THE EXPERIENCES OF MATERNAL CAREGIVERS OF CHILDREN WITH AUTISM

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In Memoriam

Dr. Donald William “Bill” Wood
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“Somewhere, something incredible is waiting to be known.” – Carl Sagan

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Abstract

Autism is a complex neurobiological disorder that currently affects approximately 1 in 59 children in the United States (CDC 2018). Some common symptoms associated with autism include inappropriate and repetitive behaviors, difficulties with communication and social interaction, and gastrointestinal problems. These characteristics can make caring for a child with autism particularly challenging and stressful. Caring for children with autism has been shown to affect the well-being and mental health of parents, particularly mothers (Benson 2010; Gatzoyia et al. 2014; Peters-Scheffer, Didden, and Korzilius 2012; Stuart and McGrew 2009). In addition, autism can be a particularly expensive disability to deal with (Green 2007; Wang et al. 2013).

The purpose of this study was to describe and understand the maternal experience of caring for children with autism. Using the Stress Process Theory as a guide, this study aimed to identify the challenges and positive aspects of caring for a child with autism, as well as the financial, emotional, and physical impacts of caring for a child with autism. This study also looked at how these mothers utilize social support and coping to mediate the stress of caregiving, and how the meanings they ascribe to their caregiving experience help to explain whether the demands of caring for their children is seen as positive or burdensome.

In-depth semi-structured interviews of 21 mothers of children with autism under the age of 18 in Honolulu, Hawaii were completed for this study. The thematic analysis revealed four themes that can be categorized as stressors (concern for the child's future independence, finding the right services for autism, safety, and trust), two themes that can be categorized as resources (social support and learning about autism), and two themes that can be classified as outcomes (emotional reactions to caring for a child with autism and mother's self-care). The overarching theme of the study was the unclear path that the mothers must take after their children have been diagnosed with autism.

The majority of the mothers interviewed for this study expressed that they experienced stress, anxiety, depression, or anger since the diagnosis of their children. The majority of the mothers also said that they experienced some form of adverse physical effect (e.g., exhaustion or high blood pressure) since the diagnosis. The findings of this study highlight the need for more support for mothers of children with autism and the need for coordination between the medical community, the mental health resources, the behavioral analysts, and the government agencies that provide autism services.

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Chapter 1
Introduction

Caregiving

Caregiving has been defined as a “complex, multidimensional activity” that can involve formal or informal; primary or non-primary; and in-home, institutional, or community care (Bruhn and Rebach 2014:5-6). Caregiving consists of activities such as direct physical care, including feeding, dressing, and bathing; emotional and social support; financial assistance; errand and transportation assistance; and household chores. The need for caregiving spans an entire lifetime, beginning before birth and ending after death (Talley and Montgomery 2013). Women tend to take on the role of caregiver in the family (Glenn 2010), as well as outside the family as paid home care workers, many of whom are minority women (Glenn 2010). However, much of the caregiving is unpaid. According to the 2015 report by the National Alliance for Caregiving and the AARP Public Policy Institute, “Caregiving in the U.S.,” approximately 60% of those who provide unpaid care are women (6).

Caregiving during the childhood years, especially the early childhood years, is marked by the dependency of children on adults for their needs. According to Mrazek (2013), the mother is the primary provider of a child’s physical and emotional care in most cultures. This is true whether or not a child is typically developing or disabled (Kostantareas and Homatidis 1992). It has been suggested that mothers are more seriously affected by caring for children with disabilities because they tend to be more involved with the care of the children (Hastings et al. 2005). For example, a study by Leiter et al. (2004) found that caring for children with special needs adversely impacted the employment status of mothers. In this study, the majority of the mothers who worked full-time reported reducing their hours at work and the majority of stay at home mothers reported leaving the workforce due to the caregiving needs of their children.

Caring for Children with Autism

With the recent significant rise in the prevalence of autism particular attention has been paid to the consequences for parents in caring for children with autism. Autism is a complex neurobiological disorder that currently affects approximately 1 in 68 children in the United States (CDC 2016). The Child and Adolescent Health Measurement Initiative of the Bloomberg School of Public Health reported that more than 1.1 million children in the U.S. may have an autism spectrum disorder (CAHMI 2016). Autism affects children in five major areas including verbal and non-verbal communication, social skills, behavior, learning, and medical issues (TACA 2016). Autism is a spectrum disorder, which means that the symptoms vary in number and degree across people. Those with milder cases may have a large vocabulary, yet have extreme difficulties sustaining conversations and understanding social cues and body language. Others who are considered to be severely autistic may have significant language deficits or even be nonverbal. Most people with autism exhibit some degree of repetitive behaviors or engage in restricted activities, such as jumping or hand flapping, repeating words or phrases, or being knowledgeable to the extreme about a subject. In addition, physical health issues, such as gastrointestinal disorders, are common among those with autism (Adams et al. 2011).

Children with autism are recipients of caregiving above and beyond what is considered to be typically required for children their age. Their parents may need to coordinate medical appointments and treatments, speech therapy, occupational therapy, physical therapy, psychotherapy, and behavioral therapy. The prognosis of autism is uncertain, even with early diagnosis (Fernell, Eriksson, and Gillberg 2013), which can add to the stress involved with caregiving. Parents typically seek public services from the health or education departments, or private services that must be paid for out-of-pocket or through insurance (if available), or both. Other families may choose to provide in-home therapies for their children themselves. The decision to choose one treatment path over another is dependent on such factors as the availability of expertise in the area, personal finances, time, and social support. Consequently, the decisions regarding the care of children with autism and the coordination and cost of that care have been shown to affect the well-being and mental health of the caregiver, particularly mothers (Gatzoyia et al. 2014; Peters-Scheffer, Didden, and Korzilius 2012; Stuart and McGrew 2009).

Stress Process Framework

A qualitative study, using the Stress Process framework (Pearlin et al. 1990) as a guide, was conducted in order to explore the caregiving experience of mothers of children with autism and to ascertain how the chronic stress of caring for their disabled children affects their well-being. Stress Process theory is important for the understanding of the experience of caregiving. Pearlin et al. (1990) described informal caregiving as “activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves” (583). The domains of the stress process include the background and context of stress, the stressors, the mediators of stress, and the outcomes of stress (Pearlin et al. 1990). The background and context consist of characteristics of the caregiver, such as socioeconomic status, age, and gender. Stressors include both primary and secondary stressors, where the primary stressors are those that deal directly with the caregiving needs of the recipient and the secondary stressors are problems that occur as a result of the demands of caregiving. Mediators, such as social support, are protective factors that buffer the effects of the stressors. Finally, the outcomes or manifestations are the effects that are observed, such as changes in mental or physical health.

This study examined the stressors related to caring for children with autism and the effects on the physical and emotional well-being of the mothers, as well as any mediating factors that may alleviate the effects of the stressors of caregiving. This study looked at how caring for a child with autism affects the family unit, and how the experience of managing the child's medical, psychological, and educational needs affects the mother's well-being. The total cost of caring for children with autism in the U.S. was estimated to be $11.5 billion in 2011 (Lavelle et al. 2014). Although much of this economic burden is on public funding streams for educational programs and services, a significant amount of the cost falls on the families of these children. This burden on families added with the extra demands involved in caring for the children with autism only increases the stress felt by the caregivers. This study highlights the impact of the chronic stress of caring for children with autism and increases the understanding of what these caregivers need for support. In addition, this study contributes to the caregiving literature by examining the development of the caregiver's heuristics and how this development impacts the way in which the caregivers respond to stressors.

Research Aims

The aims of this study were to identify the challenges and positive aspects of caring for a child with autism, as well as to identify the financial, emotional, and physical outcomes. The research questions that were evaluated aid in the examination of the lives of caregivers of children with autism. The information gained from their experiences regarding caregiver stress and coping contributes to knowledge about the complexities of caring for these children. The research questions are as follows:

1) How does the chronic stress of caring for children with autism affect the mental and physical health outcomes of their mothers?

2) How do the mothers of children with autism utilize social support and coping to mediate the stress of caregiving?

3) How do the meanings assigned to the mother's caregiving experience help to explain whether the demands of caregiving their children are seen as positive or burdensome?

In order to address the research questions regarding the maternal experience of caring for their children with autism, a qualitative study was conducted. Qualitative research is appropriate when trying to achieve a "detailed understanding" of a problem or issue by allowing people to share their stories and by focusing on the meanings they have about the problem or issue (Creswell 2007). In-depth, semi-structured interviews of 21 mothers of children with autism on Oahu were conducted. According to Ritchie and Lewis, the goals of qualitative research are "directed at providing in-depth and interpreted understanding of the social world of research participants by learning about their social and material circumstances, their experiences, perspectives, and histories" (2003:3).

Delimitations

This study only included mothers living on the island of Oahu. The study was delimited in this manner in order to reduce the travel costs and time required to fly to the other islands in the state of Hawaii. However, the mothers on Oahu may have different caregiving experiences from mothers living on the neighbor islands. Of the 1.4 million people in the state, over 900,000 live on the island of Oahu. Oahu has more than four times the population of the second most populous island, the Big Island of Hawaii, which has a little more than 200,000 residents (Census.gov). In Hawaii, most of the resources and services for children with autism are located on Oahu. The capital of the state of Hawaii, Honolulu, is located on Oahu, as are the majority of businesses, schools, physicians, and other professionals.

This chapter provided an overview of the study, including a brief background of caregiving, the research design, and the study aims. Chapter two provides a summary of the relevant background literature for this study. Chapter three describes the research methodology, the significance, and the limitations of this study. Chapter four discusses the analysis of the qualitative interview data. Finally, chapter five provides a discussion of the results of the analysis, as well as the implications of this study, and the recommendations for future research.

Chapter 2
Literature Review

To inform this study of mothers as caregivers of children with autism, literature pertaining to women as caregivers, caregiving as a chronic stressor and the Stress Process theory, the caring of children with autism, and a background of autism and its treatments are explored in this chapter. In order to gain an understanding of the complexities involved in treating a child with autism and the myriad of decisions faced by the child's mother, an extensive overview of the different treatments options and their means of acquisition are presented. Finally, because the sample of mothers in this study lived in the state of Hawaii, background information about autism in Hawaii is examined with an emphasis on how autism services are acquired in the state.

Women as Caregivers

The definition of caregiving has multiple dimensions. It encompasses notions of interactive relationships, formal and informal care, and direct and indirect care. Glenn broadly defined "caring" as, "the relationships and activities involved in maintaining people on a daily basis and intergenerationally" (2010:5). Bruhn and Rebach specifically defined the caregiver as, "a person who provides paid or unpaid assistance and support to another person who, for reasons of illness, disability, and/or age, cannot independently perform the usual activities of daily living" (2014:5). Activities of caregiving usually include but are not limited to direct physical care, such as feeding, dressing, and bathing; emotional and social support; financial assistance; errand and transportation assistance; and household chores.

Historically, the onus of caregiving in the U.S. has largely been on women (Bookman and Kimbrel 2011; England, Budig, and Folbre 2002; Glenn 2010; O'Shaughnessy 2013), and it has been argued that this burden is due to their gender (Aronson 1992; England et al. 2002;

Glenn 2010); due to women's family roles as wives, mothers, daughters or daughters-in law (Glenn 2010; O'Shaughnessy 2013); and due to their membership in a subordinate group through their race or class (Glenn 1992; Glenn 2010; Henrici 2013). It has also been suggested that women take on the caregiver role for reasons that range from obligation and responsibility (Aronson 1992), to satisfaction (Kramer 1997; Walker, Powers, and Bisconti 2016), and even to coercion (Glenn 2010).

The predominant societal view of caregiving is that it is primarily a woman's activity, and some argue that this is the case because caring is so closely associated with motherhood (England 2005; England and Folbre 1999) and femininity (Aronson 1992). This view is so widespread that a woman in a caregiving role is seen as a natural occurrence (Glenn 2010). Indeed, women are expected to shoulder the majority of the responsibility for the care of family members (Aronson 1992). For instance, some women may bear the burden of caring for multiple family members simultaneously as a sandwich caregiver (i.e., someone who is caring for their own children in addition to their aging parents), or as a compound caregiver (e.g., someone who is caring for a child with an intellectual disability in addition to another family member) (Perkins and Haley 2010).

In their family roles, women often feel obligated to perform caregiving duties due to status obligations. According to Gouldner, simply occupying the position may demand "an almost unconditional compliance" to perform the duties attached to that role (1960:170). These status obligations, according to Glenn, "…are integral to public and private *morals* that are internalized by members of a community and enforced by others in the community" so that "a woman's self-identity and reputation…rest on her fulfilling her status obligations" (2010:88). The notion of a "good mother" in contemporary society is one who demonstrates "intensive mothering." These mothers must "expend a tremendous amount of time, energy, and money in raising their children" and to dedicate their lives to the nurturing of their children (Hays 1996:x). Similar to the concept of "intensive mothering" is the "concerted cultivation" of children that middle-class parents engage in. These parents, particularly mothers, attempt to "foster children's talents" through "numerous age-specific activities that dominate family life and create enormous labor" (Lareau 2002:748). These mothers must constantly shuttle their children from one child-centered activity to another resulting in a "frenetic domestic pace" (Jacobs and Gerson 2004:82).

Grigoryeva (2014) found that not only do daughters provide more care to their elderly parents, they also tend to increase the amount of their caregiving responsibilities when they have brothers. On the other hand, she found that sons tend to decrease their caregiving activities when they have sisters, suggesting that "having a sibling of the opposite gender introduces inequality in the division of parent care" (Grigoryeva 2014:26). Daughters appear to experience feelings of role captivity when caring for their parents. Role captivity "refers to situations in which people are unwilling incumbents of social roles" (Aneshensel et al. 1993:56). Aronson (1992) found that daughters felt obliged to care for their mothers due to a lack of government services for the elderly, as well as the minimal caregiving efforts by the male family members. According to Aronson (1992:25), the women in her study felt that they had no choice but to take on the responsibility of caring for their mothers, and that they "…saw their sense of obligation as a necessity rather than a choice when they posed the question 'Who else is going to do it?'"

Unlike informal caregiving that is unpaid and remains mostly within family relationships, formal caregiving is a paid service that is done disproportionately by immigrant women or women of color (Henrici 2013). The need for caregivers, both formal and informal, has increased due to the increase in the elderly population, the deinstitutionalization of the disabled, the decrease in fertility, and the decrease in the availability of family members due to work commitments (Bianchi, Folbre, and Wolf 2012; Glenn 2010; Henrici 2013). It has been estimated that 90 percent of in-home healthcare workers are women. Of these women, more than half are women of color and almost a third are immigrants (Institute for Women's Policy Research 2012). Glenn (2010) argues that many home-care workers have limited choices for employment due to their lack of citizenship or education, and that immigrant women may be preferred by employers because they are viewed as easier to control and easily taken advantage of. According to Glenn (2010), this racial division of labor is the result of coercion, which she has defined as "physical, economic, social, or moral pressure used to induce someone to do something (2010:6)." Glenn (2010) argues that "home-care workers are disproportionately made up of those whose choices are limited" (179). Immigrants may be favored over other workers because they will work for less pay, they are seen as more diligent caregivers, and they are more easily taken advantage of. With fewer options available to them, they are easily coerced into this type of work.

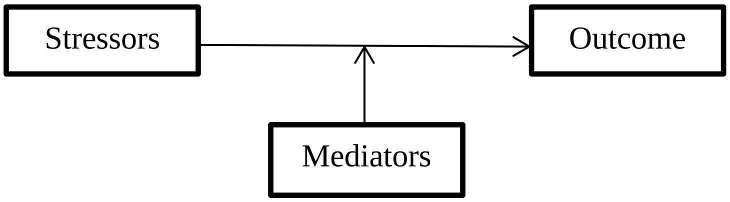
Glenn (2010) also applied the issue of coercion to high-tech home care for family members. She argues that women are pressured by societal expectations to care for disabled family members in the home, even if the family members require ventilators or other high-tech equipment. This responsibility is done at the expense of the woman's employment or other activities that give her fulfillment. In particular, she maintains that mothers feel obligated to care for their technology-dependent children at home because to not do so would be "evidence of an unnatural lack of motherly instincts" (2010:158).

As the literature above shows, women occupy the role of caregiver disproportionately. Caregiving can have a significant impact on the lives of these women. The following section discusses how caregiving can affect the well-being of the caregivers, as seen through the lens of the Stress Process theory.

Caregiving as a Chronic Stressor and the Stress Process

The Stress Process theory is an important guide for any study on caregiving. Pearlin et al. (1981) described the social stress process "…as combining three major conceptual domains: the sources of stress, the mediators of stress, and the manifestations of stress" (337) (see Figure 1). Stress can be the resulting from "discrete events" or "continuous problems." Stressful life events can create new life strains or exacerbate any life strains already in existence, which in turn can "lead to stress by adversely altering the meaning of persistent life strains" (Pearlin et al. 1981:339). Two important mediating resources, social supports and coping, can help to lessen the impact of stress. Social support refers to "the access to and use of individuals, groups, or organizations in dealing with life's vicissitudes" (Pearlin et al. 1981:340). In order to be considered a true social support system, "people's engagement with one another [must extend] to a level of involvement and concern, not when they merely touch at the surface of each other's lives" (Pearlin et al. 1981:340).

Figure 1 Stress Process Model



Pearlin (1989)

Two important coping resources are mastery or a sense of control over life and self-esteem (Thoits 1995). Coping strategies can be problem-focused, which are directed at the stressor itself, or emotion-focused, which are directed at the emotional response to the stressor.

According to Pearlin et al., both social supports and coping are used to “avoid, eliminate, or reduce distress” (1981:341). At the same time, life events and chronic life strains can diminish an individual’s sense of self-esteem and mastery (Pearlin et al. 1981).

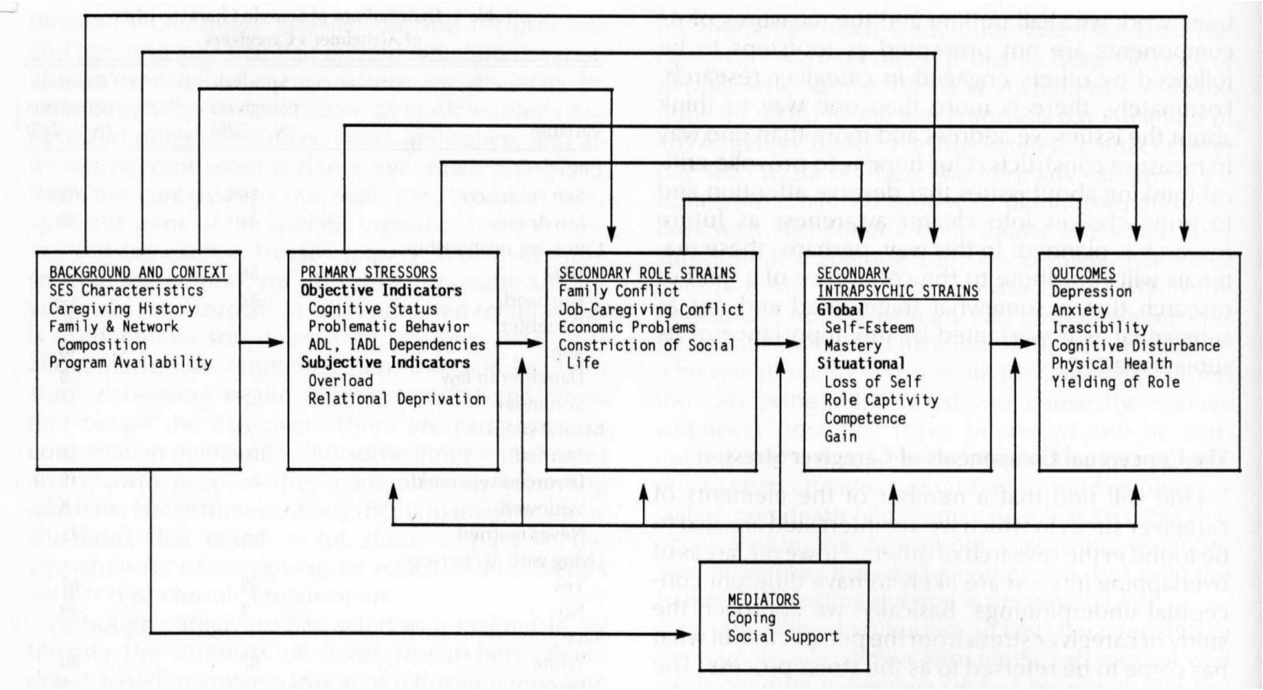
Pearlin et al. (1990) applied the social stress process to the caregiving of Alzheimer’s patients (see Figure 2). In this model, an additional domain is added to the three main domains. The four domains of the stress process in this model include the background and context, the stressors, the mediators, and the outcomes (Pearlin 1990). The background and contextual factors of the stress process include the “key characteristics of the caregiver,” such as age, gender, educational attainment, and occupation. Other background factors taken into account include the relationship between the caregiver and the recipient, the level of care required by the recipient, and the caregiver’s access to resources and programs (Pearlin 1990).

The stressors in this model are described as primary and secondary. Primary stressors are either objective or subjective. Objective stressors, such as the care recipient’s difficult behaviors, level of care required, and level of cognitive impairment, are based on the “health, behavior, and functional capabilities” of the care recipient (Pearlin et al. 1990). Subjective stressors are those that are experienced by the caregiver, such as overload, burnout, and relational deprivation (the restructuring of the relationship between the caregiver and the recipient) (Pearlin et al. 1990). Secondary stressors are those that are not directly related to caregiving but are aggravated by the activities required by caregiving. The two types of secondary stressors are role strains and intrapsychic strains. Role strains refer to the effects of caregiving on the caregivers’ roles outside of caregiving, which can lead to family conflict, economic strain, and the reduction of a social and recreational life. Intrapsychic strains refer to changes in the caregiver’s self-concept that can lead to feelings of role captivity, feelings of a loss of self, and feelings of a lack of competence in caregiving and personal growth.

As is the case in general stress research, the mediators coping and social support are also important in caregiving research and these mediators can help to explain the variability in caregivers’ responses to the stressors involved in caregiving (Pearlin et al. 1990). The mediators may decrease the effects of the stressors, and even to “block their contagion at the junctures between the primary and secondary stressors” (Pearlin et al. 1990:590). Both coping and social support can directly buffer the strength of the stressors, as well as indirectly limit the intensity of the stressors by preventing or inhibiting the development of the secondary stressors (Pearlin et al. 1990).

The outcomes of caregiver stress in the stress process framework are also the outcomes typically measured in social research that deal with the mental and physical well-being of people, including depression, anxiety, and physical injuries (Pearlin et al. 1990).

Figure 2. Conceptual model of Alzheimer's caregiver' stress



Pearlin et al. (1990:586)

There is empirical evidence suggesting that experiencing role stress may have a significant impact on caregivers' lives. Warfield (2005) found that two-earner parents of children with disabilities experienced greater parenting role stress when they found their jobs overwhelming. Parents with more children were also found to experience greater parenting role stress (Warfield 2005). Parents with children with disabilities have great difficulty finding suitable childcare for their children due to the lack of disability-specific trained providers and the reluctance of childcare providers to accommodate children with special needs.

Gordon et al. (2012) reported that the demands of work lead to both caregiving burden and work burden, causing role strain. It was also found that the combination of caregiving and work demands contribute to a work and caregiving conflict. In a study of 278 adult daughters who were concurrently caregivers to parents, mothers to children living at home, wives, and employees, it was found that 96% of the women experienced role conflict (Stephens et al. 2001). For the majority of the women, the parental caregiver role created the most role conflict. Based on their findings, the authors suggested that parental caregiving is most likely to conflict with their roles as mothers, wives, and employees when the women have high parental caregiving demands, older children (adolescents), and low socioeconomic resources (Stephens et al. 2001).

Similarly, Liu and Dupre (2016) found that caregiving has both immediate and long-term impacts on caregivers. Their analysis of the Ever-Married Women Survey of the China Health and Nutrition Survey found that women who are caregivers to parents or parents-in-law initially have poorer self-reported health than women who are not caregivers. This disparity lessens over time, showing that the women tend to adapt to their situations; however, after a decade, the disparity again widens and the women's self-reported health becomes increasingly poorer (Liu and Dupre 2016).

Although much of the focus of the research on caregiving has been on the negative aspects, some studies have found positive aspects as well. Caregivers have reported having feelings of satisfaction from their situations. Some possible effects of caregiving include having a greater sense of meaning in their lives, greater feelings of connection with the care receivers, and a greater sense of purpose (Bianchi et al. 2012; Henriksson, Carlander, and Arestedt 2015; Schultz and Sherwood 2008). With family members in particular, an increase in feelings of love has been found to be a positive effect of caregiving (Bianchi et al. 2012). The literature highlighted in this section illustrate how caregiving as a chronic stressor can have an enormous impact on the lives of the caregivers, yet caregivers may lessen the negative effects with mediating resources they have available to them. The following section focuses on the complexities of caring for children with autism and other disabilities.

Caring for Children with Autism and other Disabilities

Based on a 2015 national study of unpaid caregivers in the U.S., it has been estimated that 3.7 million adults provide care to children under the age of 18 due to an ongoing medical or serious short-term condition, or emotional, behavioral, or developmental problems (National Alliance for Caregiving and AARP 2015). The CDC reports that about one in six children 3-17 years old in the U.S. have one or more developmental disabilities. A developmental disability is a condition that begins during a child's early development, and affects a child's physical ability, language acquisition, learning, and behaviors. These disabilities can range in severity from mild to very severe (often requiring 24 hour care), and which affect the child's daily activities and typically lasts the child's lifetime. Some developmental disabilities include cerebral palsy, hearing loss, attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), intellectual disability, and vision impairment (CDC 2015).

As it was noted above, women have historically carried the burden of caregiving for children (Glenn 2010). Kostantareas and Homatidis (1992) found that mothers were more involved with caring for their children than were fathers, regardless if the children were disabled or typically developing. Caring for children with disabilities include activities that are beyond the scope of caregiving for typically developing children. The focus of these activities is on obtaining the medical, educational, and specialized support services the children need, including arranging for early intervention services, procuring referrals for specialists, coordinating treatments, and working closely with the school system (Bruhn and Rebach 2014:49).

For mothers of children with disabilities, the caregiving burden increases with the addition of work demands, due to the lack of sufficient time for both activities, as well as the overall increase in stress. Parish et al. (2004) found that mothers of children with developmental disabilities were less likely to pursue full-time employment, which seriously decreases their earnings and savings for the future. Hogan (2012) reported that mothers of children with disabilities are more likely than mothers of typically developing children to quit their jobs in order to care for their disabled children full-time. In addition, the level of mother's education appears to affect employment decisions. Leiter et al. (2004) found that mothers with more education were more likely to be full-time caregivers for their special needs children. They speculated that this may be due to the increase in choices available to mothers who are more educated, whereas the families of mothers who are less educated may be more dependent on their income (Leiter et al. 2004).

Sousa writes that mothers of children with disabilities are a subcategory of the intensive mothering paradigm and are actually "warrior-heroes" who "battle against social and political forces to gain medical and educational interventions for their children despite the high personal and financial costs to themselves and their families" (2011:220). In the past, mothers of children with autism were called "refrigerator mothers" when it was believed the disability was caused by the mothers' coldness towards the children (Bettelheim 1967). Instead, the warrior-hero identity places the burden of curing the children of their disability on the mothers (Sousa 2011). This, however, does not lessen the pressure placed on the mothers, but simply shifts their responsibility and the "mother blaming" from that of cause to cure (Courcy and des Rivières 2017).

There has been much written about caregiving, stress, and coping among parents of children with autism and other disabilities (Allik, Larsson, and Smedje 2006; Baker, Blacher, and Olsson 2003; Barker et al. 2011; Benson 2010; Catalano, Holloway, and Mpofu 2018; Gatzoyia et al. 2014; Green 2007; Hogan 2012; Moh and Magiati 2012; Peters-Scheffer, Didden, and Korzilius 2012; Seltzer et al. 2004; Seltzer et al. 2009; Stuart and McGrew 2009; Warfield 2005). Parents of children with disabilities have been found to experience the stress of financial hardships as a result of caring for children with autism and disabilities (Delaney and Smith 2012; Hogan 2012; Parish et al. 2004; Wakabayashi and Donato 2006**)** due to the increase in expenses (e.g., medical, educational) attributed to the condition and the decrease in work hours due to caregiving responsibilities.

Behavior problems of the children (e.g., socially inappropriate or repetitive behaviors, aggression, disruptive behaviors, and attention problems) have been found to increase stress in parents (Allik et al. 2006; Baker et al. 2003; Barker et al. 2011; Gatzoyia et al. 2014; Peters-Scheffer et al. 2012). Gray (2002) found that parents, especially mothers, experienced avoidance, hostile staring, and rude comments from others as a result of their children's inappropriate behaviors. The stigma experienced by parents can lead to social isolation that is "…a direct effect of the limitations placed on their activities outside the home because of their child's autism" (Gray 1993:109). This isolation in turn leads to a reduction in their social support network. This follows Goffman's (1963) concept of courtesy stigma, where the parent of the child with autism has a spoiled social identity simply by association (Gray 1993, 2002; Farrugia 2009). According to Birenbaum (1970:196), "They are 'normal' yet 'different,'" and, "…their differentness is occasionally manifested by their association with the stigmatized during encounters with normals…" However, Farrugia (2009:1024) found that some parents of children with autism used "active disclosure of otherness" and explained their children's behaviors medically in order to construct an unspoiled identity for themselves. Not only can stigma increase the number of stressors experienced by those who are stigmatized (Miller and Kaiser 2001), stigma itself has been identified as a stressor. According to Miller and Kaiser, "although stigma is defined as a devalued social identity in a particular context, for many stigmatized people the context in which they are devalued is pervasive" (2001:74).

Of particular concern to parents of children with autism is the uncertainty about their children's future when they age out of the public education system and are no longer eligible for services under the Individuals with Disabilities Education Act (IDEA). Fong et al. (1993) found that parents of adolescents with autism were anxious about their children's capability to be independent. These parents "expressed considerable uncertainty about the future, where they will live as an adult, and who will provide care, and whether the family, particularly the parents, will be able to continue to cope" (Fong et al. 1993:111).

Another source of increased stress for parents of children with autism and disabilities is their involvement with their children's schools (Burke and Hodapp 2014; Cho and Gannotti 2005; Fish 2006; Lo 2008; Reiman et al. 2010; Salas 2004; Sauer 2007). Lo (2008) studied five Chinese families of disabled children in Massachusetts and found that the parents experienced language barriers due to inadequate interpreters and disrespect by the education professionals. Cho and Gannotti (2005) interviewed Korean-American mothers in Southern California and found that while the mothers were grateful for the special education services, they also felt that some of the educators did not value their opinions. Salas (2004) interviewed Mexican-American women with disabled children in the southwest U.S. and found that the women felt marginalized by the educators. Fish (2008), on the other hand, surveyed 51 parents in a southwestern U.S. state and found that the parents were satisfied with their experiences with the educators and that they felt their opinions were valued. In a web-based survey of 965 mothers of children with developmental disabilities from all the states in the U.S. except for Hawaii, Delaware, and

Wyoming, Burke and Hodapp (2014) found that mothers with lower stress levels also had better parent-school relationships.

If left unaddressed, the stress experienced by parents of children with ASD can adversely affect their psychological, physical, and social well-being (Catalano, Holloway, and Mpofu 2018). Parents of children with ASD have been found to experience more depression, anxiety, and physical health problems (Catalano et al. 2018). A recent study reported that parents benefit from networking with other parents who care for children with autism (Catalano et al. 2018). Interaction with other parents shows them that they are not alone in facing the difficult challenges of raising their ASD children and validates their experiences (Clifford and Minnes 2013). In addition, training in stress management and problem-solving skills and receiving factual information about autism also eased the stress felt by parents (Catalano et al. 2018).

Autism Diagnosis

According to Hogan, "the difficulties parents have in getting appropriate treatment begin with the challenge of getting a timely and correct diagnosis for their child's disability" (2012:81). The diagnosis experience for autism has been found to be a source of stress for parents (Moh and Magiati 2012). This stress may be partly due to the historical confusion surrounding what autism actually is and the continued confusion surrounding its etiology and diagnosis. Autism was first widely discussed less than eighty years ago in Leo Kanner's 1943 paper, "Autistic Disturbances of Affective Contact." He described eleven children he had studied since 1938 as those "whose condition [differed] so markedly and uniquely from anything reported so far" (Kanner 1943: 217), who had a profound "inability to relate themselves in the ordinary way to people and situations from the beginning of life" (Kanner 1943:242), and whose parents were not warmhearted (Kanner 1943:250). In his 1956 paper with Leon Eisenberg, Kanner continued to attribute the children's disability to their parent's "emotionally frigid backgrounds" (Eisenberg and Kanner 1956:561) and an environment of "emotional refrigeration" (Eisenberg and Kanner 1956:562). Other researchers and professionals in the medical and psychological professions followed this line of thinking, most notably Bruno Bettelheim (1967), who has been credited with the "imagery of the 'refrigerator mother'" (Liu, King, and Bearman 2010:1392). Bettelheim even went as far as comparing the parents of children with autism to SS guards in Nazi concentration camps (1967:64-66). Though now considered "defunct," this mother-blaming mentality by professionals led to years of mistreatment of children with autism and their mothers.

Autism Diagnosis and the Changing DSM

Over the years, the diagnosis of autism has been based on the Diagnostic and Statistical Manual of Mental Disorders (DSM) published by the American Psychiatric Association (APA), which lists the classification criteria for mental disorders and is the standard used by mental health professionals in the U.S. Because there was so much confusion surrounding autism, the classification of the disorder in the DSM has bounced from one section to another and categories and criteria have been added or removed. The first edition of the DSM, which was published in 1952, did not contain a diagnostic category for autism, but it rather appeared under a type of childhood schizophrenia (Silberman 2015). It was not until almost thirty years later in 1980, when the third edition of the DSM (DSM-III) was published, that autism was finally separated from schizophrenia and was included as its own diagnostic category under Infantile Autism (Baker 2013).

In 1987 the word "Infantile" was removed and the category was renamed Autistic Disorder (Silberman 2015). Adding to the confusion was the addition of a new category, Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS), to offer a diagnosis to children who met most of the criteria but who did not necessarily meet all of them (Baker 2013). The fourth edition of the DSM (DSM-IV) was published in 1994, and the revised version was published in 2000 (DSM-IV-R). The diagnostic criteria were tightened somewhat and separate categories for Asperger's Disorder, Rett's Disorder, and Childhood Disintegrative Disorder (CDD) were added (Volkmar and Reichow 2013).

Yet another change occurred to autism in the DSM when the fifth edition of the DSM-5 was released in May 2013. According to the APA (2013), whereas the previous DSM (DSM-IV-TR) had distinct categories for Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, PDD-NOS, and autistic disorder, the new DSM-5 created a single umbrella condition called autism spectrum disorders (ASD's). Rett's syndrome was eliminated because it is now known to be caused by a single gene mutation (Volkmar and Reichow 2013). The APA considers the revised DSM to "[represent] a new, more accurate, and medically and scientifically useful way of diagnosing individuals with autism-related disorders" (APA 2013). According to the APA, the new DSM should "improve the diagnosis of ASD without limiting the sensitivity of the criteria, or substantially changing the number of children being diagnosed" and that "anyone diagnosed with [autistic disorder, Asperger's Disorder, Childhood Disintegrative Disorder, or PDD-NOS] from the DSM-IV should still meet the criteria for ASD in DSM-5…" (APA 2013).

However, studies have shown that not everyone with an autism diagnosis under the DSM-IV-TR will also be diagnosed with ASD under the DSM-5. In a study by Young and Rodi (2014:758), of the 210 subjects who met the DSM-IV-TR criteria for either autistic disorder, Asperger's disorder, or PDD-NOS, only 57.1% met the DSM-5 criteria for ASD. About 74% of those diagnosed with autistic disorder under the DSM-IV-TR were diagnosed with ASD under the DSM-V. A little more than half (56.1%) of those diagnosed with Asperger's Disorder received a DSM-5 ASD diagnosis. None of the PDD-NOS children received an ASD diagnosis under the DSM-5 (Young and Rodi 2014:761). The most common reason for the failure to receive an ASD diagnosis under the DSM-5 was the inability to satisfy all three requirements for the social communication section.

A meta-analysis by Bennett and Goodall (2016) found an average reduction of 37% in the number of people with a DSM-IV-TR ASD diagnosis who qualified for a DSM-5 ASD diagnosis. Under the DSM-5, there was a 45% reduction of Asperger's Disorder, 20% reduction of autism, and 74% reduction of PDD-NOS diagnoses as compared to the DSM-IV-TR (Bennett and Goodall 2016). According to these studies, those who are higher-functioning will be less likely to receive an ASD diagnosis under the DSM-5.

Changes in Autism Prevalence

The prevalence of autism has increased considerably over the years. The reported prevalence of autism has increased from less than 1 in 10,000 in the 1970's to 1 in 2500 in the mid-1980's. Most recently, the Center for Disease Control and Prevention's (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network reported the prevalence of autism as 1 in 59 for children aged 8 years (CDC 2018). This was based on 11 sites used for the 2014 surveillance year. The sites included Alabama, Arizona, Arkansas, Colorado, Georgia, Maryland, Missouri, New Jersey, North Carolina, Utah, and Wisconsin. The ADDM report also reported that about four times as many boys as girls were identified with an ASD and that autism was more common among white children than black children (CDC 2018).

The reasons for the historical prevalence changes for ASD, as well as the current prevalence variations between gender and ethnicity, are unclear. The CDC ADDM report suggests that increased awareness and changes in diagnostic practice or service availability may play some part (CDC 2014). A report on the increase in prevalence of parent-reported ASD in school-aged children in the U.S. from 2007 to 2011-12 suggested that the change was due to the diagnoses of children who were previously undiagnosed (Blumberg, Bramlett, Kogan, Schieve, Jones, and Lu 2013). Liu, King, and Bearman (2010) suggested that "localized person-to-person contact may affect a parent's decision to seek out professional help," which may in turn lead to an increase in diagnosis (1425). King and Bearman (2011) found that high parental education and high parental economic resources increased the likelihood of diagnosis of ASD. Another study found a strong positive association between neighborhood-level diagnostic resources and spatial clusters of autism prevalence (Mazumdar et al. 2013).

Ethnic and racial variations may be due to the misdiagnosis of certain groups. A study of Hispanic children found that they were more likely to be diagnosed with other psychological or behavioral disorders before being diagnosed with ASD (Overton, Fielding, and Garcia de Alba 2007). A study of Medicaid-eligible children in Philadelphia found that African-American children were more likely to receive another diagnosis before getting diagnosed with ASD (Mandell, Ittenbach, Levy, and Pinto-Martin 2007).

Another possible reason for the increased prevalence for ASD was suggested by Steve Silberman, the author of the book, "Neurotribes" (2015). In his book, Silberman tells the story of how the lives of Leo Kanner, Hans Asperger, and a psychologist named Lorna Wing, the mother of a child with autism, intersected and created the autism "epidemic." Silberman describes how Hans Asperger "discovered" high functioning autism in his clinic in Vienna at the same time Kanner “discovered” the more severe cases of autism in the U.S. Asperger’s work wasn’t widely known at the time because of the start of World War II and because Asperger’s work was written in German. However, Hans Asperger’s diagnostician in Vienna, Georg Frankl, immigrated to the U.S. with Leo Kanner’s help. Silberman claims that because Kanner and Frankl knew each other, Frankl must have informed Kanner about Asperger’s work. Kanner always insisted that the disorder he discovered was rare, lifelong, debilitating, and above all unique. Based on these details, Silberman concludes that Kanner must have suppressed Asperger’s work.

Then, Lorna Wing, while doing her own research on autism in England, came across a 1971 paper by Dirk Arn Van Krevelen of the University of Leiden School of Medicine in Holland which compared Leo Kanner’s infantile autism diagnosis and Hans Asperger’s autistic psychopathy (Silberman 2015). While reading the paper, Wing realized that the children she had seen in the U.K. matched Asperger’s description. After reading a translated version of Asperger’s 1944 paper, she became convinced that Kanner’s more severe version of autism was only part of the condition, and she set about to expand the definition of autism to also include Asperger’s less severe version. In 1981 she published a paper called, “Asperger’s Syndrome: A Clinical Account.” This led to some criticism from the field, but eventually the concept of autism was expanded into a spectrum disorder (Silberman 2015).

This change of autism from a rare, severe disorder to a wide-ranging spectrum disorder, Silberman asserts, is the main reason for the dramatic increase in autism prevalence. Autism was no longer categorized as schizophrenia or simply mental retardation. This led to diagnostic substitutions, where children who were once labeled as mentally retarded are now labeled as autistic.

Additionally, when the DSM-IV was released, “Asperger’s” was included, which again caused an increase in the prevalence of autism. However, according to Silberman, there was a crucial typographical error in the DSM-IV for the PDD-NOS diagnosis. An “or” was substituted for an “and,” thereby allowing the diagnosis of PDD-NOS for 2 criteria instead of 3. This was not corrected for six years until the year 2000, when the DSM-IV-TR was released. The result, according to Silberman, added to the notion of an autism epidemic.

Even after more than seventy years since autism was first identified, the ambiguity surrounding autism continues because there is no litmus test for it. The diagnosis of autism is based on a checklist of observed symptoms rather than on a tissue sample or blood test, and the observations are left up to the interpretation of the diagnosing professional, who may be a psychologist, a psychiatrist, a developmental pediatrician, or a “school psychologist.” This uncertainty has the potential to cause a great deal of stress for the parent, not only because the diagnosis is crucial to getting services but also because there is always an element of doubt.

Autism Treatments and Interventions

The autism diagnosis is one of the many stressors involved in caring for a child with ASD. For many parents, treatment decision-making is a source of great stress and anxiety that can last for many years, and for some a lifetime. In addition, trying to acquire these services through publically funded sources or by paying for them out-of-pocket increases the stress involved in the treatment decision-making. There is a finite amount of public and private funds and parents must decide the best course of action to take.

The Interactive Autism Network (IAN), an online community created by the Kennedy Krieger Institute to advance autism research, collected information on treatments employed by parents of children with autism. According to IAN, there are hundreds of different treatment options in use with "little or no scientific evidence" to support the effectiveness for many of them (IAN 2011). Because parents feel the urgency for early intervention, they sometimes make choices based on little information, often adding and dropping treatments in order to find the right combination that will enable their child to progress (IAN 2011).

At the start of the medical community's awareness of autism, the treatment was mainly psychotherapy, and many of the children were removed from the parental homes and placed into hospitals, clinics, or institutions. Autism at that time was seen as rare and rather a novelty, which resulted in the children essentially being "studied" rather than "treated." As a result, experiments were performed on those with autism under the guise of medical treatment, using electric shock and hallucinogenic drugs, such as LSD, to modify autistic behaviors (Lovaas et al. 1965; Risley 1968; Sigafoos et al. 2007; Simmons et al. 1966). The rationale behind using LSD, for instance, was "based on the default logic that other treatment efforts had failed" (Sigafoos 2007:75).

In order to understand the difficulties surrounding the decisions that parents of children with autism must make regarding treatments, an overview of the current treatment options that parents consider for their children are discussed. The decision to select one treatment over another due to issues of money, time, or safety is a daunting task that these parents must face on a daily basis.

Behavioral Modification Techniques

Treatments based on behavioral therapy were also used to help children with autism manage behaviors and gain skills during this time. Applied Behavior Analysis (ABA), currently considered the “gold standard” for autism treatment in the U.S. (McPhilemy and Dillenburger 2013:154), was developed by psychologist O. Ivar Lovaas in the 1960s (Smith and Eikeseth 2011). ABA is “…the process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviors [e.g., academics, social and communication skills, self-care skills, and daily living skills] to a meaningful degree…” (Center for Autism and Related Disorders). A teaching method that is a part of ABA is called “discrete trial teaching” or DTT (Leaf and McEachin 1999). DTT breaks down each skill into smaller steps and “focuses on teaching small, measurable units of behavior systematically” (Maurice 1996:30). Instruction (or a cue) is given for each smaller step repeatedly until corrections or prompts are no longer needed and the task is mastered and performed independently (Maurice 1996). Consistently reinforcing appropriate responses or behaviors and ignoring or redirecting inappropriate ones each time is a key element of the therapy. The ABA is data driven; therefore, careful data is taken for each trial and the data is compiled, graphed, and analyzed to determine if the program is successful or if it must be modified.

Lovaas (1987) reported that 47% of the children in his study who received intensive behavioral therapy or ABA for an average of 40 hours per week for 2 or more years were able to achieve normal intellectual and educational functioning, as compared to 2% of the control group. A follow-up study of the 1987 research showed that the children in the experimental group maintained their intellectual functioning gains and scored higher on adaptive functioning measures. Other studies have also shown that children with autism benefit from intensive behavioral interventions like ABA. Eldevik et al. (2102) found that after two years, preschool children with autism who received intensive behavioral intervention in a regular mainstream preschool classroom had higher IQs and adaptive scores than the children who were educated in typical special education classroom without any intensive behavioral interventions. According to McPhilemy and Dillenburger, parents who used ABA-based interventions for their children with autism reported that ABA had a "…significant positive impact not only on the lives of the child, in particular in areas of communication, challenging behaviours and independence, but also on the family as a whole and their overall quality of life" (2013:159). Citing the Lovaas studies, the 1999 Report of the Surgeon General on Mental Health recommended ABA for children with autism and stated that, "…years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior" (162).

A variation of the highly structured ABA is Verbal Behavior (ABA/VB). The verbal behavior method is based on the 1957 book by B. F. Skinner, *Verbal Behavior*, which discussed the idea of language as behavior. The verbal behavior approach uses Skinner's analysis of language as the foundation, along with the basic ideas of ABA. In verbal behavior, language is expanded beyond the "cognitively based expressive-receptive distinction" (Bondy et al. 2010:199). Instead of using the general category of "expressive language," verbal behavior breaks it down into the mand (requesting), the tact (labeling or identifying objects), the intraverbal (answering wh- questions), the echoic (repeating), the textual (reading), and transcriptive (writing). The general category of "receptive language" is broken down into listener discriminations or receptive language, audience participation (listening as an audience member), mediator of reinforcement (acknowledge and reinforce a speaker), and emotional responder (e.g., displaying empathy) (Sundberg 2016).

The Behavior Analyst Certification Board (BACB) certifies individuals who have been trained in behavior analysis. There are three levels of certification for the behavior analyst: the bachelor’s level or the BCaBA, the master’s level or the BCBA, and the doctorate level or the BCBA-D. The BCBA or the BCBA-D creates the ABA program for the children with autism. All three levels (BCBA-D, BCBA, and BCaBA) may supervise the implementation of the program by lower-level therapists, although the bachelor’s level BCaBA must work under the supervision of a BCBA or BCBA-D (Behavior Analyst Certification Board 2017).

Other approaches to behavioral interventions have been developed that are more flexible and are implemented in more natural settings. With these “Naturalistic Developmental Behavioral Interventions,” such as Pivotal Response Training (PRT), Early Start Denver Model (ESDM), Incidental Teaching, and Project ImPACT, skills are taught “…in the course of the child’s typical daily interactions, experiences, and routines, with multiple materials and by multiple people” (Schreibman et al. 2015:2416). For example, PRT is a play-based, child initiated treatment based on the principles of ABA that was developed by Robert Koegel, Ph.D. and Lyn Koegel, Ph.D. at the University of California, Santa Barbara (Autism Speaks 2017). The intervention focuses on wider “pivotal” areas of development such as motivation, responsivity to multiple cues, self-management, and social initiations with the idea that improvement in these pivotal areas will extend to other areas of communication, social skills, and behaviors (Koegel Autism Consultants 2017). The use of research-based motivation techniques (e.g., varying tasks, and using natural reinforcers) and the implementation of the intervention in natural environments (e.g., home, school, community) are key elements of PRT (Koegel Autism Consultants 2017). The Koegel Autism Center at the University of California, Santa Barbara offers PRT training and certification for providers.

Another example is The ESDM, which is a behavioral, relationship, developmental, and play-based intervention for young children 12-48 months of age developed by Sally Rogers, Ph.D. and Geraldine Dawson, Ph.D. (UC Davis MIND Institute 2017). This early intervention program is conducted during play and normal routine activities by ESDM-trained therapists and parents. ESDM training classes and certification for parents and providers are offered at the University of California, Davis MIND Institute (UC Davis MIND Institute 2017).

Applied behavior analysis has also garnered some criticism, primarily from self-advocates. According to Ari Ne'eman, co-founder of the Autistic Self Advocacy Network (ASAN) who served as president from 2006 to 2016 (ASAN 2017), "We don't think it is possible to fundamentally rewire our brains to change the way we think and interact with the world…But even if such a thing were possible, we don't think it would be ethical" (Padawer 2014). Critics of ABA feel that it teaches children to mechanically repeat phrases in a robotic manner. The goal of teaching socially appropriate behaviors and speech is to make them appear "normal" like their typically developing peers. The goal of the neurodiversity movement, however, is for society to be accepting of neurological differences rather than making people fit in.

Structured Teaching

Structured teaching is an approach to educating children with autism that was developed by Division TEACCH (Treatment and Education of Autistic and Communication Related Handicapped Children) of the University of North Carolina at Chapel Hill. TEACCH was started by Eric Schopler, Ph.D. in 1972 and is now a state-wide comprehensive program (with nine regional centers in North Carolina) for people with autism of all ages (Mesibov and Shea 2010). The purpose of TEACCH is to develop the student's current skills (Cohen 1998). The children work on repetitive tasks that are highly structured and that have visual cues, such as pictures or color-coding (Maurice 1996). The TEACCH approach is organized around five basic principles: physical structure, scheduling, work system, routine, and visual structure (Autism Research Institute 2017). Physical structure refers to the organization of the classroom, where the furniture and supplies are placed in a way that is conducive to learning. Scheduling refers to the individualized schedule for each child that is clearly marked (with words, pictures, etc.) so that the child knows what is planned for the day. Work system refers to the organization of the tasks that the child must complete. The system is organized so that the child can easily figure out what is expected of him or her. Each child learns and follows the routines of the schedule and work systems. The materials of the tasks and activities are visually structured in a way that helps to make expectations clear (Autism Search Institute 2017).

A meta-analysis of 13 TEACCH studies found that the reported effects of TEACCH on communication and activities of daily living were not significant and the effect on motor skills was small. Moreover, the reported effects of TEACCH on perceptual, motor, verbal, and cognitive skills were small (Virues-Ortega, Julio, and Pastor-Barriuso 2013). It also appeared that the effects of TEACCH on social behavior and maladaptive behavior were moderate to large, although these studies were affected by study quality and publication bias issues. In fact, the paper concluded that their findings were "…limited by the inherent methodological quality of the original studies…" (Virues-Ortega et al. 2013:951).

Social/Relationship Approaches

Other approaches to treating autism focus on social interaction rather than on the behaviors of the children. One such approach, called Floor-time, was developed by Stanley Greenspan in the 1980's. Floor-time is based on the developmental, individual-difference, relationship-based model (DIR), a framework that "…examines the functional developmental capacities of children in the context of their unique biologically based processing profile and their family relationships and interactive patterns" (Wieder and Greenspan 2003:425). Floor-time is a type of play therapy that is child-focused, rather than therapist-focused. Greenspan and Wieder emphasized that parents must "…follow [their] child's lead and play at whatever captures [their child's] interest, but to do so in a way that encourages [their] child to interact with [them]" (1998:124). This requires that the parent or floor time professional actively build on the child's activity of interest in order to increase interactions while working on the four main goals of floor-time: 1) encouraging attention and intimacy, 2) two-way communication, 3) encouraging the expression and use of feelings and ideas, and 4) logical thought (Greenspan and Wieder 1998).

A study compared the effects of adding DIR/Floortime to the current programs of children aged 2-6 years versus continuing with the current behavioral or discrete trial treatment alone. It was found that the children who also received the DIR/Floortime intervention for an average of 15.2 hours per week for three months made greater improvements on the Functional Emotional Assessment Scale, the Childhood Autism Rating Scale, and the Functional Emotional Questionnaires (Pajareya and Nopmaneejumruslers 2011).

Relationship Development Intervention (RDI), developed by Steven E. Gutstein, Ph.D., is a parent-based approach that focuses on helping the child with autism to build social relationships by developing the child's dynamic intelligence. Dynamic intelligence refers to the ability to have flexible thinking, to see different perspectives, to cope with changes, and to process different sensory information at once (Autism Speaks 2017). With RDI, the parents and primary caregivers are considered the main therapists. They are guided through the RDI program by a certified RDI consultant with regular meetings and an intensive evaluation every six months (Gutstein et al. 2007). A study evaluating the effectiveness of the RDI program on

16 children with autism found that after a minimum of 30 months of RDI treatment, all 16 children no longer met the criteria for autism according to the Autism Diagnostic Observation Schedule (ADOS) and the Autism Diagnostic Interview-Revised (ADI-R) assessments (Gutstein et al. 2007). This study had neither a control nor comparison group, however.

Allied Health Services

Allied health professionals, most notably speech-language pathologists (SLP), occupational therapists (OTs), and physical therapists (PTs), often provide treatment to those with ASD. Speech-language pathologists address the range of communication deficits associated with autism. While some individuals with autism are non-verbal, others have difficulty with understanding non-verbal cues and pragmatics, or using language appropriately in social situations. The SLP also helps with the mechanics of speech, such as articulation or stuttering, in addition to the meanings of speech. The non-verbal person may require the help of assistive communication devices or augmentative and alternative communicative (AAC) devices and methods, such as the Picture Exchange Communication System (PECS) (Autism Speaks 2017). A person is taught to communicate by using pictures and symbols in order to form ideas and sentences. Keyboards or electronic communication devices may also be used.

Occupational therapists address fine or gross motor skills that are needed for self-care or daily living skills, and leisure or play skills which many individuals with autism have difficulty with. The OT may focus on dressing, grooming, toileting, and feeding for independent self-care. The OT may also focus on handwriting and using a scissors for fine motor skills used in school, or kicking a ball, throwing and catching, and other play skills.

Physical therapists address the challenges with balance, coordination, and motor skills that people with autism may have, as well as problems with poor muscle tone. They may focus on skills such as walking, running, jumping, and sitting (Autism Speaks 2017).

People with autism may have difficulties with processing sensory information such as smell, taste, touch, sight, and hearing. They also may have difficulties with their sense of balance, as well as their sense of where their body is in space. Occupational and physical therapists can provide therapy that helps people with autism process sensory information, called sensory integration therapy (Autism Speaks 2017). According to Lorna Jean King, a pioneer of sensory integration therapy, “The goal of sensory integrative therapy is to facilitate the development of the nervous system’s ability to process sensory input in a more normal way” (Autism Research Institute 2017).

Sensory integration focuses on three major areas: vestibular, proprioceptive, and tactile. The vestibular system, which helps to control a person’s sense of balance, is located in the inner ear. This system relates the body to gravity and gives one the sensation of the body’s weight (Autism Research Institute 2017). A dysfunctional vestibular system can be hypersensitive, where a child may be clumsy and have trouble climbing stairs or walking on uneven surfaces. The hyposensitive child may engage in excessive spinning or jumping (Autism Research Institute 2017).

The proprioceptive system refers to the neuroreceptors in the tendons, muscles, and joints. These proprioceptors allow us to sit upright in a chair, walk smoothly, climb stairs, kick a ball, write with a pencil, use a spoon or fork, or button a shirt. A dysfunctional proprioceptive system can lead to clumsiness, difficulty manipulating small objects, and difficulty writing with a pencil (Autism Research Institute 2017).

The tactile system refers to the receptors under the skin's surface that send messages to the brain regarding temperature, pressure, movement, and pain. A dysfunctional tactile system can also lead to hypersensitivity or hyposensitivity. For example, a child may only eat smooth foods and refuse to eat foods that have texture, or vice versa. The child may also refuse to wear certain fabrics, or refuse to be touched.

Auxiliary therapies

Parents may also acquire auxiliary therapies for their children with autism such as music therapy, therapies in water (e.g., surfing and aquatic), therapies with animals (e.g., hippotherapy, swimming with dolphins), movement activities (e.g., Brain Gym, interactive metronome), learning programs (e.g., Fast ForWord), social skills programs, communication methods (e.g., facilitated communication, rapid prompting method), brain retraining and bodywork therapies (e.g., neurofeedback, craniosacral, auditory integration), and psychotherapy (e.g., cognitive behavior therapy).

According to the American Music Therapy Association, "…music is used within a therapeutic relationship to address physical, emotional, cognitive, and social needs of individuals" by "creating, singing, moving to, and/or listening to music" (AMTA 2017). Music can help to improve communication skills, to stimulate the different senses (auditory, visual, proprioceptive, vestibular, and tactile), and to reduce negative and self-stimulatory behaviors (AMTA 2012). Kim et al. (2008) found that improvisational music therapy, more than play therapy, improved eye contact and joint attention skills of children with autism. However, a randomized clinical trial by Bieleninik et al. (2017) found no significant difference in the severity of symptoms between children receiving improvisational music therapy and those receiving usual care supplemented with parent counseling.

Surfing has become a popular therapeutic activity for people with autism. Organizations such as Surfers Healing and Surfers for Autism have introduced the sport to many families of children on the spectrum. It has been reported that surfing and other water activities can decrease behaviors and improve cognitive development (Clapham et al. 2014). A study by Pan (2010) found that a water exercise swimming program decreased antisocial behaviors (e.g., hostile/irritable, antisocial/aggressive, defiant/disruptive) and improved aquatic skills of boys with high functioning autism and Aspergers. The study did not find improvement of social competence behaviors (e.g., peer relations, self-management/compliance, and academic behaviors), however.

Animal-assisted intervention (AAI) or animal-assisted therapy (AAT) involves the use of animals for therapeutic purposes, such as assisting with social interaction, anxiety, or stress. Animals commonly used in therapy are dog, horses, and dolphins. A systematic literature review of animal assisted intervention for autism by Ohaire (2013) concluded that while the studies reported improvements in socialization, communication, and problem behaviors, these studies commonly suffered from a lack of methodological rigor. Peters and Wood (2017) reviewed literature on equine-assisted interventions and reported that while there are limitations in the studies reviewed, the “preliminary evidence suggests that equine-assisted interventions for people with ASD are promising” (1). Both studies emphasize the need for more rigorous methodologic approaches to assess animal assisted interventions.

Brain Gym and Interactive Metronome are therapies that use movement to help the body-brain balance. Brain Gym consists of a series of bilateral exercises that cross the midline between the left and right hemispheres of the brain. The purpose of performing these movements is to "improve the integration of specific brain functions with body movements" (Hyatt 2017:118) and, according to the Brain Gym International website, to improve concentration and focus, memory, academics, physical coordination, relationships, self-responsibility, organization skills, and attitude (Brain Gym 2016). Hyatt (2017) reviewed four peer reviewed articles on the effectiveness of the Brain Gym method. Five articles were originally identified, but one was not included in the review due to the author's participation in the study. Hyatt concluded that the four remaining studies "…failed to support claims that Brain Gym movements were effective interventions for academic learning" (122). In addition, the studies had serious methodological problems. However, Dustow (2007) completed a study of 20 public preschool special education classrooms and found that bilateral exercises that cross the midline decreased off task behaviors of preschool children with autism. The off task behaviors included verbal/nonverbal aggressive behaviors, eloping, flopping, inappropriate talking, non-focused behavior, and noncompliant incidences.

Interactive Metronome (IM) is a computer-based interactive program that requires a person to work on timing and rhythm by striving to be in sync with an established beat. IM has been reported to have some benefit for motor function (Beckelhimer 2011 et al.; Shank and Harron 2015), visual motor control (Cosper et al. 2009), and timing (Libkuman et al. 2002). A study by Shaffer et al. (2001) concluded that boys diagnosed with ADHD who received Interactive Metronome therapy improved in attention, motor control, language processing, reading, and ability to regulate aggression. Ritter, Colson, and Park (2013) compared the reading scores of children with language and reading impairments who participated in a traditional reading program with children who both participated in a traditional reading program and received IM treatment. The improvements in reading scores were much larger for the children who also received IM treatment. Although some preliminary studies show improvements with the use of Brain Gym and Interactive Metronome, studies with methodological rigor that specifically focus on autism are needed.

Fast ForWord Language (FFWL) is a computer program that is intended to correct auditory processing deficits that impede language development (Olsen 2011). The language-based audiovisual computer games have been used extensively by schools to help students with language and reading disabilities (Olsen 2011). Strong et al. (2011) reviewed literature on Fast ForWord but could find no evidence that the program was effective in improving children's language and oral skills. A study by Fey et al. (2010) did not support the use of Fast ForWord as an enhancement of conventional narrative-based language intervention. Troia and Whitney (2003) compared a group of students who were treated with Fast ForWord with a no-contact control group. They found no differences in pre- and post-test scores between the groups, except for expressive oral language, which showed significantly greater improvements in the Fast ForWord group. However, they did find that the lowest performing students in the Fast ForWord group had greater improvements in expressive oral language, syllable and sound blending, and problem behaviors than the lowest performing students in the no-contact control group.

Communication methods that require assistance from an aide include facilitated communication (FC) and rapid prompting method (RPM). Both methods are controversial due to the lack of randomized control studies. Facilitated communication requires an aide to physically support the hand or wrist of the person in order to allow the person with disabilities to type out messages on a keyboard or letterboard. The articles on FC overwhelmingly refute its efficacy. One article in particular warned against its use lest parents and caregivers be accused of sexual abuse by "facilitator generated" allegations (Lilienfeld et al. 2014). According to Jacobson et al. (1995), single and double blind research in laboratory and natural settings determined that "…not only are the people with disabilities unable to respond accurately to label or describe stimuli unseen by their assistants, but that the responses are controlled by the assistants" (750). The most subjects of the studies supportive of FC were not consistently accurate in their responses, although some were quite accurate. A case study by Weiss, Wagner, and Bauman (1996) of a 13 year-old boy diagnosed with autism, severe mental retardation, and a seizure disorder found that he was able to demonstrate valid FC. The boy was asked questions regarding short stories he was told. The facilitator in the study was not told the stories and was kept uninformed. The researchers reported that the responses given by the boy clearly showed that it was he who was answering the questions, and not the uninformed facilitator. The researchers concluded that the case study demonstrated that FC may be used as a "valid method for at least some individuals with developmental disabilities" (Weiss et al. 1996:220).

Rapid Prompting Method (RPM) is similar to FC in that it also involves a keyboard or letterboard. However, instead of the aide supporting the hand or wrist of the person with disabilities, the aide supports the keyboard or letterboard while the person with disabilities moves their own hand over the board. RPM is used as an educational method in as well as a means of communication. The child is asked a question and is then prompted by the RPM teacher to choose between two answers written on two pieces of paper. The main role of the RPM teacher is to use prompts to divert the attention of the autistic student from their repetitive behaviors long enough to choose an answer. A study by Chen et al. (2012) reported that using

RPM for children with autism appeared to decrease repetitive stereotypical behaviors. They also reported that there was a positive relationship between the rate of prompting by the teacher and the rate of response by the student.

Lang et al. (2014) reviewed the study by Chen et al. and concluded that the study was flawed and that the data suggests that RPM leads to prompt dependency because RPM does not necessarily fade prompts. Tostanoski et al. (2014) compared FC with RPM and concluded that, like FC, “RPM appears to be pseudoscientific” (222) and warns that scientific validation of RPM is needed.

Therapies that attempt to balance or retrain the brain and body include neurofeedback, craniosacral, and auditory integration therapy. Like the other auxiliary therapies above, these therapies are controversial and require more rigorous research studies. Neurofeedback is a “form of operant conditioning of electrical brain activity, in which desirable brain activity is rewarded and undesirable brain activity is inhibited (Kouijzer et al. 2009:145). It “…refers to training in self-regulation aiming to achieve control over cortical electrical activity …[which is]… realized through a process of operant learning using real-time representation of electroencephalographic (EEG) parameters” (Holtmann et al. 2011:987). Holtmann et al. (2011) reviewed five controlled studies on the effectiveness of neurofeedback on autism. Although the children in the studies showed improvements in symptoms, Holtmann et al. concluded that the treatment may have actually improved the comorbid ADHD symptoms and not the core autism symptoms. However, Coben, Linden, and Myers (2010) also reviewed the literature on autism and neurofeedback and concluded that the studies are “encouraging” and that the treatment is “probably efficacious,” but research that “demonstrate efficacy according to current research standards” are required.

Craniosacral (or cranial sacral) therapy is a treatment that aims to “release restrictions around the spinal cord and brain and subsequently restore body function” (Jakel and von Hauenschild 2012:456). It is theorized that by “…physically pressing on different parts of the skull and spine…the therapy can change the flow of the spinal fluid…” which can eliminate, ”…learning, behavioral, and emotional problems that are caused by disruptions, interruptions, or blockage of the flow of the cerebral spinal fluid…” (Zane 2011:2). Green et al. (1999) reviewed the available research at the time on craniosacral therapy as a therapeutic intervention and found that there was insufficient research to support the therapy. Jakel and von Hauenschild (2012) reviewed the literature thirteen years after Green et al. and found that while some positive outcomes were reported in the area of pain and well-being, further research is needed.

Auditory integration therapy (AIT) is used to treat people with auditory processing or hypersensitivity to sound (Autism Speaks 2017). The treatment involves two half-hour daily sessions over ten days of listening through headphones to filtered music that is electronically modified to dampen the frequencies to which the person is “hypersensitive” (Dawson and Watling 2000). The sounds are randomly alternated with high and low frequencies. Dawson and Watling (2000) reviewed the studies on the effects of AIT on autism and concluded that the research did not support use of AIT as a treatment for autism. Similarly, Sinha et al. (2006) conducted a systematic review of six randomized controlled trials of AIT and adults and children with autism. The studies did not show improvements in autism symptoms across the board; three studies showed no benefit and the remaining three studies used the Aberrant Behavior Checklist (which the Sinha et al. deemed to be a questionable assessment) to determine the effect of AIT on autism symptoms.

According to the APA, “Cognitive behavior therapy (CBT) is a form of psychological treatment that has been demonstrated to be effective for a range of problems including depression, anxiety disorders, alcohol and drug use problems, marital problems, eating disorders, and severe mental illness” (Society of Clinical Psychology n.d.). For autism, CBT helps people with autism reduce their fears and anxieties and develop impulse control, which in turn improves their behavior (Autism Speaks 2017). The treatment’s goal is to change thinking and behavioral patterns. Cappadocia and Weiss (2011) compared CBT social skills training groups with traditional and parent-inclusive social skills training groups. Improvements were seen in the majority of the studies regardless of type of training group. Although all three of the CBT training group showed improvements in social skills, elements of the CBT interventions were also identified within the traditional and parent-inclusive interventions. Studies with larger sample sizes and more controlled methodological designs are recommended. Danial and Wood (2013) reviewed studies of cognitive behavioral interventions for children with autism that focused on anxiety, disruptive behavior, and core autism symptoms. They concluded that although there is emerging evidence that CBT is possibly efficacious for anxiety and autism symptoms, future research should include studies using randomized controlled trial design and independent evaluators. Also, the studies should also use more “stringent methodology and evidence-based outcome measures to draw clearer causal conclusions” (Danial and Wood 2013:713).

Psychotropic Medication

According to Ji and Findling, “…there is no known efficacious pharmacotherapy for core symptoms of autism spectrum disorder (ASD)” (2015:91). However, psychotropic medications, or medications that affect mood and behavior, are commonly prescribed to treat symptoms associated with autism, such as irritability, anxiety, hyperactivity, and repetitive behaviors (Ji and Findling 2015; LeClerc and Easley 2015). Most of the medications are prescribed for off-label use, as only the antipsychotic medications (or neuroleptics) risperidone (Risperdal) and aripiprazole (Abilify) have been approved by the U.S. Food and Drug Administration (FDA) for irritability associated with autism (Ji and Findling 2015; LeClerc and Easley 2015). Risperidone was approved in 2006 for use in children 5 years and older and aripiprazole was approved in 2009 for children 6 to 17 years old (LeClerc and Easley 2015). Aripiprazole is also used for schizophrenia, bipolar I disorder, major depressive disorder, and Tourette's syndrome (LeClerc and Easley 2015). Studies have shown improvements in tantrums and aggression in children with the use of risperidone, but adverse side effects have been observed including weight gain, increased appetite, dizziness, drooling, and fatigue; in addition, tardive dyskinesia, or uncontrolled repetitive movements, is a potential effect of long term use (Ji and Findling 2015; LeClerc and Easley 2015). Similarly, studies have shown improvements in irritability with the use of aripiprazole, but adverse side effects have also been observed including weight gain, fatigue, sedation, sleepiness, and uncontrolled muscle movements (Ji and Findling 2015; LeClerc and Easley 2015). Increased symptoms of depression and suicidal thoughts and behaviors are also a concern when taking aripiprazole (FDA 2017).

Besides antipsychotics, other psychotropic medications prescribed for symptoms of autism are stimulants, antidepressants, anticonvulsants, and anxiolytics (Autism Speaks 2017). The stimulant methylphenidate (Ritalin, Concerta, Daytrana, Focalin) is used to treat hyperactivity, attention deficits and narcolepsy. Studies have shown improvements in hyperactivity, impulsivity, and inattention in children, but side effects observed include increased irritability, decreased appetite, social withdrawal, and restlessness (LeClerc and Easley 2015).

According to the Ritalin manufacturer Novartis and the Concerta manufactuer Janssen, serious side effects of methylphenidate include a long-term suppression of growth in children, seizures, blurred vision, and priapism or painful and prolonged erections in both children and adults (Janssen 2013; Novartis 2017). Methylphenidate use has not been studied in children under the age of 6 years (Janssen 2013; Novartis 2017). The combination drug amphetamine-dextroamphetamine (Adderall), a stimulant that is used for the treatment of ADHD and narcolepsy, is also prescribed for symptoms of autism. Like methylphenidate, amphetamine-dextroamphetamine also has adverse side effects such as long-term suppression of growth, blurred vision, decreased appetite, nervousness, and seizures (Teva Pharmaceuticals 2015).

Antidepressants like fluoxetine (Prozac) or sertraline (Zoloft) are prescribed for autism to treat repetitive behaviors, unstable moods, anxiety, and depression (IAN 2009). Anticonvulsant medications (e.g., divalproex sodium or Depakote, lamotrigine or Lamictal) are prescribed to treat unstable moods, epileptic seizures, and migraine headaches (IAN 2009). Anxiolytic medications like lorazepam (Ativan) or buspirone (Buspar) are used to treat anxiety.

“Alternative” Biomedical Treatments

Although many believed that the cause of autism was a psychological one, not everyone held this view. In his 1964 book, *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*, Bernard Rimland hypothesized that the cause of autism was found in the brain stem, thereby being biological in origin. Rather than adhering to the belief that autism was the result of cold mothering, he felt, “…that autism was in fact the result of neurological and hereditable factors…” (Jepson and Johnson 2007:18). Rimland, who was an experimental psychologist as well as a father of a son with autism, founded the Autism Society of America (ASA) in 1965 and the Autism Research Institute (ARI) in 1967. According to their website, "ARI is dedicated to developing a standard of care for individuals with autism spectrum disorders and their families" (ARI 2017). The focus of ARI is to research biomedical interventions for autism, including the effects of dietary changes (gluten/casein free), supplements, and detoxification. A program of ARI was Defeat Autism Now! (DAN!). DAN! brought together clinicians who followed the alternative biomedical approach to autism. Although this program ended in 2011, a new independent program began in its place, Medical Academy of Pediatric Special Needs (MAPS). This program offers fellowships to medical professionals to train them in the care of children with autism.

There are a number of physiological symptoms associated with autism, such as impairment with the gastrointestinal system (Buie et al. 2010; Valicenti-McDermott 2006), oxidative stress (Herbert and Weintraub 2012; James et al. 2004), mitochondrial dysfunction (Giulivi et al. 2010; Rossignol and Frye 2012; Frye et al. 2013), and immune dysfunction (Ashwood et al. 2011; Onore et al. 2012). According to Jepson and Johnson (2007), "[seventy] to eighty percent of children with autism have gastrointestinal symptoms, including abdominal pain, diarrhea, constipation, abdominal bloating, or abdominal posturing (applying pressure to the abdomen for pain relief)" (p. 210). These symptoms can manifest as behavioral issues (Buie et al. 2010b). A study by researchers at Vanderbilt University and Massachusetts General Hospital found that "gastrointestinal conditions are more prevalent in individuals with ASD than in their immediate family members" (Campbell et al. 2009:1020). These conditions may be due to an imbalance of the normal microflora in the gastrointestinal tract, or gut dysbiosis (Jepson and Johnson 2007).

A study by Jill James (2004) found that children with autism had a metabolic imbalance that resulted in more oxidative stress and less capacity for methylation. She also found an association between gene mutations in the methylation pathway and a higher risk of autism (Herbert 2013). The methylation cycle is “a critical metabolic pathway that among other things produces precursor molecules for detoxification and anti-oxidation” (Jepson and Johnson 2007:101); therefore, an impaired methylation pathway inhibits the body’s ability to eliminate toxins.

Autism spectrum disorder has also been associated with mitochondrial dysfunction and disease. Mitochondrial dysfunction may influence neurodevelopment and as a result contribute to autism (Giulivi et al. 2010). “Primary” mitochondrial disease, or mitochondrial disease caused by a specific gene mutation, seems to account for only a portion of the disease in children with autism (Giulivi et al. 2010; Frye et al. 2013). This suggests that most of the cases may be “secondary” mitochondrial disease, or mitochondrial disease that is acquired and due to the environment (Frye et al. 2013; Herbert and Weintraub 2012). Environmental factors that have been shown to affect mitochondrial function are heavy metals, chemicals, pesticides, polychlorinated biphenyls (PCBs), and short-chain fatty acid fermentation products of bacteria associated with autism (e.g., Clostridia) such as proprionic acid (PPA) (MacFabe 2012).

The purpose of the alternative biomedical treatments is to address these physiological symptoms associated with autism. This involves extensive laboratory testing to determine, for example, the nutritional deficiencies and possible bacterial overgrowth in the GI tract with the guidance of an experienced clinician.

A related and highly controversial and divisive issue surrounding autism is the relationship between autism and vaccines. This controversy first became widely known following the 1998 study by Wakefield et al., “Ileal-Lymphoid-Nodular Hyperplasia, Non-

Specific Colitis, and Pervasive Developmental Disorder in Children." The results of this study led to widespread media coverage linking the MMR vaccine with autism. In the United Kingdom, vaccination rates of the MMR declined and parents began to question the safety of the vaccine program (Burgess, Burgess, and Leask 2006). In 2010, the journal that published the article, the *Lancet*, retracted the article citing problems with the way the children were recruited and the lack of ethical approval for the study.

In 2010, the General Medical Council (GMC), the organization that sets the educational standards for doctors in the UK and manages the country's medical register, concluded that Dr. Wakefield and Professor Walker-Smith, two of the thirteen authors of the controversial paper, were guilty of "serious professional misconduct" and ordered their names to be deleted from the medical register (Walker-Smith v GMC[2012] EWHC 503). Professor Walker-Smith proceeded with an appeal and was subsequently exonerated by the High Court of Justice in 2012. In the decision, Justice Mitting wrote, "…the [GMC] panel's overall conclusion that Professor Walker-Smith was guilty of serious professional misconduct was flawed, in two respects: inadequate and superficial reasoning, and, in a number of instances, a wrong conclusion" (Walker-Smith v GMC[2012] EWHC 503).

It is interesting to note that the Wakefield paper did not state that the MMR causes autism, as it has been often reported. In actuality, the paper states, "We did not prove an association between measles, mumps, and rubella vaccine and the syndrome described" (Wakefield et al. 1998:641). It also states, "We have identified a chronic enterocolitis in children that may be related to neuropsychiatric dysfunction," and, "Further investigations are needed to examine this syndrome and its possible relation to this vaccine" (Wakefield et al. 1998:641).

Another issue surrounding vaccines and autism that is highly controversial is the use of thimerosal, an ethylmercury-based preservative used in multiple-dose vaccines. Since 2003, most pediatric vaccines no longer contained thimerosal. The exception is the multi-dose influenza vaccine. Prior to this, however, thimerosal was commonly found in most of the pediatric vaccines (with the exception of live virus vaccines). The CDC has always maintained that ethylmercury "…is cleared from the human body more quickly than methylmercury [the type of mercury found in fish], and is therefore less likely to cause any harm" (CDC 2015).

A case-control study was conducted by Price et al. (2010) in 3 managed care organizations to examine the relationships between prenatal and infant ethylmercury exposure from thimerosal-containing vaccines and/or immunoglobulin preparations and ASD. Of the 771 potential case-children and 2760 controls identified, 256 case-children and 752 controls participated. Lack of time was stated by the mothers as the primary reason for non-participation. Based on their findings, the researchers reported that they found no increased risk for ASD. Interestingly, for their analysis, 2 SD units of prenatal exposure to ethylmercury was 16.34 µg. However, the prenatal exposure of ethylmercury for the case-children with ASD was between 0 and 74 µg. A multi-dose influenza vaccine, like the Fluzone Quadrivalent, contains 25 µg of mercury (FDA 2016).

Burbacher et al. (2005) compared the mercury levels in the brains of infant monkeys who were injected with thimerosal containing vaccines with those who were fed equal amounts of methylmercury. The routes of administration were selected in order to mimic the typical means of exposure in humans. They found that although the mercury levels in the blood cleared faster and the total amount of mercury in the brain was less for the thimerosal-exposed monkeys, the brain-to-blood ratio and the ratio of inorganic mercury in the brain was higher for the thimerosal group. According to the study, “Absolute inorganic Hg [mercury] concentrations in the brains of the thimerosal-exposed monkeys were approximately twice that of the MeHg [methylmercury] monkeys” (Burbacher et al. 2005:1020). Caneiro et al. (2014) found ethylmercury as well as inorganic mercury in the brain tissue of mice after being injected with 20 µg of thimerosal. The study also found that ethylmercury is both transported from muscle to tissue and converted to inorganic mercury quickly. According to Bigazzi (1999) inorganic forms of mercury, like organic mercury, have immunotoxic effects.

Recently, two researchers at the CDC’s Agency for Toxic Substances and Disease Registry completed a meta-analysis on mercury studies (Risher and Tucker 2016). They concluded that methylmercury and ethylmercury are similar in toxicity. According to the study, “There are many commonalities/similarities in the mechanisms of toxic action of methylmercury and ethylmercury (from thimerosal)” (Risher and Tucker 2016:141). The researchers listed examples of the similarities in toxicity, such as both types of mercury decrease glutathione activity which in turn provides less protection from oxidative stress as a result of mercury exposure and both cause DNA damage (Risher and Tucker 2016).

In addition to thimerosal, other ingredients in vaccines have also led the public to question their safety. One example is aluminum, which is used as an adjuvant to increase the immune response to the antigen in the vaccine. According to the U.S. Food and Drug Administration, “Aluminum adjuvant containing vaccines have a demonstrated safety profile of over six decades of use and have only uncommonly been associated with severe local reactions” (FDA 2014). The CDC states that aluminum has been used in vaccines safely since the 1930’s and that the amount of aluminum in vaccines is low and is regulated by the FDA (CDC 2016). The CDC webpage on “Vaccine Adjuvants” links to a summary of the study by Mitkus et al.

(2011) of the FDA that concludes that, “the risk to infants posed by the total aluminum exposure received from the entire recommended series of childhood vaccines over the first year of life is extremely low” (FDA 2015). The researchers of the study calculated the maximum doses of aluminum that a child might receive through routine childhood vaccines over the course of a year. They determined that “the body burden of aluminum is less than 50% of the oral safe level for [aluminum phosphate or aluminum hydroxide] at all times during the first year or so of life” (Mitkus et al. 2011:9541). Based on a study by Flarend (1997), where the researchers injected 2 rabbits each with aluminum phosphate and aluminum hydroxide, Mitkus et al. (2011) assumed that as a result of an intramuscular injection of aluminum, only 51% of aluminum phosphate and 17% of aluminum hydroxide would be absorbed into the blood over 28 days of exposure, and that aluminum phosphate would be absorbed at a constant rate over the next 28 days but that aluminum hydroxide would be absorbed at a constant rate over the next 137 days. Mitkus et al. based the elimination and retention of aluminum in humans on a study by Priest et al. (1995), where researchers injected a single male volunteer with aluminum citrate over the course of 12 years.

The American Academy of Pediatrics Committee on Nutrition from 1994 to 1995 wrote that the toxic effect of aluminum is “…being implicated as interfering with a variety of cellular and metabolic processes in the nervous system and in other tissues” (AAP 1996:413) and recommended the reduction in aluminum exposure for children and infants at risk of renal failure as well as premature infants. The report, “Toxicological Profile for Aluminum” by the Agency for Toxic Substances and Disease Registry of the U.S. Department of Health and Human Services (2008) stated that children with kidney disease have had brain and bone disease caused by high levels of aluminum in the body and that children taking medications with aluminum have also had bone disease. It also states that, “We do not know if aluminum will cause birth defects in people” (USDHHS 2008:6). In addition, it states that, “Aluminum is generally considered to be neurotoxic in animals, and there is an adequate basis to conclude that neurotoxicity/neurodevelopmental toxicity is the critical effect of oral exposure in animals. Whether the subtle neurotoxic effects seen in adult and developing animals exposed to relatively low doses of aluminum would definitely manifest in humans under similar exposure conditions remains to be determined” (USDHHS 2008:119).

Acquiring Autism Treatments and Services

While making treatment decisions for their autistic children can be overwhelming for parents, there is the added stress of actually acquiring them. The cost of paying for these treatments and services out-of-pocket can be unaffordable; therefore, most parents attempt to acquire these treatments and services through the Individualized Education Plan (IEP), Medicaid (e.g., waivers, EPSDT), and/or private insurance policies. States are required to provide a free and appropriate public education (FAPE) to all children with disabilities due to a federal law called IDEA, or the Individuals with Disabilities Education Act. The IEP is the document that outlines a child’s free and appropriate public education. Medicaid is a health insurance program for low-income adults, children, pregnant women, the elderly, and people with disabilities that is administered by the states and funded by both the states and the federal government (Medicaid N.d.). The July 7, 2014 informational bulletin from the Center for Medicaid and CHIP Services (CMCS) stated that the Medicaid program may reimburse services for autism spectrum disorders through sections 1905(a) of the Social Security Act, 1915(i) state plan Home and Community-Based Services, 1915(c) Home and Community-Based Services (HCBS) waiver programs, and 1115 research and demonstration programs (CMCS 2014). Private health insurance coverage for autism in the past has been typically minimal. Autism was normally treated as other mental health conditions with regards to coverage of services. Psychiatric and psychological visits, as well as psychotropic drugs, were generally covered by health insurers. Speech, occupational, and physical therapies were often limited to rehabilitative versus habilitative services. TRICARE, the insurance program for active military personnel, was one of the rare insurance plans that covered basic, though minimal, behavioral therapies like applied behavior analysis or ABA. In the last decade, there has been a push for autism insurance legislation in the U.S. Currently, 46 states (plus District of Columbia and the U.S. Virgin Islands) have passed some form of autism insurance mandate (Autism Speaks 2017).

IDEA and the IEP

In 1975, Congress enacted Public Law 94-142, or the Education for All Handicapped Children Act (EHA). This law, which would eventually be renamed the Individuals with Disabilities Education Act (IDEA) in 1990, "…established the right of children with disabilities to attend public schools, to receive services designed to meet their needs free of charge, and, to the greatest extent possible, to receive instruction in regular education classrooms alongside nondisabled children" (Aaron and Loprest 2012:99). The schools were required to create an Individualized Education Plan (IEP) for disabled children ages 3-21 (except where it was inconsistent with state law), which was to be implemented in a least restrictive environment (LRE). Prior to the passage of this law, children with mental and physical disabilities were placed in institutions that accommodated the children's disabilities, but separated them from the greater community. Many children with autism, however, were not educated at all and were placed in state institutions for the "feeble-minded." These institutions minimally provided food, clothing, and shelter. Schools in the U.S. in 1970 only educated 1 in 5 children with disabilities, and many states had laws that excluded students who were deaf, blind, emotionally disturbed, or mentally disturbed (U.S. Dept. of Educ. 2007). The Public Law 94-142 was designed to rectify the situation. There were "four purposes" of this law:

- "to assure that all children with disabilities have available to them…a free appropriate public education which emphasizes special education and related services designed to meet their unique needs"
- "to assure that the rights of children with disabilities and their parents…are protected"
- "to assist States and localities to provide for the education of all children with disabilities"
- "to assess and assure the effectiveness of efforts to educate all children with disabilities" (U.S. Department of Education 2007)

At the time the EHA was enacted, more than one million children with disabilities were either entirely excluded from the education system, or had only limited access to an education. Over the years, the EHA was amended to provide more rights to children with disabilities and their parents. In 1983, the EHA was amended to include parent training and Parent Information Centers so that parents could get training on how to protect their children's rights. In 1986, the law was amended to allow for the reimbursement of legal costs for parents or guardians if they won a hearing regarding their children's rights to a free and appropriate public education (Ferrell 2000). An amendment provided financial incentives to states to established family-centered early intervention programs and mandated that states provide services to disabled children from birth (Ferrell 2000; U.S. DOE 2017).

In 1997, amendments to IDEA expanded upon the issue of transition from school to adult living, and mandated that the IEP transition planning should begin at age 14, and that appropriate employment and other post-school objectives should be identified (U.S. DOE 2007). The reauthorized version of IDEA, IDEIA 2004 or the Individuals with Disabilities Education Improvement Act of 2004, included some portions of the No Child Left Behind Act (NCLB) of 2001. However, the Every Student Succeeds Act (ESSA) of 2015 yet again amended the provisions in IDEA. For example, under the No Child Left Behind Act, special education teachers who taught core academic subjects had to meet the NCLB requirements for "highly qualified teachers" (i.e., must have full state certification, be licensed to teach, and meets all state requirements) (Wright and Wright 2006). Under the ESSA, all references to the definition of "highly qualified" were eliminated. In addition, while the NCLB required states and districts to include special education students in the same statewide assessments as the general education students (with "appropriate accommodations"), the ESSA allows states to give alternate assessments (Wright and Wright 2009).

There has been some backlash as a result of the passage of IDEA. For instance, the Supreme Court ruled in Schaffer v. Weast (2005) that the burden of proof falls on the party challenging an IEP in an administrative hearing. This means that a parent who files a due process complaint under IDEA would bear the burden to prove that FAPE was not provided. Although the Court ruled in favor of the school district, Justice Ginsberg, in her dissenting opinion, stated that, "Saddled with a proof burden in administrative 'due process' hearings, parents are likely to find a district-proposed IEP 'resistant to challenge," and that, "…school districts striving to balance their budgets, if '[l]eft to [their] own devices,' will favor educational options that enable them to conserve resources" (Schaffer v. Weast). Wilson (2007) emphasized that, “Bearing the burden of proof in a hearing, especially with a statute as complicated as IDEA, requires far more than most pleadings” (185), making it especially difficult for low-income or minority families.

In 2006, in Arlington Central School District v. Murphy, the Supreme Court held that parents who prevail in due process hearings are not entitled to recover expert witness fees, despite the fact that “the majority opinion acknowledged that the legislative history of the Individuals with Disabilities Education Act supported the interpretation that ‘costs’ includes reimbursement for expert witness fees” (Wrightslaw 2006). Both of these rulings placed a financial burden on parents and guardians and put families at a huge disadvantage in any litigation against a school district, as the cost of an attorney or expert witnesses may be unaffordable. Without the benefit of a legal professional to present the case or expert witnesses to testify on behalf of the child, a family’s chance of success is “severely limited” (Fleischer and Zames 2011).

Medicaid

Medicaid was established in 1965 as Title XIX of the Social Security Act. It is a health insurance program that is jointly funded by the states and the federal government. The original purpose of Medicaid was to fund health care for the poor (Medicaid N.d.). Today, Medicaid covers low-income adults, children, pregnant women, elderly adults, and people with disabilities (Medicaid N.d.). Medicaid also provides coverage for long-term care services that are needed as the result of chronic illnesses or disabilities (Medicaid N.d.). The Medicaid program may reimburse services for ASD through sections 1905(a) of the Social Security Act, 1915(i) state plan Home and Community-Based Services, 1915(c) Home and Community-Based Services (HCBS) waiver programs, and 1115 research and demonstration programs (CMCS 2014).

The Medicaid state plan allows coverage of autism services under section 1905(a) benefit categories including Other Licensed Practitioners (OLP) or “medical or remedial care or services, other than physicians’ services”; Preventive Services, or “services recommended by a physician or other licensed practitioner of the healing arts” to “prevent disease, disability, and other health conditions or their progression,” “prolong life,” and “promote physical and mental health and efficiency”; and Therapy Services, or physical, occupational, and speech/language therapies (CMCS:2014:2-3).

States may also provide services in addition to the services provided under section 1915(a). These services may be provided under a section 1915(i) state plan Home and Community-Based Services (HCBS) benefit that targets specific populations, including those with ASDs. These services may include dental services, skills nursing services, respite care, supported employment, habilitative supports, and environmental modifications (CMCS 2014).

The Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit was introduced in 1967. All states are required to provide this Medicaid benefit which includes comprehensive and preventive health care services for eligible children less than 21 years of age (Medicaid N.d.). The services that are offered should assess and identify health problems early (“Early”); check the health of the children at periodic intervals (“Periodic”); provide screening tests and evaluations to detect potential physical, mental, developmental, dental, hearing, and vision problems (“Screening”); perform diagnostic tests when a risk or problem is identified (“Diagnostic”), and control, correct, or ameliorate any health problems that are found (“Treatment”) (Medicaid N.d.).

According to the September 2014 Center for Medicare and Medicaid Services autism services FAQs, “States are expected to adhere to long-standing EPSDT obligations for individuals from birth to age 21, including providing medically necessary services available for the treatment of ASD” (CMS 2014). The July 7, 2014 CMCS Informational Bulletin listed the treatments for ASDs, including: “1) behavioral and communication approaches; 2) dietary approaches; 3) medications; and 4) complementary and alternative medicine” (CMCS 2014). Applied behavior analysis (ABA) was named as one of several treatment modalities for autism.

In 1981, the Home and Community-Based Services (HCBS) Waiver program was established for Medicaid beneficiaries. HCBS waivers, or 1915(c) waivers, allow for services to be provided outside of institutionalized settings for those who prefer to get long-term care services and supports in their home or community (Medicaid N.d.). In 1999, the Supreme Court ruled in Olmstead v. L.C. that unjustified institutionalization is discriminatory and violates the American with Disabilities Act (ADA N.d.). The Medicaid HCBS waiver is one avenue that allows states to comply with this law (Duckett and Guy 2000). In fact, in her decision in the Olmstead case, Justice Ginsberg stated that, “Since 1981, Medicaid has provided funding for state-run home and community-based care through a waiver program” (Olmstead v. L.C.).

The services specifically listed in the law are case management services, homemaker services, home health aide services, personal care services, adult day health services, habilitation services, and respite care (Social Security N.d.). Most of the states in the U.S. offer HCBS Waiver services, except for Arizona, Rhode Island, and Vermont (Center on Disability 2017). The waiver means that states can “waive” certain Medicaid requirements for the HCBS Waivers so that individual states may: 1) focus the waivers on areas where the need is greatest, or where there is availability of providers; 2) make the services only available to groups who are at risk of institutionalization, such as the elderly or individuals with intellectual disabilities; and 3) provide Medicaid services to those who normally would only be eligible in an institutional setting because of the income and resources of a parent or spouse. Nationwide, there are more than 300 HCBS Waiver programs (Medicaid N.d.).

In 2014, twelve states had autism waivers, or waivers that specifically provide services for ASDs. These states were Arkansas, Colorado, Connecticut, Kansas, Massachusetts, Maryland, Missouri, Montana, Nebraska, North Dakota, South Carolina, and Utah (Easter Seals 2014). Then, the July 7, 2014 CMCS bulletin clarified that for those who are under 21 years old and who qualify for EPSDT services, the HCBS waiver could be used to provide services beyond what is provided by section 1905(a). On September 2014, CMS issued an autism services FAQs that further clarified that "ASD-related services for EPSDT eligible individuals (under age 21) must be provided under the Medicaid state plan and not under th1915(c) waiver" (CMS 2014). Currently, there are only ten states with autism waivers. Missouri and Nebraska now offer ABA through the Medicaid state plans and the remaining services though other existing waivers instead.

The criteria for qualification and the services that are provided vary by state. For instance, the Colorado waiver is for children up to 6 years of age and offers case management and behavioral therapy, whereas the Maryland waiver is for children aged 1-21 years and includes family training and intensive individual support (L&M Policy Research, Inc. 2014). The number of autism waiver slots also varies by state. Whereas Connecticut provides autism waivers to 50 children at a time, Maryland recently increased their slots by 100 for a total of 1,100. Because waivers allow states to limit the number of individuals served, moving the services for autism to the State Plan under EPSDT would enable the states to provide services to all eligible children under the age of 21 years.

Health Insurance and Autism Insurance Laws

Until recently, most private health insurance policies did not cover autism treatments (Wang et al. 2013). Insurance companies typically consider autism treatments to be "unnecessary or ineffective" as well as "ongoing and extremely costly" (Autism Science Foundation 2017). According to Stuart (2011), insurance companies have historically excluded individuals with ASD from health coverage through the pre-existing condition exclusion and through post-enrollment coverage limitations. These limitations included "treating ASDs as non-medical conditions; finding treatments to be experimental, educational, not medically necessary, or habilitative in nature; or denying claims because there is no qualified provider" (Stuart 2011:509). Additionally, insurance companies have argued that there is no standard of care for autism because it is individually-based and that most medical treatments for autism are already covered (Bunce and Wieske 2009). With the passage of the Affordable Care Act (ACA), insurance companies can no longer deny coverage for pre-existing conditions, such as ASD.

In spite of the opposition from the private health insurance companies, Indiana's Commission on Autism recommended in October 2000 that an autism insurance mandate be introduced in the state's legislature. Indiana became the first state to enact an autism insurance mandate in 2001. The second state didn't enact autism insurance legislation until 2007 when South Carolina's House and Senate overrode the veto of the bill by then Governor Mark Sanford (Autism Speaks 2007). Since then, autism insurance mandates have passed each year. Currently, 46 states plus the District of Columbia and the U.S. Virgin Islands have enacted autism insurance reform mandates (Autism Speaks 2017). The states that have not yet passed an autism insurance reform law are Idaho, Wyoming, North Dakota, and Tennessee.

Opponents of autism insurance reform have argued that mandating insurance companies to cover treatments for autism will raise premiums significantly (NCSL 2017). Others have argued that the trend is a way for states to transfer the cost for autism treatments from the government to the private sector (Stuart 2011). They maintain that the responsibility of caring for individuals with autism rests with the parents and the school system (NCSL 2017), noting that ABA therapy is considered educational and not medical (Stuart 2011). However, proponents of the autism insurance mandate argue that the federal government has never fully funded IDEA according to the law, causing the states to absorb the cost of special education (Stuart 2011), which in turn leads the states to limit the amount of services provided to the children. They also argue that insurance premiums would not increase dramatically. A study by Bouder, Spielman, and Mandell (2009) estimated that the premium increase resulting from autism insurance mandates would be between 0.19% (prevalence of 2 per 1,000 children and an annual expenditure of $10,000 for children less than 21 years of age) and 2.31%, (prevalence of 6.7 per 1,000 children and an annual expenditure of $36,000 per year for children less than 21 years of age). They concluded that even if the treated prevalence were to increase to 1 in 150 children, with an annual per capita expenditure of $36,000, the monthly family contribution would be $6.53 (Bouder et al. 2009).

Autism insurance mandates vary from state to state. Some states have a yearly cap for autism treatment (e.g., both Illinois and Louisiana have limits of $36,000), others have a yearly cap as well as a lifetime cap (e.g., Florida has a yearly limit of $36,000 and a lifetime cap of $200,000). Others, like Indiana, California, and Massachusetts, have no cap at all. Still others have a gradual reduction in maximum yearly benefits, allowing a greater amount for treatments when the child is younger and reducing the amount as the child ages (e.g., In Connecticut, for children under 9 years of age, the limit is $50,000; for children 9-13 years of age, the limit is $35,000; for children 13-15 years of age, the limit is $25,000).

In addition to maximum yearly benefit amounts, some states have age limits for autism treatments. The majority of states provide coverage for children up to 21 years of age, but some end coverage prior to that age (e.g., Arizona and Connecticut end coverage at age 16 years). A few states have no age limit (e.g., New York, Massachusetts, Indiana, California).

Still, private health insurance companies continue to avoid coverage of autism treatments even if prescribed by a treating physician by determining that a therapy, laboratory test, or medication is not medically necessary (Stuart 2011). For example, Aetna lists procedures and services that the company considers to be “experimental and investigational” for the assessment and treatment of autism and other pervasive developmental disorders because they are not currently supported by peer-reviewed literature (Aetna 2017). Some of these are allergy testing, stool analysis, tests for mitochondrial disorders, Floor time therapy, music therapy, and sensory integration therapy (Aetna 2017).

Even if all fifty states pass autism insurance mandates, however, not all health insurance policies would be impacted. State autism insurance reform laws do not apply to insurance plans that are self-funded. Instead, self-funded plans only fall under the federal law, the Employee Retirement Income Security Act of 1974, or ERISA. ERISA sets the minimum standards of protection for most pension (or retirement) and health plans in private industry (Department of Labor N.d.). Self-funded insurance policies are offered by large companies. These companies assume the financial risk of providing health benefits to their employees and generally set up a trust fund to pay for the claims (Self-Insured Institute of America 2015). Still, although they are not required to offer coverage for autism treatments, some companies that offer self-funded insurance plans elect to cover autism treatments on their own. Caregivers of children with ASD must make hard decisions about which treatments to attempt and by which means to acquire them, which increases the stress they already experience from dealing with autism on a daily basis.

Autism in Hawaii

The sample for this study consisted of mothers who lived in Hawaii on the island of Oahu. Therefore, it is important to understand the state of autism and its treatments and services in this community. In Hawaii, the exact number of children with autism is unknown, as there is no state autism registry. The report to the 2009 Hawaii Legislature by the Autism Spectrum Disorders Benefits and Coverage Task Force estimated that the number of children with autism under the age of 21 in the state was 1,240 (Hawaii State Legislature 2009). This figure was based on the number of children who received services from the Hawaii State Departments of Health and/or Education under the autism category. However, the task force report noted that the actual number was higher, as some children who were categorized as having multiple disabilities also had autism. According to the U.S. Department of Education “Child Count,” in accordance with Section 618 of IDEA, 1,713 children aged 3-21 years who received special education services through IDEA Part B in the school year 2015-16 were categorized as having autism in Hawaii (U.S. Dept. of Education 2017). Like the rest of the U.S., treatments and services for autism in Hawaii are acquired primarily through the Department of Education, Medicaid, and private insurance.

Education

Hawaii's school system is comprised of three categories: the single, statewide public school system (including public charter schools); the private school system (religious and secular); and homeschooling. In the U.S., all public schools receiving federal funds are required under IDEA to provide a free and appropriate public education (FAPE) to children with mental and physical disabilities aged 3 to 21. Therefore, schools must create for each disabled child an Individualized Education Plan (IEP), which is to be implemented in a least restrictive environment (LRE). The law further protects the families of the disabled children by providing for procedural safeguards and due process of the law (Zettel 1997). Section 504 of the Rehabilitation Act of 1973 also protects disabled students by prohibiting discrimination against individuals with disabilities by entities that receive federal funds. Disabled students who attend private schools or who are homeschooled are not entitled to special educational services provided by the state government (with the exception of those who attain the services through mediation or due process). The parents of these children must obtain special education services on their own.

Hawaii's single statewide school district is unique in the U.S. The Hawaii Department of Education essentially serves as the state's local education and state education agencies simultaneously. The single statewide school district is broken down into 7 geographical districts (Honolulu, Leeward, Central, and Windward on the island of Oahu; Hawaii on the island of Hawaii; Maui, which includes the island of Molokai and Lanai; Kauai, which includes the island of Niihau) (Benitez et al. 2011). These geographical districts are further broken down into 15 complex areas for the state's 256 public schools and 36 public charter schools. Whereas in other states there are multiple local school districts that each have their own local school board and local superintendent, in Hawaii there are no local school districts, local school boards, or local superintendents. Rather, Hawaii has one superintendent and one school board for the entire state system. In spite of the single system, the services obtained through the IEP process can vary from child to child, from school to school, from complex area to complex area, and from geographical district to geographical district.

Parents and guardians of children with autism must be well-versed on IDEA law in order to know what services their children are eligible to receive. Special Education advocates advise getting private evaluations done by experienced professionals (e.g., psychologists, speech therapists, etc.), who can then make recommendations on the appropriate services that are needed for the child. There is technically no limit as to how many hours of one-to-one skills training, speech therapy, occupational therapy, or any other related service a child may receive under IDEA. The amount and type of services that are provided are technically up to the discretion of the child's school, but in actuality they are determined by the complex areas (also known as "districts") and the superintendent. Regardless of the amount of services a child receives, the services outlined in the Individualized Education Plan (IEP) should be the equivalent of a Free and Appropriate Public Education (FAPE) that is specific to the child. Any disputes regarding special education services with the Department of Education may be settled through a due process hearing under IDEA. Anything beyond a due process hearing is heard in federal court.

In 1993, a class-action lawsuit was filed against the State of Hawaii (specifically, Governor John Waihe'e, the Director of the Department of Health, and the Superintendent of the Department of Education) by the parents of Jennifer Felix and parents of six other children with disabilities (Wataoka 2002). They alleged that the state failed to comply with IDEA, and did not provide appropriate educational and mental health services to these children. U.S. District Court

Judge David Ezra found the State to be in violation of IDEA and Section 504 of the Rehabilitation Act of 1973 (Higa 2001). The lawsuit resulted in a settlement in 1994, which is known as the Felix Consent Decree. In the settlement, the state agreed to "establish a system of care of programs, placements, services, and an organization and managerial infrastructure" by following the requirements of IDEA, Section 504, and the Child and Adolescent Services System Program (CASSP) principles (Higa 1998:49). The state also agreed to implement the terms of the consent decree by June 30, 2000 (Higa 1998:50). CASSP principles include a child-centered and culturally sensitive system of care, a least restrictive and natural environment for services, a coordinated and therapeutic manner of delivery of services, and the promotion of early identification (Higa 1998). Although a coordinated effort between the education and health departments was required for the decree, "the emphasis was on the schools as the agency of primary responsibility" (Behar 2003:211).

The state was found to be in contempt on May 30, 2000 by the U.S. District Court for failing to comply with the terms of the Felix Consent Decree (Higa 2001). Attorneys for the state requested an extension to December 31, 2001, which was granted by Judge Ezra (Wataoka 2002). This gave the state a further 18 months "to design and implement both a seamless system of care and an infrastructure to support that system " (Higa 2001:2).

The December 2001 report by the "Joint Senate-House Investigation Committee to Investigate the State's Compliance with the Felix Consent Decree" concluded that the decree led to a "Pandora's box of unintended consequences" (Hawaii State Legislature 2001). In particular, the committee highlighted that the requirements for compliance were unclear, there was "departmental exploitation of the court's 'money is no object' expectations," the oversight and accountability of the Departments of Education and Health in their implementation of the decree were poor, and the superintendent of education and the director of health were given "superpowers" that allowed them to ignore state procurement and personnel laws (Hawaii State Legislature 2001).

The Hawaii State Auditor's December 2001 report concluded that "the system of care focused more on procedural compliance rather than on a system to effectively help the children" and found that the Departments of Education and Health did not coordinate the educational goals and mental health treatment plans of the children (Higa 2001:Summary). The report also found a lack of transparency with the Departments of Education and Health with regard to the costs of compliance and that "the departments [lacked] an adequate financial management infrastructure to support the Felix compliance effort" (Higa 2001:Summary). In addition, the state reorganized the delivery system of care for 6,000 of the 11,000 students who fell under the Felix consent decree (those requiring a "low-end of care") and transferred the responsibility for their mental health services from the Department of Health to the Department of Education (DOE), effective July 1, 2001 (Higa 2001). The auditor's report warned that the "Department of Education [had] not adequately planned for this transition" (Higa 2001:15). In particular, the auditor reported that the Hawaii DOE, "…[did] not have the in-house expertise to administer clinical standards for mental health services provided by private sector mental health professionals" (Higa 2001:15). Indeed, the student services coordinators, who are generally teachers by profession, were to be put in control of the quality of the students' mental health services (Higa 2001). The auditor cautioned that the time needed to bring the Hawaii DOE up to the level of expertise of the CAMHD may be as much as three years (Higa 2001).

By September 2002, Judge Ezra found the state to be in "substantial compliance" which allowed the state to move into the "Sustainability Phase" of the decree (Bennett 2005). During this period, the state was required to continue to be in substantial compliance with the Felix Consent Decree (Bennett 2005). The federal oversight officially ended on May 27, 2005 when Judge Ezra dismissed the case. Attorney General Mark Bennett remarked that the end of the consent decree was an "example of the progress we have made in meeting our legal and social obligations to provide quality state services to children, adolescents, and adults with disabilities" (Bennet 2005). The Hawaii DOE's Superintendent at the time, Patricia Hamamoto, declared that, "The Department takes our moral obligation and duty to provide quality educational and behavioral services for our children seriously" (Bennet 2005).

Since the end of the Felix Consent Decree, the state has tried to find a balance between providing special education services with the cost of doing so through the legislature, the courts, and internally within the Hawaii DOE. One way to reduce the cost of special education is to reduce the number of due process cases that are filed by the parents of special education students. Prior to 2005, ten states assigned the burden of proof to the school district and seventeen states assigned the burden of proof to the moving party (in most cases, the parents of the child). However, most states did not have a statute that assigned the burden of proof in a due process case to either the school district or to the moving party. In Schaffer v. Weast, the Supreme Court ruled that the burden of proof in due process hearings is placed on the party seeking relief. Most states were silent on this matter and did not submit amicus briefs in support of either party. In Maryland, where the case originated, the state's Office of the Attorney General cited the need for the state's department of education to remain impartial, and therefore did not submit a brief (Sullivan 2005). Nine states (Connecticut, Illinois, Kansas, Minnesota, Nevada, Rhode Island, Virginia, Washington, and Wisconsin) filed an amicus brief in support of the parents in the case (Wrightslaw 2011). In contrast, only three states – Hawaii among them –

and Guam filed briefs on behalf of the school district (the other states were Alaska and Oklahoma).

Justice Stevens concurred with the majority decision and reasoned that, "…we should presume that public school officials…are properly performing their difficult responsibilities under [IDEA]" (Schaffer v. Weast). Justice Ginsburg wrote in her dissenting opinion that although the burden is ordinarily on the party initiating the proceeding, "'other factors,' prime among them 'policy considerations, convenience, and fairness,' may warrant a different allocation" (Schaffer v. Weast). She went on to say that, "…nine states…have urged that the placement of the burden of persuasion on the school district best comports with IDEA's aim" (Schaffer v. Weast). She reasoned that, "If allocating the burden to school districts would saddle school systems with inordinate costs, it is doubtful that these States would have filed in favor of petitioners" (Schaffer v. Weast).

Another way to ease the cost of special education is to reduce the number of years that special education students are eligible to receive services. The Individuals with Disabilities Education Act requires that states provide special education to students with disabilities through 21 years of age unless there is a state statute that ends public education for all students at a different age. Most states provide special education services up to the age of 22 years, with a few states providing services beyond that age (Michigan provides services up to age 26 years) (Michigan DOE 2015). It was the practice of the state of Hawaii to end special education at age 20 years, although general education students were allowed to continue their education beyond that age (Hawaii Disability Rights Center 2010). In BT v. Hawaii Department of Education, the parents of a severely autistic son challenged the Hawaii DOE's decision to end his special education services upon his 20th birthday in federal court. Hawaii law at the time stated that no child 17 years or older would be admitted into the ninth grade and that no child 18 years or older would be admitted into the tenth grade. The law was silent on the entering age for twelfth grade, however. The Hawaii DOE's school code stated that public education ends at age 20 years; however, students over 20 years may request an exception from a principal. The Hawaii DOE conceded that any special education students admitted to a Hawaii public school after the age of 20 years were the result of settlements from due process cases, and not simply from requests to the principal. The judge ruled that, "The State is only allowed to deviate from the requirements of the IDEA if there is a clear State law that says otherwise. In this case, there is no such law, and thus, Hawaii must abide by the IDEA's provision of special education programs for those 18 through 21" (BT v. Hawaii DOE 2009).

In response to this ruling, the Hawaii legislature passed a bill that ended high school admissions for all students at the age of 20 years. In her written testimony supporting the bill, Superintendent Kathryn Matayoshi wrote that if the age was not reduced to 20 years, "…additional costs will be incurred for special education and related services, the costs associated with the development of IEPs, additional classroom, teachers, therapists, along with the costs of due process hearings and transcripts" (HB2077 HD1 testimony 2010). This bill was signed as Act 163 on June 3, 2010 (Hawaii Disability Rights Center 2010). In response to this legislation, a class action lawsuit was filed on behalf of special education students affected by the law. In ERK v. Hawaii DOE, the 9th Court of Appeals ruled that the Hawaii DOE was in violation of IDEA because, in spite of the passage of Act 163, nondisabled students aged 20 to 22 years are still able to continue their public education through the Community Schools for Adults. The court ruled that, "As long as [the State of Hawaii] continues to [offer public education to students between the ages of 20 and 22 through the Community Schools for Adults], the IDEA requires the state to continue to provide a free and appropriate public education to disabled students who have not yet obtained the age of 22" (ERK v. Hawaii DOE 2013).

Other bills have been introduced in the state legislature that have addressed special education issues. In 2011, a bill was passed by the Hawaii State Legislature that required the Hawaii DOE to withhold tuition payments and fees to any private schools or placement (other than those in good standing with the Hawaii Association of Independent Schools) that restricted or denied the Hawaii DOE access to the monitoring of a student who was placed in that school at Hawaii DOE expense by a hearings officer, court, or by programmatic placement (Act 129 2011). The bill, signed as Act 129, ensured that the Hawaii DOE is able to monitor a private placement's compliance with health and safety laws, as well as to monitor the student's curriculum and instruction to ensure they are in keeping with the state's standards and the student's IEP. A portion of the bill's definition of monitoring gave the Hawaii DOE the authority to observe a student in the private placement "with or without notice to the private school or placement" (Act 129 2011).

The U.S. District Court found that the Act 129 was preempted by IDEA and prohibited the Hawaii DOE from withholding tuition to a private special needs school by issuing a preliminary injunction on June 22, 2012 (Hawaii Parents Special Education Advisory Council 2015). Further, on September 4, 2015, the District Court found that Section (i) of Act 129, "The department shall withhold payment to any private school or placement that restricts or denies monitoring by the department …" is preempted by the IDEA because "federal law preempts state law where the two conflict" and that, "This type of 'conflict preemption' occurs when 'compliance with both federal and state regulations is a physical impossibility' or where state law ‘stands as an obstacle to the accomplishment and execution of the full purposes and objectives of Congress’” (F.K. v. Hawaii Department of Education v. Loveland Academy).

In 2014, a bill was introduced to add a section to the statutes that addressed the use of restraints or seclusion in the public schools. The second version of the bill (HD1) stated that restraints or seclusion, while otherwise prohibited, could be used on public school students in order to protect the student or another person from harm if any other less extreme measures have failed, or if the parents of a student have given written consent for the use of restraints or seclusion during the development of a behavior intervention plan. The definition of restraint in the bill included, “A chemical restraint, which means a drug or medication used on a student to control behavior or restrict freedom of movement that is not prescribed by a licensed physician or other qualified health professional acting under the scope of the professional’s authority under state law for the standard treatment of a student’s medical or psychiatric condition” and that is <u>not</u> “Administered as prescribed by the licensed physician or other qualified health professional acting under the scope of the professional’s authority under state law” (HB1796HD1 2014).

Testimonies in support of this bill were submitted by the Hawaii DOE, some special education advocacy groups, and a few parents; however, some parents of special needs children submitted testimony against the use of restraints and seclusion. While the bill was praised for restricting the use of restraints and seclusion to “emergency situations,” the testimonies of parents pointed to “loopholes” that allowed for abuse by school personnel. The portion of the bill that allowed for chemical restraints was a major concern. Since the passage of Act 51, Reinventing Education Act of 2004, the direct supervisors of the school health aides transferred from the Department of Health Public Health Nurses to the school principals, who are not required to have any medical training (Act 51 2004). The restraint bill allowed school personnel, who are not medically qualified, to determine when it was appropriate to administer chemical restraints. The Hawaii Disability Rights Center stated in its testimony that, “The involuntary use of drugs on a child in a school setting is an alarming prospect” (HB1796HD1 Testimony 2014).

As a result of the concerns raised by the public, the final version of the bill prohibited the use of seclusion, chemical restraints, and mechanical restraints, and physical restraints were only allowed if “a student’s behavior poses an imminent danger of property damage or physical injury to the student, school personnel, or to others and only for so long as the danger persists” (HB1796CD1 2014).

If a dispute arises regarding a child’s IEP, the parents or guardians may file for an impartial due process hearing. This right is protected by IDEA. Parents or guardians may also opt for mediation, which may not be used to deny or delay a due process hearing (Hawaii DOE 2017). From October 2002 to August 2017 the Office of Administrative Hearings of the State of Hawaii Department of Commerce and Consumer Affairs (DCCA) was responsible for conducting these hearings. As of August 2017, that responsibility was transferred to the Hawaii Department of the Attorney General. A new office within the Attorney General’s office, the Office of Dispute Resolution, was created for this purpose. There is concern that there may be a conflict of interest due this change as the Department of the Attorney General also represents the Hawaii DOE in due process cases.

Medicaid

Under the 1915(c) waiver program, Hawaii’s Home and Community-Based Services (HCBS) waiver for persons with developmental disabilities and/or intellectual disabilities (DD/ID) offers a variety of services for affected individuals of all ages: chore, personal assistance/habilitation (PAB), respite, employment services, skilled nursing, transportation, adult day health, DD/ID emergency services (respite, outreach, shelter), training and consultation, specialized medical equipment and supplies, environmental accessibility adaptations, vehicular modifications, assistive technology, and personal emergency response system. Currently, one to one support in the form of skills training is not provided under the waiver program. This waiver is implemented by the Hawaii Department of Health Developmental Disabilities Division. Hawaii currently does not have a specific Autism Waiver Program.

To be eligible for the waiver, a person must 1) be diagnosed with a DD/ID as defined by the Hawaii Revised Statutes (Section 333F-1), 2) be determined to require an Intermediate Care Facility for the Intellectually Disabled (ICF/ID) or institutional level of care, 3) qualify for Medicaid by the Hawaii Department of Human Services, and 4) have Long Term Care (LTC) eligibility determination. In order to meet the required ICF-ID level of care, the developmental disability must be due to a mental or physical impairment (or a combination of the two) that is manifested prior to the age of 22 years and is likely to continue indefinitely, and which results in significant limitations in three or more areas of functional skills (i.e. self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic sufficiency). The disability must indicate a need for lifelong or extended services. An individual who has an intellectual disability must have significantly subaverage general intellectual functioning that results in, or is associated with, concurrent moderate, severe, or profound impairments in adaptive behavior and is manifested during the individual’s developmental period (HRS333F-1).

For those who do not qualify for Medicaid, the Family Support Services Program is available through the Hawaii Department of Health. This program is only intended to supplement family resources and does not duplicate services that are available through other programs. Services that may be available include adaptive equipment, chore services, limited modification to the home and vehicle, fees to register for conferences or workshops, transportation to and from medical appointments, and other supplies that are not covered by health insurance (e.g., diapers for individuals over the age of three years). Services such as respite are not available through this program because it is offered in other programs. The Hawaii Department of Health has maintained that, as an agency, it does not provide services that would otherwise be provided by other departments due to a sentence in the Hawaii Revised Statutes (333F-2), "The department shall not supplant or duplicate services provided under other federal, state, or county acts." Therefore, the Department of Health will not provide skills training and behavior analysis services for children with autism since these services are provided by the Hawaii DOE.

Health coverage through Medicaid in Hawaii, called Quest, is financed jointly by the State of Hawaii and the Federal Centers for Medicare and Medicaid Services and is administered by the Hawaii Department of Human Services (DHS). Quest is available for eligible low-income residents. The July 7, 2014 Center for Medicaid and CHIP Services bulletin recognized ABA as a treatment modality for children with autism; however, the Hawaii DHS did not deem ABA to be evidence-based (J.E. v. Wong 2016). It was not until the Hawaii DHS Medicaid administrator, Dr. Kenneth Fink, reviewed the August 2014 Agency for Healthcare Research and Quality report on behavioral interventions for autism that DHS's attitude toward ABA began to change. During this period, a lawsuit was filed in September 2014 by a mother of a child with autism together with the Hawaii Disability Rights Center, alleging that the Hawaii DHS was in violation of the Medicaid EPSDT mandate. While the lawsuit was pending, DHS drafted a memorandum requesting that the Medicaid health plans consider ABA coverage. Dr. Fink, however, insisted that it was "too late" for simply consideration, but rather it was necessary for the department to finalize their guidelines on ABA treatments for autism (J.E. v. Wong 2016). Finally, on January 13, 2015, a memorandum by DHS that stated that ABA was an effective treatment for autism was issued to the Hawaii Medicaid health plans and service providers (J.E. v. Wong 2016).

<u>Insurance Mandate</u>

Legislation for autism insurance was first introduced in Hawaii in 2008. Named "Dylan's Law," the bill mandated insurance coverage for the diagnosis and treatment of ASD for individuals under the age of 21 years (HB2727 2008; SB2532 2008). The bill required up to $75,000 of coverage per year for autism treatments, including intensive behavioral therapy, and any treatment deemed medically necessary by a qualified professional. Those who opposed the legislation were from the private insurance companies and private health associations in Hawaii. The bill was tabled pending the formation of a temporary ASD benefits and coverage task force, which was instructed to produce a report on autism in Hawaii before the start of the next legislative session. The State Auditor was also requested to do an audit on the costs and effects of Dylan's Law (SCR196). Although the autism task force recommended the insurance bill with amendments (e.g., reducing the maximum coverage to $50,000), the State Auditor (2009) did not recommend the measure and stated that, "[w]e found the social impacts appear minimal in Hawaii, since both educational interventions and health services, including applied behavior analysis, are generally available through federal and state-funded programs under the *Individuals with Disabilities Education Act* and implemented by the Departments of Health (DOH) and Education." This report was submitted to the 2010 session of the Hawaii legislature. In response to the auditor’s report, the Hawaii Department of Health disagreed with the auditor’s position and stated that, “[w]hile educational and behavioral interventions are available through the Departments of Education and Health, these are not comprehensive services that meet all the needs of all children with autism.”

Subsequently, several different variations of the autism insurance bill were introduced. A report on the effects of mandating insurance coverage for autism was prepared by the Legislative Reference Bureau in 2013 and the Department of Commerce and Consumer Affairs was requested to prepare an actuarial analysis in 2014. In 2015, Hawaii became the 42nd state in the country to pass autism insurance legislation (Autism Speaks 2015). Known as Luke’s Law, the legislative bill mandated the coverage of applied behavior analysis up to $25,000 for children 13 years of age and under, as well as the coverage of medically necessary behavioral health treatment, pharmacy care, psychiatric care, psychological care, and therapeutic care (SB791CD1 2015). Figure 3 is a diagram showing the treatment and payments options following the autism diagnosis. For example, behavior modification therapies can be acquired through IDEA, Medicaid, health insurance, or payment out-of-pocket, but auxiliary therapies can only be acquired through IDEA or payment out-of-pocket.

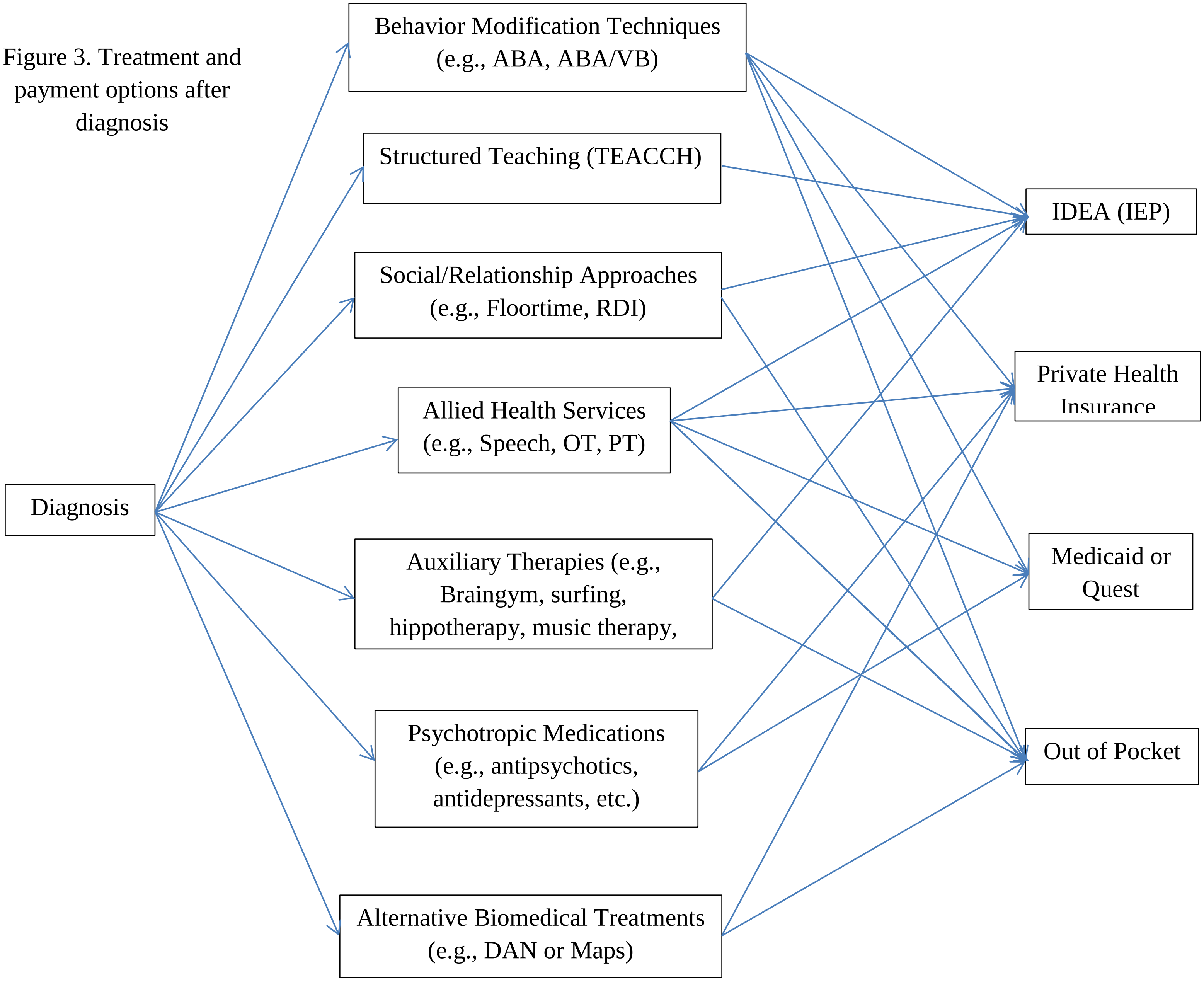


Figure 3. Treatment and payment options after diagnosis

Summary

Autism is a disability that affects many areas of both the affected individual’s life and the life of the individual’s caregiver. Caring for a child with autism occurs over the long-term and is a chronic stressor that can have negative consequences on the caregiver’s well-being. The complex nature of autism results in a multitude of decisions that the caregiver must make regarding the care of the child. In this chapter, literature pertaining to caregiving and the relevance of the Stress Process theory on caregiving were reviewed. The difficulties surrounding the care of a child with autism, from getting a diagnosis to finding and acquiring autism treatments, were also examined. In addition, because the study sample of mothers resided on the island of Oahu in Hawaii, the state of autism and its treatments and services in Hawaii were discussed.

Chapter 3
Research Methods

Introduction

A qualitative study was conducted in order to explore the caregiving experience of mothers of children with autism in the state of Hawaii. This study examined the relationship between the stressors of caring for a child with autism, the mental and physical effects of caring for a child with autism, and the effects that mediating factors may have on the caregiving experience. In addition, this study looked at how caring for a child with autism impacts the mother's caregiving experience. In this chapter, the research methods used for this study are described. First, the research aims and questions are introduced. Then, the sample and interview process are described. Finally, the ethical considerations, limitations, and the study significance are reviewed.

Research Aims and Questions

The goals of this study were to describe the maternal experience of caring for children with autism and to identify how caring for a child with autism impacts the mother's life. Using the Stress Process theory as a guide, the aims of this study were to identify the challenges and positive aspects of caring for a child with autism, as well as to identify the financial, emotional, and physical impacts.

The research questions that were investigated are as follows:

1) How does the chronic stress of caring for children with autism affect the mental and physical health outcomes of their mothers?

2) How do the mothers of children with autism utilize social support and coping to mediate the stress of caregiving?

3) How do the meanings assigned to the mother's caregiving experience help to explain whether the demands of caregiving their children are seen as positive or burdensome?

This study followed a qualitative methodology for data collection. The goals of qualitative research are to obtain "…in-depth and intimate information about a smaller group of persons…[and to]…learn about how and why people behave, think, and make meaning as they do, rather than focusing on what people do or believe on a large scale" (Ambert et al. 1995:880). In addition, qualitative research, "…may involve compete redirection, or modification of, or additions to, existing ideas" (Ambert et al. 1995:880).

In-depth, semi-structured interviews of twenty-one mothers of children with autism were conducted. According to Yin (2014:110), the interview should "resemble guided conversations." The in-depth interview allows the interviewer to ask the respondents about their knowledge of the details, as well as their opinions about a particular matter or event (Yin 2009). During an interview, one is able to keep the line of questioning focused on the research topic. In an in-depth interview, the respondents may be able to provide some insights into the subject matter, such as their own perceptions about "causal inferences and explanations" (Yin 2009:102). They may also provide the interviewer with names of other potential respondents. In this way, a respondent in an in-depth interview may even be considered an "informant" (Yin 2009). However, an interviewer must exercise caution and be aware of any response bias and reflexivity, bias due to questions that are not clearly articulated, and inaccurate responses due to poor recall (Yin 2009).

Sample

The respondents were obtained through convenience, snowball sampling by contacting the local chapter coordinator of Talk About Curing Autism (TACA), which is a national parent support network for families of children with autism, and the past-president of the Hawaii Psychological Association, which is a professional organization for local psychologists. The purpose of the interviews was explained and the researcher's contact information was provided. These organizations were asked for referrals to mothers of children with autism who reside on the island of Oahu. In addition, the researcher posted a request for interviewees on the TACA Hawaii Yahoo Group. Subsequent respondents were obtained through referrals from these initial respondents. In all, twenty-one mothers of children with autism who live on the island of Oahu were interviewed. Only one mother was acquired through a referral from the Hawaii Psychological Association. Of the three psychologists who contacted the researcher regarding the study, only one psychologist was able to refer a suitable respondent (mother of a child under the age of 18 years who was diagnosed with autism). The twenty remaining mothers were acquired through the local chapter of TACA.

Interview Process

After a mother agreed to participate in the study, the location, date, and time were mutually agreed upon for the interview. The researcher met with the mother at the predetermined location, thanked the mother for her participation, and again explained the purpose of the interview. The form that gave consent for the interview and digital recording was discussed. Each mother granted her permission for both by signing the form. The contact information for 2 national support hotlines was provided to the mother in the event that the mother experienced any distress as the result of the interview and she felt the need to seek counseling.

An interview guide was developed to ascertain the mothers' attitudes, perceptions, and experiences of caring for a child with autism. The interviewees were asked questions that were open-ended in order to obtain a broader set of perspectives and to gain deeper insight into this topic. The interview guide focused on the impact of autism on the family, the impact of autism's medical issues, the impact of educational issues surrounding autism, and the effects of caring for a child with autism on a mother's well-being. Demographic questions such as the mother's age and educational attainment were also asked.

Ethical Considerations

Approval was obtained by the University of Hawaii Social and Behavioral Sciences Institutional Review Board (IRB). The research, which did not involve a vulnerable population, posed minimal risk to the subjects. Informed consent was acquired for all the participants. Information explaining the purpose of this research project, as well as the contact information of the investigator, was provided to all subjects. Any questions and concerns of the respondents were addressed by the researcher.

The interviewees were asked for written permission to tape record the interview sessions. The interviews were digitally recorded, with the recorder in full view of the interviewees. Each interview averaged 60 minutes and was conducted in a location that was convenient for the respondent (e.g., the respondent's home, a coffee shop or restaurant, a private office, or shopping mall). The investigator hand carried the completed digital recorder and any notes taken back to the project office, where it was stored in a locked file cabinet to assure confidentiality. All names of the subjects and the subjects' children were kept separately on a list. Each subject was assigned a code which was marked on their corresponding questionnaire. Every precaution was taken to ensure that no identifiable information was used in the study.

Limitations

There were limitations that may have impacted the findings in this study. Because the survey respondents were obtained through only two organizations, with the majority of the respondents from the parent support group, the sample may have resulted in families who were similar to one another. Mothers who were not in contact with a psychologist for their children or mothers who were not currently on the email list for the Hawaii chapter of TACA during the recruitment phase of the study were most likely to be unaware of the study, and therefore did not contact the researcher to request participation. Also, in order to keep travel time and cost to a minimum, the research focused on the island of Oahu only. There may be differences in the caregiving experience between the islands. For instance, the majority of the service providers and medical professionals are located on Oahu, so mothers on the neighbor islands may have difficulties finding therapists and doctors. There may also be differences in the caregiving experiences for mothers who have not contacted the Hawaii Chapter of TACA or who have not sought the services of a psychologist. The mothers who were recruited from TACA, in particular, may be better able to find appropriate resources through the contacts they have made in the organization. Because these mothers took the initiative to seek out and contact a support group, they may be more inclined to seek help from others.

In addition, the investigator is known in the autism community in Hawaii as having once been an active advocate and activist for children with ASDs in Hawaii. This may have influenced the interviewees’ answers to the questions. The researcher also has personal experience, as she has two children who have been diagnosed with autism. The parents may have made assumptions about the researcher's knowledge about their experiences and may have made adjustments to their responses as a result. However, this knowledge may have also put the respondents at ease and enabled them to be more open with their responses. The researcher maintained her objectivity to the best of her ability at all times.

Other limitations were related to the interview method of data collection, where some of the mothers may not have accurately recalled the details of their history. In addition, they may have altered their answers in order to conceal information or to provide answers they felt the interviewer wanted to hear. None of the responses, including the information about the child's diagnosis, were evaluated for accuracy.

Delimitations

The study only included mothers living in the on the island of Oahu in order to reduce the travel costs and time required to fly to the other islands in the state of Hawaii. The mothers on Oahu may have different caregiving experiences from mothers living on the neighbor islands. Of the 1.4 million people in the state, over 900,000 live on the island of Oahu. Oahu has more than four times the population of the second most populous island, the Big Island of Hawaii, which has a little more than 200,000 residents (Census.gov). In Hawaii, most of the resources and services for children with autism are located on Oahu. The capital of the state of Hawaii, Honolulu, is located on Oahu, as are the majority of businesses, schools, physicians, and other professionals. Therefore, the mothers living on Oahu have much more access to the resources than the mothers on the neighbor islands in the state.

Significance

The purpose of this study was to describe the maternal attitudes, perceptions, and experiences of caring for a child with ASD. The study focused on maternal caregiving in relation to three areas: the impact of autism on the family, the medical impact of autism, and the educational impact of autism. In addition, this study explored the factors that may influence a mother's perceptions of her caregiving experience such as the level of severity of the child's autism, the mother's educational attainment, and the mother's marital status. Finally, this study examined the effects of caring for a child with autism on a mother's well-being.

Since mothers tend to be the primary caregivers of children they bear a greater share of the responsibilities associated with caregiving. The caregiving of children with autism includes additional challenges that these mothers must face, such as medical, psychological, and educational needs. Moreover, since women more than men tend to also care for their aging parents in addition to their children, they are at a greater risk of experiencing role overload and role stress. This study provides a lens through which to view how mothers of children with autism use their social resources, such as social supports and coping skills, to reduce their feelings of distress. The information gained from the results of this study helps to identify areas for future research.

Data Analysis

A thematic analysis of the interview data was conducted, with a focus on the Stress Process theory (Pearlin et al. 1990). According to Bryman (2008:554), thematic analysis is one of the most common methods of qualitative data analysis. The data was reviewed, examined and indexed for main ideas, concepts, themes and subthemes. The data was then organized into a chart (or matrix), according to the Framework approach. After systematically indexing the data and organizing the matrix, the subsequent themes were interpreted for associations and explanations.

The Framework approach was developed during the 1980's by Jane Ritchie and Liz Spencer at the National Centre for Social Research in Great Britain to be used for applied qualitative research (Ritchie and Spencer 1994; Ritchie, Spencer, and O'Connor 2003). This method allows for systematic analysis and enables the researcher to "move back and forth between different levels of abstraction" while always keeping an eye on the raw data (Ritchie, Spencer, and O'Connor 2003:220).

The five stages of data analysis in the framework approach are:

1) Familiarization with the raw data,
2) Identifying a thematic framework, or identifying the key issues, concepts, and themes,
3) Indexing, or systematically organizing the data in textual form,
4) Charting, or "rearranging the data according to the appropriate part of the thematic framework to which they relate," and
5) Mapping and interpretation, or "using the charts to define concepts" and "map the range and nature of phenomena, create typologies and find associations between themes" in order to explain the findings.

(Pope, Ziebland, and Mays (2000:116)

During the familiarization stage, the researcher studies the interview transcripts and tapes in order to absorb the data that was collected. In other words, this stage "involves immersion in the data" (Ritchie and Spencer 1994:178). At this time, recurring themes and idea are noted (Ritchie and Spencer 1994). In the next stage, the researcher identifies the thematic framework, or categories, that the data can be organized into. According to Ritchie and Spencer, developing a thematic framework "involves both logical and intuitive thinking" and "…making judgements about meaning, about the relevance and importance of issues, and about implicit connections between them" (1994:180).

During the indexing stage, the thematic framework is applied to the transcripts systematically (Ritchie and Spencer 1994). The researcher reviews each passage and uses his or her judgment to decide how to apply the index to the passage (Ritchie and Spencer 1994). Each passage is indexed and marked using a numerical or descriptive textual system that corresponds to the framework (Ritchie and Spencer 1994).

After the indexing is completed, the data is charted into a matrix with headings taken from the thematic framework or the research questions, or "according to considerations about how best to present and write up the study" (Ritchie and Spencer 1994:182). In other words, the data is summarized by categories into a matrix (Gale et al. 2013).

Finally, during the mapping and interpretation stage, the charts are used by the researcher to look for patterns and associations between the themes, while searching for explanations for the findings (Ritchie and Spencer 1994; Pope, Ziebland, and Mays 2000). This stage is "influenced by the original research objectives as well as by the themes that have emerged from the data themselves" (Pope, Ziebland, and Mays 2000:116). The themes for this study were formed based on the stress process framework, with the themes categorized by stressors, mediators, and outcomes.

Chapter 4
Data Analysis

Introduction

In this chapter, the results of the data analysis are discussed. A general profile of the respondents is presented and is followed by the findings of the questionnaire itself. The questionnaire was divided into five parts: the mother's overall experiences of caring for a child with autism; the experiences within the family; the mother's experiences of managing the child's medical and psychological needs; the mother's experiences of managing the child's educational needs; and the physical, emotional, and financial effects of caring for the child. The thematic analysis of the interview findings and the resultant themes in relation to the Stress Process framework are then discussed.

The thematic analysis revealed eight themes: four themes that can be categorized as stressors (concern for the child's future independence, finding the right services for autism, safety, and trust), two themes that can be categorized as resources (social support and learning about autism), and two themes that can be classified as outcomes (emotional reactions to caring for a child with autism and mother's self-care). The central theme of the study was the unclear path that the mother must follow after her child's diagnosis with autism. This central theme can be categorized as an overarching stressor. Finally, the findings that did not easily fit into the Stress Process will be reviewed.

The Respondents

Twenty-one mothers of children with autism who resided on the island of Oahu were interviewed. Only one mother was acquired through a referral from the Hawaii Psychological Association. The twenty remaining mothers were acquired through the local chapter of TACA.

The mothers' ages ranged from 29 to 54. One mother was in her 20's (5%), 3 mothers were in their 30's (14%), 11 mothers were in their 40's (52%), and 6 were in their 50's (29%). Nine of the mothers were stay-at-home moms, one mother worked part-time, and eleven mothers were full-time professionals. The majority of the mothers were married (18 of 21 mothers), one mother was separated, and two mothers were divorced. The household income ranged from approximately $70,000 to more than $200,000. One mother declined to answer the income question. The majority of the mothers had a college degree (18 of 21 mothers), one mother complete high school, and two mothers had some college credits. Six of the mothers had graduate degrees. The ethnic background of the mothers was diverse: four of the mothers were Japanese, five were Caucasian, two were Chinese, two were Filipino, one was Korean, one was Hispanic, one was Black, two were part-Hawaiian, and three were mixed (not Hawaiian). The majority of the mothers had one child who was diagnosed with autism. Two of the mothers had 2 children with the diagnosis (see Tables 1a and 1b).

The majority of the children were males (19 out of 23 children); only four of the children were female. The children's ages ranged from 4 to 17 years. More than half of the children were under the age of 12 years (14 of 23), five of the children were 12-13 years of age, and four of the children were 14-17 years of age. Eleven children were considered by their mothers to be high functioning, nine of the children were thought to be functioning at a moderate level, two children were considered to be low functioning, and one mother declined to give her opinion about the level of functioning of her child. The majority of the children had siblings who were typically developing, but four of the children with autism were only children. The two families who had two children diagnosed with autism did not have other children.

A pseudonym is used for each respondent to help to maintain anonymity; however, given Oahu's small geographic area and relatively small population, it is important to discuss the respondents in a general manner and to withhold specific details that might make them identifiable. While a pseudonym might ensure external confidentiality, or confidentiality in the context of the outside world, it does not ensure that the respondent will be unidentifiable to their friends, relatives, co-workers, neighbors, their child's school, and the providers (Kaiser 2009).

Table 1a. The Respondents

Respondents	Mom's Age (years)	Child's Gender	Child's Age (years)	Age Diagnosis	Function Level	Grade	No. other Children
April	39	Male	10	2 y 5 m	Mod	5	4 (1 son 3 daughters)
Barbara	36	Male	7	3 y	High	2	0
Carol	54	Male	17	1 y 10 m	Low	12	0
Dana	45	Male, Male	9, 5	7 y, 5 y	High, High	3, 2	0
Emma	44	Male	11	2 y 5 m	High	5	1 daughter
Fran	52	Male	9	4 y 6 m	Mod	3	3 boys
Gina	47	Male	9	6 y 6 m	High	4	1 son
Holly	41	Male	4	2 y 6 m	Mod	Preschool	1 daughter
Ivy	43	Male	10	1 y 7 m	High	4	0
Janice	49	Male	17	3 y 1 m	No Answer	10	2 sons
Karen	29	Male	9	2 y 6 m	High	3	2 daughters
Lois	50	Female	16	2 y 6 m	Mod	10	0
Mary	44	Male, Male	13, 8	3 y 6 m, 6 y 6 m	High, High	7, 2	0
Natalie	48	Female	7	5 y 6 m	low	1	1 son
Olivia	52	Male	11	5 y 3 m	Mod	6	1 son
Pamela	50	Female	15	1 y 10 m	High	10	1 son
Quinn	47	Female	12	2 y 3 m	Mod	6	2 sons
Rhonda	34	Male	13	2 y	Mod	8	1 daughter
Sally	46	Male	13	2 y 9 m	High	7	2 (daughter and son)
Tracy	45	Male	11	3 y 6 m	Mod	6	2 (son and daughter)
Vivian	52	Male	12	2 y	Mod	4	1 daughter

Table 1b. The Respondents

Respondents	Income	Education	Marital Status	Occupation	Ethnicity
April	$80,000	College Degree	Married	Stay at home mom	Mixed (not Hawaiian)
Barbara	$80,000	College Degree	Married	Stay at home mom	Caucasian
Carol	$130,000	College Degree	Separated	Full-time Professional	Japanese
Dana	$175,000	Graduate Degree	Married	Full-time Professional	Caucasian
Emma	$100,000+	College Degree	Married	Stay at home mom	Part-Hawaiian
Fran	$200,000	Graduate Degree	Married	Full-time Professional	Caucasian
Gina	$120,000	College Degree	Married	Full-time Professional	Filipino
Holly	$50,000	Graduate Degree	Divorced	Full-time Professional	Japanese
Ivy	$100,000	College Degree	Married	Full-time Professional	Korean
Janice	$200,000	College Degree	Married	Stay at Home Mom	Mixed (Not Hawaiian)
Karen	$70,000	College Degree	Married	Stay at home mom	African American
Lois	No answer	College Degree	Divorced	Full-time Professional	Part-Hawaiian
Mary	$120,000	Some college	Married	Part-time professional	Mixed (Not Hawaiian)
Natalie	$200,000+	College Degree	Married	Full-time Professional	Japanese
Olivia	$70,000	Graduate Degree	Married	Stay at home mom	Caucasian
Pamela	$100,000	College Degree	Married	Full-time Professional	Chinese
Quinn	$150,000	Graduate Degree	Married	Full-time Professional	Caucasian
Rhonda	$150,000	Some college	Married	Stay at home mom	Filipino
Sally	$200,000	Graduate Degree	Married	Stay at home mom	Chinese
Tracy	$80,000	High school	Married	Full-time Professional	Hispanic
Vivian	$130,000	College Degree	Married	Stay at home mom	Japanese

Results from Interviews

Overall Experiences of caring for a child with autism

Diagnosis experience

Each mother was asked to describe her diagnosis experience. The children were diagnosed from as young as under the age of two (19 months) up to seven years old. The average age of diagnosis was 41.7 months or approximately 3 years 5 months. The majority of the children were diagnosed by a psychologist (15 of 23); seven of the psychologists were private, six were from state Early Intervention services, and two were from the Hawaii DOE. Four of the children were diagnosed by a developmental pediatrician, three were diagnosed by a neurologist, and only one was diagnosed by a psychiatrist.

The path to the autism diagnosis was fairly straightforward for five of the children; their mothers said they were able to get their children diagnosed by the professionals “quickly.” All five of the mothers expressed concerns about their children’s development to the pediatricians. Two of the mothers (Holly and Ivy) were referred to Early Intervention, one mother was referred to a developmental pediatrician (Karen), and one mother was referred to a pediatric neurologist (Pamela).

On the other hand, one pediatrician did not take the mother’s (Carol) concern seriously and told her that boys develop speech later than girls. She contacted Early Intervention on the advice of her friends. Two of the mothers, Carol and Pamela, whose children were diagnosed in the early 2000’s, stated that they were surprised by the diagnosis. Carol said that it was “a total shock to us.” Pamela explained, “We didn’t know because it was not common back then. So we didn’t know anything…So it came from left field.” Carol praised the psychologist from Early Intervention for her son’s quick diagnosis, given the lack of awareness at the time, “We got it at

22 months, the diagnosis…That's why I do give [the psychologist] credit because she got it right off the bat."

Most of the mothers stated that they had some difficulties during the diagnosis process. More than half (12 of 21) of the mothers specifically commented their children's pediatricians did not convey any concerns that their children may have autism. Of these mothers, six (April, Carol, Natalie, Barbara, Rhonda, and Tracy) noted that although they expressed their own concerns to the doctors, their concerns were dismissed. Tracy recalled, "I think he was about two and a half years old when I started noticing all those [behaviors], and every time we went to the doctor, his pediatrician…he'll say, 'No, he'll catch up. Everything is okay. He'll catch up.' And that went on and on and on." Barbara said, "…when he was age one, I went to the pediatrician with a whole list of concerns and she just brushed me off and said that's how kids are."

April, whose son's pediatrician didn't believe that her son had autism until he was five, expressed feelings of guilt for not trusting her own feelings:

> But obviously, it's my fault. I'm the mom. I should have known better. But at the time, being that young, I thought, the doctors know. They went to medical school. They know. They know better than me…But at that point [when her son was five years old], she obviously doesn't know. I need to find someone else that can help me.

Rhonda, a stay at home mom, had a similar experience. She expressed her concerns about her son's lack of speech to the pediatrician and raised the question about autism, having read a story about it in a magazine. The doctor, however, felt that her son was too "affectionate" to be autistic. Rhonda continued to insist that something was wrong for the next year until she finally asked for a referral to a specialist.

Barbara, also a stay at home mom, said, “I went to the pediatrician with a whole list of concerns and she just brushed me off and said that’s how kids are.” She didn’t get a referral to Early Intervention until her son’s regular pediatrician wasn’t available and she saw a substitute physician.

Natalie, a full-time professional, was finally referred to a developmental pediatrician after expressing numerous concerns to her daughter’s physician. The developmental pediatrician, however, blamed the daughter’s behavior on parenting style.

Eleven of the children (from nine mothers: Barbara, Dana, Fran, Gina, Janice, Mary, Natalie, Olivia, Tracy) were diagnosed after their third birthday. The reasons reported by the mothers for the late diagnosis ranged from the dismissal by others of the mother’s concerns, to the misdiagnosis of the children, to the prudence of the professionals.

Rewarding

Each mother was asked what she finds most rewarding about caring for her child with autism. A little over half of the mothers (11 of 21) reported that seeing their children’s successes and accomplishments are particularly rewarding for them. Olivia said of her son, “I just enjoy seeing his accomplishments because it’s so hard fought for him.” April replied that she enjoys seeing the things she was told “he could never do or never say or never be.”

Tracy spoke not only of her son’s accomplishments, but also how rewarding it is to know how she and her husband have helped her son’s achievements:

> What’s rewarding is to know how far we have helped him to come. Because if we decided not to do anything, then he would be at home all day, all night. He would maybe not be talking and maybe not eating all the kinds of foods he eats. So what’s rewarding is the fact that he’s able to go out of the house and be around other people and that he is able to tell me what he wants and what he

> doesn't want. So even though it's draining, it's amazing to [see] how far he has come.

Two of the mothers (Rhonda and Pamela) replied that their children's loving manner was rewarding for them. Rhonda explained, "He's innocent, you know? There's just this love." Fran said that caring for her son is most rewarding for her when her son says, "I love you."

Sally talked about how her caring for her son taught her how to appreciate the little things. Mary related that caring for her son has made her "a better person" because, "It's made me a lot more patient, a lot more accepting and forgiving." Being able to communicate with her son is most rewarding for Janice. Lois said that her daughter brings so much joy to her family. Two mothers spoke about how much fun their children are (Holly and Dana) and Karen spoke about her son's unique personality. Vivian said that she finds caring for her son is rewarding because of the constant stream of activity and that there is "never a dull moment."

Sally also talked about how caring for her son has led to her own personal growth. She said she has had to learn to accept him for who he is and she has learned to be more courageous:

> …it forced me to be proactive and fight for him to get the services I felt that he was entitled to. And also it just forced me to be a stronger person. Personally, I learned a lot and continue to learn about myself and to grow. In that way it was rewarding. It's not rewarding in the day to day, but it's rewarding in my own personal growth. It's definitely more of a long term, deeper, looking back…

Challenging

The mothers were asked what they found to be the most challenging about caring for their children with autism. Some of the mothers (Holly, Pamela, Ivy, Natalie, Vivian, and Mary) focused on the characteristics related to autism. Mary expressed that she finds "dealing with their quirks" to be challenging and feels frustrated by the "challenges that come up over and over and over again." Natalie discussed how she feels frustrated by her daughter's need for routines: "It guides our day. Always. Everything we do. It's comforting to her. As soon as we go outside of the routine, it's not comforting; she gets anxious." Ivy finds her son's difficulty with following directions to be challenging. Pamela would like her daughter to be able to improve her problem solving skills because she has to be directed with step by step instructions. Both Vivian and Holly expressed that the day to day experiences of caring for their sons is challenging, but whereas Vivian said her son "keeps her on her toes" and that "plans change a lot," Holly said her main challenge is to remember to slow down to her son's tempo. Rushing her son does not work because "It totally bypasses him and so you really have to stop and think."

Gina, Olivia, Tracy, and Emma discussed challenges with their children's education and related services. Gina spoke of the difficulty with finding ABA services on Oahu because of the lack of therapists: "They say, 'You're on the waiting list,' or, 'We're not taking any more clients.'" Olivia talked about the challenges of finding the right educational program for her son and the things that "work best" for her son. Tracy and Emma explained that their greatest challenge is helping their sons with homework.

Carol and Rhonda, whose sons are in high school and middle school, respectively, talked about the changing nature of the challenges of autism. According to Carol:

> …there's been a lot of phases. I think early on, the challenge was to accept the diagnosis and then learning how to, you know, how to move forward…And everything was difficult…Challenging now is, I think, the social part as he got older. I find it's really hard because there's not opportunities for them to be able to participate in anything. School, academic kind of things, sports activities, social activities…

Rhonda talked about how the challenges are constantly shifting: "Right when you think you've got something figured out, then a new one comes."

The challenge for Dana and Fran is dealing with judgmental people. Fran finds her son's behaviors in public can be difficult to manage when others don't understand. On one occasion, when her son was upset that she had taken his electronic tablet away, he ran screaming and yelling through a group of people: "And they were all looking…'Why is he acting like this?' I mean it was just mortifying." Dana feels that interacting with the world beyond her "comfortable family universe" can be frustrating because people do not understand her sons:

> But when we enter the so-called real world, if there's a school context, or sports, or other activities, suddenly we're in a context where everyone's asking me what the problem is with my children or my children get upset about something and I have to calm them down...And either my kids have a hard time or other people have a hard time with my kids and I have to be kind of that bridge figuring out how to negotiate that conflict. And a lot of times I can't do that…And at the same time I'm frustrated by…the inability of a lot of people to have a more open mind or have a more accepting attitude towards people who are different from them.

The lack of understanding of others can lead to social isolation for the mothers. Carol spoke of the difficulty family and friends have of relating to her life with autism:

> Family…they'll try to understand, but they don't always get it. And so, you know, they don't live with it so they don't see everything. And then I think with your friends, too. When the kids were small we could go on social outings because the kids are small, but as they get older – and older is only maybe even by the time they're kindergarten – it's different…The friends that I had I couldn't relate to because they didn't know what our life was like. And just everything that they could enjoy with their kids, we didn't have. You know, success in preschool. Just everything from there…It's very isolating.

As the children get older, concerns are raised about what's ahead for them in the future. Sally said she finds having to "adjust" her expectations about her son's future to be challenging: "Just his slower progression on his developmental milestones, worrying that he would never learn to talk properly, what's going to happen to him, how his is going to function in school…" Similarly, Lois discussed the challenge of changing expectations:

> I think we worry a great deal about her future. Most people, you know your child will grow up, they'll get a job, they'll move out…and they'll be independent someday. When you have a child with a disability, it takes time to realize because when you're younger you don't know how far they're going to go. [My daughter is now a teenager] and we realized that she's never going to be independent and living on her own. That took time for us to realize that.

Hopes and concerns for the future

The mothers were asked what their hopes and concerns were for their children's future. All of the mothers voiced their hope of some level of independence for their children. This was expressed in various ways. Four of the mothers (Quinn, Pamela, Gina, Vivian) specifically expressed that they wanted their children to be "independent" and three mothers (Rhonda, Emma, Sally) said they wanted their children to have a "normal life." Both Fran and Natalie expressed their hope that their children will be cured. The mothers described what they feel an independent life involves, such as graduating from high school, going to college, getting a job, getting married, having a family of their own, and gaining financial self-sufficiency.

However, complete independence was not the hope for all of the mothers. Carol said she hoped that her son will "just be able to lead a happy and productive life" and to "contribute to society in some way." Janice expressed her hope of her son having "the components of happiness":

> My hopes are that he has a really well-defined life post-high school, has social interaction with friends, has opportunities for work or volunteer, opportunities that feels that he's a part of the community and dialed into socializing, and travel, exercise…

Both Olivia and Quinn spoke of the need to maintain hope in the face of uncertainty. According to Olivia:

> I would like him to be totally functioning as an adult and everything like that. Where he is now, it's almost hard to see, but I'm not counting him out on any of

> that stuff. That's my hope. That's what we're aiming for. If you're not even aiming for that, you'll never get there.

Quinn echoed this feeling, "I'm not going to ditch the hope train. You never know…"

The mothers' hope for independence is linked to the most serious concern for six of the mothers (Lois, April, Gina, Holly, Karen, Natalie): if their children are not independent in the future, what will happen to their children when they are no longer able to care for them? As Natalie said, "And so that's my biggest fear. If she doesn't become self-sustaining, who is going to take care of her?" The children's care after their parents are gone was also a concern for six (Carol, Gina, Rhonda, Quinn, Vivian, Janice) of the other mothers as well. Rhonda and Quinn focused on the services their children will be able to receive when they are older. Carol's concern is for the future placement of her son in a group home because of the lack of potential caregivers within the family. Vivian, Janice, and Carol are concerned for their sons' safety if they aren't independent. Janice and Carol, whose sons attend high school, are specifically concerned about keeping their sons safe from sexual predators. As Carol pointed out, "If he's unattended in the [public] bathroom, it can only take a minute or 5 minutes for him to get pulled into a stall…"

Experiences in the Family

Overall effect on the family

The mothers were asked how caring for a child with autism affects their family. The majority (17 out of 21) of the mothers expressed that caring for their children created difficulties for their families overall. Of these, six mothers (Quinn, Natalie, Fran, Ivy, Barbara, Sally) specifically identified stress as a consequence. According to Barbara

> And if you think about it, with autism, you have not only the behaviors – your child which nobody understands and it's really stressful and you're trying to deal with – but then the financial aspect, then you throw the school in and all that

> stress that causes and you combine all of that. It's a disaster. It's a nightmare. That's the best way I always describe it: It's a nightmare. You're living a nightmare. Everything that when you become a parent that you worry about, it's actually true now.

Janice explained that in the typical autism family "…it overwhelms you in terms of focusing on autism: education, health care, just the amount of attention that a person with autism needs in all the different areas." Mary, who described the effect on the family as "very challenging," said, "It was almost like a loss that we had to deal with in our own way and go through a grieving process."

For both Rhonda and Carol, the autism resulted in their families being more isolated from their extended families. Both moms described how they used to participate in family functions at first, but stopped after issues arose. Carol explained that the fireworks during the New Year's celebrations bothered her son. Rhonda said she used to "force" her family to attend family parties. Later, though, "…I was like, what the heck am I torturing myself for? He hates it. We all hate it…I kind of just had to realize that we don't need to go to every family thing and I don't need to explain everything to all my family members."

Carol said that when her son was younger, she and her husband made a good team because they were on the "same page"; however, as her son aged the differences in their priorities became more pronounced. They now disagree on his placement in the future, where Carol sees the need to explore group homes and her husband feels their son should remain at home. On the other hand, Mary commented that although things were difficult for the family at first, taking care of her sons has strengthened the bond within her immediate family, "But now I think it makes us a lot closer and stronger because we've gone through so much together."

Olivia and Tracy both replied that autism has taught their families how to be patient. Olivia went on to say that it has taught her family to not be selfish and to think about the less fortunate. Tracy also remarked that caring for her son has taught her other children to be more thoughtful of others, “I know that the other kids are caring for the other kids at school and their friends and teammates if they play sports.”

Of the twenty-one mothers, only two mothers said that taking care of their children had no real overall effect on their families. Pamela explained that her daughter’s autism simply became the new normal, “That’s what’s normal to us. That’s just the norm.” Gina said because her family was already very close and she had support from her extended family, taking care of her son did not result in any stress between her and her husband. Her main reason for the lack of change in the family is because, “We try not to make like he’s autistic.”

Positive effect on the family

The mothers were also asked how caring for their children with autism has affected their families in a positive way. Six of the mothers (Sally, Vivian, April, Tracy, Mary, Olivia) said that their families are closer as a result of caring for their children. April explained that autism has brought her family closer together because the family will “do everything together,” including going to therapy sessions. Tracy said that as a family, they know that they have to “depend on each other” for support.

Five mothers (Karen, Rhonda, Janice, Barbara. Quinn) described how their families have become more compassionate and tolerant of others. According to Janice:

> On the positive side, it has created a meaningful recognition that there are a lot of people out there, good people that want to help families, want to help kids with disabilities. There’s a lot of care. We have been humbled by autism and so…we’re as a family more empathetic and understanding and sympathetic to other people who have hardships.

Other positive effects on the family that were discussed include more open communication (Gina) and meeting other autism families (Natalie). Pamela said that caring for her child with autism resulted in her family being healthier. Since she had put her daughter on the gluten free and casein free diet for ten years, it made the whole family more "mindful" of what they were eating (such as reading labels).

Three mothers (Lois, Fran, Ivy) admitted that they couldn't think of any positive effects for their families as a result of the experience. As Ivy remarked, "My family, I don't think there were any positives in there."

Challenges for the family

All the mothers described the challenges that their families have experienced as the result of caring for their children with autism. Five mothers (Tracy, Janice, April, Dana, Emma) pointed out how expensive autism can be. As Dana said, "When they tell you your kid is special needs, they should say it's special expensive." The lack of medical coverage for treatments was cited as one reason for the financial hardship. April explained that because her son's speech therapy is not covered because he doesn't have apraxia. She also said that her insurance company does not pay for certain laboratory tests (e.g., heavy metal testing) that are ordered by her son's physician. Dana said although her insurance company preapproved her son's ABA, in the end it was rejected and she had to consult an attorney. Subsequently, the insurance company only paid a portion of the cost, stating that they felt the amount of therapy her son received was "excessive."

The other expenses discussed by the mothers were the extra cost of caregivers who are experienced in autism and the price of foods for the special diets. The financial cost of going from a two-income family to one-income also takes its toll. According to Emma, "I mean, I quit my job, right, because of this. Taking care of him became a full-time ordeal, along with juggling all the skills trainers and everything else. And then refinance the house…I could have bought my townhouse in cash with what I've spent on him."

Five mothers (Olivia Rhonda, Lois, Natalie, Quinn) discussed the challenges their families face as the result of the various characteristics of autism and how activities tend to revolve around the child with autism. For instance, Olivia and her family "temper the environment" to avoid the wait in long lines that can result in meltdowns. Quinn's family will take two cars to events so that one parent can leave with her daughter if it becomes too much for her. This focus on the child with autism can make it difficult for other children in the family. Quinn said if they decide to go to an event together but then have to leave early because her daughter cannot handle the stimulation, her sons will complain. According to Rhonda:

> Things basically revolve around him. You know, it's hard not to, but almost everything does. Whether what we're doing for the day or our vacations. Just everything kind of revolves around him and it's hard to, as a parent especially, to balance it. I want to feel like I'm looking out for both of them the same or we're all being equal. I'd say it's hard to get our attention…evenly rather than just on him.

Other moms (Sally, Vivian, Carol, Barbara, Ivy, Holly) discussed how the lack of acceptance and understanding by some family members and the general public is a challenge for their families. Vivian explained how the lack of understanding by the public makes it difficult to find a "normal" gymnastics or swimming program for her son, "That's really challenging because the door automatically gets shut…" This limits the type of activities she and her family can participate in. When other family members lack understanding, judgmental attitudes can result. According to Barbara:

> They don't understand because they're basically not having to deal with it, so they can't understand it. They judge you. Negatively, having to deal with other people, especially family members, judging things that you do to try to help your

> child whether it's medically or with the school or therapies that you get or choices that you make, they always have their opinion when they have no idea what you're talking about or what you're doing.

Pamela, Natalie, and Gina pointed out that dealing with their children's schools led to challenges for their families. Pamela explained that the challenge was when her daughter was in special education:

> I guess it was especially when she was in SPED, when she was in the public school system. And trying to find what's best for her, looking for the right providers, looking for the right BISS [behavioral consultant who supervises the skills trainers] and programs…Trying to get goals in the IEP was super challenging.

Other challenges cited were finding and getting the proper care and programs for the child (Karen) and finding agreement between husband and wife on the expectations for the child (Mary). Fran, however, felt that caring for her son was challenging "emotionally, financially, spiritually, physically," and that it is a "huge stressor" to the family unit.

Helpful to the family

The mothers were asked what has been helpful to them in the care of their children. Nine mothers (Pamela, Quinn, April, Janice, Tracy, Emma, Carol, Barbara, Karen) stated that meeting other autism families and attending autism support groups have been the most helpful for them. Tracy explained:

> Reaching out to other families that have children with autism. And joining groups like TACA, Autism Society of Hawaii because they have activities that you can join and you don't have to worry so much about how your child is going to behave. You know, it's okay, everything is okay here. We are all in the same boat.

Janice described it as a "momentum of shared information." Quinn spoke about how much other parents have taught her, "I would say other parents hands down have been the most helpful because no one's going to fight for your kid more than a parent. I learn so much from other parents. Helps you save steps." In addition to parents and support groups, Mary included everyone in her family's life who has helped, including the therapists, counselors, and teachers. She also added that many of the online resources have been helpful, such as chat rooms for special needs families.

For Gina, Holly, Ivy, and Olivia, other family members (either within their own families or their extended families) have been the most helpful. The family members help with caregiving and "trade off," according to Holly, which helps to prevent her from being overly stressed or exhausted. For Gina, being able to participate in activities as a family has been helpful because her son enjoys it.

Spirituality was stated as being helpful to the families in caring for the children with autism, according to Sally, Fran, and Vivian. Fran said that attending church is her form of respite and she is able to focus on her spirituality during that time. Sally said that "trusting in God" and the support she receives from her church community are the most helpful. She explained that her church community is open and understanding about her son and she never feels judged by them. "I feel they accept him for who he is."

Quinn and Dana said that living in Hawaii has been helpful for their families. According to Quinn, "Just the village has been helpful. Hawaii's been helpful because it's just a mellow way of life." Dana also talked about the advantages of bringing up her children in this state, "I do appreciate that we're raising them here in the sense that there's a very strong culture of caring and we definitely benefit from that. So I think just the kind of social values." She went on to say that Hawaii is very different from the area where she grew up on the East Coast. There, "It's a very different world view…It's just a very judgmental society, a very exclusionary society."

Other things that were noted as being helpful to the families were having a “steady nanny” for the children (Natalie) and the use of electronics (e.g., iPads, computers) to help with communication and learning (Rhonda). Lois said actively and constantly advocating for her child in the school system with the assistance of an attorney, if necessary, has been the most helpful for her family, “So unfortunately, the funding [for services] comes from the Department of Education, and that being the case, they are always ready to cut services. Which is why you are advocating for your child at all times. All times.”

What can be done to improve the caregiving experience (family)

When asked what can be done to improve their family’s caregiving experience, the mothers gave a variety of answers. Barbara and Dana both feel there should be a single place to get the all the information you need to care for your child with autism, a kind of “one-stop shop.” Dana described the caregiving path that parents follow:

> Everything is so ad hoc. I think the whole process of trying to take care of them, trying to find schools that will work out for them, trying to find medical care that’s appropriate, everything has felt really starting from scratch in terms of our having to really do a lot of work to find answers to questions. I know there are organizations [that] exist to support families of kids with special needs and I think they do an amazing job, but I also think that that gap between the moment when you have a problem and the moment when you figure out the answer to the problem is a very big gap.

Barbara suggested that there be an autism center that offered “integrative approaches” and “all these ways of dealing with it” which would makes things easier for parents.

Vivian, Mary, and Ivy said that increasing awareness and education about autism for others (including doctors, schools, and the public) would improve things for their families Four mothers (Karen, Pamela, Gina, Quinn) pointed out that more locally-based resources and autism friendly activities would improve their caregiving experience. Pamela bemoans the lack of activities and resources for kids once they become teenagers. Quinn and Karen would like to see more autism friendly community events and activities so their kids can easily participate in them. As Gina stated, "I wish we had more things to do for kids in Hawaii that have autism."

Natalie and Fran both said that being better off financially would improve things for their families. Fran said, "If I had unlimited financial resources and didn't work two jobs in this crazy expensive state, that would be the first thing." Natalie explained how financial security would help her family:

> I think if I was financially stable, like if I was wealthy, I wouldn't have to worry, truly. Because then I would know I could set up some kind of trust for her. And in the meantime I could probably have private services for her. I wouldn't have to deal with the DOE. And I'd actually be able to hire someone who's actually good. And I would actually be able to spend time with her. Right now I'm just working. I have to work.

The cost of autism was the root of the answers given the other mothers. April and Olivia both said they would like to see more comprehensive insurance coverage for autism. Olivia, in particular, would like to see other therapies covered besides ABA, such as music therapy. Tracy said she would like to see more affordable programs for the kids because "not everybody has the money to do those things." Janice and Tracy said that having respite from the Department of Health would improve things for their families. Tracy explained that she and her husband aren't able to go out on their own because they are always with their children.

However, finding the people to do the respite is problematic because of the difficulty of finding qualified people, as well as the added cost of sitters who are trained in autism. Janice and Carol would like to see some kind of "caregiver network" (Carol) or "autism sitter hotline" (Janice) because, according to Carol, "…it's so hard to find someone that I would trust with my child." They both would also like to find a safe place for their sons. As Janice said, a place "where you know it's safe where you can drop your kid off and have a totally safe place…"

Emma and Ivy said that Early Intervention by the DOH should be extended past the age of 3. According to Emma, whose son was receiving over 30 hours of one-to-one services through the DOH, "once we left the Department of Health, we tried to go through Department of Ed and it was just a nightmare that we just ended up paying everything out of our own pocket." She said, "if he could have stayed in the Department of Health services until 5, I mean, that would have made a huge, huge difference." Ivy described the experience, "When Early Intervention ended, I felt a shock…It was really a lot less than he used to have…So much that I cried...I felt really emotional because I really didn't know what was coming but I could see that it was a lot less than it used to be."

The other responses given to the question of what would help to improve the family's experience of caring for the child with autism include having more collaborative schools (Lois), more federally funded programs (Rhonda), finding a support group locally that is more like-minded (Holly), and improving the spousal relationship (Sally).

Experiences in the Management of the Medical/Psychological Needs

Overall experience (Medical/Psychological Needs)

When asked to describe the overall experience of managing their children's medical and psychological needs, the majority of the mothers (13 of 21) talked about the challenges involved, including the high cost of alternative biomedical interventions and the burden placed on the parents to educate themselves. Vivian, Gina, and Barbara described the process as being overwhelming. Barbara explained, "…basically I've had to do a lot of research which, if I'm dealing with behaviors at school at the same time, it's kind of like I…have to focus on one thing because it's so much information." Gina spoke of the exhaustion she felt from researching the academic strategies, the special diets, and the different supplements at the same time. Sally talked about having to do it on her own without much support. "Yeah, it's a big responsibility. I've had to make a lot of these decisions on my own and do my own research. And I'll bounce the ideas off my husband, but in general...he was so busy with [work] that he just didn't have the time or the energy to put towards this. So it was hard." Janice explained the parent's role in treating children with autism:

> Very complicated and a lot of parent responsibility to drive that forward. Nobody is saying, 'Hey, let me investigate what's going on with your child.' It's all parent driven. Parent financed, parent driven…But it's expensive. There's so much responsibility placed on the parent to investigate. Find, fund, try. You know, trial and error. And, you know, it's very stressful.

April and Sally emphasized the time commitment of doing the alternative treatments, including seeing the physicians, getting the laboratory work (e.g., blood tests) done, and finding out what can be covered by the medical insurance. Emma described it as being "all-consuming." April said communicating with her health insurance company about what is covered and what is not took a great deal of time. She questioned why her insurance company doesn't have a better idea what will be covered when there are so many kids diagnosed these days.

Natalie, who does not do any alternative treatments, but whose daughter has many complicated medical issues, said her overall experience has been "extremely challenging" primarily because there is no one locally who is very knowledgeable.

The remaining eight mothers (Lois, Pamela, Carol, Holly, Dana, Olivia, Karen, Mary) have found the overall experience of managing their children's medical and psychological needs to be relatively manageable. Six of the remaining eight mothers (Carol, Holly, Dana, Olivia, Karen, Mary) have never tried any alternative interventions, and none of them are currently seeing any alternative physicians.

Of the twenty-one mothers, five mothers (Ivy, Sally, Mary, Dana, Rhonda) currently take their children to a psychologist for behaviors, social skills, or depression. Of the twenty-three children, only three are prescribed psychotropic medications for behaviors or to help with sleep.

Carol spoke of the feelings of guilt regarding her overall experience of managing her son's medical needs. She said that although she has learned about many of the alternative treatments from going to conferences and speaking to parents, she has not tried them. This has led her to feel that she "didn't do enough."

How it has affected her in a positive way (Medical/Psychological Needs)

Nine mothers said that managing their children's medical and psychological needs was a positive experience because they learned a great deal by doing their own research. Fran said, "I learned things I didn't know I needed to know! I'm getting a PhD in biochemistry and immunology." Ivy concurred, "I've been learning so much about what is evidence-based and what is not, what to believe." Quinn compared her experience with mothers who don't have children with autism:

> I've learned so much that I would have never known before. I love that. I just always want to be learning…You stay sharp and it's interesting. I remember being at the park and these moms…were like, 'Oh, you should read *50 Shades of Grey*.' I went online and read a review and I'm like, really? I had no idea what they were talking about. I'm like, they're moms without autism in their life. I said, I'm good, thanks. I'm reading a study tonight about cerebral folate [deficiency]

Mary, Barbara, and Gina said that they have learned to have more compassion for others. In addition, Barbara said that being able to help other parents in similar circumstances has been a positive effect of managing the medical and psychological needs. Janice said that it has made her feel more empowered to be able to get her son what he needs. Other positive effects of managing their children's medical and psychological needs include being more responsible

(Pamela), never giving up hope (Tracy), and being aware of their needs (Dana). Three mothers (Lois, Olivia, Holly), however, said that managing their children's medical and psychological needs did not affect them in a positive way.

How it has been challenging for her (Medical/Psychological Needs)

The mothers were asked what has been challenging about managing their children's medical and psychological needs. Six mothers (April, Quinn, Emma, Pamela, Sally, Janice) said that it has been a financial burden. Pamela pointed out, "The naturopath wasn't covered by insurance and all the supplements weren't covered by insurance." Janice said it was "overwhelming financially" and that it was "almost like running a business." She explained, "You've got to order supplies and stay on top of things and do things you've never done before, never been trained to do before." Quinn said, "It's so costly. It's out of pocket. You see all the things you can do and then you have to prioritize. What do we do first? The doctor's like, 'Here's the 12 things you should do," and I'm like, here's the money we have…"

Five mothers (Vivian, Tracy, Barbara, Ivy, Rhonda) talked about the uncertainty involved with the treatments. Vivian said, "There's just too many different things to try not knowing if it's going to work or what it's supposed to do. So you really have to weigh a lot of things before doing it like the cost, the trust…" Barbara explained, "I guess because there aren't clear answers. A lot of times it's like this is the problem but there's no one fix for each child, so you have to try multiple things before you find what actually works for your child."

Barbara, Tracy, Ivy, and Rhonda also talked about the challenge of finding local physicians who understand autism. Barbara said,

> I wanted to mention that that's the really hard part about living in Hawaii: It's the lack of doctors that are trained, because for people on the mainland, they can drive to the next state. We cannot just drive to the next state. And yeah, we can call them, but then our insurance is not going to cover that [and] we are going to have to pay [for] that.

Tracy also discussed the difficulty with having to call a physician on the mainland for support because of the cost and the time difference, as well as the inability to physically take her son to see the doctor on a regular basis.

Natalie concurred that finding a doctor who is knowledgeable about specialized conditions is difficult in Hawaii. Her daughter's local physician follows the recommendations of a specialist on the mainland.

> It's a challenge to find anybody here locally who's, I think, well-versed enough to do the right thing. I think the intention is there, but they just don't know it. And I feel bad for everyone else because those people who have no means ever of going to the mainland have no chance of seeing someone who actually knows what they're doing. That's the problem about living on this small rock because we have so little population that they're not going to be able to attract a well-known, a very good doctor. They're going to go someplace that's going to be able to support them.

Rhonda said, "Gosh, it's frustrating because it's almost like there's nothing out there for them. You're kind of left on your own to research for your own kid. I wish doctors were more proactive…" Rhonda's experience has been that the doctors here would rather sedate her son. She said the last psychiatrist who saw her son kept increasing the dosage of his psychotropic medication:

> I'm like, this isn't what I'm trying to get at. We keep going higher and higher. Let's go lower…I have to tell them I'm trying to get off. That's what I usually say when I go there. We're trying to get him OFF this. Have you heard about any other new things that might possibly work better? But yeah, they definitely want to try to give him more.

Ivy said her main challenge is picking apart the studies that get published. "Because there are studies and studies, but when you read them, sometimes you even doubt the studies…Who paid for the studies? What are their interests? Why did they start all this? I'm very suspicious of a lot of things now."

Gina said managing her son's medical and psychological needs is challenging for her because it increases her stress. Fran also talked about the stress of it all. "It's overwhelming." She said it's overwhelming for her even if she works in the health field. "How does a regular parent do it?"

Dana's challenge is the anxiety her sons feel when getting any medical exam or treatment. Carol finds the issues with puberty (e.g., masturbation) to be especially challenging. Only one mother (Holly) did not feel that managing the medical and psychological issues to be challenging in any way.

What has been helpful (Medical/Psychological Needs)

The mothers were asked what has helped them in managing their children's medical and psychological needs. Ten mothers (Fran, Carol, Gina, Natalie, Emma, Quinn, Vivian, Barbara, Rhonda, Mary) said that talking to other parents and attending parent support groups has been the most helpful for them. Barbara said, "Having support from other parents has been huge, especially parents who have already gone through things, that are ahead of the journey. I can ask questions and get answers really quickly." Gina said talking to other parents helps her feel that she's not alone. "So it's just being around other parents that's going through the same things that I am going through and I'm not the only one."

Janice, April, Tracy, and Pamela said that having the support of their spouses has been the most helpful for them. Tracy explained that "having someone else be part of the whole mixture" by discussing her son's treatments with her husband has helped her. April said that she had heard a mother's advice about the importance of having the support of your spouse when dealing with the child's biomedical treatments. In the beginning, her husband didn't understand why she wanted to spend so much money on the treatments. She said it was "really rocky" in the beginning until she was able to better communicate her ideas to her husband. "It made a world of difference to have the support from your spouse. You can be on this journey and be mad and be upset or it can be rewarding and you can do it as a family."

Dana, Ivy, Karen, and Holly said that doing research and learning about autism has helped them manage the medical and psychological needs. Sally said having the time to organize the treatments is helpful. Olivia said she has found most doctors to be accommodating to the needs of her son. Lois, however, said that nothing has really been helpful for her in managing her daughter's medical and psychological needs.

What can be done to improve her experience (Medical/Psychological Needs)

When asked what can be done to improve their experience of managing their children's medical and psychological needs, ten mothers (Gina, Natalie, Tracy, April, Olivia, Mary, Sally, Lois, Holly, Vivian) discussed the need for better trained professionals and resources in Hawaii. Sally explained that it would be better if "we had an MD here that really took an interest in it and took it upon themselves to attend the conferences and to talk to people and to be familiar with the treatments, who would be able to help us, make good recommendations. Someone local…" Lois and Olivia pointed out that in addition to having them here in Hawaii, it is also important for them to be accessible with respect to proximity and waiting lists.

Five mothers (Ivy, Dana, Carol, Rhonda, Barbara) discussed the need for the information to be readily available for parents. Ivy said, "If you need help, you should be able to get help faster and more effectively. Not go from here to here to here to here to get to where you have to go." Carol suggested having a manual for parents and Barbara suggested having a list of resources in the doctor's office. Rhonda argued, "There needs to be a system in place or something. I feel like nothing's organized as far as medical. Parents are on their own…"

Four mothers (Janice, Pamela, Quinn, Vivian) focused on the high cost of the biomedical interventions and said that having extra income, affordable interventions, or insurance coverage for the treatments would improve their ability to manage their children's medical and psychological needs.

Fran said having regular support groups would improve things for her, as well as being able to get her husband's support in the treatments. Karen would like to see physicians take each case of autism individually. "They say, 'Kids on the spectrum this, kids on the spectrum tend to do that.' Even though a lot of the kids on the spectrum do share a lot of the same difficulties, they're so different." She said it would be preferable if "they would individualize us a little bit" so that they wouldn't "make us like the last patient they saw." Emma would also like to see the doctors treat children individually, especially with regard to the vaccine schedule.

Experiences in the Management of the Educational Needs

Overall experience (Educational Needs)

When asked to describe their overall experience managing their children's educational needs, all twenty-one mothers expressed that the experience was challenging in some way. Sally and Rhonda said that the process was difficult for them because they have had to decide on their own what their children's educational needs are and how to get them. Dana said it was challenging because it requires so much organization. Holly also talked about the need to be organized and how important it is for her to be “the conduit and the hub of information of everything” about her son’s needs.

Twenty out of twenty-one parents said they experienced some challenges when dealing with the Hawaii DOE. Natalie described her overall experience as “exhaustive” and “overwhelming.” She said, “We’re obviously dealing with a system that is not meant for the child or the parents.” Mary talked about the IEP experience as being difficult because she feels outnumbered during the meetings. “I hate confrontation so it’s been really hard to stand up to them because there’s so many of them and there’s just my husband and I.” Emma described her first IEP meeting when her son transitioned to the DOE from Early Intervention. “I think I had 12, 15 people at that table. It was like me and [her private consultant and the DOH case worker] and the rest was Department of Ed people.” Karen also talked about her frustration with the IEP process:

> You sit in those IEP meetings. You have all this faith in them that they’re going to do all these services and do what they need to do and – they don’t, you know? And they make you think they’re going to do all the stuff and they don’t. And they really don’t know what they’re doing as much as they try to make it seem like they know what they’re doing.

Mary described her IEP experience when the “district” person attended the meetings. “And [the district person] was almost confrontational…kind of challenging the evaluation that I had gotten. And posturing that they were going to have to do their own research and that in the end they were the ones who were in control of everything.”

Barbara described her overall experience with managing her son’s educational needs as frustrating. “I feel it’s like banging your head on the wall. They’re not listening. They’re set in their ways.” She also discussed her son’s transition from the DOH to the DOE:

> Trying to transition from Early Intervention to the DOE, you would think it would be a natural transition. You already have all the needs, you already have

> everything identified or most of it should be identified by now. If you're having multiple services in Early Intervention, why wouldn't your child get that and go into special education? How is it you can go in and they can do five assessments and then tell you, 'Oh, he's fine. He doesn't qualify'? And then later, you get an advocate and you find out he does qualify…That was our situation.

Although Karen described her initial experience with the DOE as being "pretty poor," she now feels more optimistic after learning more about how to advocate for her child. On the other hand, Janice felt that the early years of her son's education was "awesome up until 3rd grade." She said that when her son was in preschool, she had "a really exceptional experience" where her son was placed by the DOE in a private preschool that integrated a few kids with disabilities along with neurotypical children. Then, she said, she noticed there was "less integration, less qualified support" in the years that followed. Now that her son is in high school, it has become "sorely disappointing." She said that as the child goes up the grade levels, "the bar gets lowered." Quinn said that although her daughter was more integrated when she was in elementary school, she has noticed that her daughter has less interaction with neurotypical kids and is "getting more and more isolated" now that she is in middle school.

Carol said that managing her son's educational needs has "always been a stressor" because "you're never going to get what you want for your child" from the DOE. For Lois, hanging onto the services is a challenge. She said, "The DOE is trying to take away services every day. How do you <u>not</u> have them do that?" Of all the mothers who were interviewed, only Holly did not express any frustration with the DOE

In addition to her challenges with the DOE, Lois also talked about the difficulties she has had over the years with having to decide on educational programs and strategies for her daughter without really knowing what would work best. "I didn't have the answers. And not knowing, the overwhelming feeling that you weren't doing enough, or were you doing the right thing, was unbelievably stressful."

How it has affected her in a positive way (Educational Needs)

The mothers were asked how managing their children's educational needs affected them in a positive way. The mothers gave a variety of answers from 'seeing their children progress' to 'none.' Five mothers (Emma, Mary, Gina, Fran, Quinn) replied that it was a learning experience. Quinn and Fran said they learned a great deal about the different therapies and programs used for autism, such as Floortime, Applied Behavior Analysis (ABA), and Rapid Prompting Method (RPM). Mary and Gina said they learned about the procedures for getting services (IEP). Mary said that she tries to pass her knowledge along to other parents and Gina hopes to one day help other parents by becoming an advocate. Emma said that she has had to learn her son's school subjects in order to help him with his homework.

Like Mary, Barbara said that as a result of her experiences dealing the educational system, she is able to help other parents. "That's basically the only silver lining I've found – that I can help other people." Dana and Vivian said that managing their children's education has made them become better at educating others. According to Dana, "The kind of awareness and patience that I've had to learn how to develop more of for my kids has made me a better teacher."

Karen, Tracy, Sally, and Janice said that the experience has made them more confident and assertive. Tracy said:

> It makes you realize that if you want your child to improve, you have to fight for them. You have to be their voice. You have to, as much as it might be stressful, when you know that they can do better for your child, then you just got to push hard. So it makes you be a stronger person.

Lois and Rhonda said that they have met good people as a result of managing their children's educational needs. April said she has learned to keep a positive attitude when dealing with the teachers and administrators at her child's school. Holly, who is a teacher, said that managing her son's education has made her more aware of the educational standards for her own students. Pamela said that the positive effect for her was a spiritual one, where she needed to "ask for forgiveness from the principal" which for her was "like a way of bridging the gap and having it be better." She said her experience with the school had been "constant battling" which always left her feeling "angry and upset." According to Pamela, "I just felt like it was best just to ask forgiveness and let it go and just work with them rather than try and fight them. And so after that…it got better."

Ivy and Carol said that there was no positive effect from managing their children's educational needs. Carol explained:

> If anything it's a regular cycle. You know that every year you're going to come up for your IEP…to look back and see the progress that he's made and what the plan is going forward. But honestly, I think for me, at the point where they fall so far behind, and he's…mostly nonverbal, I hate to say this, but the expectations are disheartening…I just feel beaten down after all these years.

How it has been challenging for her (Educational Needs)

When asked how managing their children's educational needs has been challenging, fourteen of the mothers talked about dealing with the DOE. They discussed matters related to acquiring services for their children from the school system. April said that her concerns aren't taken seriously by the staff. "They think that just because they're educated and they're educators, they know better than the parent does. And I feel that if you hear the parent out…I think it would be a better setting." Carol said that her challenge is the need to have IEP meetings every year:

> I don't think any parent looks forward to it. It's like a necessary evil and it's a reality. And it's challenging because you fight for everything that you child needs. I think you have to try and always be one step ahead to know what services are available, what is my child entitled to because they won't offer you anything from their side. So you always have to try and be one step ahead of them. But then you're outnumbered.

Holly said trying to schedule the numerous IEP meetings has been difficult for her. Karen talked about having to be up to date with the system's rules and regulations:

> I guess it's challenging trying to keep up with changes. I don't want to say the DOE is deceptive, but there's always new things that come into play and a way they find to kind of get around it. So it's challenging trying to keep up with the laws and how things change and how to phrase things the right way on your IEP's so you can get what you need.

Tracy said it's challenging for her have to send her child to the school even though "it feels like you're fighting the system." She said, "And I think what's challenging also is the fact that they are supposed to be the experts in their field and a lot of times you trust them to do what they should do for your child and you later find out they didn't." She summed up her experience with the educational system as having to "be always on your toes and always hoping for the best but expecting the worst."

Barbara said her number one challenge is getting the DOE to do assessments accurately. Her explanation for the lack of accurate assessments and the difficulties she's had with getting the school to provide services for her son is "corruption."

> I don't know how to else to say it, but they're not doing their job…And the ones that are doing their job are afraid of being retaliated against. And so there's this fine line where I can tell that they're trying to do their job but if they put the wrong thing in their evaluation, then they're afraid of losing their job. That's our personal experience.

Janice said it's been a challenge to try to find teachers and staff who are qualified, especially in the upper grade levels. "Once a kid graduates from intermediate/middle school, I feel like the quality of teachers goes down significantly…Quality and expectations are low." She said it's difficult to find "hard working people out there who are able to maintain that level of professionalism."

Natalie said her challenge is "just dealing with the DOE." She said that "it's too much because I really feel they're not for the child." Both she and Quinn talked about the challenges of having to go to due process to get services for their children when the IEPs don't meet their needs. Quinn said 'just the idea that you have to go to court" was difficult for her. Fran talked about the challenges she has had with the school system. She said, "The last IEP, they tried to rewrite the whole thing with different goals and I caught them at it. We ended up having…9 hours for one IEP…" Her main challenge is trying to maintain her composure when dealing with the DOE because, as she said, "they've pushed me to the limit."

Vivian and Olivia, who both homeschool their children, said that their main challenge is trying to find the right curriculum. Olivia asks herself, "Is this the right material? Do I need better material? I wish we can afford every program under the sun." For Olivia, managing her son's educational needs can be "tiring." She said, "I don't get a lot of days off." Vivian said her challenge is also to get her son to do his homework. "It took about almost three years before I finally got him to be independent to do his work, everything on his own." Ivy said her challenge is to get her son to be organized and on task.

Sally and Mary said they had to essentially manage the educational needs on their own. Sally, whose son is in private school, said that the challenge is "not knowing what the best course of action [is], questioning my decisions, whether he's in the best place, having to stay really active with the teachers and all that." Mary, who moved here from the mainland, commented that she moved from a state that had a kind of "clearinghouse for services" that gave you a list of options and let you know what was available. She said, "As far as I know there's nothing like that here…I felt like I really had to find it all myself."

Rhonda said she has had to quit her job in order to focus on her son's educational needs. She explained, "For a while I was doing it all and I felt like I was losing my mind. You know, it was kind of like something had to give." Emma, who also stopped working in order to focus on her son, described how the financial situation has been a challenge because she purchases the same materials as her son's private school in order to "mimic the classroom." In addition to the cost of his educational needs, she also said that she has had to learn to be patient because she tutors her son, who requires repetition in order to learn something new. She said, "I've always mimicked everything that he does in the classroom at home. I do a lot to supplement him."

What has been helpful (Educational Needs)

The mothers were asked what has been helpful in their management of their children's educational needs. Sixteen out of twenty-one mothers identified other people or organizations as being helpful. Gina said that her husband's support has been important in managing her son's education. "So as a family, he's meeting me half-way" by working with their son on his school work. Lois, Tracy, and Quinn expressed that talking to parents who have the same experiences has been helpful. Tracy said that "talking to people that have fought or are fighting the same battle as you are for your child" has helped her. Barbara, Quinn, and Mary commented that TACA has been helpful. Barbara also identified advocacy centers like the Learning Disabilities and Achievement of Hawaii (LDAH) and the Hawaii Disability Rights Center (HDRC) as being helpful. Lois also said her attorney has assisted her in managing her daughter's educational needs.

Olivia and Mary said they each have their own support network of mothers with special needs. Olivia explained, “There’s a group of us moms that meet monthly, sometimes more than that…That’s probably one of the, for me, most positive support thing that I have.” Mary said of her group, “So we’re really a tight knit support team for each other on ideas and strategies and venting and comparing notes.”

Sally, Pamela, Carol, Emma, and Janice talked about how their children’s behavior therapists or skills trainers have been helpful in their management of their children’s educational needs. Carol explained that the detailed communication she receives from her son’s behavior therapist has been “invaluable” because she gets more information about “what’s really going on” with the programming and how well her son is actually doing than from the teachers. Rhonda and Ivy said that good communication with the teachers has been helpful for them.

Karen and Natalie said that their children’s private special needs school has been very helpful. Natalie explained, “They’ve been very accommodating as far as that’s concerned. And every time we say we have an issue to deal with…they don’t hesitate. They say, ‘Okay, let’s figure out a way we can incorporate that into another behavior plan’ that they can work on.” Karen said, “They sat down with me, many occasions and gone over things to put on his IEP...I would say [the private special needs school], they’ve been awesome with helping me figure out things that would help him and how to break it down so the school can put it on his IEP and they can work on it in a way that’s manageable.”

The remaining five mothers identified other items and activities, such as doing research, as being helpful. Vivian and Fran both named the internet as being helpful for them. Fran said she does research on the computer when her children are finally in bed. Dana said that she tries to "access as much information" and educates herself on what her sons need as much as she can. Vivian also said that seeing her son's progress has helped her because she can see what's possible. "To have been able to see all of that is what keeps me pressing forward." Holly, who is a teacher, commented that working in education has helped her to understand her son's needs. And April described how having her other children in the same school has helped because they provide other non-special education experiences for her at the school and improves her relationship with the school.

What can be done to improve her experience (Educational Needs)

The mothers were asked what can be done to improve the management of their children's educational needs. Five mothers (Mary, Holly, Lois, Tracy, Gina) replied that getting more information would be an improvement. Mary suggested that there be a kind of "clearinghouse" of information that would help to connect the parent to the services and the providers. Lois added that there needs to be a "constant diligence and follow-up" beyond the initial referrals. She said, "It's a matter of: what's appropriate? What's working? How do we monitor that? And if it's not working, then we need to do something different. And who's going to pay for it?" Gina said more information about special education law and the IEP would help to improve things. Holly expressed how she would like to know where to go to get the information, or even to know where to network with people. "But I just don't know where to go," she said.

Karen, Ivy, and Carol said that better communication between the parents and the school would help to improve their ability to manage their children's educational needs. Karen explained that it would help to improve things "if they would really push towards really having parents a part of the education process." Ivy said she needs more data and more detailed information on the kinds of strategies the school is doing with her child. She said that she does not know what they are actually doing during the school day. "I feel like they're not doing anything. Why is it not working? What's happening?" Carol has found the school to be closed-off and unwilling to share simple information, such as the names of her son's classmates:

> So regular and open communication would be very helpful. And the teachers seem so wary. And I think they're looking at us as, 'I've got to be careful of what I say because the parents are going to take and everything and twist it and if we go to court…' And that's why too they're so protective of the classroom. Because if my kid was in regular ed, I would have his class list on the wall. I would know who his classmates are. I would know who his different teachers are.

Fran said her management of her son's education would improve if the DOE had better qualified autism specialists. She also expressed that parents should not have to "beg" for services, such as assistive technology. "You have to beg for all kinds of stuff. You shouldn't have to beg for it. They end the IEP with, 'This is our offer of free and appropriate education.' And I'm thinking, it's free but it's not appropriate. Not appropriate." Barbara said that the DOE needs to be held accountable for their actions. She explained, "I think there needs to be independent accountability because they investigate themselves. What good is that?" Both Pamela and Barbara said that it would be an improvement if the DOE worked with private autism providers who are not contracted by the DOE. Pamela said, "It would have been nice if the school could have taken on ABA programs from outside that we thought would be helpful and beneficial to [her daughter]." Barbara talked about how the DOE should be open to the recommendations made by outside providers:

> They don't want to put [the recommendations] in his IEP; they don't even want to look at it. So then, I have to do all of it at home. Which, if he needs it in school, how is that going to help him? And then with autism, they're supposed to learn these skills across every environment. If the school's not going to do it, which he's at for six hours, how does that make any sense? So they don't want to work with you, they don't want to work with private providers who have more

> experience, more knowledge. They just want to do what they want to do. I think there's a lot of brokenness.

Rhonda said she wished the DOE could provide a comprehensive book about autism and autism services. She said, "It's hard because I would say that I wish the DOE would provide something, but then it's like, no, I don't really trust them."

Both April and Janice expressed that their experience with managing their children's educational needs would improve if teachers were paid a higher salary. Janice explained, "If they were paid really well, you would get a higher caliber person and then you'd know that that teacher was always moving things forward because that leadership is so important." April said teachers may be putting in less effort because they feel underpaid. She said, "I feel that because they don't feel like they're taken care of from our system, from our state – I could be wrong – but they don't put that kind of effort. I think teaching has become just like a job." She talked about how when she was young, people became teachers because they loved watching children learn something new:

And I remember that's what teachers would say, 'That's why I became a teacher.' Now, I think it's like, 'I don't want to become a teacher. Teachers don't get paid enough.' I feel like, maybe if they were treated better also then maybe they would treat us better?

Natalie and Quinn said they would be able to better manage their children's education if they had more time. Natalie explained, "I really feel like if I didn't have to work that I would have more time in organizing things, being able to be more detailed about things. I want to be but I just cannot…Really, if I could clone myself, I'd be really happy." Quinn said she would like to find a part-time job because taking care of her daughter's needs is "like a full-time job."

Emma said if private schools were open to having skills trainers in their classrooms, it would improve her management of her son's educational needs. Sally wondered if developing more contacts with parents in the autism community might help to improve things. Vivian said having a positive attitude may help her to better manage her son's educational needs. Dana talked about the need for schools to address the issue of diversity and "managing differences within schools." She said it was a question of "how the educational philosophy embraces tolerance" for all children and to "have it be more interwoven within the fabric of our outlook."

Physical, Emotional, and Financial Effects

Changes to her physical health since the diagnosis

The mothers were asked if there have been any changes to their physical health since their children's diagnoses. Sixteen out of the twenty-one mothers reported some form of adverse physical change, such as high blood pressure, high blood sugar, glaucoma, psoriasis, and eczema. The lack of self-care was reported by eleven of the mothers (Janice, Mary, Gina, Fran, Tracy, Dana, Barbara, April, Quinn, Karen, Sally). These mothers talked about their lack of rest and sleep, their lack of exercise, gaining weight or losing too much weight, not eating healthy foods, and not taking medications or seeking a doctor's advice in a timely manner. Janice said she was diagnosed with chronic fatigue syndrome and hypothyroidism. She said, "I don't go to the doctors or take care of myself. I've attempted to on multiple occasions. But, I think that the ongoing stress of having a child on the spectrum…I haven't had much time to care for myself…" Karen said, "I feel like I don't take as much time for myself as I did. Who really takes that much time when you have kids? But, it's like now if I brush my hair, it's a good day." She said if she becomes ill, instead of having a "sick day," she will now just "push through it."

Dana said she had pneumonia two years in a row. “I was sick and I couldn’t really rest, or I didn’t sufficiently. And you keep working and then suddenly, the doctor’s like, ‘Well, you have pneumonia.’ It’s like, really?” Sally talked about how the tissue in her shoulder had frozen, but she didn’t seek medical attention right away and in the end had surgery to resolve it. “It was really bad because I waited a long time to get treatment. And when I finally did, it was really far gone.”

Ivy and Holly talked about being more tired. Rhonda and Fran talked about feeling exhausted. Rhonda explained, “It’s a different ‘exhausting’ than caring for a baby or caring for another kid. It’s just a different exhaustion.” Fran said that the exhaustion is due to “intense chaos every day with no respite.”

However, Emma said there haven’t been any changes to her physical health. Pamela, meanwhile, said that she did not know if her physical health changed at all. Vivian and Olivia both said that their physical health improved since their children’s diagnoses. Vivian said she was “healthier” due to “weight loss” and “eating better.” Olivia said she also has lost weight because she goes on the same diets as her son (e.g., cutting out sugar). She said, “Actually, I’m super healthy. And it’s your attitude towards your child. It’s your attitude. I just have a very positive attitude about everything we’ve done.”

Changes to her emotional health since the diagnosis

The mothers were asked if there have been any changes to their emotional health since their children’s diagnoses. Eighteen out of the twenty-one mothers reported an adverse change to their emotional health. Seven mothers (Carol, Quinn, Mary, Tracy, Rhonda, Fran, Ivy) said they have experienced depression. Mary said that she was “really depressed.” She explained, “I mean it was such a life change and it was so overwhelming...And I don't have the outlets. I don't do the things I used to do that would be emotionally nurturing." Tracy said she experienced depression around the time her son was diagnosed. "And I think all of the depression and anxiety that I was having is because of him, because of me not knowing what to do with him. And I felt helpless."

Gina spoke of being "more emotional" and asks herself, "Why me?" Barbara talked about her feelings when her son was diagnosed. "It was really heartbreaking. And you go through blaming yourself. I guess they say it's the stages of grief; it's like a grieving process."

April, Natalie, Quinn, and Sally said that they experienced anger. April said:

> I was always angry. I was angry at everything, at my relationship, at my husband. Because he works so much I felt he wasn't there to help me, and when he is, it's not really a help because he's too tired. And I felt financial-wise, the burden, all the extra time I had to figure out what test I'm going to do with [her son] – is it this doctor, that doctor?

Finally, April sought help from a therapist. Sally said when her third child had just been born, she felt overwhelmed because of the responsibility of caring for the children, in addition to all of her son's autism services and care. "And so I think I really had a lot of resentment and I focused it on my husband because he should be helping more."

Six mothers (Janice, Vivian, Carol, Gina, Tracy, Sally) said they experienced anxiety after their children's diagnoses. Tracy said she's "very anxious all the time." Carol, who is going through a divorce, explained that her anxiety comes from not knowing what will happen to her son when she's no longer around.

> And there's always anxiety because when you die, what's going to happen to your child? I mean, that's always hanging over your head…There's always anxiety and I think even more so now because we're going to go through a divorce and I

> don't trust that the time that he's with his father without me being there is going to be what's best for him.

Janice said she feels anxiety when her son has behaviors in public. She explained that when he isn't feeling well "he has a lot more behaviors then it's hard to go in public places." On one occasion when they were waiting in line at the supermarket, he started to touch people and make a lot of noise. "As he was making more noise, people were getting quieter and looking down…I just giggle through it, but it does actually affect me."

Dana spoke of feeling greater social isolation as a result of the public being judgmental. She said, "We talk so much about how important community is in terms of people's long term emotional health. But if you're in a situation where those communities are not accepting and they're not available, that's unfortunate and that has an impact."

Holly, Lois, Emma, Dana, Vivian, and Carol said that they have more stress in their lives after the diagnosis. Lois talked about the demands on her time and the need to be able to separate the different parts of her life.

> I'm sure my stress level is higher. I have a demanding life. I work a lot. Plus I have the kid, then I had the litigation at one point. There were so many things pulling at me. I have learned to compartmentalize. You put it in a box, you put it in a corner, you deal with it when you have to, otherwise you can't function.

Holly said the diagnosis "added to the stress of everything," including her relationships. "You know, everybody else has expectations of you."

Janice talked about the impact of not being able to have the freedom she had before her son. "I feel more trapped in terms of my future and even my present because I was always the person who traveled quite a bit and valued my freedom." However, she said the experience of raising her son has changed her perspective and focus. “I guess it changed my psyche in terms of what really is valued, what is a really good life.”

Three mothers reported that they did not experience any negative emotional effects after the diagnosis. Pamela said she did not notice any changes to her emotional health. Karen said she feels she is “emotionally stronger than I was.” She said, “I’ve learned to be more assertive. I’m a lot more capable of dealing with challenges, versus before I would have a breakdown and now…I take it as it comes.” Olivia described the effect on her emotional health as being “positive.” She explained how her faith affects her perspective:

> Everyone worries about their kid. You get hit every so often...something happens, what are you going to do? You can go there, right? We’re going to do everything we can. And just who I am, I’m just going to trust God and the rest. And so I have a peace about it, where [her son] will end up. So I don’t worry about that, to be honest with you.

<u>Changes to her financial situation or job status since the of diagnosis</u>

Seventeen out of the twenty-one mothers reported that they have extra expenses or more debt since the diagnoses. April said her family became practically bankrupt. She said she had “literally maxed out every credit card” with her son’s therapies and doctor’s visits. Dana and Holly talked about how childcare option for special needs children costs more and are more limited than care for typically developing children.

Emma, Rhonda, and Fran said their savings have been depleted because of the expense of caring for their children. Rhonda said, “There’s no savings going on…A lot of our money would go towards a summer program or swings or anything.” Emma, Sally, Vivian, and Dana discussed the cost of paying for ABA services. Emma paid for private ABA services for her son, including the skills trainers and the supervisor, plus private speech therapy and private school tuition. One year, she said her medical expense write-off for her taxes was $70,000. Vivian and Olivia both talked about the added expense of a homeschool curriculum.

Natalie said she had to take out a loan in order to pay for her daughter's private education. She talked about the stress of knowing that her job is crucial to her family's financial health:

> If I'm without a job, that's everything. I have no money to pay for everything I need to do. I have no insurance, no medical. I mean, it's everything. So I feel like I'm tied – I have my hands tied and I have to stay in this job…This has been a source of much stress, much anxiety.

Vivian summed up her thoughts on the cost of autism services: "Autism is a money-sucking machine." Of the twenty-one mothers, only Carol, Ivy, Karen, and Mary did not specifically talk about the added expense of caring for their children.

Five mothers (Emma, Karen, Mary, Rhonda, Vivian) said they left their jobs after the diagnoses to care for their children. According to Karen, "When he got diagnosed I quit work. I stayed home just to be with him full-time. Since then I haven't gone back to work. So we're now a single, one income family. And I would love to go back to work but I know I can't…It just wouldn't be feasible right now with all his needs…" Mary, who now works part-time, said that after the diagnosis she became a stay at home mom even though, she said, "I didn't think I would ever do that."

Barbara said, although she had always intended to be a stay at home mom when her son was young, she now feels she can't go back to work. "I literally can't go back to work because of all the help he needs." When she found part-time work, she said it didn't work out. She said, "There's too much I have to do for him. Because for him, and most children I think on the spectrum, they need the parent's full attention." She explained, "For my son, because of the food allergy and all the medical conditions, I have to cook almost everything for him, and that's half my day right there, between shopping and cooking." Tracy said she only recently started working full-time. "For the longest time I could only do part-time because who's going to pick him up and who's going to be with him?" Gina said she has cut back on the number of hours she works in order to concentrate on raising her sons. She said, "My schedule is worked around my kids, my priority."

Other ways the diagnosis affects her

The mothers were asked if their children's autism diagnoses affect them in any other way that wasn't discussed. Janice and Vivian commented that that they are both more isolated from their friends because of their sons' autism. Vivian said, "You kind of end up in your own world." Janice explained, "I think that many times because of his diet and because of his behavior and because of the cost, we'll just end up staying home on the weekends…Because it takes a lot of work to stay social."

Barbara, Natalie, and Janice said their personalities have changed since their children were diagnosed. Natalie said she has become more open with people and will tell them her daughter has autism before knowing them well. "I'll just say, 'We'll, she's autistic. Let's move on.'" Barbara has also become more open and outgoing:

> I used to be an introvert and now I've learned how to advocate for him. A total introvert. I couldn't talk in front of people. I wouldn't be able to articulate. Still, I kind of have times like that, but it's really changed me because…I guess first and foremost when you go into an IEP meeting you can't be an introvert or you're going to get nothing. It's really boost my confidence. How do they say it? If you're passionate about something it changes you.

Janice said she has become a braver person since her son’s diagnosis. “I’ve had to develop a part of my personality that I would call courage because you don’t want to do it and you’re forced to do it, and then you just do it.”

Pamela said she is more concerned than a “typical parent of a typical kid” that her daughter has a good friend. She finds that it gets more difficult the older her daughter gets. “It used to be that I could set up play dates, but now there’s not anything I can do about it, except encourage her to talk to people or be herself.”

Dana and Ivy both said that they see some traits of autism in themselves. Ivy said she is more particular about being systematic, even to the point of being a “perfectionist.” Dana said:

> I definitely think that there are a lot of my own ways that I am that are in fact what is being labeled in my children as autistic…I mean it’s very apparent to me that many of us in this community, including myself, once you’re aware of what you’re looking at, it becomes much clearer that it’s not just the kids.

Karen said that in the past, she just “went along business as usual.” However, as a result of her son’s diagnosis, she now worries more about the future. Olivia said that the diagnosis makes you prioritize your life. She said it makes you ask yourself, “What’s really important in your life?”

Tracy said that since the diagnosis, "my husband and I have become closer because it’s our fight,” especially since her son “doesn’t have yet a voice of his own.” She commented that she and her husband are fortunate since couples who have children with disabilities often have problems. “So we support each other, my husband and I. It has worked out really good for us.”

On the other hand, Mary said that her children’s diagnoses have strained some of her friendships. She explained that there were times when her children did not get along with her friends' children due to social challenges or issues of being too rough. This led to her friends not wanting their children around her children, as well as her friends not having any understanding of her current life. She also envied some of their families who were free from autism. "I've lost some relationships over that."

Sally discussed "the concept of love being a choice." She said her son can be difficult, so she finds she has to "search for the good things in him." She explained, "I have to choose to be grateful for things about him. I have to choose to be more positive in my interactions with him." It would be more accurate, she said, to say that she has to "choose to act lovingly towards him" because although she loves him, at times his behaviors and eccentricities make it difficult for her to feel like behaving in a loving manner.

Carol and Fran also both admit that there is more than one way to look at their lives with autism. Carol said that although she enjoys "all of the successes and joys along the way," she can't help but notice how "far behind" and "deficient" her son is because her husband often points this out. She said her husband feels that they, as parents, got the "short end of the stick" because if their son was "normal," he would be an "awesome kid."

> And I guess I never really thought of what [her son] would be like if he wasn't autistic until my husband said that. And when he said that it just popped my bubble. It was like, wow, how can you? So in the back of my mind, I'm always thinking, what would he be like if he was a full potential normal kid? And we will never have that.

According to Carol, "It's a big dark cloud that hangs over your head." Fran said that at times she feels a "sense of hopelessness." At the same time, she says:

> I flip it over because I'm always the eternal optimist. And I go, you know what? There's a problem in our society and I need to be the warrior to figure it out. Because this is an epidemic now and nobody's yelling and screaming about it and fixing it. And that's my calling to do that, and I'm going to figure it out with concrete labs…And I think it's those immunizations.

Emma and Lois have a matter of fact attitude to the diagnosis. Lois said, “I don’t think about it. I just do it. I just do what needs to be done. It is what it is. I do what I feel I need to do to give her the best life possible.” Emma said, “It is what it is at this point. What else do you do?” They are living on one income since she stopped working to be with the children. “So could we still use the money financially? Of course we still can. But, I said, you know what? It’s not the end of the world. We’re always going to have bills…It’s alright, we’ll figure it out.”

Janice pointed out that there is an even greater issue at hand, where families who believe that vaccines have played a role in their children’s autism have a “double loss:”

> I think also because of the whole vaccine and autism component, it has made me more jaded about power structures and politics and corporate involvement with our country as a whole. And I almost feel like this is even more problematic – an equal loss of the dreams that you had for the child’s achievement in life and also the loss of your understanding of how the world works in a positive way. So there’s a double loss that happens for those families who believe that vaccines have injured or caused autism. And there’s the whole mustering of us against the world.

However, she said there comes a time when families have to “make peace” with it all in order to “claim” their happiness. “You just have to claim it,” she said.

Themes and the Stress Process

This study used the Stress Process theory as a guide for the analysis of the data. Themes were searched for and categorized according to the domains of the stress process: the stressors, the stress mediators, and the stress outcomes. The themes identified as stressors are those that the mothers of children with autism are especially burdened with. The mediator themes are those that help the mothers to cope with their exposure to the stressors. The outcome themes are the effects on the mothers’ well-being due to the stressors.

To evaluate the interviews for themes, each interview was transcribed into a Word file by the researcher. After all twenty-one interviews were transcribed, the transcriptions were inputted into NVivo. The interviews were reviewed and examined multiple times and the data were coded into key issues and ideas. Initially, the ideas were categorized by the twenty-four open-ended questions that were asked in the interview. Several sub-categories were then created within each category. After an extensive review of the transcripts, the categories and sub-categories that had emerged were sorted and similar ideas were combined and renamed to form the main themes. A thematic matrix was created in Microsoft Excel.

The thematic analysis of the data revealed eight themes that fit into the Stress Process framework: four themes that can be categorized as stressors (concern for the child's future independence, finding the right services for autism, safety, and trust), two themes that can be categorized as mediators (social support and learning about autism), and two themes that can be classified as outcomes (emotional reactions to caring for a child with autism and mother's self-care). The central theme of the study was the unclear path that the mother must follow after her child's diagnosis with autism, which can also be classified as the central stressor (see Tables 2a and 2b). Each theme, as well as the sub-ideas within each theme, is discussed below.

Table 2a Themes

Respondents	Concern for Future Independence (Stressor)	Finding Services (Stressor)	Trust (Stressor)	Safety (Stressor)
April	Afraid of what will become of her son if something happens to her or her husband	Difficulties with school and insurance companies, out of pocket expenses are expensive, research is time consuming.	Difficulty with trusting the school, loss of trust for doctors	Concern for her son's care and safety after she is gone
Barbara	Hopeful that son will have a good future, but concerned health issues may get worse	No clear answers, lack of trained physicians in Hawaii, difficulties with insurance and school	Difficulty with trusting the school, loss of trust for doctors	Concern for her son's health
Carol	Anxiety from fear of what will happen to her son if she dies	Feels you need to be one step ahead of the DOE, IEP is a "necessary evil"	Difficulty with trusting the school, difficulty with finding trusting caregivers	Concern for her son's care and safety after she is gone, keeping her son safe from predators
Dana	Wonders if Hawaii will have enough options and programs to help them	Would like all information in one place. Difficulties with DOE and insurance, out of pocket expenses are expensive	Difficulty with trusting the school	Keeping sons safe from judgmental people
Emma	Wants a "normal" life for her son	Difficulties with DOE, private services and biomed treatments expensive	Difficulty with trusting the school, loss of trust for doctors	Concern that her son will be able to take care of himself when he is older
Fran	Worries about son mentally, physically, biologically	Difficulties with DOE, challenging finding the right doctor locally	Difficulty trusting the school, loss of trust for doctors	Concern for her son's health. Son used to elope
Gina	Wants him to be able to speak out for himself	Difficulties with DOE and with finding private providers	Difficulty with trusting the school	Concern for her son's care and safety after she is gone

Holly	Concerned what will happen when she is gone	Too many meetings with school, does not know where to go to get information or where to network	Difficulty with trusting message of support group	Concern for her son's care and safety after she is gone, son is a wanderer
Ivy	Concerned about her son taking care of himself	Difficulties with DOE	Difficulty trusting doctors, difficulty with trusting the school	Concern for her son's health, concern for his safety when driving in the future because he is very distracted
Janice	Worries about him being abused	Difficulties with DOE, biomed very expensive and difficult to access in Hawaii	Difficulty with finding caregivers she can trust, difficulty with trusting conventional medicine, difficulty with trusting the school	Keeping son safe from predators, concern for her son's care and safety in the future
Karen	Concerned what will happen after she is gone	Difficulties with DOE and finding right ABA providers, feels doctors do not understand autism	Difficulty with trusting military physicians, difficulty with trusting the school	Concern for her son's care and safety after she is gone
Lois	Worried she will be abused or taken advantage of	Difficulties with DOE and private providers	Difficultly with trusting the school	Keeping daughter safe from abusers or those who will take advantage of her
Mary	Would like them to be independent	Difficulties with DOE, difficult finding resources in Hawaii	Loss of trust with local resources	Concern for her son's emotional health
Natalie	Wants her to be cured, worries what will happen after she is gone	Difficulties with local physicians and DOE	Difficulty with trusting the school, difficulty with trusting local physicians	Keeping her daughter safe from those who will take advantage of her

Olivia	Wants him to be a functioning adult	Difficulties with DOE, currently homeschools, resources far from home	Difficulty with trusting the school	Concern for her son's emotional health
Pamela	Wants her to have a meaningful job, common sense, and a good friend	Difficulties with DOE, private providers expensive	Difficulty with trusting the school, difficulty with trusting doctors	Concern her daughter's lack of common sense may hinder her future safety
Quinn	Concerned about future services, wants her to be independent	Difficulties finding resources, physicians who understand autism in Hawaii, autism resources very expensive	Difficulty with trusting conventional medicine	Concern for her daughter's care and safety after she is gone
Rhonda	Wants him to have a normal life	Difficulties with DOE, used private consultant, feels doctors are not proactive	Difficulty with trusting the school, difficulty with trusting doctors	Keeping son safe from abuse, concern for her son's safety after she is gone
Sally	Wants him to be independent, have friends	Pulled son from DOE, finding appropriate private school difficult, private ABA and biomed expensive	Difficulty with trusting the school, difficulty with trusting doctors	Concerned that she was not managing the biomedical treatments correctly because there was no local support
Tracy	Wants him to be married with a job	Difficulties with DOE, local doctors don't understand autism	Difficulty with trusting the school, difficulty with trusting doctors	Concerned that she was not managing the biomedical treatments correctly because there was no local support
Vivian	Wants him to be a productive member of society and not end up on the streets	Difficulties with DOE and finding private providers, difficult finding appropriate homeschool curriculum, difficult finding doctors who understand autism in Hawaii	Difficulty with trusting the school, difficulty with trusting doctors	Concern for her son's care and safety after she is gone

Table 2b Themes

Respondents	Social Support (Mediator)	Learning About Autism (Mediator)	Emotional Reactions (Outcome)	Mother's Self-Care (Outcome)
April	Parent support group (TACA), Husband, Mother	Researches alternative biomed treatments, has attended conferences	Anger, depression, frustration, upset, fear	No one else could watch her son for years
Barbara	Parent support group (TACA), Advocacy centers	Learned about ABA, biomed, how to deal with school system; attended workshops	Stress, overwhelmed, grieving process	Weaker immune system, gets sick all the time, needs longer time to recover, lack of sleep.
Carol	Parent support groups like TACA, former skills trainers, mother-in-law	Has attended conferences about autism	Depression, anxiety, stress, frustration, guilt	High blood pressure, diabetes, glaucoma
Dana	Mother, husband	Researched on her own and attended workshops	Stress, isolation	Less time for self-care
Emma	Parent support group (Generation Rescue), other parents, husband	Internet research	Stress, depression	Health is okay, but very stressed
Fran	Parent support group (TACA), church	Attends conferences, researches on internet	Stress, overwhelming, frustration, depression	Exhaustion from lack of sleep
Gina	Parent support group (TACA), other autism parents, husband, mother	Learns about IDEA and IEP procedures	Stress, anxiety, more emotional	No longer exercises, high blood pressure
Holly	Parents, sister, brother-in-law	Attends workshops and conferences	Stress	More tired
Ivy	Sister-in-law	Attended college courses	Stress, depression	Tired

Janice	Husband, parent support groups (TACA)	Attends conferences, networks with professionals, researches on her own	Stress, anxiety	No time for self-care, chronic fatigue, hypothyroid
Karen	Parent support group (TACA)	Attends conferences, does her own research	Overwhelming, worries more, emotionally stronger	Hasn't focused on self-care
Lois	Mother, in-laws, other parents	Researches on her own	Stress, worry	Stress causing health issues, eczema
Mary	Other parents	Researches on her own	Depression	Doesn't exercise as much or eat healthy
Natalie	Nanny, husband	Attends workshops, learns from private providers	Stress, anxiety, guilt, overwhelming, frustration	Stress causing health issues, psoriasis
Olivia	Mother-in-law, husband, homeschool network	Internet research	Thinks positive, trusts God	Lost weight, goes on walks with son and husband
Pamela	Husband, her faith, other parents in support groups	Support groups	Frustration	Family's diet became healthier, noticed no changes to her health
Quinn	Husband, in-laws, other parents	Attends conferences, workshops, internet research, other parents	Anger, sadness, guilt, depression, stress	Did not do self-care
Rhonda	Husband, daughter	Internet research	Frustration, depression	Exhaustion, gets sick more often
Sally	Church, other parents	Learns from private providers, other parents, advocates	Stress, overwhelmed, depression, anxiety, sadness	Did not go to doctor for frozen shoulder, in the end had surgery
Tracy	Husband, other parents, support groups	Other parents, internet research, support group	Anxiety, stress, worry, depression	Less sleep
Vivian	Sprirituality	Attends conferences, workshops, internet research, support groups	Anxiety, stress	Healthier, weight loss

Concern for the child’s future independence and care (Stressor)

As it was reported above, every mother who was interviewed expressed concern for their child’s ability to have some degree of autonomy. The amount of independence that was hoped for the child ranged from having a “normal life” to simply having “opportunities” for employment. Mary said she wants her sons to be “able to go to college, find a rewarding job, and be able to function on their own in the world.” Tracy said she would like her son to be married and employed. Natalie talked about how she hopes her daughter will be “cured” so she will be “like a normal person”:

> I hope she will be cured because she’s a smart girl…and that she could get a regular education, hold a job, and be a successful citizen…I’m not going to say she’s going to be some CEO or whatever, but if she could hold a job, pay taxes, and be a sustaining citizen in the world, then I think we’ll be successful. I want her to be cured, really, because I want her to be able to communicate like a normal person, to hold a job like a normal person, to hopefully have a family.

Emma said that although she wants her son to have a normal life, she understands that there are still hurdles to overcome:

> Being able to read and comprehend things goes across everything in life. So if you can’t do that very well, what kind of job – where will you be in your life? Will you be able to take care of yourself financially and be able to quote-unquote have a normal life – get married, have kids – that’s the part to see what he can do…

Fran, Rhonda, Olivia, and Quinn, also expressed that the future isn’t clear. Like Natalie, Fran spoke of her desire to find a cure for her child:

> Many concerns about him mentally, physically, biologically. All the treatments we’re doing, how are they affecting him? Are they actually going to help cure him so he can function in life? Is he going to have a future? I’d like to see him go to college. At this moment, I don’t know…

Rhonda admitted that her vision of her son’s future has changed as he’s aged:

> Ideally I want him to live a normal life like everyone else, you know. Realistically? He’s getting old. It’s hard to…I don’t know. I think before when he was younger, I would just dream…

Lois, who has come to the realization that her daughter will probably never be fully independent, would like her to have a job or two:

> I mean basically be engaged in some kind of work where she can get paid so that she can get monies in the future from her own endeavors. And life is short in a sense that you can't stay home and play with your iPad all day. I mean, you know, her dad and I still work so [she] needs to have something to do and we hope not just cleaning a classroom or something because she's not low functioning, but she's not super high functioning.

The mothers expressed the hope that if their children with autism did not achieve independence, then their care will be in the hands of siblings or other family members. April discussed how her younger daughter talks about taking care of her autistic brother when they are older and how she says, "He's going to live with me." However, the mothers also acknowledged that this wish may not happen. Natalie said she would like her son to care for her daughter, but realizes he may not want to. "What if he rejects that and doesn't help take care of her? Because I'm hoping he's going to be basically either her custodian or guardian." She worries about what will become of her daughter if her son decides not to take on that responsibility. "If I can't depend on him for whatever reason, whatever happens, then is she going to be the ward of the state? How is she going to take care of herself? Who's going to take care of her?"

Holly discussed her concern that her daughter is in the "teen phase" and so is not inclined to be very helpful with her son. She is hopeful that her daughter will take on more responsibility later. "I'm hoping that when she's a little older, then she'll realize that she has to help. Or, she's going to be a big integral part, because if I'm not here, then – I think that's the bigger piece for me. If I'm not here, then what happens?" Rhonda said although she fully expects her daughter to "watch over" her son, she does not want her son to become a "burden to her." She said, "I just don’t want anyone to have to feel that and, you know, it’d be a choice for them. For me, it’s something I’ll always do.”

Carol talked about how she and her husband disagree on her son’s care when he’s an adult. Since they have no other family to care for her son after they are gone, she is considering a group home placement for him. Her husband, however, tells her, “Over my dead body. You’re not going to put him into a group home…I’m going to watch him until the day I die.” However, Carol says there is no one else to care for her son. She said that other than her husband’s elderly mother, she and her husband have been their son’s only caregivers. “We don’t have anyone…a strong family member.”

Finding the right services for autism (Stressor)

All of the mothers talked about the difficulties they experienced with trying to determine and acquire the appropriate services for their children. Most of the mothers said that autism treatments and therapies, whether behavioral or biomedical, are expensive and difficult to locate and access in Hawaii. Barbara, Dana, Lois, Mary, and Olivia talked about the need for a “one-stop shop” locally where parents can find out all the necessary information about how to care for their children. Barbara suggested:

> One of the things I think Hawaii needs…is someplace you can go to get all the information at once…I think that’s what parents are looking for. They don’t want to have to go everywhere because you’re spending all this time going all over looking for the information and if it’s one place…it makes it easier for parents.

Dana concurred, “I wish there was more information for parents and more one-stop shopping kind of information. And it wasn’t so much like you lucked-out and found the one person who could help you…” Mary said things would improve in Hawaii if there was a kind of “clearinghouse for services” that helps to “connect you with services and provide advocates for you…" Lois said although there are various organizations in Hawaii, no one organization actually gives you a list of all the available resources with detailed information about what is offered and how get what is offered. She said, "I mean, you end up spending so much time and energy in tracking down services."

April, Holly, Ivy, and Natalie talked about how more resources are needed in Hawaii. Holly explained, "When you search for autism in Hawaii, you come up with the same sites over and over again." She said she would like to find other resources. "But being able to find other pockets, I don't know how to get that." Ivy said that in addition to Hawaii's need for more sources of information, the resources available should be better so a person can "get help faster and more effectively." Natalie talked about the need for more informed physicians in Hawaii. She suggested that a list of physicians who are knowledgeable about "recent information about autism" could be compiled, or perhaps knowledgeable physicians from the mainland could be brought to Hawaii to give lectures "so that our local physicians would be made more aware and more open." She asked:

> Why do these physicians think it's only for the mainland? I don't get that! We're part of the world population. It is not just the mainland thing. So it boggles my mind that they're just <u>so</u> narrow minded about that kind of stuff. So if there was a list of physicians who are more apt to understand it, that will be great. Or somehow bring in these physicians to teach these physicians. Also just things like having a list of dentists that we could go to. Where are we going to go to get our eyes checked that the person is going to know what to do? Or get eyeglasses fitted? Oh my god, if I ever have to do that! Dreading that, you know?

Fifteen of the mothers talked about the high cost of paying for autism therapies and treatments. Parents pay for behavioral therapy on their own if they are unable to acquire it from their insurance policies or from the government. In Hawaii, ABA therapy has been covered by private health insurance since January 2016, after the passage of autism insurance legislation in

2015. April talked about how she used to pay for her son's ABA therapy out of pocket until the passage of the insurance bill. "Even though they recommended 25 hours a week of ABA, I thought I can't afford that. I can afford after school from 2:30 to 4:30, so that's what I was doing."

Although the autism insurance legislation is a financial help for families, it has a cap of $25,000 per year which is insufficient for the recommended 25-40 hours per week of ABA (Autism Speaks 2018). The bill also states that a person must be licensed to practice behavior analysis in the state of Hawaii. Currently, an ABA program must be overseen by a licensed BCBA in order to be covered by insurance. The number of BCBAs in the state of Hawaii is limited, however. There are several bills currently being heard in the state legislature that may broaden the definition of an ABA provider.

Fran said she has been unable to find a licensed provider in her area. Gina's employer has a self-funded insurance policy which is exempt from the autism insurance bill. Although she subsequently discovered that her husband's insurance will cover ABA, she also has been unable to find a licensed provider. "So now I have ABA therapy, but there's no place here in Hawaii. They say, 'You're on the waiting list,' or 'We're not taking any more clients.'" As a result, she has been on a waiting list for months.

In addition to ABA, parents will pay for other services on their own, such as speech therapy and one-to-one skills training. Parents like Emma and Sally, who send their children to private schools and do not receive any state services (from DOE or DOH), paid for their children's one-to-one service provider, plus the supervisor, on their own. Sometimes insurance policies have restrictions on who can qualify for certain therapies. For example, April tried to get her son private speech therapy through her health insurance, but "because he doesn't have apraxia, then he can't get speech therapy covered." In these cases, parents have no choice but to pay for these treatments out of pocket or their children will simply have to do without.

Another substantial cost for families is the cost of biomedical treatments that are not covered by health insurance in Hawaii. Medical Academy of Pediatric Special Needs (MAPS) doctors are typically not covered by local health insurance policies because most of these doctors are located on the mainland. Barbara, whose son was diagnosed with mitochondrial dysfunction, has had some difficulty finding a physician who can give her clear answers. She said, "I had someone tell me, well just get a different doctor. I'm like, yeah, it's not that easy. Because certain doctors know about this condition and they don't know about this other condition. They don't know how they overlap. And then they're all on the mainland."

Some families have been able to receive the TACA Hawaii and Hawaii Autism Foundation Family Scholarship which is used to offset the cost of the prescribed biomedical treatment of a MAPS doctor. However, without the help of a scholarship the cost of the MAPS physician, the laboratory testing, and the supplements and medications can be prohibitive. Janice explained, "Affordable interventions could have really helped. Because we never got scholarships right, but we could have used them. But if insurance covered the biomedical interventions, I think we could have…kept on going with a lot."

The high cost of autism treatments and services has forced families to make difficult choices regarding their finances. Emma and Barbara said they were forced to refinance their homes in order to pay for their children's services. Natalie said she had to get a loan to pay for her daughter's private autism education. Other families, like Quinn, have used money from the sale of their homes to pay for these services. Lois described the situation for many families, "There are families that have mortgaged their futures, their homes, to pay for these services. You end up damaging your own future because you're trying so hard to provide for your children."

All of the mothers expressed some challenges with getting appropriate services for their children through the DOE. The challenges discussed ranged from the number of meetings needed to determine what their child needs (Holly) to having to go to due process in order to acquire the services for their children (Lois, Natalie, Quinn, Sally, Vivian). Emma talked about her meetings with the DOE when her son transitioned from Early Intervention at age 3 years. Her son had been receiving 35 hours of intensive behavioral therapy, in addition to speech therapy and occupational therapy from Early Intervention. However, she said she was offered "very minimal" services by the DOE for her son. She didn't feel the services offered were appropriate for him and that he would have "gotten lost" if she sent him to the DOE program. In the end, she decided to send him to a regular private school with support and pay for all of the services on her own. She described her experience with the DOE:

> I kept arguing with them, arguing with them…And then it was like I almost had to let him <u>fail</u> in order for me to have a case to then sue them. I told my husband, it's not even worth it. Why are we going to let him fail for? So he didn't even really get any services from Department of Ed. It was just through the meetings process before I decided, you know what? I'm done. We're going to just do it privately. So he never actually started with Department of Ed because it was so evident that that's what it would be – he'd have to fail and regress.

Similarly, Sally also pulled her son from the DOE after the transition from Early Intervention because the DOE program did not have any typically developing peers. She had to go to due process to acquire the services recommended by her private autism experts.

Lois had to move her daughter to another school when the care coordinator decided to alter her daughter's IEP without the consent of the other members of the IEP team, including the parents. She, too, had to contact an attorney and go to due process in order to remedy the situation. She said, "as a parent, the goal is always to mutually work toward the same satisfying positive future. But if you have people that can run amok and have no supervision like [the care coordinator], what are you going to do? And that's where having an attorney…comes in."

Pamela, who pulled her daughter from public school when she was in the 6th grade, described her interaction with the DOE as being "really rough." She said, "Looking back on it now, it was really awful, that part of her life. In hindsight, it felt like we were always battling the school and the administration, trying to get what we thought was her best interests. It was really hard. Every IEP meeting was really hard."

In addition to trying to acquire services during school, there is the difficulty of finding services when school is not in session, including holidays, waivers days, breaks, and even after school. While some parents are able to have "extended school year" services (ESY) and after school services included in the children's IEP, others have to fend for themselves. Fran said she put her son in a non-profit disability program after school that charged her $500 a month. "And then they called me to pick him up last Friday because they're like, 'Well he has behaviors and you need to pick him up.' I'm like, excuse me, you're not trained to deal with behaviors?" Carol, whose son previously had after school and intercession one to one services, used to be able to send her son to that same disability program during school breaks. According to Carol, after he lost his one to one service provider, the disability program was not keen to have her son attend. "And then just now they're like, 'Oh, we're full.'" The result is that parents must find care for their children during these periods on their own which can be costly. Dana explained that there is an extra cost to hiring someone who can handle children with autism. “So that’s minimally another $10-$20 an hour to hire that babysitter, as opposed to the babysitter who has no experience, no idea.”

Trust (Stressor)

The issue of trust was a common theme throughout the interviews. Trust has been defined in various ways. Kramer defined trust as “a state of perceived vulnerability or risk that is derived from individuals’ uncertainty regarding the motives, intentions, and prospective actions of others on whom they depend” (1999:571). According to Robinson, trust consists of “one’s expectations, assumptions, or beliefs about the likelihood that another’s future actions will be beneficial, favorable, or at least not detrimental to one’s interests” (1996:576).

Rather than viewing trust as solely a psychological concept, Lewis and Weigert wrote that “the primary function of trust is sociological rather than psychological, since individuals would have no occasion or need to trust apart from social relationships” and that trust is based on “distinct cognitive, emotional, and behavioral dimensions which are merged into a unitary social experience” (1985:969). The cognitive component helps us to “discriminate among persons and institutions that are trustworthy, distrusted, and unknown (Lewis and Weigert 1985:970). The emotional component “creates a social situation in which intense emotional investments may be made” (Lewis and Weigert 1985:971). Finally, the behavioral component is the “undertaking of a risky course of action on the confident expectation that all persons involved in the action will act competently and dutifully” (Lewis and Weigert 1985:971). As Luhman wrote, “trust, in the broadest sense of confidence in one’s expectations, is a basic fact of social life” (1980:4).

Barber stated that trust has two meanings, “each of which is important for the understanding of social relationships and social systems” (1983:14). The first meaning involves “the expectation of technically competent role performance” where the competent role performance consists of “expert knowledge, technical facility, or everyday routine performance” (Barber 1983:14). The second meaning involves “the expectations of fiduciary obligation and responsibility,” or “the expectation that some others in our social relationships have moral obligations and responsibility to demonstrate a special concern for other’s interests above our own” (Barber 1983:14).

The mothers who were interviewed brought up the issue of trust when discussing the care of their children. Carol talked about the need to have people she can trust to watch her son because it is “actually practically impossible” to find someone to care for him when she has to attend an event. Janice also pointed out that there is a need for families to have an “autism sitter hotline” or somewhere a parent can drop their child off and trust that it’s a “totally safe place.” Although she feels more at ease when her son is with his skills trainer at school, she still feels the “vulnerability” and never feels like “it’s totally safe.”

The mothers also described their issue of trust with the schools. Tracy talked about trusting the school “to be the experts in their field” and “to do what they should do for your child” but discovering later that both assumptions were not true. As a result, she feels like she’s “fighting the system.” Rhonda said although she would like the DOE to provide a more streamlined program for autism or a comprehensive manual, she doesn’t trust them to implement it. “I wish we could trust the DOE to do something and to provide something like that.” Lois explained that her lack of trust of the DOE has led her to advocate for her child “at all times.” She does regular school observations and has monthly meetings with the school in order to ensure that they are following through with the IEP services. Emma, Sally, and Vivian talked about how their lack of trust with the DOE led them to decide to place their children in private schools. Emma said if she placed her son in the public school, she risked him regressing. She did not trust the school's speech and psychological assessments and did not believe they were capable of teaching her son appropriately. "He just wouldn't have grown."

April, Barbara, Fran, Gina, and Pamela talked about the need to get an advocate to help them navigate the DOE because they could not trust the school to do the right thing for their children's needs. Gina described how even though her son was diagnosed with autism, her son's school did not change his eligibility to autism which kept him from being eligible for more services. She finally decided to hire an advocate to help her because she did not trust the school's assessment of her son. "And when I went for those meetings, you know like his report card, everything was all way below. I'm like, something's wrong. It cannot be just fine motor skills and language."

The difficulty with fully trusting the principles of conventional medicine has led April, Barbara, Emma, Fran, Gina, Ivy, Janice, Lois, Pamela, Quinn, Rhonda, Sally, Tracy, and Vivian to seek the advice of alternative physicians. April, whose son's pediatrician did not recognize that her son had autism, has taken her son to two MAPS doctors for alternative biomedical treatments. She described how, before she had children, she witnessed a friend's autistic child bang his head on the walls and throw terrible tantrums. "I was like, I can't watch it, this kid's like banging his head on the wall, and he's like on the ground and trying to hurt himself. It was really hard to watch." Several years later when her own son was four years old, she saw her friend and her son at a store. The friend's son walked up to her and said hello. Her shock at the improvement in the boy's behavior led her to investigate everything her friend did to help her son, which was the MAPS protocol. It also led her to find another pediatrician for her children.

Quinn described how she lost her trust of the conventional medical establishment. She and her family were living in New Jersey when her daughter started regressing after her first birthday. She stopped walking, she lost some eye contact, and she would have diarrhea "up to the top of her neck."

> You know, I'd go to the pediatrician, what is this, what is this? As I was getting more vaccinations, not really putting it together. Then I met some…parents and we kind of found a Dallas Buyers Club of autism. You know like, 'Here's some doctors who can help.' And I couldn't wrap my head around it because I was like, what? It freaked me out that it could be an environmental factor that you're getting at the doctor's office. But it makes sense. Like she had a genetic susceptibility, she still does. And then New Jersey has the most vaccines on the schedule because they were able…to get 2 flu shots on the schedule for the year because our governor used to work at Goldman Sachs and he's kind of in bed with all the pharmaceuticals. So it's like, highest rate of autism in the country – this was at the time – it's where all the pharmaceuticals are based and they had the most aggressive schedule. Okay, that's not really a coincidence.

For Janice, who also believes vaccines have injured her child, her loss of trust in the conventional medical community has made her question the way society works. As she said, "I think…because of the whole vaccine and autism component, it has made me more jaded about power structures and politics and corporate involvement with our country as a whole."

Karen talked about her experience with military physicians that has led to her difficulty with fully trusting their advice. She explained that, "From the military standpoint, it's hard getting that specialized care because a lot of them, especially if they're active duty, it's not their specialty." She talked about how it's obvious to her that her son's developmental pediatrician is still in the process of learning about his specialty. "I've had doctors come and I'm telling them things and they're like opening their book and looking and I'm like, aren't you supposed to know this already?" She said she now does her own research rather than simply listening to the doctor:

> You know before we would just go to the doctor and be like, okay let's just do what the doctor said…But now I kind of get an opinion…So I'll still take into consideration with what they're suggesting, but I do the research and I form my own opinion based off of what I find.

Holly and Mary question the validity of alternative treatments. This has led her to question the message of the TACA support group. She explained that in her opinion, "…some of the topics that they're talking about are a little too extreme." The example she gave as being extreme was the recommendation of the use of the hyperbaric oxygen chamber. "I was like, this is a little too far out for me…Some of the other things they were talking about I agree with, but some of these other things were – some of the ideas were just a little too way off for me." Mary said that she's "very skeptical of any kind of treatment that isn't a generally accepted mainstream course of treatment."

Safety (Stressor)

The issue of safety was also a common theme throughout the interviews of mothers of children with autism. According to Maslow's Hierarchy of Basic Needs, "…the basic human needs are organized into a hierarchy of relative prepotency" (Maslow 1943:375). Maslow's hierarchy starts with physiological needs (e.g., hunger) at the bottom, followed by safety needs (e.g., free from harm and danger), love needs (i.e., love, affection, and belonging), esteem needs (i.e., respect and esteem for themselves and for others), the need for self-actualization (i.e., self-fulfillment), and the need for self-transcendence (i.e., a cause beyond the self) (Kolto-Rivera 2006; Maslow 1943). In other words, if the physiological needs of an individual are met, the next tier or safety needs takes precedence. According to Maslow:

> …the average child and, less obviously, the average adult in our society generally prefers a safe, orderly, predictable, lawful, organized world, which he can count on and in which unexpected, unmanageable, chaotic, or other dangerous things do not happen, and in which, in any case, he has powerful parents or protectors who shield him from harm
>
> (Maslow 1970:41).

Janice and Carol discussed their concerns about keeping their sons safe from sexual predators. Carol said that her "greatest secret concern" and fear is that her son will be sexually abused in the public restroom or on the Handi-Van (the city's paratransit for people with disabilities). Her need to keep him safe led her to continue to take him into the women's restrooms until he was in high school despite getting comments from other patrons. Janice talked about the problem of prosecuting abusers of children with autism. She has been told that children with limited language cannot manage being cross-examined so sexual abusers of children with autism tend to remain free. Rhonda said her concern is her son being abused at school but not being aware of it because he cannot tell her. She reasons that she can keep her son safe from abuse by being "way nicer to teachers than anyone else" and by going out of her way to please them "no matter what."

Lois said her concern is keeping her daughter safe from abusers after she and the father are gone because there are no other family members to look after her. In addition to physical abuse, she is concerned that her daughter will be vulnerable to those who will financially take advantage of her. Natalie worried that if her son does not want to care for her daughter in the future that she may end up as a ward of the state. In that case, she will not be able to ensure her daughter's safety from those who will "take advantage of her."

Like Lois and Natalie, April, Carol, Holly, Janice, Karen, Quinn, Rhonda, and Vivian worried about the care and safety of their children after the parents are gone. Vivian said she's concerned about his future safety because he currently can't be left alone. "So you have to be with him all the time." For the children who are currently able to care for themselves somewhat, their mothers still have concerns that they will be able to be safe in the future. Pamela said she worries that her daughter's lack of common sense may affect her ability to be safe. "Just trusting that she's not going to seriously burn down the house or get burned taking something out of the oven…" Ivy said she worries that her son will not be able to take care of his health. "I think that's going to be really difficult…Will he ever be able to be aware of what he needs?"

Eloping or running away is a great safety concern for parents of children with autism. Fran's son was four when he ran out of the house then "ran over the golf course and disappeared." He was found by golfers on the course who admonished her for not properly watching him, "You need to watch your kid." He eloped again at an after school program and was not found until 9:00 in the evening nearly two miles away. He also escaped through a hole in the fence while she met with a teacher at his elementary school.

Holly's son wandered away from the bus stop one morning while he was waiting with his grandparents for the school bus to arrive. He had walked along a main road and crossed the street to a bridge. "We always need to know where he is." When her son was younger, Ivy's son used to also wander off. She said, "I lost him a couple of times."

Although Fran, Holly, and Ivy's children were unharmed by their elopements, Karen's son was not so lucky. She said, "Initially when we went to [the elementary school], we had so many problems with elopement…They lost him one time, he fell down, and got a concussion…" The school placed the blame on the child for the incident and told her, "'Well, you know if he would have stayed with the group…'" Keeping their children safe from harm, especially after the parents are no longer there to care for them is, as Carol said, “always hanging over your head.”

Social support (Mediator)

All the mothers reported having some form of social support during their experience with their children’s autism. Fifteen of the mothers described their social support network as including parent support groups or other parents of children with autism (or other disabilities). Not surprisingly, since the majority of the respondents were acquired from the local chapter of TACA, TACA was mentioned specifically by seven of the mothers (April, Barbara, Carol, Fran, Gina, Janice, Karen). Barbara said that TACA has been the “single best support” that she has had. Gina said when her son was diagnosed with autism, she was in denial until she joined TACA and learned that she can be proactive. “That’s when I started being more positive…He can get treated so that’s what I did. So I was moving forward now.”

The mothers talked about the importance of networking with other parents with autism. Carol said connecting with other parents whose children are similar to her son and learning about what they do to help their children has been a great support to her. Lois and Tracy said talking with other parents has helped them to learn how to navigate the school system, especially, according to Tracy, “talking to people that have fought or are fighting the same battle as you are for your child.” Quinn concurred that other parents and the support groups have been the best social support “because no one’s going to fight for your kid more than a parent.” She said she has learned the most from the “village.” For Karen, being with others who understand what she is going through is helpful beyond simply what she can learn from them:

> Not even getting information, but just being able to be with other parents who have the same struggles. And we can go out together and if it’s too chaotic they understand, ‘Hey, let’s leave.’ Instead of, you know, ‘It’s fine. You should stay.’

> That kind of thing. It's kind of like a little weight lifted off your shoulder. We can go out with another parent and they understand when your child is having a meltdown in the Lego Store, that you know, we got to leave.

Nine mothers (April, Dana, Gina, Janice, Natalie, Olivia, Pamela, Quinn, Tracy) described how their husbands have been supportive. They talked about how important it is to be able to discuss their concerns with their spouses. Gina said that she and her husband work as a team for the family, "from bringing them to school, from bringing them to their practices…it's all us." April, Tracy, Pamela, and Janice talked about how important it is to have a supportive spouse when doing the biomedical treatments. Tracy stressed that being able to discuss the treatments with her husband has been a great help because she doesn't feel that she's in it alone. Janice also talked about how she and her husband work collaboratively on all aspects of their son's life.

Ten mothers (April, Carol, Dana, Gina, Holly, Ivy, Lois, Olivia, Quinn, Rhonda) talked about how other members of their families have been supportive. April, Dana, And Gina described how their own mothers have been supportive. Dana talked about how her mother is accepting of her children. "She's much more open to difference in a lot of ways and has really always tried to be a person who's accepting in general, so it's not such a stretch for her to be like, 'Well, I accept my grandchildren because I'm different, lots of people are different.'" April said, "I'm very close with my mom." She explained how her mother encourages her to go to conferences and to learn about autism treatments. "I don't think I can do what I do if I didn't have that kind of support and understanding."

Carol, Lois, Ivy, Quinn, and Olivia described how their in-laws have been helpful with childcare. Carol spoke of how her mother-in-law has always been the most supportive of all the family members in terms of helping to care for her son. "She's the only one if I had to go somewhere I would trust and feel that if I left him in her care, he's good." Quinn said her husband's parents have been "wonderful" about being a phone call away when they need a sitter.

Fran and Sally said their church has been a big support in their lives. For Fran, going to church is her "only respite" because neither she nor her husband has family in Hawaii. "I have to come to church an hour and a half to talk to God and say, give me superhuman powers." Sally said the support she gets from her church community is important because "they're just people that are really kind and compassionate and so I never feel like I'm judged by them for anything that my kids do." As Hogan said, "Church is often not only a place of worship and community, but somewhere that families pray for strength to deal with the special challenges they face, pray together with their church community for the well-being of their disabled child, and participate in one of the few community groups that tries to welcome all persons regardless of their behaviors or disabilities" (2012:56).

Rhonda described how her daughter is very helpful with her son. Although her daughter is younger than her son, she behaves like a "little-big sister" and looks out for her brother. Rhonda said, "I honestly think siblings of children with autism are amazing. Like every one I've ever met, I'm just like, what the heck! You guys are like angels."

Learning about autism (Mediator)

All of the mothers discussed the importance of doing their own research and learning about autism. The mothers gathered their information from the internet, books, conferences and workshops, support group meetings, professionals, advocates, and other parents. Ten mothers commented that researching and learning about autism has had positive outcomes. Fran said that doing her own research has helped her find different learning programs and therapies for her son.

"Anytime I have free time, which isn't much, I'm always on my computer researching." April said she enjoys reading about new research and learning about new therapies at conferences. If what she learns is going to help her son, she said, "it's something I can look forward to." Vivian said, "The experience is always positive when you learn something from it."

All of the mothers described how learning about all the aspects of autism, from treatments and therapies to special education law, has helped them to decide and to pursue what their children need. Sally said she learned a great deal for her son, especially in the early years after his diagnosis, by "doing a lot of research and talking to people and service providers and attending support group meetings and getting all the education that I could." Fran and Gina said they research in order to reinforce their requests for services to the DOE. Gina explained that she feels the school personnel are not experts in autism. "That's why I do my research to back up what I request for or what kind of service I request for." She also said that doing research helps her to see different perspectives. "It's a learning process. I know sometimes I hit a brick wall, but I always have faith that maybe that's a reason why I'm hitting a brick wall is because I had to do more research and find another way."

Barbara's research helped her gain the support of her son's pediatrician with regard to the alternative biomedical treatments prescribed by her son's MAPS physician. The pediatrician did not agree with the treatments and expressed her concerns. As a result, Barbara decided to research the issue by seeking the opinions of other physicians, speaking to parents who were dealing with the same health issues, and reading scientific journal articles. She returned to the pediatrician after a year had passed.

> Then we came back – she saw the difference. And then I started sharing with her and then I actually started giving her research papers and I think she kind of came

> around. I wouldn't say she's 100% on board, but she's supportive because she knows that I'm not blindly just doing whatever I want.

Quinn, Pamela, Sally, Tracy, Vivian, Carol, April, Lois, Janice, and Olivia talked about how they are able to get information from other parents. Janice described the autism community as being one of "shared information." She said, "I think the most helpful thing is being collaborative with other families." As Tracy said, "talking to people that have fought or are fighting the same battle as you are for your child" is extremely helpful because they all want the same things for their children.

Emotional reactions to caring for a child with autism (Outcome)

Having a child with autism evokes a variety of emotions. Nearly all of the mothers interviewed (twenty out of twenty-one) said that they experienced stress, depression, or anxiety as a result of caring for their children with autism. By far, 'stress' was the word used most often (fifteen mothers) to describe how they feel. Janice, Lois, Sally, Tracy, and Barbara spoke of feeling stressed due to having to determine which treatment options are best for their children, as well following through with them. Sally said:

> Yeah, it's been a big responsibility. I've had to make a lot of these decisions on my own and do my own research. And I'll bounce the ideas off of my husband, but in general, especially back then, he was so busy with his career and getting his business off the ground that he just didn't have the time or the energy to put towards this. So it was hard.

The high cost of autism treatments is also a source of stress for the mothers (Barbara, Dana, Natalie, Tracy, Quinn). Dana explained, "…probably all parenting is financially stressful, but I do think that there's an element there that's very intense." The mothers experienced stress as a result of dealing with the DOE (Carol, Fran, Gina, Tracy). Tracy explained:

> That's the most stressful part of overall. It's draining. It's exhausting. It's nerve-racking. It's frustrating. It feels like it's yourself, your husband against the school. It doesn't feel, for the most part, it doesn't feel you can let your guard

> down because you don’t know what they’re thinking. You don’t know…So it’s very stressful.

Holly, Fran, Lois, Natalie, Sally, and Ivy said that the autism has led to stress on family relationships. According to Lois, the stress of caring for a child with autism was a factor in the dissolution of her marriage. “Having a child with a disability where you have no idea what you can do or what needs to be done probably contributed a great deal to my divorce.” Fran talked about how she feels the stress of feeling like she’s doing it all. She commented on the level of her husband’s assistance with the needs of the family. “Because he’s not a helper. So there’s that stress. The working mom of 2 jobs managing all these 4 kids, special needs, and all that. I do 200 percent he does 10.”

Ten of the mothers said they experienced some degree of depression. April, who also experienced post-partum depression, is currently on medication for her symptoms:

> I didn’t start getting help until, 4 years ago, when that was my low point because I was angry all the time because I was frustrated, upset…I felt like I had too much to do and not enough time in the day to do it. And then I’m like, ’I don’t have time to sleep. I have to take [her son] to do this, take him to therapy, do this, do that. We don’t make enough money to do that. It was just very overwhelming, frustrating. A lot of times I would forget to eat. I would only eat only once a day. I’d finally be at dinner and I would be like, oh my god. I never took care of myself.

Fran said she feels overwhelmed after dealing with her son’s autism for the last five years. “Actually in the last 3 months I’ve been getting more depressed. Just worn out, man. Just worn out.” Mary talked about how the autism diagnosis was such a “life changing” event that overwhelmed her to the point that she required medication for her depression. Rhonda, who has experienced depression throughout her life, said her son’s diagnosis has exacerbated her symptoms. “There’s definitely times when it’s really bad for me.”

Seven mothers (Natalie, Tracy, Carol, Sally, Vivian, Janice, Gina) said they experience anxiety as a result of their children's diagnoses. Carol said that, "There's always anxiety…" Her anxiety, she said, is due to her constant worrying about her son's future when she is gone because she will not be able to control how he taken care of. She is concerned that her husband (from whom she is getting a divorce) will not care for their son in a manner that she thinks is best. "Like he told me, 'I can take care of him but it isn't going to be the way you want it to be." Tracy said that since her son's diagnosis, she feels "very anxious all the time." "Obviously, you don't have a good night's sleep because you are always thinking of tomorrow and you're always thinking of the future and I don't think I have me time because I'm always worrying about him." Gina also talked about how constantly thinking and worrying about her son causes anxiety. "It doesn't show sometimes, but I feel it every single day. My mind is racing. Even when I'm [at work], I'm thinking of what I have to do. So my mind is constantly going."

Nine mothers (April, Barbara, Dana, Fran, Ivy, Mary, Olivia, Pamela, Rhonda) said that caring for their children has led to frustration. April, Barbara, Olivia, Pamela, and Rhonda said that trying to get services through the DOE leads to frustration. Rhonda explained that she had to move her son to another school in order to get the services she felt he needed. She said, "I would say, sadly, I think it matters what district you're in…Just the way they assume you're not going to care, or…to pull things over on you." Rhonda said it's frustrating because parents have to figure out what their children need and how to get it. "It's not easy. You're basically stranded on your own…So it's kind of like we have to figure it out on your own and search and discover things on your own." April agreed that the parent has to research and fight in order to get services for the child from the school. "Now, if you're not educated or if you don't know the law…then you think whatever you're getting, that's what your kid deserves to get. It's unfortunate. The parent has to do all the work." Olivia was frustrated with how the school was educating her child. "Because he was so used to, 'If I can figure out what they want, and I get it all done, I get an iPad to play on.' And so he was never really learning. He was just trying to get the iPad. So that's been really challenging to break him of that, you know…"

Carol said she had feelings of guilt because she hasn't tried any of the alternative biomedical interventions, such as the gluten free/casein free diet. She said, "And I always wonder whether I'm doing enough because I haven't delved into bloodwork and labs and the other intense things…" She said she feels like she didn't do enough. But, she said, "That's all I could do."

April and Quinn said that they have experienced feelings of anger. April said that she felt angry because she was overwhelmed by all of her responsibilities. She said she was "angry at everything." Quinn talked about her anger with the lack of investigation into the causes of autism and the "whitewashing it." "It's so emotional to see them trying to mainstream it and normalize it…You know, kids are getting really sick and it doesn't really bother you unless it's right in front of your face." She talked about the "mixed emotions" she has for the new autistic character on Sesame Street named Julia:

> It's like, okay great. Yes, people might then be more accepting. But she's shy and quirky. It's like, okay, where's the kid in the helmet with the diapers? More and more kids are more and more severe and they're like [whispering], 'We're not going to talk about it.

Quinn also said her anger was the result of being overwhelmed with all of her responsibilities. "You know how the mom does more a little bit? It's like I didn't have enough energy to do everything I was trying to do. I was so exhausted. So it really took its toll on me."

Although most of the emotions discussed by the mothers were as a result of the challenges they face in caring for their children with autism, positive emotions were also expressed. All of the mothers talked about their children's accomplishments with a note of pride. Olivia said:

> I just enjoy seeing his accomplishments because it's so hard fought for him...My husband and I were like, 'Hey, he's using pronouns. He's using them correctly.' Because that was always a toughie for him. We're like, 'Wow that's just really awesome to see him use it in his speech.' So everything he does it's hard fought. It's just so rewarding to see that.

Carol also talked about how rewarding it is, "…when they are successful at learning a new thing because it takes so long for them to learn, and it's so much work. You know, simple things that parents take for granted, it takes our kids a long time to learn. I mean the greatest thing is when they have success in anything, a task."

Rhonda and Janice talked about how caring for their children has made them learn humility. Rhonda said of her son, "He humbles me." Janice talked about how dealing with autism in the family affected her:

> It definitely has humbled me in terms of my perspective of life in general. You know you used to judge people based on what they have achieved or not achieved, and so when you have a child who has…you celebrate the smallest of achievements, and you love that person so deeply and you respect them so much, it shifts your perspective of all people and their abilities to achieve

All of the mothers expressed how much they care for their children and how they are determined to help their children improve. Lois explained how her daughter brings her "a lot of joy" because her daughter is happy and has a "pure heart." "And so even though she has this disability and it comes with certain things, I think her dad and I just love her dearly for the person she is." Dana talked about how much she enjoys being with her sons. "They are two of my favorite people on the planet. I have so much fun with them every day. They're just really funny and very warm and just a blast."

The mothers talked about their determination and the lengths they go through to address their children's needs. Janice explained how she did the legwork to volunteer work for her son at his high school and in the community so that he can be engaged. "I've had to step in," she said. "I feel like it's always the parent's role to keep quality control, unfortunately, unless you get lucky and you have a good teacher…" She also related how she has flown her son to the mainland on multiple occasions so he could be seen by medical specialists who are not available in Hawaii. Because her son has been diagnosed with colitis, he is on a very specialized diet. "It's time consuming and expensive. It's a commitment."

Natalie, whose daughter was born with a severe medical condition, has also flown her daughter to the mainland on multiple occasions to see specialists because there is no one here in Hawaii who is knowledgeable. In addition to the stress of having to makes repeated trips to the mainland, Natalie said, "All our finances are just tied up. With everything that we do for her, it's a big financial burden."

Rhonda and Lois said they moved residences in order to get their children into what they hoped were better schools with more appropriate services. Lois talked about the need for parents to put in the extra effort in order to ensure their children's needs are met in the school system. "You have to be involved. You have to be willing to speak up. And you also have to find an environment where they're going to listen and work with you." When she found out her daughter's previous school was violating IDEA, she sought legal help. "We didn't want to sue them, but what are you going to do when you're backed up into a corner and they're doing things they're not supposed to do?"

Lack of mother's self-care (Outcome)

Throughout the interviews, the mothers stated that they often put their children's needs ahead of their own, sometimes to the point of putting their own health at risk. The mothers consistently spoke of the amount of time and energy they devote to the care of their children. This interferes with the time and energy for their self-care. They talked about not getting adequate sleep, not eating healthy foods, not exercising, not seeing the doctor, and not following medical advice.

Quinn described how she failed to take her thyroid medication after her daughter's diagnosis because her attention was concentrated on the other members of her family. She admitted that she let her health go. "I did not put on my oxygen mask first. You know how they say that? I was focused on everyone else and I was so tired." Similarly, Dana reported that she has "less time to go off and so self-care." Her lack of rest and self-care resulted in her having pneumonia two years in a row. Rhonda and Barbara reported that they get sick more often. Rhonda said she's constantly tired and says she never feels "a hundred percent."

April described her experience when her son was more difficult to handle and no other family member was willing to care for him. During this time, self-care was not a priority:

> My husband couldn't even help because he didn't know what [her son] needed or what he wanted…So I couldn't even get an hour away. Like I had to keep him in the bathroom with me if I had to take a shower or something so he doesn't go and do something or put something in his mouth or whatever. There was literally nothing I could do by myself for years.

In addition, most of the mothers talked about the adverse effects on their emotional health. Nineteen of the mothers talked about how they experienced stress, depression, anxiety, anger, or worry, but only four of these mothers (April, Rhonda, Quinn, Tracy) reported that they sought professional help. Emma said she just deals with the emotional issues on her own. "I remember my doctor telling me, 'Do you think you need to talk to somebody,' but I never did. It was just one of those things. I think you got to work through it on your own time." However, it may be more difficult for other to simply "work through it." Mary said that although she battles depression, she doesn't do the things that would help, such as activities that are "emotionally nourishing" for her.

Some of the mothers discussed how these emotional effects have led to physical problems. Lois, who suffers from eczema which is at times severe, said the stress "really took a toll" on her physically. Likewise, Natalie said her psoriasis and other physical ailments are caused by the stress in her life. Sally, who had a frozen shoulder that required surgery, described it as being "emotional as well as physical." Janice, who has been diagnosed with chronic fatigue syndrome and hypothyroidism, said the "ongoing stress of having a child on the spectrum" has led to her health problems, especially because she does not take the time for self-care.

Not all of the mothers reported adverse effects in their physical or mental health after their children's diagnoses. Two mothers, Olivia and Vivian, reported becoming physically healthier after their children's diagnoses. Both said they watch what they eat and have lost weight as a result. Pamela said she has not noticed any changes to her physical health, but she also said her family has gotten healthier because they are now "mindful" of what they eat. Olivia said she and her family exercise together by going for daily walks. Emotionally, Olivia said she feels positive about her situation. "I just have a very positive attitude about everything we're doing…While every parent thinks you can do more, should do more, but I mean I’m doing all that I can and feel good about what we’re doing...” Pamela was the only mother who said she has not noticed any changes to her emotional health since her daughter’s diagnosis.

Overarching Theme: Unclear path of autism (Main Stressor)

The overarching theme of the interviews was the unclear path of autism, which also can be classified as a main stressor. Every mother who was interviewed expressed uncertainty regarding the right course of action after their child’s diagnosis. For the majority of the mothers (16 of 21), the path to the autism diagnosis was also not straightforward, where even getting the diagnosis itself was difficult. Beyond the diagnosis, the mothers found they had to research the treatments for autism on their own by going on the internet, reading books or articles, speaking to various professionals, or meeting other parents. As Dana said, “I wish there was more information for parents and more one-stop shopping kind of information. And it wasn’t so much like you lucked-out and found the one person who could help you.”

The mothers also expressed that the educational experience was filled with frustration and they were faced with making difficult decisions as far as which school their children should attend, whether they should seek legal advice, or if they should simply homeschool their children. Medically, the mothers were forced to make decisions about giving their children psychotropic medications, putting their children on the gluten free and casein free diet, following an alternate vaccine schedule, or changing physicians.

The resources and treatments for autism are overly fragmented and there is no clear consensus as to what is the right path. As a result, mothers of children with autism have unique and difficult challenges that they must overcome in order to make the best choices for their children.

Chapter 5
Discussion

Introduction

The goals of this study were to describe the maternal experience of caring for children with autism and to identify how caring for a child with autism impacts the mother's life. The aims of this study were to identify the challenges and positive aspects of caring for a child with autism, as well as to identify the financial, emotional, and physical impacts. The mother's use of social support and coping to mediate the stress of caregiving and the meanings they assigned to their caregiving experience were also investigated. In order to address the study aims, qualitative interviews of twenty-one mothers of children with autism who lived on the island of Oahu were conducted. Using the Stress Process Theory as a guide, eight major themes emerged from the analysis of the interview data: concern for the child's future independence and care, finding the right services for autism, trust, safety, social support, learning about autism, emotional reactions to caring for a child with autism, lack of mother's self-care, and the unclear path of autism.

The interviews showed that caring for children with autism is a highly stressful activity that can lead to adverse emotional and physical effects in spite of the presence of social support and coping resources. The interviews also revealed that the burden of caring for these children is shouldered primarily by the mothers and that they approach this responsibility with an intense determination.

This study contributes to caregiving research by providing valuable insights into the impact of providing care and what factors contribute or alleviate the burdens of caregiving, as well as insights into the caregivers themselves. It is a lens into the complicated world of autism and the particular difficulties their caregivers must be able to navigate in order to provide sufficient care without becoming overburdened. The information gained from the results of this study helps to identify areas for future caregiving research. In this chapter, the findings of the study are discussed, followed by the implications of the findings, the limitations of the study, and the suggestions for future research.

Findings

The interviews revealed that caring for children with autism can be all-consuming, causing both adverse emotional and physical effects on their caregiver's health and well-being despite having social supports and coping in place. Although all of the mothers had some form of social support and coping resources, the stress of caring for their children with autism permeated throughout their lives. This was especially true for mothers of children who had severe health or behavioral issues. These mothers, in particular, were highly concerned with their children's future ability to be independent, healthy, and safe. All of the mothers, regardless of the level of attention their children require, expressed how deeply they care about their children and how they accept and confront any burdens that come their way.

The analysis of the interviews supports the findings of the literature on caregiving children with autism. The mothers interviewed for this study experienced stress at every point in the caring of their children, from the diagnosis of the disability (Hogan 2012; Moh and Magiati 2012) to dealing with the school system (Burke and Hodapp 2014; Cho and Gannotti 2005; Fish 2006; Fish 2008; Lo 2008; Reiman et al. 2010; Salas 2004; Sauer 2007) to the financial hardships from increased expenses and reduced work hours (Delaney and Smith 2012; Hogan 2012; Parish et al. 2004; Wakabayashi and Donato 2006 Delaney and Smith 2012; Hogan 2012; Parish et al. 2004; Wakabayashi and Donato 2006).

A major finding of this study was that the burden of caring for children with autism largely fell on the mothers. This included not only the daily caregiving activities such as bathing and feeding, but also included most of the medical and educational decision making. The mothers in this study were responsible for almost every aspect of care for their children and as a result constantly thought about their children's needs. This division of labor was true whether or not the mothers were employed outside the home. Within the family unit, the parent who ultimately quit their job or decreased their work hours in order to care for the child with autism full-time was the mother rather than the father. This finding agrees with previous research that found mothers of children with disabilities, as well as mothers of children with no disabilities, are more likely to leave the paid labor force or to reduce their work hours than the fathers (Hogan 2012; Parish et al. 2004). The mothers interviewed for this study were also highly educated, which supports a previous finding that mothers with more education were more likely to be full-time caregivers (Leiter et al. 2004). It was surmised that mothers with more education may feel they have more employment options that allow them to leave the workplace temporarily (Leiter et al. 2004). The stay-at-home mothers in this study, however, talked about their husbands' earnings being enough so that they could afford to stay out of the workforce for the time being.

The intensity of caring described by the mothers interviewed for this study was another finding. The mothers talked about having to advocate for their children and to "fight" for their children's right to an education and appropriate medical care. The mothers are what Sousa (2011) calls "warrior-heroes," or mothers of children with disabilities, including autism, who go to battle for their children in order to get the services and treatments they need. Like the self-sacrifice that is expected of "intensive mothering" (Hays 1996), mother-heroes also place their children's needs ahead of their own. The mothers in this study performed the warrior-hero role by attending conferences, flying their children to see doctors outside the state, hiring advocates or attorneys to help them navigate the educational system, studying medical journal articles, placing their children on special diets and supplements, and being their children's educators. The focus of the warrior-hero mother is on curing the child of the disability, or at least to alleviate the symptoms to the greatest degree (Sousa 2011).

Although the majority of the mothers were acquired through the parent support group, Talk About Curing Autism, whose very name implies that their primary goal is to cure a person of autism, not all of the mothers interviewed adhere to the belief that autism can be "cured." While just a few of the mothers spoke of curing their children of autism, all of the mothers spoke of independence as the marker of success. They focus their attention on getting their children as self-sufficient as possible. In this sense, acquiring the skills for independent living and achieving a successful and independent life (i.e., a well-paying job, marriage, and children) is equal to a cure.

To achieve this, these "warrior-hero" mothers spend their "free time" researching on the internet for treatments or therapies that may possibly be the "silver bullet" that would make their children more typically developing. Some of the mothers said they forego sleep to make time for internet research. These mothers arm themselves with information when taking their children to the doctor's appointments and will even second-guess the doctors. The mothers expressed how they did not have confidence in the local physicians and more than one mother commented that she felt she had to be her "own doctor." Those who could afford to flew their children out of state in order to have their children seen by specialists. Others had long distance phone consultations that were not covered by insurance. Some of the mothers applied a similar process for their children's behavior consultants and flew in consultants from out of state to see their children.

The consequence of the extensive amount of time and effort spent on the quest for the children's independence and the added financial strain from the extra expense of the various treatments was that the mothers were left emotionally exhausted and severely stressed. Nearly all of the mothers interviewed expressed that caring for their children has taken an emotional toll on them and many reported having health problems. This finding supports Pearlin's Stress Process Theory, where the stressors involved in caregiving can adversely affect the mental and physical health outcomes of caregivers. However, although all of the mothers reported that they have some form of social support or coping resources, the majority of the mothers still described themselves as being highly stressed, overwhelmed, and/or depressed.

The finding that women bear most of the burden of caregiving in the family supports the findings of caregiving research (Aronson 1992; England 2005; England and Folbre 1999; Glenn 2010; Grigoryeva 2014; Hogan 2012; Leiter et al. 2004; Mrazek 2013; Kostantareas and Homatidis 1992; O'Shaughnessy 2013; Parish et al. 2004; Ryan and Cole 2009; Walker, Powers, and Bisconti 2016). Glenn (2010) said that a woman's identity and reputation rests on her ability to fulfill her status obligation of caregiving, and that a woman is coerced into believing it is her duty to provide care to the point of sacrificing her own livelihood in order to do so. In addition, to be a successful caregiver, the care recipient (in this case, the child) must appropriately respond to the care provided. The women in this study discussed taking on the responsibility of caring for their children with autism as if it wasn't a matter of choice, but something they had to do as a duty to their children and families, even if it was at the detriment of their own health. Their primary concern was getting their children to be independent. Independence in the context of caring for children denotes success. Therefore, to be a successful mother of a child with or without autism, the child must grow up to be fully independent and anything less represents an inability to fulfill her status obligation. For the mothers of children who have autism, the unclear path to independence and uncertainty of its achievement make the responsibility an even heavier burden.

Implications

The focus of this study was on caregiving children with autism. However, the experiences of caregivers of children with other disabilities (Dabrowska and Pisula 2010; Pisula 2007) or adults with dementia (Badana, Marino and Haley 2017; Kim and Schulz 2008) are similar. Research has found that caregivers of chronic or long-term care recipients (children or adults who have mental or physical health issues) experience emotional stress, physical strain, and financial hardship (AARP and NAC 2015). The stress level of the caregiver is dependent on the degree of burden of care, which is naturally dependent on the level of severity of the condition (AARP and NAC 2015). Nevertheless, when comparing caregivers of children with autism versus other disabilities, the caregivers of children with autism have been found to have higher levels of stress (Dabrowski and Pisula 2010; Dunn et al. 2001; Pisula 2007) due to behavioral and communication problems associated with the disability.

Theoretical Implications

The findings of this study have theoretical implications of caregiving. While all of the mothers were negatively affected by the stress of caregiving their children, some mothers felt the burden more than others. All of the mothers had protective mediating resources in place, yet while some mothers experienced more anxiety and depression, others appeared to better manage the stressors. The differences of the personal qualities of caregivers may play an important role in how stressors affect them. Pearlin's (1989) theory speaks of "coping behavior" but does not take into account individual personality differences or "elements of coping that uniquely characterize individuals," such as a person's ability to be resilient. Hogan stated that "personal resilience" can be a buffer for families that helps to protect them from "more serious consequences of raising a child with a disability" (2012:94). Resilience has been defined as "an individual's capacity to cope with stressors and to resist the harmful effects of future negative events" (Bitsika, Sharpley, and Bell 2013:534) and as a trait that enables an individual "to thrive in the face of adversity" (Connor and Davidson 2003:76). The characteristics of people who are resilient include patience, sense of humor, self-efficacy, adaptability to change, optimism, faith, and the view of change or stress as a challenge or opportunity (Connor and Davidson 2003).

Although Stress Process theory incorporates self-esteem and mastery as mediators that help to alleviate the effects of stressors after they occur, it does not take into account how individual traits can moderate a person's appraisal of stressors. Its positive and protective influence is "prior to emotional and coping responses" rather than in response to stressful encounters (Fletcher and Sarkar 2011:13). Its protective influence is in place prior to the occurrence of the stressful event. It is possible that individual personality traits of the mothers influenced how they were affected by the stressors which resulted in the varied outcomes.

The findings of this study also imply that mastery increases for caregivers over time. Mastery is defined as "the extent to which people see themselves as being in control of the forces that importantly affect their lives" (Pearlin et al. 1981:340). It has been suggested that mastery is "susceptible to change in response to conditions in people's lives" (Skaff, Pearlin, and Mullan 1996:254). At the early stage of their caregiving careers, the mothers in the study appeared to be low in mastery. The mothers described their diagnosis experience as being very difficult and highly stressful and they used words such as “denial,” “shock,” and “overwhelming.” This period was marked with confusion as to the proper course of action to take where the mothers were left with many questions and few answers. Over time, as the mothers gained information about the disability and developed a care plan, their level of mastery appeared to increase. Although they still had feelings of extreme stress, they spoke of their lives with more confidence and appeared to have more control over their lives after the initial period of adjustment.

Another implication of this study is that a clear approach to caregiving can decrease the burden of caring, but an unclear approach can increase feelings of stress in a caregiver. All of the mothers in the study expressed confusion and a lack of confidence regarding the proper care of their children which negatively affected their emotional well-being. This lack of clarity decreased their sense of control and reduced their mastery. Without a clear path of caregiving, the caregivers are forced to make decisions without adequate information and without a good grasp of what to expect in the future. This makes it difficult for caregivers to successfully manage the burden of caregiving. In this study, the ambiguous nature of the disorder and the unclear caregiving path was an overarching theme that permeated the lives of the caregivers. This suggests that an uncertain care plan of the care recipient may be considered a primary stressor, or a stressor that is directly a result of the needs of the care recipient (Pearlin et al. 1990).

Practical Implications

The findings of this study also have several implications for caregiving policies, both for autism as well as for other conditions. For autism specifically, the interviews revealed a shortage of physicians with autism expertise, as well as a shortage of licensed BCBA’s. The medical community across the U.S. must broaden and intensify physician education on autism. Medical schools must include courses about autism and other disabilities in their curriculum and medical residents should have hands on experience with these patients. Medical students who wish to specialize in pediatrics should be required to undergo extensive training in disabilities. In particular, the interviews revealed that physicians should be taught how to recognize very young children on the autism spectrum. To increase the number of ABA professionals, more institutions of higher education should offer graduate programs geared toward the BCBA certification and these universities should encourage their students to pursue this field.

As the interviews showed, children with autism or other mental health issues are sometimes “runners” who wander off unsupervised and become lost in the community. Some of these children are also non-verbal or have behavior issues which can be extreme (e.g., vocalizing loudly, hitting others or self, etc.). Law enforcement and other first responders should be trained on how to deal with children with mental health issues, especially in cases where the children are mature-looking or near adulthood, in order to prevent the use of excessive force to subdue them. A mature-looking child who is easily agitated or who experiences extreme anxiety and has outbursts has the potential of being mistaken as a threat. Proper training may prevent the risk of such occurrences.

The children of the mothers who were interviewed were educated in every educational setting. Children with emotional or physical disabilities are not exclusively in special education programs; rather, they may be in general education classes in both public and private schools. Therefore, public and private schools for children of all ages and abilities need to better train their teachers and staff on disabilities in order to better serve these students. Inadequate disability training of the teachers and staff will only lead to frustration of both the schools and the families. In addition to training, having an open dialogue between the schools and families to address any issues may serve to lessen the need for any legal recourse. Disability training should also extend to institutions of higher education as more students with disabilities enroll in universities. In 2011, eleven percent of undergraduates reported having a disability, including a specific learning disability, a visual impairment, hard of hearing, deafness, a speech impairment, an orthopedic impairment, or a health impairment (IES-NCES 2015).

The mothers in the study expressed a great need for respite care by qualified individuals who are knowledgeable and sensitive about their children's individual needs. Government funding for respite care for caregivers, through the HCBS program for instance, should be increased so that more families will be able to receive this benefit. Caregivers need regular breaks from caregiving, especially when their care recipients are severely affected. These breaks may allow caregivers to focus on their own needs and in turn help to lessen the adverse effects of caregiving, such as depression.

Employers of caregivers need to be open to offering flexible schedules or telecommuting. These alternative work situations can help caregivers continue to be employed while providing care. Allowing employees to start at different times or to work from home on certain days can help caregivers attend to their family member's needs without losing their jobs and salaries. This is crucial when one considers the financial strain of caregiving. For instance, mothers of children of all disabilities have increased caregiving responsibilities, such as the coordination of medical and educational services and supports (Bruhn and Rebach 2014), which impact their employment and finances (Parish et al. 2004). By balancing the caregiver's work and caregiving duties, the overall stress of caregiving may be reduced.

The importance of social support has been well-documented as a stress buffer (Dunn et al. 2001; Pearlin et al 1981; Smith et al. 2012; Thoits 1995; Thoits 2011). Caregivers must overcome time constraints and caregiving responsibilities in order to have the opportunity to attend traditional support group meetings that may be held at distant locations or inconvenient times. An online support group is one way for caregivers to receive the support they need at their convenience (Clifford and Minnes 2013). Research has found that online support groups can be empowering (van Uden-Kraan et al. 2008) and that accessibility may be improved with multiple meetings that are held on different days and times throughout the week (Martin et al. 2017). Research has shown that while families acknowledge the value of support groups, they vary in their preferences in support group design (Jackson et al. 2018). More online support groups and forums may be created to reach families who require the flexibility that the internet offers.

Limitations of the Study Sample

The majority of the mothers in the sample were highly educated, married, and had high incomes. Mothers who have more resources may be more likely to seek out support from support groups and to research information on the internet. Seeking help and information will make them more likely to gain knowledge about the different treatment options. Their higher incomes mean that they are able to better afford the expensive therapies and treatments. Mothers who are not educated may not know where and how to seek the support they need. Those who have less income cannot afford the treatments and therapies for their children, including the insurance premiums and copayments. The mothers with less income are less likely to file due process against the schools for IDEA violations because they cannot afford the attorney and expert witness fees. Finally, all the mothers interviewed for this study resided on the island of Oahu, where most of the resources for autism are located. These mothers have much more access to the resources than the mothers on the neighbor islands in the state. Therefore, their place of residence may have influenced their interview responses. All of the limitations discussed limit the generalizability of the study. However, it is important to note that in spite of the mothers' increased access to services, as well as their relatively high socioeconomic status, they still experienced a great deal of stress.

Recommendations for Future Research

This study revealed a need for more research in the future in several areas. Only four of the mothers had children who were in high school; the majority of the mothers had children who were under the age of fourteen. The interviews showed that a mother's focus changes as the child ages. Whereas the emphasis for younger children is on "curing" the children or getting the children to be as "normal" as possible through behavioral or biomedical treatments, the emphasis for older children who are nearing adulthood and who are not independent is on their care (in the home or in community-based homes), job placement, and community involvement. The parents of children who are independent enough to attend higher education have concerns about their children's ability to manage college life and make friends. Future research studies may focus on each stage of development in order to get a deeper understanding of the issues the groups face. In addition, the pressure placed on the mothers by the "warrior-hero" identity increases the stress in their lives. Research should be conducted that looks into the relationship between the extent that a mother becomes the "warrior-hero" and the level of emotional and physical effects that she experiences at each stage in the child's development.

This study also revealed that families react differently to the diagnosis, where some families grow closer and others grow apart. More research needs to be done to discover what may impact the family dynamic, for instance the level of care required for the child, the socioeconomic background of the families, or the marital status of the parents. The study also showed that siblings can play a large role in the care of the child with autism. More research may be done on how siblings cope with having a brother or sister with autism, on the relationships between them, and how their gender or age affects the sibling dynamics.

Although the Stress Process theory does not take into account how resilience can moderate a person's appraisal of stressors, others have investigated the relationship between resilience and stress with respect to coping, or "the things that people do to avoid being harmed by lifestrains" (Pearlin and Schooler 1978:2). Bitsika et al. (2013) looked at the buffering effect of resilience on stress, anxiety, and depression for parents of children with autism and found that although these parents experienced severe anxiety and depression due to high levels of stress, even low levels of resilience successfully acted as a buffer. To measure resilience, the researchers administered the Connor-Davidson Resilience Scale (CD-RISC) (Connor and Davidson 2003). The self-rated resilience questionnaire includes 25 items such as "Able to adapt to change," "Tend to bounce back after illness or hardship," "Best effort no matter what," "Think of self as strong person," and "Can deal with whatever comes" (Connor and Davidson 2003:78).

In their study, Bitsika et al. compared the resilience of mothers and fathers and found that although both mothers and fathers scored similarly on the CD-RISC, mothers reported more anxiety and depression than fathers. However, because mothers are typically the primary caregiver of children than fathers, future research should compare the resilience among mothers, such as by mother's age, age of children, functioning level of the children, marital status, or socio-economic status.

Finally, the spirituality of the mother, coupled with a supportive spouse, was found to be a positive mediating influence for two of the mothers in this study. The mothers who stated that both these factors were important for them spoke more positively about their caregiving experience and also indicated that their health was not affected in an adverse way. The spirituality/supportive spouse factor may be researched more in the future in relation to caregiving children with autism and other disabilities, as well as caregiving in general.

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Appendix A

Caregiver Code:_______________

Date:_________________________

Child's Gender:_______________

Thank you for meeting with me today. This interview will take about an hour of your time. I appreciate your willingness to speak with me.

The questions I am going to ask you are related to your experiences caring for your child with autism. Your responses will be totally confidential and will have no impact on any of the services you receive. Your responses will help to increase our understanding of the caregiving experience of mothers of children with autism in Hawaii.

Overall Experiences of Caregiving a Child with Autism

I'm going to ask you a few questions about your general experience of taking care of (child's name).

1. Tell me about your experience when (child's name) was diagnosed?
2. What do you find most rewarding about caring for (child's name)?
3. What do you find challenging about caring for (child's name)?
4. Tell me about your hopes and concerns for (child's name)'s future.

Experiences in the Family

I'm going to ask you a few questions about your experiences of taking care of (child's name) within your family.

1. How has caring for (child's name) affected you and your family overall?
2. How has caring for (child's name) positively affected you and your family?
3. How has caring for (child's name) been challenging for you and your family?
4. What has been helpful for you and your family in the care of (child's name)?
5. What can be done to improve your family's experience of caring for (child's name)?

Experiences in the area of Medical/Psychological Needs

I'm going to ask you a few questions about your experiences of managing of (child's name) medical and psychological needs.

1. What has been your overall experience of managing (child's name)'s medical and psychological needs? Please describe (child's name)'s medical and psychological needs.
2. How has managing (child's name)'s medical and psychological needs positively affected you?
3. How has managing (child's name)'s medical and psychological needs been challenging for you?
4. What has been helpful for you in the management of (child's name)'s medical and psychological needs?
5. What can be done to improve your experience of managing (child's name)'s medical and psychological needs?

Experiences in the area of Education

I'm going to ask you a few questions about your experiences of managing of (child's name) education.

1. What has been your overall experience of managing (child's name)'s education? Please describe (child's name)'s curriculum (setting, type).
2. How has managing (child's name)'s education positively affected you?
3. How has managing (child's name)'s education been challenging for you?
4. What has been helpful for you and your family in managing (child's name)'s education?
5. What can be done to improve your experience of managing (child's name)'s education?

Physical, Emotional, and Financial Effects

I'm going to ask you a few questions about your health and finances.

1. What changes (if any) have there been to your physical health since (child's name)'s diagnosis? (example: illnesses)
2. What changes (if any) have there been to your emotional health since (child's name)'s diagnosis? (example: sadness, depression, anxiety)
3. What changes (if any) have there been to your financial situation and job status since (child's name)'s diagnosis?
   If yes, please explain.
4. What other ways has (child's name)'s diagnosis affected you? Please explain.

Demographics

1. How old are you?
2. How old is (child’s name) (years and months)?
3. How old was (child’s name) when he/she was first diagnosed with autism?
4. How many other children do you have and what are their ages? How many of them live with you and (child’s name)?
5. What is your (child’s name) level of functioning (low, moderate, high)?
6. What is the current grade of (child’s name)?
7. What is your household income?
8. What is your highest level of education?
9. What is the highest level of education of your child’s father?
10. What is your marital status?
11. What is your occupation?
12. What is the occupation of (child’s name)’s father?
13. What is your ethnicity?

Appendix B
University of Hawai'i

Consent for Parent to Participate in Research Project:

The Experiences of Maternal Caregivers of Children with Autism: A Case Study of Hawaii

My name is Kalma Wong. I am a graduate student at the University of Hawaii at Manoa in the Department of Sociology. As part of the requirements for earning my graduate degree, I am doing a research project. The purpose of my project is to measure the positive aspects and challenges of caregiving children with autism in Hawaii. I am asking you to participate because you have a child with autism spectrum disorder.

Activities and Time Commitment: In this research project, you will be asked to share your experiences of caring for a child with autism, how raising and caring for a child with autism has impacted you, and what you have learned from your experiences. The interview will be held at a location and time convenient for you and will last approximately 60-90 minutes. Only you and I will be present during the interview. I will audio-record the interview so that I can later transcribe the interview and analyze the responses. I will also take written notes during the interview for my own reference.

Benefits and Risks: There will be no direct compensation to you for participating in this interview. The knowledge gained in this project may benefit families caring for children with autism in the future. I believe there is little risk to you in participating in this research project. You may become stressed or uncomfortable answering any of the interview questions or discussing topics with me during the interview. If you do become stressed or uncomfortable, you can skip the question or take a break. You can also stop the interview or you can withdraw from the project altogether.

Privacy and Confidentiality: I will keep all information in a safe place. Only my University of Hawaii advisor and I will have access to the information. Other agencies that have legal permission have the right to review research records. The University of Hawaii Human Studies Program has the right to review research records for this study. After I write a copy of the interviews, I will erase or destroy the audio-recordings. When I report the results of my research project, I will not use your name. I will not use any other personal identifying information that can identify you. I will use pseudonyms (fake names) and report my findings in a way that protects your privacy and confidentiality to the extent allowed by law.

Voluntary Participation: Your participation in this project is completely voluntary. You may stop participating at any time. If you stop being in the study, there will be no penalty or loss to you. Your choice to participate or not participate will not affect your rights to services at the UH Career Development and Counseling Program.

Questions: If you have any questions about this study, please call or email me at [(808) 393-5218 & kalma@hawaii.edu]. You may also contact my adviser, Dr. Wei Zhang, at [(808) 956-7689 & weizhang@hawaii.edu]. If you have questions about your rights as a research participant, you may contact the UH Human Studies Program at (808) 956-5007 or by e-mail at uhirb@hawaii.edu to discuss problems, concerns, and questions; obtain information; or offer input with an informed individual who is unaffiliated with the specific research protocol. Please visit https://www.hawaii.edu/researchcompliance/information-research-participants for more information on your rights as a research participant.

Please keep the section above for your records.

If you consent to be in this project, please sign the signature section below and return it to Kalma Wong.

Tear or cut here

Signature(s) for Consent:

I give permission to join the research project entitled, "The Experiences of Maternal Caregivers of Children with Autism: A Case Study of Hawaii."

Please initial next to either "Yes" or "No" to the following:

_____ Yes _____ No I consent to be audio-recorded for the interview portion of this research.

Name of Participant (Print): ____

Participant's Signature: ____

Signature of the Person Obtaining Consent: __________________________________

Date: ___________________________

Appendix C

UNIVERSITY of HAWAIʻI
SYSTEM

Office of Research Compliance
Human Studies Program

TO:	Zhang, Wei, University of Hawaii at Manoa, Sociology Wong, Kalma
FROM:	Rivera, Victoria, Interim Dir, Ofc of Rsch Compliance, Social&Behav Exempt
PROTOCOL TITLE:	The Experiences of Maternal Caregivers of Children with Autism
FUNDING SOURCE:	
PROTOCOL NUMBER:	2016-30303
	Approval Date: September 25, 2018 Expiration Date: December 31, 2999

NOTICE OF APPROVAL FOR HUMAN RESEARCH

This letter is your record of the Human Studies Program approval of this study as exempt.

On September 25, 2018, the request for IRB approval of changes to your exempt project noted above has been reviewed and approved. The proposed amendments will be added into your current project file. The proposed changes do not alter the exempt status of your project. The authority for the exemption applicable to your study is documented in the Code of Federal Regulations at 45 CFR 46.101(b) 2.

This approval does not expire. However, please notify the Human Studies Program when your study is complete. Upon notification, we will close our files pertaining to your study.

If you have any questions relating to the protection of human research participants, please contact the Human Studies Program by phone at 956-5007 or email uhirb@hawaii.edu. We wish you success in carrying out your research project.