (2000) state that concealing a stigma “leads to a turmoil that is remarkable for its intensity and its capacity for absorbing an individual’s mental life” (p. 221). Parents may, inadvertently, become subject to this turmoil when they actively suppress the knowledge of their child’s disorder through denial. In a 2005 study of parents’ coping strategies, active-avoidance coping (e.g., denial, drug/alcohol abuse, abandoning hope) was related to more stress and mental health problems in both mothers and fathers (Hastings et al., 2005). As one of the coping strategies often used to deal with stigmatization, denial can clearly initiate problems in parental functioning.

Though it may seem as if revealing the child’s condition would solve these problems, it is not necessarily that simple. Some families do want people to know and understand their child’s disorder, while others are uncomfortable sharing this information. Their fears may be related to the second element of this stigma—the blame placed on the parents for their child’s condition.

**Perceived Responsibility**

Autism spectrum disorders are neurological, not psychological or environmental. Because impairments are so behaviorally-linked, however, it is simple to lose sight of this fact and turn blame on the parents. This is historically a common trend. As early as the 1950’s, Bruno Bettelheim coined the term “refrigerator mother,” convinced that autism was the result of an upbringing by mothers who did not want their children to live (either consciously or unconsciously) which in turn caused them to restrain contact and fail to establish an emotional connection with their child (In from the Cold, 2004). Unfortunately, Bettelheim’s continual
“maligning of parents of children with autism caused irreparable harm and unnecessary guilt to generations of parents” (Scott, Clark & Brady, 2000, p. 51). In 1961, a study on the etiology of autism concluded that in 80 children with autism studied, their difficulties “invariably involved the particular developmental stage when the mother was the primary object to the child, so that the disturbance caused the child to adopt a basic paranoid attitude toward the mother” (Sarvis & Garcia, 1961).

Unfortunately, these primitive theories still color how parents of autistic children are viewed today. It’s often as if their parenting practices are evaluated harshly; even professionals tend to make this error, simplifying the etiology of autism and becoming involved in a cycle of pity and blame in parental interaction (Hingley-Jones, 2005). This attitude does little to ease the guilt parents already tend to feel, and indeed may exacerbate what becomes a “powerful sense of shame and persecutory guilt resulting from the parents’ unconscious feeling of responsibility for somehow causing the disability” (Hingley-Jones, 2005, p. 124). A 2000 study found a much greater degree of guilt in mothers of children for whom regression was a part of the developmental course of autism (Davidovitch, Glick, Holtzman, Tirosh & Safir, 2000), illustrating that parents may feel especially guilty when their children begin development normally and then regress.

The need to blame someone is not solely reserved for the general public. Even parents are searching wildly for some source of responsibility for their child’s disorder with an intense need to find a scapegoat. Klauber argues that this can be explained by looking at parents of children with autism as if they are experiencing a trauma (the child’s diagnosis) for which they have inadequate coping resources (as cited in Hingley-Jones, 2005, p. 124). It has been shown that those who do not have the internal resources to process such a trauma may make use of primitive projective processes to get rid of the unwanted feelings of guilt, projecting fault to varied available sources. A contemporary example of this is the overwhelming number of
parents who cite the MMR vaccine their child received as the “cause” of their child’s autism. Research has consistently shown that there is no link of causation between the receipt of this vaccine and the presence of autism, yet many parents still believe wholeheartedly that the immunization is to blame. Still others look to diet, childhood trauma, fever, and a multitude of other factors as the reason for their child’s autism. Although in a small percentage of cases such a trigger may in fact be identified, it is impossible to distinguish a consistent cause-and-effect relationship between any one factor and a diagnosis of autism. This intense need to do just that, and avoid responsibility, illustrates that somehow, whether intentionally or not, society tends to place the responsibility on the parents when there is no other scapegoat, which in turn increases their stigmatization and parental stress. Avoiding personal responsibility and attributing causality to external factors is a means of emotion-focused coping used to manage stigmatization that can certainly be observed in this particular population.
Chapter 3: Integrating the Data

Methods

I used a qualitative approach to gather data for this study. I chose to do a qualitative analysis to examine more deeply the experiences of a focused group of subjects. I wanted to perform a global and in-depth assessment of the parents’ experiences to best understand how their identity as a parent of a child with autism impacted each realm of life, and this was most effectively accomplished through personal interviews.

Participants were three parents of children with autism. Two participants are currently parenting their school-age children, and one participant is the parent of a grown child (subjects one, two and three, respectively). Each interview was performed with the mother.

Subject One is the single mother of a six-year-old son who was diagnosed at age two. Her child is non-verbal, often exhibits self-stimulating behavior, and is educationally placed in a kindergarten classroom for students with autism spectrum disorders. Subject Two is married and has two children. Her daughter, currently ten years old, was diagnosed at age three-and-a-half. Her typically developing son is six years old. The child diagnosed with autism communicates primarily through illustration and is very sensitive to emotional extremes. She attends school in a 4th-grade classroom for students with autism spectrum disorders. Subject Three is also married, and the mother of a 23-year-old male who was diagnosed with autism at age two-and-a-half. She and her husband have a typically developing daughter who is 25. In his childhood, her son was extremely destructive and exhibited difficult-to-manage behaviors. He currently lives semi-independently and maintains employment through an Mental Retardation and Developmental Disabilities (MRDD) board.
To recruit the parents of grown children, a request for voluntary participation was sent out through the Butler County (OH) Mental Retardation and Developmental Disabilities Board (MRDD). Similarly, to recruit parents of school-age children, a request for voluntary participation was sent out through an Akron Public Schools (OH) administrator. Volunteers contacted the researcher directly. Participants signed a form of consent before engaging in the study.

The primary material used to interview participants was a questionnaire developed by the investigator (Appendix A). The questionnaire was comprised of 26 questions concerning the participants’ child, family life, resources, and experiences as a parent. The interviews were conducted over the phone. Open-ended and appropriate questions encouraged reflection and responsiveness in the interview.

While I certainly collected valuable information from these interviews, a small sample was used, and thus cannot be presumed to account for the entire population of interest. Because the data was gathered from personal accounts and reflection, it is subject to some level of bias. This research, however, has significance in approaching a previously unexplored facet of the parental experience, and I hope that there is value in probing this territory.

Trends

Several trends emerged in analyzing the quantitative data that was gathered. Some of these are illustrative of the behaviors or coping strategies that can be used to manage stigmatization. In this section, I highlight and describe these trends.
Negative Experiences & Personal Isolation

Each subject noted negative experiences that have been associated with raising a child with autism. These experiences most often came in the form of the rude comments or harsh treatment of strangers. Autism is so behaviorally-linked in its manifestation that it can be easy for strangers to make assumptions about parenting based on the child’s behavior, and this is exactly what the subjects perceived as happening. They cited hearing comments such as, “I would never let my child get away with that,” or “If that were my child, I would have smacked her by now” (personal communication, April 3, 2008). Unfortunately, regularly hearing such comments can certainly damage the parent’s self-perception and increase their feelings of guilt by reinforcing that they are the ones perceived to be responsible for the child’s disorder. The emotion-focused coping strategies discussed that attribute stigmatizing conditions to external factors rather than to internal or personal factors illustrate the parent’s strong need to avoid responsibility, and thus, stigma. When confronted with such accusatory perceptions from observers, it is not a surprise that parents feel further stigmatized.

A second area of negativity parents expressed were feelings of personal isolation. They often felt alone, especially soon after their child’s diagnosis, and felt like there was an initial absence of support from outside their immediate family. Such feelings of isolation compounded with the socially imposed feelings of guilt can exacerbate what is already a significant amount of stress on the family.

Screening Activities

A second area of concern that emerged was the tendency of parents to screen their activities with regard to their child with autism. This practice mirrored the coping strategy of “suppressing activities” to manage stigmatization. Each subject described situations in which
their family was unable to participate or function as a unit because of the limitations of their child with autism. Subject Two revealed that she screens everything they do as a family to ensure that everyone will have an enjoyable experience, whether this means including her child with autism or not. She noted that a primary concern in her family is forcing her typically developing son to modify his behaviors and interests to accommodate those of his sister. She hopes to avoid such situations by evaluating events before they happen to determine their appropriateness for her daughter. Additionally, limiting activities can limit the parents’ exposure to negative treatment and stigmatization.

Similarly, Subject Three described their family engagement as slowly funnelling more and more into a restricted network of other parents of children with autism. They began engaging in activities primarily through this community, until every domain of life was dominated by autism. This became a “defense mechanism,” enabling the family to screen out negativity before it could damage them (personal communication, April 15, 2008), as well as allowing for social comparison to similar individuals to reduce feelings of stigmatization.

Different Settings, Different Experiences

Two settings emerged as having the most salience for parents of children with autism. The first was the public domain, including the grocery store, restaurants, playground, or any other community setting. As mentioned, these situations often brought about the most stress and awkward interaction. Observers often passed judgment and made negative comments in the presence of the children’s undesirable behavior, which had noteworthy effects on the parents’ feelings of stress and guilt.

The child’s school environment was the second setting for which subjects cited significant experiences. Interactions in the school environment were colored by unique
perceptions and expectations. Two of the subjects described feeling confident in their children’s teachers, and in particular perceived the teachers’ desire to shape student success. Interestingly, though, Subject Three, who went through the educational system 20 years ago, described more situations in which educated professionals made the same kind of assumptions that strangers made about her child. Specifically, in manifestation determination meetings, in which the primary goal was to determine whether or not the child’s disability was to blame for some sort of misbehavior that required disciplinary action, well-informed administrators and educators would conclude that the diagnosis was not at all to blame. Even given that this child’s impairment lie primarily in his ability to self-regulate and monitor behavior, knowledgeable professionals discounted this fact and resorted to the assumption that “the parents must always let the child get away with this negative behavior at home” (personal communication, April 15, 2008).

Stress Associated with Educational Planning

A third trend that emerged in each interview was the association of some level of negativity with participation in their child’s educational planning process. The Individualized Education Plan (IEP) is written and revised yearly for any student receiving special education services, and parents are invited to be a part of the team that develops this plan. There were many difficulties cited: being ill-equipped to comprehend technical jargon, feeling unwanted at IEP meetings, feeling like their opinions were without merit, and feeling “blown-off” by teachers (personal communication, April 3, 2008). Additionally, the parents’ perceived role on the team was of interest. Each subject reported feeling like an overseer of the team’s progress, there to “keep an eye on things” or observe the function of the team. Not one parent described feeling like a viable, contributing team member, but rather, feeling like a passive observer (personal
communications, April 3 & 15, 2008). This perception, whether or not it is based in truth, will certainly impact parents’ contribution to their child’s educational planning.

*Change in Stigma over Time*

A final observation that surfaced was the change in the parental experience over time. Subject Three, whose child was diagnosed 20 years ago, cited significantly more negative experiences. She encountered the outdated term “refrigerator mother” in her experience. Family members and even educators implied and sometimes stated outright in interactions that the child wouldn’t be *as* autistic had she been a better parent. These assumptions and comments significantly impacted her self-perception (personal communication, April 15, 2008). Subject Two, whose child was diagnosed seven years ago, had similar experiences interacting with her extended family, and mentioned loneliness and an absence of people who understood her situation as one of the most difficult aspects of her parental experience (personal communication, April 3, 2008). Subject Three, however, whose child was diagnosed just three years ago, had the most experience with support groups (relative to the other subjects interviewed), and feels confident that there are people she can easily access and relate to (personal communication, April 3, 2008). Although not necessarily a function of time, it appears that the increasing prevalence and awareness of autism over time has had an impact on how the stigma is experienced by parents.

Overall, what I found to be the most valuable information expressed by the participants was the following sentiment, expressed almost verbatim by all three parents: Until you experience having a child with autism, you will never have an understanding of what it’s like. Each parent’s experience is uniquely their own, coordinating with the uniqueness of each child diagnosed with autism. Although we can certainly reach levels of understanding and facilitate
positive communication with parents, we can never fully appreciate their situation and as such, should never assume that we do.

**Conclusions & Recommendations**

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.

So what do we do? Is there a way to mitigate this stigma in such a way that parental functioning improves? Unfortunately, eliminating this stigma would involve challenging deep-rooted and unconscious perceptions of social value and deviance. It is clear that there is little to be done to eradicate the age old phenomenon of stigmatization. However, there are strategies and adjustments we can make to improve the parental experience.

As educators and professionals, the first step we must take is respecting parents for their invaluable role in the lives of our students, and accepting them as individuals we can collaborate with to ensure success for the student. 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 educators.

An important factor for educators to remember is the educational planning process. In the sample interviewed, this experience had a significant impact on their 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.

Overall, the most important things we can do for parents are to appreciate them, treat them with respect, and above all, listen to them. Each parent I spoke with expressed immense gratitude that someone was interested in understanding and improving their experience, a most rewarding aspect of this research. I hope that future research will seek to explore the stigmatization of this population further, and that professionals will continue to give consideration to the unique challenges and experience of parenting a child with autism.
Works Cited


Appendix A

Introduction
1. I’m going to be asking a lot of more specific questions, but why don’t you start off by telling me a little about your child? Your relationship with your child? Your family?
2. Characteristics of the child—communication skills, behaviors, educational placement, etc.

Family Life
1. How did your family respond to learning that your child has autism?
2. Has the family dynamic changed? If so, how?
3. If you have other children, how have they reacted to having a sibling with autism?
4. Was your extended family supportive/understanding?
5. How did/do you include your child with autism in family events/vacations/gatherings? How do other family members react?
6. Did/do you have to have to make decisions about when you can and cannot include your child? If so, how do you make these decisions?
7. Do you have family events without your child with autism? If so, could you describe these?

Economic Resources
1. What kinds of services have been available to you and your family to help you raise your child with autism?
2. Have you received services from any organization/group outside of the school district?
3. Are you familiar with your local MRDD services?
4. Have you ever received respite care for your child? If so, how often?

School Environment/Experiences
1. In interacting with your child’s teachers/educators, what was easy? What was difficult?
2. Did you feel heard when dealing with educators?
3. How did you feel working with the IEP team? How do you feel they viewed you?
4. What did you perceive as your role on the IEP team? How did you feel the other members of the team perceived your role?

Social/Other Communities
1. Are you involved in parent organizations? What is your level of involvement?
2. Do you feel involvement in parent organizations has been helpful for you? For your child?
3. Do you engage in social activities outside of these parent organizations? If so, what kind?
4. Do you feel like your social network has changed as a result of having a child with autism? If so, how?
5. How do you feel you are perceived by the general public (ie, in a grocery store)?
6. Are you involved in a religious community? If yes, how did this community impact your experience as a parent of a child with autism? Were you (and your child) welcomed or turned away?