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A PARENT EDUCATION CURRICULUM FOR DECREASING STRESS IN FAMILIES RAISING A CHILD WITH AN AUTISM SPECTRUM DISORDER

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A PARENT EDUCATION CURRICULUM FOR DECREASING STRESS IN
FAMILIES RAISING A CHILD WITH AN AUTISM SPECTRUM DISORDER

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts
in
Child Development

by
Hannah Lynn Wohlk
September 2017

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ABSTRACT

Research has consistently shown that parents raising a child with autism spectrum disorders, or ASDs, have higher levels of stress than parents of typically-developing children or children with other disabilities. These parents' higher levels of stress are attributed to a number of different factors, including early atypical development, getting the diagnosis, lack of awareness of resources, lack of support from their communities, unmet resource and schooling needs for their ASD child, financial strain, strain on the couple relationship, managing maladaptive behaviors, regulatory problems of the ASD child may experience, communication problems between ASD child and parent, parents' perception of their own competency, ambiguity of the ASD child's future, and the future of the family as a whole. The purpose of this project was to decrease parents' levels of stress (while increasing their perception of competency and knowledge of autism) in a four-session course. Pre- and post- test data showed that participating parents decreased their stress level, increased their knowledge about autism, and felt more competent in raising their child. For future trainings, it would be important to encourage participation and retention of participants by offering an incentive. In addition, including more specific criteria for parents eligible for the program in order to target more families raising a child with an ASD.

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To my family who has put up with me saying “I’m almost done, I’m almost done” with my project many times. They have shared in my journey in its entirety and have seen the struggles but always had faith that I would complete this.

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DEDICATION

This is to all the incredible families and children I have been able to work with over the last 5 years. This was inspired by all of you!

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CHAPTER ONE

INTRODUCTION

With the diagnosis of autism spectrum disorders on the rise in recent years, more parents and children of all backgrounds are being impacted throughout the United States, and the diagnosis will likely impact the child and family over the course of their lifetimes. The diagnosis of autism has been shown to increase stress in parents in multiple domains, including diminishing their self-efficacy and confidence in raising a child with autism, which in turn decreases their ability to meet their child's needs. The purpose of this project was, in general, to create a parenting class for parents of ASD children to help decrease parents' stress levels and increase parents' confidence in their ability to raise their child.

Autism Spectrum Disorders

Over the last few years, autism spectrum disorders have become more prevalent in young children. The diagnosis rate has increased dramatically such that it is now 1 in 68 children, according to the CDC website (<http://www.cdc.gov/>). In addition, CDC statistics show that boys' diagnoses outnumber girls' by 5:1. Autism affects children from all ethnic and socioeconomic backgrounds, and it will likely affect the child and his or her family for a lifetime. According to the DSM IV and 5 (American Psychiatric Association, 1997; 2013), autism spectrum disorders

(ASDs) are classified as neurodevelopmental disorders and they embody a number of different disorders within the spectrum. Each of the disorders varies in regard to the criteria and severity of the symptoms. Included under ASDs in the DSM-5 are Rett's disorder, Pervasive Developmental Disorder –NOS (Not Otherwise Specified), Autism, and Asperger's Disorder. According to the DSM 5, Rett's syndrome is unique in that only females are affected. Similar to autism, girls who develop Rett's syndrome exhibit stereotypic behaviors and have deficits in communication (Quest et al., 2014). Unlike autism, however, after the initial onset of Rett's (between ages 1 and 4), the child's communication skills may increase while the stereotypy decreases. Pervasive Developmental Disorder – NOS, more commonly referred to as PDD-NOS, is similar to autism in that the criteria include communication deficits and the lack of age-appropriate social skills. Individuals are diagnosed with PDD – NOS when they do not meet the exact criteria for either autism, Rett's syndrome, or Asperger's (<http://www.autismspeaks.org>). Autism, which is similar to PDD-NOS, includes social and communication deficits and repetitive, rigid behaviors. Asperger's is similar in that the repetitive behaviors and social deficits are lesser, but present, and there is likely no language delay (Lasser & Corley, 2008).

ASDs typically affect an individual's social, communication, and self-regulation competencies, with the severity varying from child to child. According to the CDC, symptoms may be noticed as early as 12 months when children do not respond to their name. Parents may also begin to see the first stages of

social deficits around 18 months of age with a lack of eye contact by the child. Since eye contact is one of the primary forms of communication and a building block for social interaction (Carbone et al., 2013; Senju & Johnson, 2009), lack of eye contact can be a key indicator of ASDs. Children with ASDs also tend to prefer to be alone rather than engaged in activities with others. Another commonality is the lack of reciprocated facial expressions and emotions, i.e., having a “flat” affect. According to Brezis et al. (2014), the ability to retain information regarding social stimuli is also difficult for children with autism. For example, in Brezis et al.’s (2014) study, children with autism had more difficulty achieving accurate responses when compared to the control group of typically-developing children. Furthermore, these social impairments are seen across multiple settings.

In addition to social deficits, deficits in communication may also be present. According to the CDC (<http://www.cdc.gov/>), children’s communication skills can vary from being non-verbal to verbal, with non-verbal and verbal communication differing for each child. For example, children who express their needs non-verbally can range from communicating with gestures (e.g., nodding and pointing) to using sign language (Valentino et al., 2011). On the other hand, verbal skills can range from using functional to less functional language (i.e., scripting or echolalia). Functional language can include appropriate responses to questions, engaging in conversation, or commenting on their environment.

Approximately 40% of children with ASD are unable to talk, whereas some are delayed and may begin to talk later (<http://www.cdc.gov/>).

A third area in which children with autism are affected is in self-regulation and stereotypy. Children with autism tend to have self-stimulatory behaviors that are unique to each child. These self-stimulatory behaviors fall into two categories: repetitive motor behavior (e.g., hand flapping or rocking back and forth) and “sameness” (e.g., behaviors and obsessions such as rigidity and rituals) (Lidstone et al., 2014). Most repetitive behaviors fall under the latter category. These behaviors serve different functions which tend to vary from child to child (i.e., a child who exhibits a certain behavior may do it for one particular reason, while another child may exhibit the identical behavior to achieve a different goal).

Causes of Autism

According to the CDC website (<http://www.cdc.gov/>), there are still no known causes of autism spectrum disorders. There are, however, certain risk factors which have been shown to increase the risk of developing ASDs including both biological and environmental factors. It is currently unclear as to whether there is one particular cause, or if there are multiple causes that together can develop into ASDs (<http://www.cdc.gov/>).

Biological factors are considered to be of significance in autism research. Genetic factors, the “broken-mirror” theory, and events during pregnancy have been carefully researched in order to gather more information on the probable

causes of autism. Genetic factors are currently being explored because they are probable contributing factors to autism (Williams et al., 2014). Research on twin studies has shown that identical twins have a higher rate than both siblings having the diagnosis. An 80% heritability rate was found between siblings according to research by Luckhardt et al. (2014).

Also, a recent theory referred to as the “broken mirror theory” (Luckhardt et al., 2014) refers to the mirror neurons that would, in a typically-developing child, encourage reciprocal interactions. Mirror neurons also are involved in goal-directed behaviors and actions, as well as in cognitive empathy (i.e., understanding and relating to others’ feelings), which most children with autism lack (Luckhardt et al., 2014). Some research has also examined mirror neurons as not the cause of, but rather the result of, an inability to read social cues (Southgate & Hamilton, 2008). In addition, much research has pointed to events during pregnancy as being a probable starting point for autism. Prenatal and perinatal time frames are currently being investigated more thoroughly including additional environmental factors and how they affect mothers during pregnancy (Mamidala et al., 2013). A few of the risk factors being investigated are low birth weight, complications during pregnancy, psychological stress on the mother, being born preterm, environmental factors, and abnormal brain development during pregnancy (Dudova et al., 2014; Mamidala et al., 2013). Having low birth weight can cause ventricular enlargement, which in turn causes disorganized brain circuitry and a decrease in white matter volume (Movsas et al., 2013).

Head circumference studies dating back to the early 2000s have found via longitudinal data that there is a correlation between increased and rapid head growth and the development of autism. However, over the years, the head circumference studies have lacked consistency (Raznahan, 2014). An increase in serotonin levels has also been shown to play a role prenatally in the development of autism (Gabriele et al., 2014). Lastly, MRI studies have shown an increased volume and thickness in certain regions of the brain (e.g., corpus callosum, frontal lobe, parietal lobe, amygdala) prenatally in children who develop autism (Gentile, 2015).

Environmental factors have raised concern in the research surrounding causes of autism (e.g., chemicals in air pollution and consumer products) (Wong, Wais, & Crawford, 2015). Studies have shown mixed results regarding the impact of environmental factors in terms of chemical exposure on autism (El Baz Mohamed et al., 2015).

Comorbidities of Autism. The diagnosis of autism often has comorbid diagnoses (Mayes et al., 2012). These comorbid diagnoses may include maladaptive behaviors (e.g., tantrums, aggression, self-injurious behavior or SIBs, and irritable behaviors), learning disabilities (e.g., processing time, inattention, inability to express themselves), sleeping difficulties, epilepsy, food refusal, and/or other various eating problems.

First, maladaptive behaviors such as tantrums, aggression, SIBs, repetitive behaviors, and irritability are often exhibited due to the inability of the

ASD child to communicate effectively (Hall & Graff, 2012). Frustrations can build up in ASD children and may result in maladaptive behaviors that more readily express how they may be feeling, and may be expressed in aggression or tantrums. Repetitive behaviors, which may be considered maladaptive due to a lack of social awareness, may include such behaviors as lining up toys in a straight line, mouthing toys, or twirling string. These repetitive behaviors may result from an inability to play with these toys in a way which is considered socially appropriate (Hall & Graff, 2012).

Second, learning disabilities, which may include anything from processing delays to cognitive delays, can stem from possible executive dysfunction (Mashal & Kasirer, 2011). These difficulties are thought to result from autism, rather than autism being caused by the executive dysfunction. Executive functions are responsible for aiding in daily tasks such as planning, flexibility, and shifting. Since performing well on comprehension tasks (both written and spoken) is heavily rooted in executive functioning (e.g., understanding metaphors), children with autism also tend to have difficulties comprehending these concepts (Mashal & Kasirer, 2011). In addition, much research has shown that in children with autism, there is a disconnect when discriminating between literal language and metaphoric language. Typically, all language in ASD children is interpreted literally, which makes it difficult for them to process and understand spoken and written language. Thus, children with autism will typically benefit from language that is concrete and straightforward (Mashal & Kasirer, 2011). In addition,

children with autism may need more time to respond in any given situation or dialogue since it usually takes them longer to process information due to the deficits in executive functioning and attention (Yu et al., 2013).

Third, sleeping difficulties are common in ASD children, and are significantly correlated with behavior problems (Mannion & Leader, 2013). One study which investigated sleep difficulties found that children who experience trouble sleeping are also the children who exhibit more self-injurious behaviors, aggression, sensory issues, and language delays (Goldman et al., 2011). It has been concluded that trouble sleeping is higher in children who have more severe diagnoses of autism (Goldman et al., 2011; Mannion & Leader, 2013).

Fourth, epilepsy is a common co-morbid diagnosis in children with autism, but less frequent in children with Asperger's (Jokieranta et al., 2014). Epilepsy is a disorder in which an individual has recurring seizures. Like children with autism, children with epilepsy vary in terms of the severity of the disorder. There have been instances in which children may regress to lower functioning autism due to the presence of epileptic seizures (Armstrong et al., 2014). The earlier the onset of epileptic seizures, the more likely it is that the child will exhibit behaviors that are present in children with autism. The disorders can become apparent and manifest themselves at a young age (Armstrong et al., 2014). Children who are diagnosed with both autism and epilepsy have more maladaptive behaviors than children who have one diagnosis alone (Viscidi et al., 2014). In addition, it has been found that children with these dual diagnoses have more motor

development delays as well as difficulty with daily living skills and self-help skills. However, social skills are typically no different than in a child with only one diagnosis (Viscidi et al., 2014).

Fifth, food selectivity and eating difficulties are often present in children with autism. Research has shown that many children with autism have difficulty when it comes to eating, especially regarding the limited amount of food they are willing to eat (Sharp et al., 2013). This is referred to as food selectivity. Children with autism tend to shy away from fruits and vegetables, while only consuming starchy foods (Sharp et al., 2013). This can lead to later health problems such as vitamin deficiencies, obesity, and/or poor bone growth.

Autism Spectrum Disorders and Family Stress

The diagnosis of autism causes changes in family dynamics including creating significant stress in multiple areas of the families' lives. Parents who are raising children on the autism spectrum have consistently been shown to have higher levels of stress than those raising typically-developing children or children with various other delays or disorders (e.g., Down syndrome) (Brobst, et al., 2008; Dabrowska & Pisula, 2010; Davis & Carter, 2008; Ekas & Whitman, 2010; Estes et al., 2013; Foody et al., 2014; Hayes & Watson, 2013; Huang et al., 2014). There are many sources of stress for families with an ASD child, including the atypical development of the child, getting the diagnosis, lack of awareness of resources, lack of support from the community, unmet resource and schooling needs for ASD children, financial strain, strain on the couple relationship,

managing maladaptive behaviors, regulatory problems, communication problems between the child and parent, parent perception of competency, ambiguity of an ASD child's future, and the future of the family. Each of these is reviewed below.

Early Atypical Development. Children with autism may miss many of the early developmental milestones, and this has been shown to be stressful for parents. Research studies have shown that parents first begin to notice signs of atypical development as early as 11 months of age (Estes et al., 2013). Since autism is typically diagnosed at age three, there is a large gap of time between the first signs of atypical development and getting the diagnosis, which can be very stressful and worrisome for parents (Estes et al., 2013). This stress may be especially high for parents of first born children because parents are still new to the parenting role, and the possibility of being diagnosed with autism can make the parenting role more difficult to transition into. Realizing these missed milestones and differences in their child's development may compel parents to get their child assessed professionally (Estes et al., 2013).

One of the first signs of atypical development is the avoidance or general lack of eye contact and the lack of joint attention skills, such as following another person's gaze or gesture (Carbone et al., 2013; Senju, 2013). These skills are known as non-verbal social-communicative behaviors, and they are some of the first skills that typically-developing infants and toddlers use to communicate with their parents and express themselves prior to acquiring spoken language. (Carbone et al., 2013; Senju & Johnson, 2009). Very young typically-developing

children and their parents reinforce one another while engaging in reciprocal unspoken communication through, for example, eye contact (Senju & Johnson, 2009). When there is a disconnect between parents and their ASD child, parents can feel detached from their child and may feel that the connection to their child is not as strong as it could or should be (Lasser & Corley, 2008; Wu et al., 2015).

In addition to lacking eye contact early in life, another milestone of typically-developing children is the acquisition of language (Hellendoorn et al., 2015). The lack of communication and functional language in an ASD child is stressful for parents because it makes it difficult for the child's needs to be known, received, and responded to appropriately (Hellendoorn et al., 2015).

Children with autism may also develop differently in regard to motor development. Both fine and gross motor development are built on the same foundational experiences that language is, i.e., exploring and getting to know the surrounding environment (Hellendoorn et al., 2015). The development of these motor skills in turn guides further exploration (Hellendoorn et al., 2015). Parent stress is likely to increase if these motor milestones are not being met, especially once the child reaches school age and has to begin writing and engaging in developmentally-appropriate physical play with peers (Hellendoorn et al., 2015). Missing these early milestones is particularly stressful because parents may become worried about a potential diagnosis and the ambiguity of what is to come.

In order to cope with these differences and missed milestones, parents have found it to be beneficial to look to professionals and consider such early interventions for their child as ABA therapy (applied behavior analysis). Professionals in the field are knowledgeable of resources and are available to answer questions. That way parents can receive answers and get help with their child as soon as possible (Smith, Kloman, & Mruzek, 2015).

Getting the Diagnosis. The diagnostic process for parents is also stressful and can bring about many different emotions for parents (Lasser & Corley, 2008). Research has found that parents who go through the diagnostic process often feel it was an experience which left them both relieved yet worried, especially regarding knowing what would come next for themselves and their newly diagnosed child (Shuntermann, 2002). When parents receive a diagnosis, they may feel grief, similar to what a parent might experience in dealing with the death of a child (Lasser & Corley, 2008). Grief is often experienced by parents upon the diagnosis as their “ideal” child is gone, and parents are forced to change their ideas and behaviors in order to benefit their child. Since there are no known causes of ASD, parents can likely feel as if they are the cause of their child’s developmental delays (Mercer et al., 2006). Grief and feelings of self-blame may also occur as parents may feel like their parenting skills are responsible for the diagnosis, even though parenting behaviors have not been shown to cause autism in children (Lasser & Corley, 2008).

In addition to the grief cycle, parents may experience feelings of resistance, i.e., denial or fear, regarding the child's future and what steps to take next. Some parents, for example, feel as though this stage of their child's development may simply be "just a phase" (Lasser & Corley, 2008).

Understanding that the disorder is long lasting and will likely remain for the entirety of a child's life is often frightening for parents (Lasser & Corley, 2008).

Simply receiving the label "autism" has shown to be very stressful for some parents (Firth & Dryer, 2013; Hayes & Watson, 2013), and parents are unlikely to have feelings of optimism when given this news (Mulligan et al., 2010). According to Lasser and Corley (2008), however, some parents have feelings of relief because with the diagnosis come resources. Getting a diagnosis from a professional can result in gaining knowledge of resources that parents may be able to benefit from (Shunterman, 2002). Parents may feel affirmed in that the atypical development they have suspected is justified. Another emotion that may be felt by parents is a sense of closure.

A sense of uncertainty is also a stressful component of getting the diagnosis (Mulligan et al., 2010). There might also be feelings of guilt that consume parents of children who seem to be developing atypically. The ambiguity of the future and how they can best help their child becomes an overwhelming question (Lasser & Corley, 2008).

Research studies have shown that parents go through a number of different emotions upon getting the diagnosis, so different coping strategies may

be utilized depending on the family's needs. Having support from the community and family members has been shown to significantly decrease parental stress levels when getting the diagnosis. In addition, using active coping strategies such as problem-focused coping and/or emotion-approach coping has been shown to be beneficial in decreasing stress in families (McGrew & Keyes, 2014).

Lack of Awareness of Resources. Parents' level of stress can also be influenced by whether or not additional resources are given to them upon getting the diagnosis of autism (Mulligan et al., 2010). Parents report that when they are left to find resources themselves for their newly diagnosed child, there are high levels of dissatisfaction and stress which can lead to feelings of helplessness in parents (Mulligan et al., 2010). Parents who receive information about resources upon their child's diagnosis have been found to be significantly less stressed than those parents who did not receive any resources (Mulligan et al., 2010). Therefore, getting resources and answers from a professional at the time of diagnosis may help decrease parent stress (Mulligan et al., 2010).

Lack of Support from the Community. Research studies have also shown that parents of children with autism feel as though they do not receive enough familial or community support (both physical and emotional support) (Johnson & Simpson, 2013). Community support generally refers to parents and families having access to resources, physical support, emotional support, and counseling, if needed (Hall, 2012). Physical support refers to assistance with the daily demands that are placed on the family such as going to the store, school, etc.,

while emotional support refers to parents wishing their family members or members in the community would be available just to simply listen to them (Weiss et al., 2014). Also, mothers in particular have been found to engage in avoidance behaviors (i.e., isolation of the parent from their child, and from their child to peers or family) if there is a lack of support compounded by high levels of stress (Johnson & Simpson, 2013).

Research has shown that parents who receive support from community programs and other parents who may also be raising a child with autism have a better understanding of autism and are better able to cope with the diagnosis. Stress levels of those who receive community or family support (i.e. respite care) are lower than those parents who do not have community programs available to them. A parent's stress level can be lowered just by knowing that they are not alone in this new lifestyle that they must adapt to (Hall, 2012).

Unmet Resource and Schooling Needs for Children with an Autism Spectrum Disorder. Some parents of children with autism express concern regarding the availability of therapy services that they should be able to receive and quality of services offered (i.e., various therapies and healthcare). Parents also find it more difficult to find services as their children become older. In addition, some parents are concerned about the amount of time that their children are able to spend with typically-developing peers both at home and at school. In the school system, parents sometimes feel as though they are unable to meet as often as they would like with their child's teacher and others involved

with their child's education plan (Algood et al., 2011; Bitterman et al., 2008; Dabrowska & Pisula, 2010; Davis & Carter, 2008; Liptak et al., 2006; Wang et al., 2013).

Research studies have shown that frequent and consistent communication between all parties involved with the child (i.e., parents, teachers, and school officials) benefits parents and aids in a better outcome for the child (e.g., Mount & Dillon, 2014).

Financial Strain. Financial demands are significant for parents raising a child with autism. Expenses can be three to ten times more annually for parents raising children with autism compared to those raising typically-developing children (Parish, 2015). Expenses include direct costs of early interventions, medications, medical expenses such as health care, becoming a single income household, specialized childcare, and education.

Although health insurance does cover some expenses for families, there are many other expenses that families are left to pay for including behavioral therapy like ABA (i.e., applied behavior analysis). Children who receive this intensive intervention at a young age typically increase their social and communication skills and learn adaptive life skills (Couper, 2004), so arranging for this type of early intervention even when it is not covered by a family's insurance plans is critical (Sharpe & Baker, 2007). Other types of therapy that are likely to be paid for out of pocket by families are sensory integration therapies such as horse therapy and music therapy (which incorporate sensory stimuli in

order to increase tolerating environmental stimuli on a regular basis). With higher functioning children with autism, sensory integration therapies are important but are also likely to be out of pocket costs for parents (Sharpe & Baker, 2007; Weiss et al., 2014). Not only are these types of therapies expensive, it is also important to find one that is accommodating to the family and that works well with the child.

Medications for children with autism, which may be prescribed in order to manage some symptomologies of autism (e.g., self-injurious behaviors, aggression, sleep problems), are other expenses that parents may have to pay for out of pocket. (Schubart, Camacho, & Leslie, 2013). In addition, research studies have shown that health insurance is likely to cover the medicinal expenses, but not those that address such behaviors as listed above (Sharpe & Baker, 2007). In order to help families in this situation there are community funded programs, but these programs are likely to have a long waiting list so it is unclear when parents may receive the help they need (Sharpe & Baker, 2007).

Medical expenses and health care are the primary sources of financial strain for families. It has been estimated that it costs families up to \$12,000 a year to raise a child with autism (Barrett et al., 2015). Some costs are paid directly out of pocket, while others can be covered by insurance. Expenses tend to be higher for families with an ASD child because there are more visits to the physician than with typically-developing children (Liptak, Stuart, & Auinger, 2006).

Research studies have shown that parents often have to stop working completely or work only part-time jobs when raising a child with autism because raising a child on the autism spectrum can become a full time job. Therefore, the family may have to become a single income household (Cidav et al., 2012; Parish, 2015). Financial concerns can be decreased by getting enrolled in the programs they are qualified for. That way, some of the financial strain can potentially be alleviated (Saunders et al., 2015).

Specialized childcare can be a financial burden on the family both indirectly and directly. Not only can it cost more for the family, but the higher cost of specialized childcare can result in parents leaving their jobs in order to care for the child themselves, thus reducing the amount of income in the household (Cidav et al., 2012; Sharpe & Baker, 2007). In addition, specialized childcare may be required for a longer period of time since children with autism often need more attention when compared to a typically-developing child (Sharpe & Baker, 2007). Research studies have shown that federal programs can help alleviate these costs, but that is not always the case (Sharpe & Baker, 2007).

Education and special education costs are also substantially higher for ASD children and the school district (Barrett et al., 2015). A child's needs may not be met by the staff that the school has, and outside interventionists or therapies may be necessary for the successful schooling for children with autism (Sharpe & Baker, 2007). Some therapies are available through school districts such as speech therapy; however, ABA and other behavior therapies are very

costly for the district. Outside therapies are typically necessary if they cannot be fulfilled in school which increases the cost for families (Sharpe & Baker, 2007). In summary, while education is not paid for by parents, additional therapy that a child may need can increase the cost for families outside of schooling.

Strain on the Couple Relationship. Another major source of stress is the toll that the child with autism may put on his or her parents' marriage. The foundation of a strong marriage is rooted in communication, flexibility, intimacy, commitment, and shared resources (Maricano et al., 2015). Research studies have shown that when raising a child with autism, these components can be compromised (Marciano et al., 2015). Unfortunately, divorce rates among parents raising a child with autism are higher than parents raising typically-developing children (Bluth et al., 2013; Brobst, Clopton, & Hendrick, 2008).

Research studies show that parents must dedicate a significant amount of their time creating a successful environment for their child with autism. Therefore, time that might otherwise be spent with a spouse becomes quite limited, and this lack of couple time can create distance between the partners. The significant financial burdens described above may also increase the stress in the couple relationship (Brobst, Clopton, & Hendrick, 2008), further diminishing marital intimacy (Tomanik, Harris & Hawkins, 2004).

Couples who have higher levels of positive affect (i.e., higher levels of feeling happiness and joy) have been found to be able to decrease parental stress and increase marital satisfaction (Ekas & Whitman, 2011). Respite care

can also increase marital satisfaction as it can allow the couple to spend time together alone outside of the house (Ekas et al., 2015). Higher relationship satisfaction has also been found in couples who have planning skills and are more optimistic (Ekas et al., 2015). Engaging in a daily optimism exercises can also help improve the couple relationship (Ekas et al., 2015).

Managing Maladaptive Behaviors of Children with an Autism Spectrum Disorder. Maladaptive behaviors in ASD children (e.g., self-injurious behaviors, self-stimulatory behaviors, aggression, destructive behaviors to self, others, and/or property, or behaviors to escape certain situations) can also be a source of stress for the family (Samson, et al., 2015; Woodman et al., 2014).

Self-injurious behaviors (SIBs) are especially stressful for parents and families of children with autism because these behaviors are destructive in nature and the child's safety is at risk (Devine, 2014). SIBs include, but are not limited to, banging their head, biting self, and/or pulling their own hair. These harmful behaviors, especially when they target the child's head, may also cause regression and traumatic tissue damage when they are severe. Less severe SIBs can result in interference in both social and learning situations (e.g., during class or during their behavior therapy). The cost of treatment for SIBs is also significant (Devine, 2014).

Self-stimulatory behaviors are behaviors that interfere with children playing with toys appropriately, which can interfere with socially acceptable play that may bring additional unwanted attention to the ASD child (and hence stress

to the parent) (Epstein et al., 1985). These behaviors can interrupt learning (Rosenthal-Malek & Mitchell, 1997) and can get in the way of an ASD child being mainstreamed into a regular class (Epstein et al., 1985; Rosenthal-Malek & Mitchell, 1997). Not only are these behaviors distracting in a school setting, they can also be distracting in stores, movie theatres, restaurants, etc. This can cause uneasiness in parents (Ekas & Whitman, 2011) as maladaptive and self-stimulatory behaviors are distracting and generally deemed socially-inappropriate, which can make parents hesitant about bringing their ASD child out in public for fear of making a scene (Tominak, Harris, & Hawkins, 2004).

Research studies have found that parents who have ASD children with maladaptive behaviors such as those listed above have eased their stress by creating more positive perceptions of their children's behaviors (Ekas et al., 2015). Instead of feeling frustration or anger while a child with autism is exhibiting a maladaptive behavior, learning what the function of a particular behavior is in order to better manage it has been shown to be beneficial in decreasing parental stress. Understanding the function of such behaviors can help parents get a better grasp of what the child may want or need in any given situation (Ekas et al., 2015). Lastly, it has been shown that continuous support from one's spouse for one another benefits parents and likely decreases stress levels as well (Ekas et al., 2015).

Stress levels in parents can also be decreased through parents targeting these behaviors and creating opportunities to teach ASD children other ways to

express their wants and needs (Estes et al., 2013). Learning adaptive behaviors, which aid in mastering daily skills that children need to learn in order to decrease dependency is important for the child as well as for decreasing parent stress (Hall & Graff, 2011; Estes et al., 2013).

Regulatory Problems. Regulatory problems in children with autism have also been shown to be a source of stress for parents. Regulatory problems can include sleeping problems, poor eating habits, and difficulties in emotional regulation in children (Davis & Carter, 2008; Kodak & Piazza, 2008). These types of problems can be stressful for parents because children's health and safety are at risk (Kodak & Piazza, 2008). Regulatory problems serve as a source of stress for parents on a daily basis because more attention and services (e.g., pediatric services and child health centers) are required to regulate these issues in the ASD child (Barnevik-Olsson et al., 2013).

Sleeping problems are common in ASD children (Barnevik-Olsson et al., 2013) and include both the inability to fall asleep at night as well as the amount of restlessness and fussiness during the night, which increase parental stress levels (Barnevik-Olsson et al., 2013; Kodak & Piazza, 2008). Stress levels in parents can increase due to the lack of sleep their child is getting since it also limits the amount of sleep they are getting while attending to their child. Research has shown that it can also increase irritability and therefore increase maladaptive behaviors in ASD children (Barnevik-Olsson et al., 2013).

Feeding problems are also common in ASD children (Kozlowski et al., 2012; Marshall et al., 2014) and include being particular in what they choose to eat (due to texture or sensitivity to smell), refusing to eat altogether, consuming only a certain type of food, and possibly becoming overweight. Feeding issues are problematic and stressful in families because the health of the child is directly impacted as the child may not be getting the nutrients they need or may be eating too much of a particular food (that can result in becoming overweight). Parents often have to allocate more time to the ASD child during meals because of these concerns (Kozlowski et al., 2012; Marshall et al., 2014).

Emotion regulation refers to the capacity for problem solving behaviors, suppression of destructive emotions (i.e., anger, impulsivity), and relaxation in children as well as adolescents (Izard, 2010). When these forms of self-regulation are unable to be reached independently (which is common in ASD children), families may have to aid the child in soothing and other coping strategies (Samson et al., 2015). Since ASD children often lack the ability to communicate appropriately, they are left to communicate their wants and needs through crying and meltdowns (Sharp, Burrell & Jaquess, 2013).

In addition to getting resources to aid in the child's specific problem areas, such as sleep or eating, it has been shown that support from family members and the community have been beneficial in helping parents deal with these regulatory problems. Issues that directly affect a child's health and safety can be

more stressful to parents, therefore support is important and welcomed (Kodak & Piazza, 2008).

Communication Problems Between the Child and Parent. Children with autism often experience difficulties expressing their needs in a way that is easily understood by family members and peers, causing frustration in both the child and family members. Research has consistently found that the child's inability to communicate increases parent stress (Algood et al., 2011; Ekas & Whitman, 2011) because it can compromise the parent and child relationship. When the ASD child's needs cannot be met (because they are unknown to the parent), children may feel as though their parents cannot be depended on (Algood et al., 2011). Lack of spoken language can also increase the use of maladaptive behaviors in order for the child to get what they want, which is stressful for parents because it can be harmful to themselves or to the parent (Algood et al., 2011). Communication between the parent and a typically-developing child is also another foundation for learning. A child with autism who lacks the ability to have dialogue with their parents can potentially lose the opportunity for these natural opportunities for learning (Shire et al., 2015). In addition, the lack of communicative abilities can be stressful because it limits the engagement between the ASD child and parent, and further limits the initiation of conversation which can create a barrier for learning (Shire et al., 2015). Language difficulties can also create barriers for ASD children later in life, in terms of advancing in their education and getting a job (Boesch et al., 2013).

Poor eye contact has also been shown to hinder ASD children's learning in school. Lack of eye contact may interfere with a child's ability to pay attention in class, resulting in educational setbacks (Carbone et al., 2013). This has been shown to be stressful because parents want their children to receive the best education possible, and any type of setback can be frustrating. Socially, children with autism lack the ability to read social cues and gather information based on body language and gestures (Centelles et al., 2013). Some research studies have found that the lack of social reciprocity is among the most stressful aspect of raising school-aged children with autism (Davis & Carter, 2008). Parents of children with higher functioning autism who are more capable of engaging with peers in social situations have been found to rate themselves as less stressed compared to parents of children with more significant difficulties in social situations (Davis & Carter, 2008; Ekas & Whitman, 2011; Firth & Dryer, 2013).

Since language can be limited in children with autism, children may have other ways of getting their wants and needs expressed. Whether it be maladaptive (i.e., tantruming, aggression, or crying) or adaptive (i.e., sign language, technology, or spoken language), parents benefit from knowing what their children want. Understanding the needs and wants of their children is likely to decrease parental stress levels. Also, recognizing what the child is wanting before the maladaptive behaviors occur can be beneficial in decreasing the maladaptive behavior in general, which would also decrease parental stress (Algood et al., 2011).

Parent Perception of Competency. The daily disruptive behaviors that ASD children exhibit and the parents' perceived ability to maintain and redirect these behaviors impact parents' stress levels (McStay et al., 2014). Some research studies have found that parent stress levels are related to their sense of competency in raising their child (McStay et al., 2014; Weiss et al., 2014). Also, studies show that parents whose children are perceived to be less happy (such as ASD children) tend to take responsibility for that unhappiness (McStay et al., 2014; Weiss et al., 2014), so it is likely that parents' perception of their ability is lower than parents with children who they perceive as being happier.

Regarding parents' sense of competency in raising a child with autism, research has shown that parents who are more involved in their child's treatment tend to feel more competent as parents, thus decreasing their stress levels (McStay et al., 2014).

Ambiguity of Future for Child with an Autism Spectrum Disorder. One of the areas of concern of parents in raising a child with autism is what the future holds for them. This particular area of concern can have multiple meanings depending on the family. For example, Dabrowska and Pisula (2010) and Lasser and Corley (2008) discuss dependency of care of ASD children. Some children may grow up and lack the skills needed for daily independent functioning, e.g., holding a job or living on their own, making their own food, bathing themselves, cleaning up after themselves, or completing schooling, and may therefore grow up to live at home and require help with basic living skills. As the parents of these

children also grow older, such caregiving tasks can become a physical burden for the parents (Dabrowska & Pisula, 2010; Lasser & Corley, 2008).

Some research studies have examined the indirect but lifelong effect of dependency of care of ASD children on the parents (e.g., the impact of caretaking on their social life, free time, and career) and have found that not only were parents' leisure activities impacted, but their careers often suffered as well. These studies suggest that each stressor can have an additive effect and can impact parents and families on multiple levels (Lambrechts et al., 2011; Meirsschaut et al., 2010).

Future of the Family as a Whole. There are many future considerations that families must discuss as they accept their child's diagnosis. For instance, families must discuss what the best option would be career-wise, and whether changing jobs (i.e., continuing as part-time) or leaving their job altogether to be at home is the most beneficial option for their child (Vacca, 2013). Research studies have shown that children with ASDs do require more time and attention on a daily basis, which could potentially lead to the decision of leaving a job. Another stressor for parents is deciding whether or not they want to have another child, since according to research the chances of having another child with autism increase when one child has the diagnosis (Hall & Graff, 2011; Shimoni et al., 2012; Vacca, 2013).

Summary of Parental Stressors. Stress in families raising a child with autism tends to stem from various aspects of the disorder and from the need for additional support for that child.

Stressors include, but are not limited to, the child's early atypical development, getting the diagnosis, lack of awareness of resources, lack of support from the community, unmet resource and schooling needs for ASD children, financial strain, strain on the couple relationship, managing maladaptive behaviors of children with autism, regulatory problems, communication between the child and parent, parent perception of competency, ambiguity of the child's future, and future of the family as a whole.

The prevalence of autism spectrum disorders is higher than ever, and it is important to get parents the help they need in order to create a better life and future for both the ASD child and the family. As much research has pointed out, there are ways in which parents can decrease their stress levels when raising a child with autism.

Factors that Impact Stress

Mothers' vs. Fathers' Stress. When comparing mothers' to fathers' stress levels, research studies have shown that stress is triggered by different aspects of the diagnosis. Mothers' stress has been found to be related to the amount of time mothers typically spend with their ASD child and the decreased amount of time they can spend on leisure activities (Johnson & Simpson, 2013). Mothers' stress also tends to stem from the maladaptive behaviors that are exhibited by

their ASD child as well as the child's lack of independence on daily life skills (Dabrowska & Pisula, 2010). Mothers also tend to become stressed by the regulatory problems that the ASD child may face such as sleeping problems and emotion regulation difficulties (Weitlauf et al., 2012). The behaviors exhibited by the ASD child are particularly stressful during daily tasks that families face such as grocery shopping (Dabrowska & Pisula, 2010).

Fathers' stress tends to stem more from how the diagnosis will impact the family financially, as well as the more observable characteristics of autism such as their child's atypical communicative skills and motor development (Dabrowska & Pisula, 2010). Fathers are also impacted by their perceived sense of helplessness regarding the ASD child and mother (Vacca, 2013), and have reported that they feel as though they get in the way of the mother and are more of a burden than a help. There is an "automatic" mother-child relationship that fathers tend to look at as intimidating which could be a factor in fathers' tendencies to shy away from being more "hands on" with their ASD child. Therapy also tends to be aimed towards mothers and not fathers, which can leave fathers feeling less competent in raising their ASD child. In turn, fathers tend to be less inclined to help on a daily basis (Vacca, 2013).

Personality Attributes and Coping with Stress. Personality characteristics such as optimism and hopefulness have been shown to aid in decreasing stress (Faso, Neal-Beevers, & Carlson, 2013). In the long run, daily positive affect (i.e., resulting from having positive experiences with the ASD child) has been

beneficial to helping parents manage stress (Ekas & Whitman, 2011). Also, optimism has been shown to positively impact parents (Faso, Neal-Beevers, & Carlson, 2013): there is a higher level of well-being in parents who have a more optimistic outlook. In addition, hopefulness has been associated with the well-being of parents. Hopefulness is different from optimism in that hopefulness refers more to the pathway that is necessary to take in order to reach their individual and achievable goals, while optimism is more general (Faso, Neal-Beevers, & Carlson, 2013). Parents with higher levels of optimism and hopefulness experience less stress. Thus, personality characteristics may also have a positive impact on parental stress levels (Faso, Neal-Beevers, & Carlson, 2013).

Current Intervention Programs for Parents

There have been a number of programs that have been created to help families with ASD children. Many are aimed at decreasing parent stress by increasing parent-child interactions, increasing parents' active participation in interventions, mindfulness training for parents, increasing parents' knowledge of autism, and increasing self-efficacy in parents.

First, many intervention programs are aimed at increasing parent-child communication since diminished parent-child communication is a major stressor for parents of children with autism. Poslawsky and colleagues (2015) targeted this particular stressor by designing and implementing an intervention referred to as the Video-feedback Intervention to promote Positive Parenting for Children

with Autism (VIPP-AUTI). Parents are recorded interacting with their child, and then are given the opportunity to view the video and further discuss particular interactions in detail with the intervener (Poslawsky et al., 2015). The video allows parents to reflect on their interactions with their child. It was expected that the intervention would help parent-child interactions improve which would likely decrease stress in parents; results suggested that it was successful (Poslawsky et al., 2015).

Second, since a parent's ability to practice techniques learned in the ASD child's therapies is an important component of the child's growth, Project imPACT was created (Stadnick, Stahmer, & Brookman-Frazee, 2015). The results of this intervention showed that parents' active participation in their child's intervention greatly benefitted the ASD child and it decreased the parents' stress levels. An important component of this particular intervention is the incorporation of community settings in order to target naturalistic learning opportunities (Stadnick, Stahmer & Brookman-Frazee, 2015). Project imPACT successfully decreased parent stress because of the skills gained by the child and the incorporation of parents' active participation in their child's learning (Stadnick, Stahmer, & Brookman-Frazee, 2015).

A similar program targeting parents' active participation in their child's therapies is the Joint-Attention Symbolic Play and Engagement, Regulation (JASPER) (Kasari et al., 2015). Parents are encouraged to play with their ASD child to better recognize their child's interests and to create more opportunities

for interaction for both parent and child. The findings of the JASPER intervention showed that it successfully expanded the child's interest and engagement in activities, but it did not successfully decrease parents' stress (Kasari et al., 2015), perhaps due to the fact that some parents preferred having a parent-directed intervention (i.e., a parenting class to build their knowledge) rather than hands-on intervention with their child (Kasari et al., 2015).

Third, mindfulness training for parents has been shown to be beneficial. A program called Mindfulness-Based Positive Behavior Support (MBPBS) was created to target parent stress that stems from ASD children's maladaptive behaviors (Singh et al., 2014). This intervention incorporated both psychological training for the parent (i.e., mindfulness) with behavior training aimed at children's behaviors. The goal of this program was to increase parents' knowledge of where their child's maladaptive behaviors stem from (i.e., the "function" of the behavior) and give parents information on how to respond and incorporate adaptive behaviors (Singh et al., 2014). The mindfulness training was to help parents better respond to the child during these more troublesome behaviors by teaching parents how to react with reasoning rather than anger or impulse (Singh et al., 2014). These and similar studies have been shown to significantly decrease maladaptive behaviors as well as parental stress levels (Singh et al., 2014).

Fourth, in order to address the stress arising from the potential lack of knowledge on autism, a program titled Psychoeducational Intervention (PEI) was

created (Kasari et al., 2015). The goal of this program was to help parents gain general knowledge about autism, as well as information on other aspects of the diagnosis. In this one-on-one program (i.e., parent to interventionist), parents are able to discuss their own child with their interventionist, allowing for parents to get individualized support. Results showed that this program has been successful in decreasing parents' stress levels (Kasari et al., 2015).

Finally, to target parent's diminished feelings of self-efficacy, a program called VIPP-AUTI benefited parents through video feedback. This study found that when parents reviewed their video of interactions with their ASD child and interventionist, their confidence in their parenting ability increased (Poslawsky et al., 2015). Studies have shown that when parents are more confident in their abilities to raise their child, children are more successful and their stress level is lowered (McStay et al., 2014; Weiss et al., 2014).

In summary, studies have shown that parents of children with autism who participate in parent-mediated interventions can significantly decrease their stress levels. By increasing parent-child communication, encouraging active participation in their child's therapy, gaining insight and mindfulness, gaining knowledge on autism and the diagnosis, and increasing parents' self-efficacy, parents can benefit and have the opportunity to better their lives as well as their child's life.

These parent support interventions, created to decrease the stress associated with raising an ASD child, have a number of limitations. First, some of

the programs included only mothers (e.g., Singh et al., 2014; Stuttard et al., 2014). As stated above, fathers often feel left out of parenting and as such, their sense of competency can be further hindered. Therefore, including fathers in an intervention program would likely benefit the entire family (Vacca, 2013). Second, many programs listed above only teach parents one strategy instead of taking a more holistic approach that would provide them with a multitude of “tools” (i.e., skills) to address stress. Third, these programs did not educate parents on autism spectrum disorders, the many sources of stress associated with raising a child on the ASD spectrum, and how to cope with these stressors. Lastly, it would be helpful to assure parents that these various interventions are not “one size fits all” because all children with autism are different and each parent has a unique combination of stressors that they have to contend with (Stuttard et al., 2014). Thus, creating a program that addresses this fact and teaches multiple strategies to address the many sources of stress involved in parenting an ASD child would be beneficial. In addition, this project differs from other current interventions in multiple ways. It targets both mothers and fathers, and includes information on autism spectrum disorders as a whole in order to increase parents’ education and knowledge of the disorder. Multiple stressors are also discussed throughout the four sessions, and research-based information regarding what coping strategies are most beneficial are addressed. Parents also are taught other stress management and coping skills.

Summary and Purpose of Project

Parenting an ASD child has consistently been shown through research to be more stressful compared to raising a typically-developing child or a child with other developmental disorders or delays (e.g., Brobst, et al., 2008; Dabrowska & Pisula, 2010; Davis & Carter, 2008; Ekas & Whitman, 2010). Therefore, the purpose of this project was to create a parenting class for parents and caregivers of ASD children to decrease stress in these families, and aid in families developing the confidence to see themselves as competent in raising their child with autism. Unfortunately, this type of parent-directed program is lacking in the local community. Parents and families who are experiencing high levels of stress and are unsure of where to go would likely benefit from a program that is aiming to decrease stress and provide additional information on ASDs.

It was expected that after the four-session class, parents would have a better understanding of autism as a whole and how to get the resources and the support they need. It was also expected that parents would gain a better understanding of the sources of stress and what helps each. Finally, it was expected that parents' stress levels would decrease, and that they would gain confidence in their ability to raise their ASD child.

CHAPTER TWO

METHOD

Overview

The purpose of this project was to create a parenting curriculum for parents raising a child with an ASD. Parents attended four sessions (held once per week) of the program titled “A Parent Education Curriculum for Decreasing Stress in Families with an ASD Child”. Thirteen topics were discussed over the course of the four sessions, with each session in the program lasting approximately 2 hours (Table 1):

Table 1. Summary of Sessions and Session Topics

Session	Session Overview and Topics
Session # 1	<ul style="list-style-type: none"> • Introductions – presenter and parents <ul style="list-style-type: none"> ○ Overview of 4 session class • Pre-training assessments • Overview of session and introduction of topics <ul style="list-style-type: none"> ○ Early atypical development ○ Getting diagnosis ○ Awareness of resources ○ Meeting school and resource needs ○ Discussion • Stress relief activity
Session # 2	<ul style="list-style-type: none"> • Overview of session topics <ul style="list-style-type: none"> ○ Lack of community support ○ Strain on couple relationship ○ Financial strain ○ Discussion • Stress relief activity
Session # 3	<ul style="list-style-type: none"> • Overview of session topics <ul style="list-style-type: none"> ○ Managing maladaptive behaviors ○ Regulatory problems ○ Communication between parent and child ○ Parent perception of competency ○ Discussion • Stress relief activity
Session # 4	<ul style="list-style-type: none"> • Overview of session topics <ul style="list-style-type: none"> ○ Ambiguity of child’s future ○ Future of family as a whole ○ Discussion • Stress relief activity • Post-training assessments • Class evaluation form

Participants

A total of six families from the University Center for Developmental Disabilities (UCDD) at California State University, San Bernardino attended the first session. Two participants (Parent 7 and Parent 8) did not attend the subsequent three sessions due to prior engagements; one participant attended all four sessions (Parent 1), and two participants (Parent 2 and Parent 3) attended 3 sessions. (The two participants who missed one session were given the powerpoint, the handouts, and the stress relief activity for the missed session. Additionally, the researcher offered to answer any questions the participants had regarding the information). Parent 4 and Parent 5 joined session two and attended the subsequent sessions. (See Table 2 for participant attendance, child's diagnosis, and assessments completed.)

Table 2. Parent Attendance and Participation

Parent #:	1	2	3	4*	5**	6***	7	8
Session attended:								
1	✓	✓	✓			✓	✓	✓
2	✓	✓		✓	✓			
3	✓		✓	✓	✓			
4	✓	✓	✓	✓	✓	✓		
Child's diagnosis:	Down Syndrome	Down Syndrome	Developmental Delay	Autism	Autism	Mandibulo Facial Psytosis	Cerebral Palsy	Autism
Number of children with diagnosis:	1	1	1	2	1	1	1	1
Pre-assessment completed:	✓	✓	✓			✓	✓	✓
Post-assessment completed:	✓	✓	✓			✓		
Class evaluation completed:	✓	✓	✓	✓				

Table 2 footnote.

- * Father attended Sessions 2 – 4, did not fill out demographics. Demographics were attained through class discussion.
- ** Father (Parent 5) attended Sessions 2 – 4. Mother (Parent 8) attended Session 1 and completed demographics. Demographics were attained through Parent 8. Parent 8 and Parent 5 are married.
- *** Attended sessions 1 and 4. Pre- and post- assessment data was Completed, but not included in results due to missing 2 sessions.

As Table 2 shows, two fathers of children with autism joined the second, third, and fourth sessions (Parent 4 and Parent 5). However, due to having missed the first session, the pre- training assessments were not completed, but demographic information was shared during the class discussions.

Parent 1, Parent 2, and Parent 3 completed the pre- assessments during Session 1, attended three of the four sessions, and completed the post- assessments. These three participants ranged in age from 27 to 51 years ($m = 43.7$); two were Hispanic and one was African American. The age of their children with a disability ranged from 10 to 18 years ($m = 12.7$). (See Table 3 for background information of Parent 1, 2, 3, 4, and 5).

Table 3. Participants' 1 - 5 Background Information.

	Parent 1*	Parent 2**	Parent 3**	Parent 4***	Parent 5***
Relationship to child:	Mother	Mother	Mother	Father	Father
Marital status:	Other	Single	Separated/divorced	Married	Married
Highest level of education:	High school graduate	Did not complete high school	Graduate or professional degree	No response	No response
Total number of children in household with ASD or another developmental disability:	1	1	1	2	1
Number of adults in the household:	2	2	2	2	2

* Attended all four sessions.

** Attended three sessions.

*** Attended Sessions 2 through 4, no pre- assessments completed.

Measures

Pre- Class Assessments. At the beginning of the first session, parents completed a demographic questionnaire, the Parenting Sense of Competence Scale (PSOC), the Parent Stress Index-Short Form (PSI-SF), and a self-assessment created for use in the current project. At the end of the four

sessions, parents again completed the PSOC, the PSI-SF, the self-assessment, and a class evaluation form.

Parenting Sense of Competence (PSOC) scale. The 17-item Parenting Sense of Competence scale (Gibaud-Wallston & Wandersman, 1978); (APPENDIX C) assesses parents' self-efficacy and satisfaction in parenting. Parents rated each item on a 6-point Likert scale (1 – strongly disagree; 6 – strongly agree).

Parenting Stress Index – Short Form (PSI-SF). The 36 item PSI-SF (APPENDIX D) was created by Abidin (1995) and assesses different domains of parental stress. Parents responded to each item on a 5-point Likert scale (1 – strongly agree; 5 – strongly disagree). The PSI-SF focuses on anxiety, relationships and attachment, and family mental health functioning. The total stress score was computed for use in the current project.

Pre- and Post- Training Self-Assessment. The 8-item self-assessment (APPENDICES E and F) was created for the current project and assessed parents' perception of their knowledge of autism, sense of confidence and competence in raising their ASD child, and how well they are managing stress. Parents responded on a 7-point Likert scale (1 – not at all knowledgeable; 7 – knowledgeable).

Class Evaluation Form. At the conclusion of the four-session class, parents were asked to fill out a class evaluation form (APPENDIX G) in order to assess the effectiveness of the program. The form asked parents whether they

felt the program was beneficial to them, what the most useful information taught in the program was, what the least useful information taught in the program was, what information should be included for a future program, whether parents expected to continue to practice the stress relief activities taught, and whether parents felt they would continue to use the information that was taught in the program.

Demographic Questionnaire. Participants were asked to report their age, sex, marital status, ethnicity, highest level of education, number of children with and without an ASD or other developmental disability in the household, the child's diagnosis, number of adults living in the household, and the major stressors/concerns they have regarding their child(ren) with an ASD (APPENDIX B).

Development of Project Materials

Session 1. The outline and powerpoint for Session 1 is in APPENDIX H. The purpose of the first session was to focus on the stress of parenting a child with ASDs, early atypical development, getting the diagnosis, awareness of resources, and meeting schooling and resource needs.

First, research studies have shown that signs of autism can be present as early as 11 months of age, such as lack of eye contact and not responding to his or her name (Carbone et al., 2013; Senju & Johnson, 2009). Knowing the signs and milestones that children are supposed to meet can likely aid parents in acknowledging when their child's development is not following a normal

developmental trajectory. Therefore, handouts from the CDC website on developmental milestones were provided (APPENDIX I) which gave parents a month-by-month checklist that identifies where a child should be at that age, and a checklist of signs indicating when development is off trajectory. In addition, another handout with information on early intervention and ABA therapies for children who are missing developmental milestones under age three was included (APPENDIX J).

Next, the diagnostic process has been shown to be stressful for parents raising a child with autism. There are often a range of emotions felt from relief to grief to guilt. Behaviors and actions of family members must change in order to adjust to the new lifestyle that a diagnosis brings (Lasser & Corley, 2008; Mercer et al., 2006; Shuntermann, 2002). Information was therefore presented on two types of coping strategies, i.e., problem-focused and emotion-focused coping. Lastly, general information on autism spectrum disorders as a whole was provided on a separate handout (APPENDIX K).

The third topic discussed in Session 1 was the availability of resources. Stress levels can increase upon diagnosis if parents are not given resources and are left to look for resources themselves (Mulligan et al., 2010). Research studies show that parents who are given resources likely have significantly lower stress levels than parents who are left to look for resources on their own (Mulligan et al., 2010). Therefore, websites were provided to give parents information and resources based on where they live.

Lastly, meeting schooling and resource needs can be stressful for parents of children with autism. Oftentimes, the child's needs cannot be met in the classroom, and outside resources may have to be considered. Although it may be difficult to get these needs met, it is important to consider. Therefore, a list of benefits of 1:1 therapy in the classroom for the child was discussed. Research studies have also shown that the availability of teachers and other professionals are often limited, and parents' questions regarding their children's progress may go unanswered (Algood et al., 2011; Bitterman et al., 2008; Dabrowska & Pisula, 2010; Davis & Carter, 2008; Liptak et al., 2006; Wang et al., 2013). Therefore, a list of ways to keep in constant communication was discussed.

At the end of the first session, questions were asked by the researcher based on the four topics in order to facilitate a discussion. A stress relief activity was provided at the end of the session.

Session 2. The outline and powerpoint for Session 2 is located in APPENDIX L. The purpose of this session was to discuss lack of community support, strain on the couple relationship, and financial strain.

First, research studies have shown parents raising a child with autism often report a lack of both physical and emotional support from peers and family members (Johnson & Simpson, 2013). "Physical demands" refer to such daily demands as going to the store or school, whereas "emotional support" refers to parents having peers to talk to (Weiss et al., 2014). Since research has consistently shown that having community support through programs and from

other families raising children with autism (Hall, 2012) helps families cope, a list of support groups in the Inland Empire was provided.

Next, research studies have shown that there is an increase in divorce rates among families raising children with autism (Bluth et al., 2013). These studies show that practicing “daily positive affect” as a couple can help increase marital satisfaction, e.g., maintaining a positive outlook in both negative and positive situations with both the ASD child and the couple relationship, engaging in effective coping strategies (emotion-focused and problem-focused), and seeking support from family or the community (Ekas et al., 2015). Therefore, daily positive affect exercises were discussed. Respite care has also been shown to increase marital satisfaction (Ekas et al., 2015). Therefore, a list of respite care facilities in the Inland Empire was shared and discussed.

Lastly, the financial aspects of raising a child with autism have been shown to be a burden for many families (Parish, 2015). Research studies show that the most common sources of financial strain are early intervention therapies, medical expenses, becoming a single income household, specialized childcare, and education (e.g., if the school’s staff does not meet the child’s needs, or if the child will need additional therapy outside of school) (Barrett et al., 2015; Cidav et al., 2012; Couper, 2004; Parish, 2015; Schubart, Camacho, & Leslie, 2013; Sharpe & Baker, 2007). In order to alleviate some of these financial burdens, it is important for families to know what services an ASD child is qualified for. Some federal programs can cover a lot of the costs. Therefore, included in this

presentation was a website listing resources that gives additional information about what is available for families.

Discussion questions were included in order to facilitate a group discussion; this session concluded with an activity (APPENDIX M) that allowed parents to point out their child's positive characteristics and write a letter to them. "Positivity" has consistently been shown in the research to be beneficial to parents.

Session 3. The outline and powerpoint for Session 3 is in APPENDIX N. The purpose of this session was to discuss managing maladaptive behaviors, regulatory problems, communication difficulties between parent and child, and parents' perceptions of competency.

First, maladaptive behaviors vary from child to child and are oftentimes a substantial trigger for higher levels of stress in parents. These behaviors are defined as non-productive behaviors that are used in order to convey a message. They can also be physically harmful or destructive to self, property, or others (Devine, 2014; Woodman et al., 2014). Research studies have shown that parents benefit from understanding the function a particular behavior, so that they can teach them a more functional way to express their needs or wants. In addition, ABC data that helps determine the function of a particular behavior was reviewed and discussed. Examples were given by parents and more appropriate consequences were discussed as a group.

Second, regulatory problems are found to be stressful for parents since they are directly related to the health of the child (Kodak & Piazza, 2008). Most common among children with autism are sleeping problems, poor eating habits, and emotional regulation (Davis & Carter, 2008). In general, research studies have shown that in order to manage these difficulties, support from community programs as well as locating services that aid in the problem area have been helpful. Therefore, additional information based on the particular problem area children with autism may experience was included, and books written about particular problem areas were listed in the powerpoint presentation. A website was included in the powerpoint as well, which led to a page with topics and books based on those topics.

Next, communication difficulties between parents and their ASD child is a stressor for parents. Parents often experience difficulties understanding what their child is trying to communicate due to the mode of communication an ASD child may use (Algood et al., 2011; Ekas & Whitman, 2011). For instance, a child may try to communicate his needs or wants through aggression if that has been successful before. If parents are unable to understand their child's needs and wants, the child may feel as though the parent is not dependable and distrust can develop (Algood et al., 2011). In order to better communicate with their child, basic sign language instructions were given to parents on a separate handout (APPENDIX O). In addition to basic sign language, information about PECs (picture exchange communication system) was discussed. Since research

studies have shown that technological advances have also helped children's communication skills and language acquisition, an informational website on Proloquo2Go was discussed. Lastly, teaching spoken language to children with autism has also been beneficial for communication among parents and children. Therefore, language facilitation based on ABA techniques was discussed.

Finally, research shows that parents who have a lower sense of competency in raising their child with autism have higher levels of stress (McStay et al., 2014; Weiss et al., 2014). Therefore, information on how parents can get involved with their child in order to increase confidence in their parenting (and decreasing stress) was discussed. This session concluded with a discussion and a stress relief activity.

Session 4. The outline and powerpoint for Session 4 is located in APPENDIX P. The purpose of this session was to discuss the ambiguity of the child's future and the future of the family as a whole.

First, according to research, the ambiguity of the child's future has different implications for each family. One of the more intimidating concerns is the dependency of care the child may need as an adult. It may become a physical burden for families as their son or daughter gets older (Dabrowska & Pisula, 2010; Lasser & Corley, 2008). Parents' careers as well as social and leisure activities may also suffer due to the dependency of care and the additional attention needed by children with an ASD (Lambrechts et al., 2011; Meirsschaut et al., 2010).

Second, the future of the family is also impacted due to the life-changing decisions that must be considered, e.g., whether or not parents want to have more children (Hall & Graff, 2011; Shimoni et al., 2012) and decisions about career(s) must be made (Vacca, 2013). In order to cope with these potential concerns, research studies have shown that personality characteristics of the families can impact the stress levels parents are experiencing regarding these issues. Therefore, information on helping parents focus on positive emotions and examples of daily exercises was included and discussed.

To conclude this session, discussion questions were asked and a mindfulness activity was taught. Participants were then asked to complete the post – class assessments, e.g., the PSOC, the PSI – SF, a post- training self-assessment and a class evaluation form.

Procedure

Participants were recruited from the UCDD’s autism parent community support group at California State University, San Bernardino. Parents from the Monday night support group were given a flyer (APPENDIX A) a week prior to the beginning of the 4- session class. Participants expressed interest in attending the class and proceeded to attend the first session. Child care was provided through UCDD’s typical program offerings.

At the beginning of Session one, the participants were given an informed consent (APPENDIX Q) to read and sign before beginning the class. Once the consent form was completed, the participants filled out a demographic

questionnaire (APPENDIX B), the PSOC (APPENDIX C), the PSI-SF (APPENDIX D), and finally a pre- training self-assessment (APPENDIX E).

The researcher arrived early to each of the four sessions in order to set up necessary materials for each particular session (e.g. powerpoints, handouts, notebooks, pens) and set out snacks and water for the participants.

Each session began with providing an overview of the topics for that session, why it is stressful, and what research studies have shown to help parents cope. Questions were presented in order to facilitate a discussion among the parents. Finally, each session ended with a stress relief activity and the activity was based on what was shown to be beneficial in the research.

To conclude the final session, the researcher passed out the PSOC, PSI-SF, a post training self-assessment and the class evaluation form for the participants to fill out. After the assessments were completed and collected, the participants were debriefed about the purpose of the four sessions and given the researcher's contact information in case they were interested in the results or needed additional questions answered in the future.

CHAPTER THREE

RESULTS

Pre- and Post- Training Assessments

The pre- and post- assessment results below are based on Parents 1, 2, and 3 as they were the only participants to attend first and last sessions, as well as at least three of the four total sessions. (Note: these participants' children were diagnosed with Down syndrome/ "developmental delay" and not ASDs per se).

Parenting Sense of Competence Scale (PSOC)

Results are shown in Table 4 and suggest that the participating parents' perception of competency increased from Session 1 to Session 4.

Table 4. Mean Scores for the Pre- and Post- Parenting Sense of Competence Scale (Maximum Possible Score: 102)

Pre-training (N=3)	Post-training (N=3)
73	84

Parenting Stress Index – Short Form (PSI-SF)

Results comparing the pre- and post- class scores for the PSI – SF are shown in Table 5 and suggest that parents' stress levels decreased after the four session course.

Table 5. Pre- and Post- Parenting Stress Index – Short Form Means (Range High to Low: 180 - 36)

Pre-training (N=3)	Post-training (N=3)
99	91

Self – Assessment

For the self- assessment, parents rated themselves on a 7-point Likert scale for the 8 items (Table 6). Since the three respondents did not have children with an ASD, results for the first question and last question were not computed.

Items 2 – 7 were general questions that were somewhat relevant for the three participants. Items 2 – 4 assessed parents’ comfort in asking professionals involved in their child’s lives about their child’s progress, and about any questions or concerns they had. Results showed that parents’ overall comfort with speaking to professionals (involved in their child’s progress) increased (Table 6).

Item 5 examined overall stress and asked participants to rate their stress level on a daily basis (1= Not At All Stressed; 7= Very Stressed). Surprisingly, results indicated a slight *increase* in stress level after the trainings (Table 6). Items 6 – 7 asked participants to rate their perceived competency and confidence in regards to communication with their child and overall parenting. Results indicated that parents’ feeling of competency in determining their child’s needs/wants increased very slightly, while confidence (#7) stayed the same (Table 6).

Table 6. Pre- and Post- Means for the Self – Assessment Scale

Items	Pre-test (N=3)	Post-test (N=3)
1. Knowledge of autism spectrum disorders.	n/a	n/a
2. Comfort in contacting the child’s teacher about progress or any questions/concerns.	6	7
3. Comfort in contacting the child’s BI/therapist about progress or any questions/concerns.	5	7
4. Comfort in contacting professionals to address resource needs or any questions/concerns.	6	7
5. Stress on a daily basis.	3.7	4
6. Competency in accurately determining their child’s needs and wants.	5.7	6.3
7. Confidence in teaching their child better ways to communicate their needs.	6.3	6.3
8. Confidence in parenting their ASD child.	n/a	n/a

Post- Class Evaluation

Parents 1, 2, 3, and 4 completed the class evaluation. (While Parent 5 attended the last session, he did not complete the class evaluation).

The post- class evaluation showed that participants responded well to the class sessions. The participants generally stated that they would continue to use the daily stress relief activities, and that they felt that they learned from the information that was presented.

The first question asked parents whether the program benefitted them and/or their family as a whole. Parents found the information and the resources given useful overall (Table 7).

Table 7. Did This Program Benefit You And/Or Your Family? Why Or Why Not? (N = 4)

P1	“Yes, I found it very helpful.”
P2	“Yes.”
P3	“Yes, even though my child doesn’t have autism, I do see [similar] traits. Received tips how to help her.”
P4	“Yes, there were a couple new resources which I’ll use in the future.”

The second question asked parents which information was the most useful or helpful to them. Parents mentioned that the stress relief and the new resources were useful to them. Another parent also mentioned the maladaptive behaviors information in the third session was useful to them (Table 8).

Table 8. What Information Was The Most Useful Or Helpful To You? (N = 4)

P1	“Stress relief [activities].”
P2	(No response)
P3	“Tips given [in session 3 on] how to work with my child’s issue with my cell phone.”
P4	“The resource links will be useful to us.”

The third question asked which information was the least helpful to them. Two parents found all of the information useful to them, while one parent found the information not as useful since they were familiar with the stressors already (Table 9).

Table 9. Which Information Was The Least Useful Or Helpful To You? (N = 4)

P1	“Not too sure.”
P2	(No response)
P3	“Nothing. All positive information is a plus for me, personally.”
P4	“Most of the causes of stress were not useful to me because I was too familiar with them already.”

The fourth question asked parents what could be included in order to improve the program in the future. Two parents said that nothing in addition to the information already given needs to be added. One parent mentioned it may be more beneficial to go in depth of fewer topics, or discuss more topics but include fewer solutions (Table 10).

Table 10. What Could Be Included In Order To Improve The Program? (N = 4)

P1	"I think [the program] is fine the way it is."
P2	(No response)
P3	"Larger print handouts. [I'm] without glasses."
P4	"I would go more in depth on fewer topics or more topics and less solutions."

The fifth question asked parents whether or not they will continue to practice the stress relief activities that were taught in the program. Parents overall mentioned that they would continue to practice the stress relief activities that were taught (Table 11).

Table 11. Will You Continue To Practice The Stress Relief Activities That Were Taught In The Program? Why Or Why Not? (N = 4).

P1	"Yes I will. They are very helpful."
P2	"Yes."
P3	"Yes, the mindful link [from session 4] helps."
P4	"I was only present for one [activity] and will use it."

The sixth question asked parents whether or not they will continue to use the information they were taught in the program. The four parents mentioned that they will continue to use the information. The links that were included were shown to be helpful overall (Table 12).

Table 12. "Will You Continue To Use The Information That Was Taught In The Program? Why Or Why Not? (N = 4)

P1	"Yes."
P2	"Yes."
P3	"Yes, I believe in positive growth!"
P4	"Yes, the resources are always useful."

Additional Findings

The demographic questionnaire was completed by participants during Session 1, and it included a question that asked parents which components of raising a child with an ASD were the most stressful to them. The major stressors/concerns noted by each parent are summarized below (Table 13).

Table 13. Parents' Most Stressful Components in Raising a Child with an Autism Spectrum Disorder

	Parent 1	Parent 2	Parent 3	Parent 4*	Parent 5*
Major Stressors/ Concerns:	Lack of community support, unmet schooling needs, finances, relationship with spouse, maladaptive behaviors, regulatory problems, communication, perception of competency, ambiguity of child's future, future of family as a whole	Resources, lack of community support, unmet schooling needs, finances, maladaptive behaviors, regulatory problems, ambiguity of child's future, future of family as a whole	Resources, lack of community support, maladaptive behaviors, regulatory problems, communication, ambiguity of child's future, future of family as a whole	No response	No response

* Parent of child with an ASD.

All of these stressors were discussed throughout the four sessions.

CHAPTER FOUR

DISCUSSION

The purpose of this project was to create a parenting class for parents and caregivers of ASD children to decrease stress and also to aid families in developing the confidence to see themselves as competent in raising their child with autism. In addition, it was expected that after the four-session class, parents would have a better understanding of autism as a whole and how to get the resources and support they need. However, since the only parents to complete both the pre- and post- assessments were not parenting an ASD child (and only one of the two parents with an ASD child completed the class evaluation), the original goal of this project was not achieved.

Participants

Unexpectedly, the parents who ended up attending the sessions were raising children with ASD as well as those with disabilities other than ASDs, and there was inconsistent attendance of parents in general. Those who completed both the pre-post assessments were not parents of ASD children. Thus, information may not have been as relevant to them as it would have been for parents of children with autism.

The families who were originally invited to attend the trainings were already a part of a community support group at California State University, San

Bernardino (CSUSB's) that takes place on Monday evenings at the University Center for Developmental Disabilities (UCDD). The researcher had been given permission to be a "guest speaker" at the UCDD which has historically served primarily families who have a child with an ASD. The researcher delivered the flyer for the classes to the parents a week prior to the first session in order to allow parents to get an understanding of what topics were going to be discussed. The counselors at the UCDD were interested in the upcoming presentations and were looking forward to beginning the classes. Parents were informed at the beginning of the class that the research and class would focus on autism spectrum disorders, although the information would still be beneficial and informative for parents raising children with other disabilities.

As it turned out, the parents who are currently a part of the UCDD's community support program have children with a number of disabilities in addition to those with an ASD. Since UCDD is known for working with families with children with ASDs, it was expected that by recruiting parents from UCDD, a larger number of parents raising children with autism were anticipated to participate. However, over the past few years, the counselors noticed that the program was becoming more appealing to parents raising children with other disabilities such as Down syndrome as well. Thus, parents who now participate in the community support groups at UCDD have children with various disabilities in addition to autism.

Once the parents attending the first class session introduced themselves, the researcher noticed that the parents were raising children with other disabilities. (As mentioned above, the researcher explained to the parents that although this presentation is focused around autism, much of the information can be beneficial and informative to them as well). One parent mentioned in the class evaluation survey administered during the last class session that although her daughter was not diagnosed with an ASD, she noticed similar traits and therefore the trainings were beneficial to her. Research studies have shown that, for instance, children with disabilities such as Down syndrome have an increased risk of engaging in maladaptive behaviors (Will et al., 2016). In addition, children diagnosed with a nonspecific developmental disorder also have a higher likelihood of engaging in maladaptive behaviors (Hepburn & Maclean, 2009). That being said, the information presented in the four-session course can likely be relevant to families raising children with not only an ASD, but other neurodevelopmental disabilities as well.

Retention Issues

Retaining the participants was difficult in that the classes at UCDD that are offered take place four nights a week. Therefore, if a parent misses the Monday night class, it is convenient to make up a session another night that same week. Since the researcher only taught Monday nights, it would have been difficult to enforce trying to come to Monday nights only. The first class session had six participants who filled out the pre-test assessments. The researcher was told

after the first class that some of the parents typically attend *another* nights' group session, and that they were making up a class. As discussed earlier, Parent #1 consistently showed up throughout the 4-session course, and 2 parents made it to 3 of the 4 sessions. Parents #2 and #3 were given the powerpoint information and handouts from the class that was missed, and additionally the stress relief activity was given and explained. Two other fathers were involved in the second, third, and fourth session but missed the initial session when the pre-assessments were completed. In the future, a make-up class could be offered to ensure the desired audience (parents of children with an ASD) could be included in the pre-post test data.

Research studies show that retention in parenting classes is a common problem: factors such as time, cost, income and distance to designated meeting place have been shown to be obstacles for parents (Ouellette & Wilkerson, 2008). In addition, studies show that parents with higher levels of stress are even less likely to attend (Ouellette & Wilkerson, 2008). Finally, another obstacle for completion of parenting classes is the intensity of child's diagnosis/behavior issues the less "intense" the problem behaviors are, the less likely parents are to attend the classes (Heinrichs et al., 2005).

Research studies have shown that parenting classes are most beneficial for those parents who attend the entirety of a program (Fleming et al., 2015). The same study mentions that the younger the child is, the more likely parents are to attend the classes. Thus, achieving the desired audience, which would be

parents of younger, more recently diagnosed children with autism, may increase the likelihood of their attendance.

Pre- Post Assessments

Overall, the results of the pre-post class assessments indicate that for those parents who completed the assessments and attended at least 3 of the 4 sessions, participation in the program had a positive experience and benefitted from the information and the resources. The assessments also indicated that parents' stress levels decreased overall, and parents' knowledge of autism spectrum disorders increased while their competency and confidence in raising their child increased as well.

The main goal in creating the program was to decrease stress in parents raising a child with an ASD. The Parenting Stress Index – Short Form (PSI – SF) was used in order to determine whether the four-session program achieved the desired goal. The presentations included slides dedicated to research based information on what has been beneficial for parents who are experiencing each stressor. A stress relief activity was also discussed and taught at the end of each session, in hopes that parents would be able to incorporate these activities into their daily lives and further, be able to manage their stress levels on their own. Research studies have shown that stress relief activities and learning (and using) adaptive coping strategies have been shown to help reduce maladaptive coping strategies (i.e., avoidant behaviors, isolation) and increase mental well-being (Lai, et al., 2015). Results indicated that parents' stress levels from the first

session to the final session did decrease, slightly. Although the results from the current project were based on the data of parents with children with various developmental disabilities, research studies have shown that stressors are similar to those raising a child with an ASD (McCarthy et al., 2016). For example, maladaptive behaviors and intellectual shortcomings are a large stressor for families when it comes to raising a child with an ASD (Craig et al., 2016; Samson et al., 2015; Woodman et al., 2014). In addition, children with Down syndrome and other various neurodevelopmental disabilities such as Specific Learning Disorder (SpLD), and Attention Deficit Hyperactivity Disorder (ADHD) are stressful to families as maladaptive behaviors and learning delays are often present among children with these disabilities as well (Craig et al., 2016).

A second goal was to increase parents' confidence and competency in raising their child. The Parent Sense of Competency Scale (PSOC) was included to determine if there was an increase in competency and knowledge from the start of the first class session to the conclusion of the final class session. Results indicated that parents' competency in raising their child with a disability increased.

Support and knowledge that they are not alone in this process can be comforting to parents with children with disabilities (Hall, 2012). With increased competency and confidence in raising their child and getting what they need resource-wise, parents are likely to feel empowered (Murray et al., 2013). This empowerment and increase in self-efficacy allows parents and families to feel as

though they are making a difference in their lives as well as their child's life. Hope for the future is also positively impacted by the increased competency and confidence in parents (Murray et al., 2013). An important component of the increased sense of self-efficacy and competency in raising a child with special needs (which includes but is not limited to ASDs) is the relationship that is built between parents and teachers/professionals. When a good relationship is built, parents feel more in control of their children's progress and their confidence can increase (Murray et al., 2013).

Although the parents who completed the pre-post assessments were not parents of children with an ASD, the information could still be helpful to them. Having that additional support in general is typically beneficial to parents who are raising children with various disabilities (Hall, 2012). When raising children with disabilities, there are more demands and daily burdens that parents have to go through. Although they may not be the exact same burdens per family, the demands are still higher. Therefore, parents raising children with additional needs may experience similar stressors (Smith & Grzywacz, 2014).

The feedback from the participants' class evaluation forms suggested that, although they were not parents of children with autism per se, they benefited from the information that was taught in the four-session program. The stressors listed and the information taught can thus be helpful and informative to all parents raising children with special needs. The first goal of the program was to decrease stress among parents and it was achieved, likely due to stressors

amongst parents raising children with developmental disabilities are similar to those raising children with autism (McCarthy et al., 2016; Smith & Grzywacz, 2014). In addition, feelings of competence and confidence in parents who are raising children with special needs are typically lower (Preece, 2014). When parents are included in the interventions and made aware of how they can help their child and improve their relationship with their child, confidence and competency can increase (Preece, 2014). Parents' self-efficacy and sense of empowerment can likely improve through learning how to better manage the disability, benefitting not only the mental health of the parents, but the child and their development as well (Murray et al., 2013). Despite the differences in the types of developmental disabilities, there are many similarities in experiences amongst families, which speaks to why the current project may still provide important information to the parents who participated.

Fathers

Another goal of this project was to incorporate fathers. Research studies have shown that fathers typically tend to feel as though they are "left out" of the parenting process (Vacca, 2013). Research studies have also shown that fathers are affected by their perceived sense of helplessness, which further limits their contribution to daily tasks (Vacca, 2013). Mothers tend to be the caregivers who are home more often than fathers with the ASD child. Many research studies have shown that regarding early intervention, mothers are present and involved more often than fathers (Flippin & Crais, 2011). In addition, fathers of children

with autism report that they lack knowledge of the disability. Unfortunately, this leaves fathers feeling helpless and with an increased level of stress (Dardas & Ahmad, 2015).

Father involvement plays an important role in the ASD child's life. Research studies have shown that positive and consistent father involvement is likely to benefit the outcome of the child in many domains such as emotional regulation, cognitive development, and language development (Flippin & Crais, 2011). In addition to providing benefits for the ASD child, father involvement is likely to benefit both parents by decreasing maternal stress and stress on the family as a whole (Dardas & Ahmad, 2015; Flippin & Crais, 2011). Families (mothers and fathers) should also try to find a way to be equally involved in their child's development. Most early intervention programs have tried targeting both mothers and fathers as equal partners and "experts" on their child (Murry & McDonald, 1996). That being said, it is hoped that fathers can view themselves as more of a part in their child's development and further, feel less helpless.

The fathers who participated in Sessions 2 through 4 responded well to the trainings. One father (Parent 4) filled out the class evaluation survey at the end of the trainings and provided valuable feedback. He mentioned that there were new resources that were presented in which he could look into trying in the future. In addition, he mentioned that the stress relief activity that he was taught during the trainings was useful to him, and therefore will continue to use it. When fathers can actively manage their stress and use coping strategies, especially

problem-focused coping, it can benefit not only fathers but families as a whole (Dardas & Ahmad, 2015). Fathers tend to “set the tone” of the family, and so managing their own stress can help them in managing the family’s stress (Dardas & Ahmad, 2015).

Limitations and Future Trainings

There were several limitations of the current project.

First, including more specific criteria for parents’ eligibility into the program would be beneficial. Due to the fact that the parents’ children were older (mean age 12.2), much of the information presented in the first session, i.e., early atypical development, getting the diagnosis, and lack of resources, could potentially be irrelevant. Therefore, including a more specific criteria for parents’ eligibility, i.e., parents of children with autism ages under 5, could make the program more relevant. The information that was taught in the first session may have been more informative and appealing to those who more recently received the diagnosis since it is a newer experience for those parents. However, even those parents of older children with an ASD or other developmental disability can benefit from the information provided, in case they are planning on having another child or if they know someone who is concerned with their child’s development.

Second, in order to address the critique on the program (e.g., having too many topics, delving deeper into each one) the researcher can adjust the

curriculum to better fit participants' needs. For instance, the researcher can get insight as to what has proven to be the most stressful aspects of the diagnosis and raising their child with an ASD prior to the class begins. The demographic questionnaire includes a question that asks participants what they are most stressed about and gives a list of the 13 topics that were discussed over the four session program. Once the researcher gains insight on what topics are most stressful to the parents attending the class, the curriculum can be adjusted accordingly. However, instead of removing the topics altogether that are not relevant to the participants, the researcher can discuss those topics in less detail and focus more on the topics that are more pressing.

Third, another change in the curriculum could involve more hands-on practice or role plays for the parents. For instance, during the session where children's maladaptive behaviors were discussed, the researcher can include role playing scenarios where the behaviors can be acted out and further, managed with step by step instructions. The likelihood that parents will carry that information and implement it at home with their children could be higher.

In order to achieve more consistent attendance, the researcher could offer a tangible incentive for completing all four scheduled classes. With an incentive in place, the likelihood that participants would attend each session may increase. In addition, changing the times and day of the trainings to a more convenient time and day, participation may be more consistent. Lastly, sending out reminder

phone calls or emails may increase the likelihood that participants return to the subsequent sessions.

Summary and Conclusions

The purpose of this project was to create a parenting class for parents and caregivers of ASD children to decrease stress in these families, aid families in developing the confidence to see themselves as competent in raising their child with autism, increasing their knowledge of autism spectrum disorders.

Although the parents who completed the pre-post assessments were not parents of children with an ASD, the information presented can still benefit them. As discussed above, there are similarities among parents raising children with various developmental disabilities including numerous stressors (especially in regards to resource needs), the permanence of the disorders, and the outward, maladaptive behaviors of these children (Dabrowska & Pisula, 2010; Griffith et al., 2010). Parents who are affected by these stressors may benefit from instruction that helps to promote problem-focused coping (actively engaging in positive activities) that will help to lower their anxiety and stress levels (e.g., Dabrowska & Pisula, 2010).

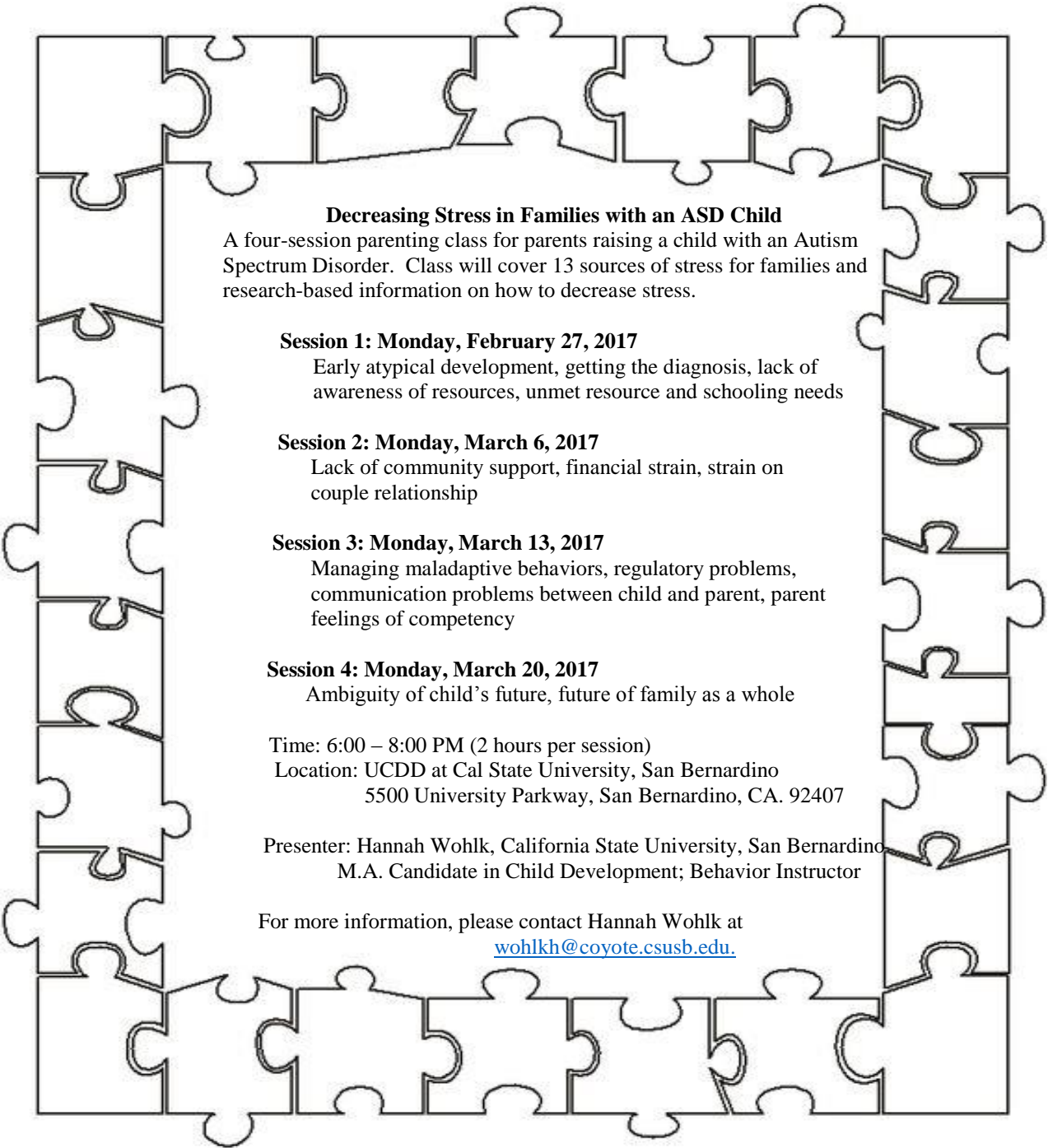
Overall, the results of the pre- post class assessments indicate that parents who participated in the program had a positive experience and benefitted from the information and the resources provided. The assessments also indicated that parents' stress levels decreased overall, while their competency

and confidence in raising their child increased as well. This project speaks to the need for more parenting classes for parents of children with developmental disabilities as issues are universal, such as stress management, problem behaviors, etc. (McCarthy, et al., 2016). Having stress levels at a more bearable level is likely to benefit families as well as the child, which is why teaching these coping strategies and stress management skills are important.

This project differs from other current interventions in multiple ways. It targeted both mothers and fathers, and included information on autism spectrum disorders as a whole in order to increase parents' education and knowledge of the disorder. Multiple stressors were discussed throughout the four sessions, and research-based information regarding what coping strategies are most beneficial was discussed. Parents also learned other stress management and coping skills. Parents were able to engage in a group discussion during these sessions to discuss personal experiences or ask any questions.

APPENDIX A

FLYER



Decreasing Stress in Families with an ASD Child

A four-session parenting class for parents raising a child with an Autism Spectrum Disorder. Class will cover 13 sources of stress for families and research-based information on how to decrease stress.

Session 1: Monday, February 27, 2017

Early atypical development, getting the diagnosis, lack of awareness of resources, unmet resource and schooling needs

Session 2: Monday, March 6, 2017

Lack of community support, financial strain, strain on couple relationship

Session 3: Monday, March 13, 2017

Managing maladaptive behaviors, regulatory problems, communication problems between child and parent, parent feelings of competency

Session 4: Monday, March 20, 2017

Ambiguity of child's future, future of family as a whole

Time: 6:00 – 8:00 PM (2 hours per session)

Location: UCDD at Cal State University, San Bernardino
5500 University Parkway, San Bernardino, CA. 92407

Presenter: Hannah Wohlk, California State University, San Bernardino
M.A. Candidate in Child Development; Behavior Instructor

For more information, please contact Hannah Wohlk at
wohlkh@coyote.csusb.edu.

APPENDIX B
DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire

code number: _____

Please fill out the following:

1. Your age: _____
2. Your sex (circle one): male female
3. Your relationship to ASD child: _____
4. Your current marital status (check one):
 single
 married
 separated/divorced
 widowed
 other (_____)
5. What is your ethnic background? (check one):
 Asian
 African American
 Caucasian
 Hispanic
 Native American
 Middle Eastern
 Biracial
 Other (_____)
6. What is the highest level of education you have completed? (check one):
 Did not complete high school
 High school graduate
 Some college/trade school
 Graduated with Bachelor's degree
 Some graduate school
 Graduate or professional degree _____
7. Number of your children diagnosed with an ASD or other developmental disability? _____
 - a. Age: _____
 - b. Sex: _____
 - c. Ethnicity: _____

8. What is your child's diagnosis/diagnoses?
- a. Autism _____
 - b. Asperger's _____
 - c. PDD-NOS _____
 - d. Other: _____
9. Number of children without a disability?
- a. Age: _____
 - b. Sex: _____
 - c. Ethnicity: _____
10. Number of adults living in the home? _____
11. What are your major stressors/concerns with parenting a child with ASD? (Circle all that apply)
- a. Diagnostic process
 - b. Resources
 - c. Lack of support from community
 - d. Unmet resource and/or schooling needs
 - e. Finances
 - f. Relationship with spouse
 - g. Child's maladaptive behaviors
 - h. Child's regulatory problems (sleeping, eating, emotion regulation/impulsivity)
 - i. Communication between you and child
 - j. Perception of competency
 - k. Ambiguity of your child's future
 - l. Future of family as a whole
 - m. Other _____

Developed by: Hannah Wohlk

APPENDIX C
PARENTING SENSE OF COMPETENCE SCALE

Parenting Sense of Competence Scale (PSOC)

code number: _____

Please respond to each of the following items by circling the number that most closely corresponds to what you believe is accurate for you, on a scale ranging from (1) strongly disagree to (6) strongly agree.

1 = strongly disagree

4 = slightly agree

2 = somewhat disagree

5 = somewhat agree

3 = slightly disagree

6 = strongly agree

	Strongly Disagree	Somewhat Disagree	Slightly Disagree	Slightly Agree	Somewhat Agree	Strongly Agree
1. The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired.	1	2	3	4	5	6
2. Even though being a parents could be rewarding, I am frustrated now while my child is at his/her present age.	1	2	3	4	5	6
3. I go to bed the same way I wake up in the morning, feeling like I have not accomplished a whole lot.	1	2	3	4	5	6
4. I do not know why it is, but sometimes when I'm supposed to be in control, I feel more like the one being manipulated.	1	2	3	4	5	6
5. My mother/father was better prepared to be a good mother/father than I am.	1	2	3	4	5	6
6. I would make a fine model for a new mother/father to follow in order to learn what she/he would need to know in order to be a good parent.	1	2	3	4	5	6
7. Being a parent is manageable, and any problems are easily solved.	1	2	3	4	5	6
8. A difficult problem in being a parent is not knowing whether you're doing a good job or not.	1	2	3	4	5	6

	Strongly Disagree	Somewhat Disagree	Slightly Disagree	Slightly Agree	Somewhat Agree	Strongly Agree
9. Sometimes I feel like I'm not getting anything done.	1	2	3	4	5	6
10. I meet my own personal expectations for expertise in caring for my child.	1	2	3	4	5	6
11. If anyone can find the answer to what is troubling my child, I am the one.	1	2	3	4	5	6
12. My talents and interests are in other areas, not in being a parent.	1	2	3	4	5	6
13. Considering how long I've been a mother/father, I feel thoroughly familiar with this role.	1	2	3	4	5	6
14. If being a mother/father was only more interesting, I would be motivated to do a better job as a parent.	1	2	3	4	5	6
15. I honestly believe I have all the skills necessary to be a good mother/father to my child.	1	2	3	4	5	6
16. Being a parent makes me tense and anxious.	1	2	3	4	5	6
17. Being a good mother/father is a reward in itself.	1	2	3	4	5	6

Johnston, C., & Mash, E. J. (1989). A measure of parenting satisfaction and efficacy. *Journal of Clinical Child Psychology, 18*(2), 167-175.

APPENDIX D
PARENTING STRESS INDEX – SHORT FORM

Parenting Stress Index - Short Form*code number:* _____**Parental Distress**

	Strongly Disagree	Slightly Disagree	Not Sure	Slightly Agree	Strongly Agree
1. I often have the feeling that I cannot handle things very well.	1	2	3	4	5
2. I find myself giving up more of my life to meet my children's needs than I ever expected.	1	2	3	4	5
3. I feel trapped by my responsibilities as a person.	1	2	3	4	5
4. Since having this child, I have been unable to do new and different things.	1	2	3	4	5
5. Since having this child, I feel that I am almost never able to do things that I like to do.	1	2	3	4	5
6. I am unhappy with the purchase of clothing that I made for myself.	1	2	3	4	5
7. There are quite a few things that bother me about my life.	1	2	3	4	5
8. Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend).	1	2	3	4	5

	Strongly Disagree	Slightly Disagree	Not Sure	Slightly Agree	Strongly Agree
9. I feel alone and without friends.	1	2	3	4	5
10. When I go to a party, I usually expect to not enjoy myself.	1	2	3	4	5
11. I am not as interested in people as I used to be.	1	2	3	4	5
12. I don't enjoy things as much as I used to.	1	2	3	4	5

Parent-Child Dysfunctional Interaction

13. My child rarely does things for me that make me feel good.
14. Most times I feel that my child likes me and wants to be close to me.
15. My child smiles at me much less than I expected.
16. When I do things for my child, I get the feelings that my efforts are not appreciated very much.
17. When playing, my child doesn't often giggle or laugh.
18. My child doesn't seem to learn as quickly as most children.

1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

	Strongly Disagree	Slightly Disagree	Not Sure	Slightly Agree	Strongly Agree
19. My child doesn't seem to smile as much as most children.	1	2	3	4	5
20. My child is not able to do as much as I expected.	1	2	3	4	5
21. It takes a long time and it is very hard for my child to get used to new things.	1	2	3	4	5

For statement 22, choose from choices 1 to 5 below.

22. I feel that I am:

1. a very good parent
2. a better than average parent
3. an average parent
4. a person who has some trouble being a parent
5. not very good at being a parent

23. I expected to have closer and warmer feelings for my child than I do and this bothers me.	1	2	3	4	5
24. Sometimes my child does things that bother me just to be mean.	1	2	3	4	5

Difficult Child

	Strongly Disagree	Slightly Disagree	Not Sure	Slightly Agree	Strongly Agree
25. My child seems to cry or fuss more often than most children.	1	2	3	4	5
26. My child generally wake up in a bad mood.	1	2	3	4	5
27. I feel that my child is very moody and easily upset.	1	2	3	4	5
28. My child does a few things which bother me a great deal.	1	2	3	4	5
29. My child reacts very strongly when something happens that my child doesn't like.	1	2	3	4	5
30. My child gets upset easily over the smallest thing.	1	2	3	4	5
31. My child's sleeping or eating schedule was much harder to establish than I expected.	1	2	3	4	5

For statement 32, choose from choices 1 to 5 below.

32. I have found that getting my child to do something or stop doing something is:

1. much harder than I expected
2. somewhat harder than I expected
3. about as hard as I expected
4. somewhat easier than I expected
5. much easier than I expected

For statement 33, choose from choices 1 to 5 below.

33. Think carefully and count the number of things your child does that bothers you.

For example: dawdles, refuses to listen, overactive, cries, interrupts, fights, whines, etc. Please circle the number which includes the number of things you counted.

1. 1-3
2. 4-5
3. 6-7
4. 8-9
5. 10+

34. There are some things my child does that really bother me a lot.

35. My child turned out to be more of a problem that I had expected.

36. My child makes more demands on me than most children.

Strongly Disagree	Slightly Disagree	Not Sure	Slightly Agree	Strongly Agree
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

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Odessa, FL: Psychological Assessment Resources, Inc.

APPENDIX E
PRE- TRAINING ASSESSMENT

Pre- training Assessment:

code number: _____

Instructions: Circle the number that best reflects how you feel **now**:

1. How **knowledgeable** about autism do you feel right now?

Not at all comfortable							Very comfortable
1	2	3	4	5	6	7	

2. How **comfortable** do you feel now with reaching out to your child's teacher to discuss your child's progress or with any questions/concerns you may have?

Not at all comfortable							Very comfortable
1	2	3	4	5	6	7	

3. How **comfortable** do you feel now asking your child's therapist/BI any questions you may have about your child or his/her progress?

Not at all comfortable							Very comfortable
1	2	3	4	5	6	7	

4. How **comfortable** do you feel now asking for help from professionals regarding your child's resource needs?

Not at all comfortable							Very comfortable
1	2	3	4	5	6	7	

5. How **well** do you feel you can accurately determine your child's wants and/or needs now?

Not at all comfortable							Very comfortable
1	2	3	4	5	6	7	

6. How **stressed** do you feel now on a daily basis?

Not at all stressed							Very stressed
1	2	3	4	5	6	7	

7. How **confident** do you feel now in teaching your child better ways to communicate their needs?

Not at all confident							Very confident
1	2	3	4	5	6	7	

8. How **confident** do feel being able to parent your ASD child now?

Not at all confident							Very confident
1	2	3	4	5	6	7	

APPENDIX F
POST- TRAINING ASSESSMENT

Post-training Assessment:

code number: _____

Instructions: Circle the number that best reflects how you feel **now**:

1. How **knowledgeable** about autism do you feel right now?

Not at all comfortable							Very comfortable
1	2	3	4	5	6	7	

2. How **comfortable** do you feel now with reaching out to your child's teacher to discuss your child's progress or with any questions/concerns you may have?

Not at all comfortable							Very comfortable
1	2	3	4	5	6	7	

3. How **comfortable** do you feel now asking your child's therapist/BI any questions you may have about your child or his/her progress?

Not at all comfortable							Very comfortable
1	2	3	4	5	6	7	

4. How **comfortable** do you feel now asking for help from professionals regarding your child's resource needs?

Not at all comfortable							Very comfortable
1	2	3	4	5	6	7	

5. How **well** do you feel you can accurately determine your child's wants and/or needs now?

Not at all comfortable							Very comfortable
1	2	3	4	5	6	7	

6. How **stressed** do you feel now on a daily basis?

Not at all stressed							Very stressed
1	2	3	4	5	6	7	

7. How **confident** do you feel now in teaching your child better ways to communicate their needs?

Not at all confident							Very confident
1	2	3	4	5	6	7	

8. How **confident** do feel being able to parent your ASD child now?

Not at all confident							Very confident
1	2	3	4	5	6	7	

Developed by Hannah Wohlk

APPENDIX G
CLASS EVALUATION

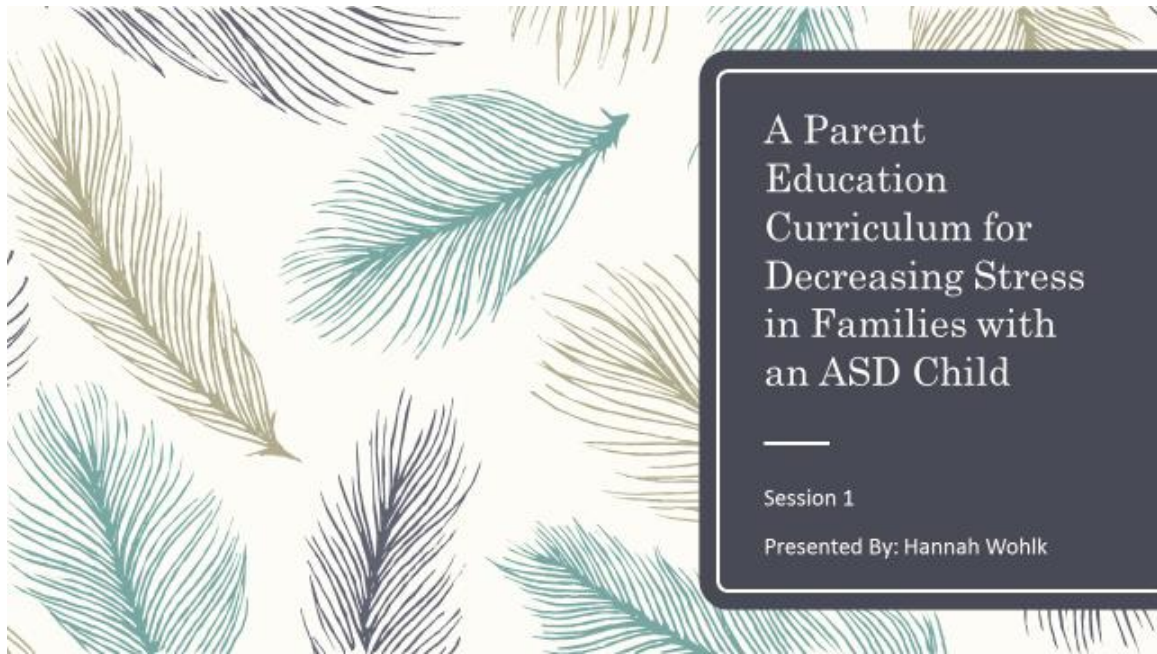
Class Evaluation

code number: _____

1. Did this program benefit you and/or your family? Why or why not?
2. What information was the most useful or helpful to you?
3. What information was least useful or helpful to you?
4. What can be included in order to improve the program?
5. Will you continue to practice the stress relief activities that were taught in the program? Why or why not?
6. Will you continue to use the information that was taught in the program? Why or why not?

Developed by Hannah Wohlk

APPENDIX H
SESSION 1 POWERPOINT



Welcome!

- Informed consent
- Introductions
- Assessments
- Overview of four-session program



Overview of Program

- Session 1
 - Stress and parenting a child with an ASD
 - Early atypical development
 - Getting the diagnosis
 - *ASD characteristics*
 - Lack of awareness of resources
- Session 2
 - Lack of community support
 - Financial strain
 - Strain on couple relationship
- Session 3
 - Managing maladaptive behaviors
 - Regulatory problems
 - Communication problems between child and parent
 - Parent perception of competency
- Session 4
 - Ambiguity of child's future
 - Future of family as a whole



Session 1

I. Early Atypical Development

- Atypical development can be noticed as early as 11 months
- Diagnoses occur at age three
- Leaves a big gap in between noticing the atypical development or behavior and receiving a formal diagnosis



Early Atypical Development continued

- Some noticeable signs are
 - Lack of eye contact (one of the earliest signs)
 - Unresponsive to name
 - No reciprocal interactions
 - Lack of language development
 - Lack of communication skills
 - Motor development difficulties
 - Playing with toys inappropriately



Why Is This Stressful?

- Research has shown that parents feel stressed in regards to early atypical development because
 - Uncertainty of why there are these missed milestones
 - Eye contact is partially the foundation of language
 - They may feel detached from their child/loss of connection
 - May be unable to keep up with peers or other children their age
 - *Communication, motor development*
 - Parents may still be adjusting to the parenting role



What Helps?

- Being proactive and being aware of your child's progress and milestones
 - *See handout from CDC website (www.cdc.gov) on milestones*
- Look to professionals
 - Ask questions!
- Look into getting your child into early intervention programs
 - ABA (applied behavior analysis)
 - *See handout with information on ABA therapy and its benefits*



II. Getting The Diagnosis

- Getting the diagnosis of autism can lead to many different emotions for parents and families
 - Relief
 - Worry
 - *What is autism?*
 - See handout
- Grief
 - Guilt/self-blame
 - Resistance
 - *Denial, fear*



Why Is This Stressful?

- The diagnosis can be stressful because with the diagnosis may come questions
- Research has shown that parents lose their “ideal child”
 - Have to change their ideas/behaviors
- Some research has shown that parents are likely to blame themselves



Why Is This Stressful? continued

- Parents may feel that it is “just a phase” when in actuality the diagnosis is likely to last a lifetime
 - Permanence of disorder
- Brings about ambiguity when looking into what the future holds for the child



What Helps?

- Community and familial support has been shown to relieve stress for parents
- Engaging in coping strategies
 - Problem-focused
 - Emotion-focused



Problem-Focused Coping

- There are two types of coping that were discussed amongst the research
- Problem-focused coping
 - Targets the actual problem, and reduces stress by the removal of the stressor itself



Emotion-Focused Coping

- Parents have benefited through use of emotion focused coping
- Emotion-focused coping:
 - A way to decrease stress by decreasing or eliminating the emotions that are negatively associated with the stressor
 - *Increase the positive emotions*
 - *Decrease the negative emotions*
- May be more beneficial because of the longevity of the disorder



III. Awareness of Resources

- Research has shown that parents who are not given resources upon time of diagnosis have increased levels of stress
- If parents are left to find resources themselves there was a higher level of dissatisfaction and helplessness



What Helps?

- Getting information upon diagnosis can help decrease stress in parents
- Asking professionals any questions and getting answers can also benefit parents
- There are websites that have resources available to parents based on what they are looking for and their location
- www.autismspeaks.org
- www.autismnow.org



IV. Meeting Resource and Schooling Needs

- When parents' needs are not met in the classroom, stress levels can increase
- There may be a lack of availability of therapy services
 - Especially as the children get older
- Services may lack
 - Healthcare
 - Therapy
- Parents also may want their child to interact more with typically developing peers
- Lack of opportunity to make time to meet with child's teachers and/or those involved in the child's education plan



Why Is This Stressful?

- Parents may feel like their child would benefit from being with their peers but with the other demands placed on them, socializing with their peers may not be the top priority
- Academics
- Behavior support
- Speech/OT (other therapies)



Therapy in School - Benefits

- Behavior management
 - *Less maladaptive behaviors*
 - More learning time for the child
 - *Child more able to engage in appropriate and positive behaviors*
- Verbal behavior
 - *Appropriate verbal behavior is reinforced*
 - *Aims to decrease inappropriate behaviors*
- ABA therapy in home and school is ideal
 - More exposure



Why Is This Stressful? continued

- There are many people involved in a child's education plan and it may be difficult to maintain contact on a regular basis
- Not hearing how their child is doing in school as often as they'd like to
- Other types of therapies may not be available so parents and the school may have to reach out to other companies in order to fulfill a particular child's needs
 - Can be expensive, time consuming



What Helps?

- For schooling needs, parents have benefited by keeping in consistent and constant communication with the individuals involved in the child's education plan
- IEPs
 - Getting all of the individuals involved in one room for a meeting in order to discuss progress, future goals, etc.



Communication Between Parents and Teachers

- Having multiple ways to contact your child's teacher
 - Email, school phone, etc.
- Attending meetings/IEPs
- Maintaining current copies of IEPs
- Asking questions and making time to discuss school



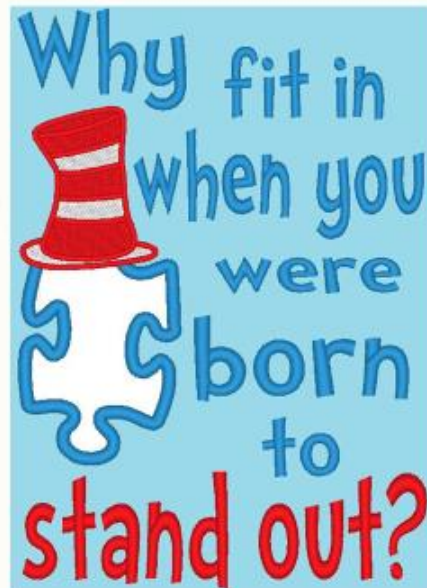
Discussion

- Were there any missed milestones that you noticed in your child?
- How did you go about the diagnostic process? How did you feel once your child was diagnosed?
- What helped you through the initial first couple months after the diagnosis?
- In regards to schooling, how do you go about making sure you and your child's teacher are on the same page?



Activity

- Research has shown that people who consistently engage in expressive writing have been able to decrease anxiety, and have an increase in psychological well-being.
- Take the next 10 minutes and write about how you are feeling right now about anything in general! It can be anything - work, family, your drive here, a fun experience, your plans for the weekend, etc.





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APPENDIX I
MILESTONES HANDOUTS

Your Baby at 2 Months



Child's Name _____

Child's Age _____

Today's Date _____

How your child plays, learns, speaks, and acts offers important clues about your child's development. Developmental milestones are things most children can do by a certain age.

Check the milestones your child has reached by the end of 2 months. Take this with you and talk with your child's doctor at every visit about the milestones your child has reached and what to expect next.

What Most Babies Do at this Age:

Social/Emotional

- Begins to smile at people
- Can briefly calm himself (may bring hands to mouth and suck on hand)
- Tries to look at parent

Language/Communication

- Coos, makes gurgling sounds
- Turns head toward sounds

Cognitive (learning, thinking, problem-solving)

- Pays attention to faces
- Begins to follow things with eyes and recognize people at a distance
- Begins to act bored (frowns, fussy) if activity doesn't change

Movement/Physical Development

- Can hold head up and begins to push up when lying on tummy
- Makes smoother movements with arms and legs

Act Early by Talking to Your Child's Doctor if Your Child:

- Doesn't respond to loud sounds
- Doesn't watch things as they move
- Doesn't smile at people
- Doesn't bring hands to mouth
- Can't hold head up when pushing up when on tummy

Tell your child's doctor or nurse if you notice any of these signs of possible developmental delay for this age, and talk with someone in your community who is familiar with services for young children in your area, such as your state's public early intervention program. For more information, go to www.cdc.gov/concerned or call 1-800-CDC-INFO.

Adapted from CHECKS FOR YOUR BABY AND YOUNG CHILD: BIRTH TO AGE 5, 3rd Edition, edited by Steven Shelov and Tanya Foster. Reprinted © 1993, 1995, 1998, 2004, 2009 by The American Academy of Pediatrics and GREAT PEDIATRIC GUIDELINES FOR HEALTH & WELLNESS OF INFANTS, CHILDREN, AND ADOLESCENTS, Third Edition, edited by Joseph Deppe, Jr., Judith S. Shaw, and Paula M. Dawson, 2008, Elk Grove Village, IL: American Academy of Pediatrics. This selection intended to not a substitute for a standardized, validated developmental screening tool.

www.cdc.gov/actearly | 1-800-CDC-INFO



Learn the Signs. Act Early.

Your Baby at 4 Months



Child's Name _____

Child's Age _____

Today's Date _____

How your child plays, learns, speaks, and acts offers important clues about your child's development. Developmental milestones are things most children can do by a certain age.

Check the milestones your child has reached by the end of 4 months. Take this with you and talk with your child's doctor at every visit about the milestones your child has reached and what to expect next.

What Most Babies Do at this Age:

Social/Emotional

- Smiles spontaneously, especially at people
- Likes to play with people and might cry when playing stops
- Copies some movements and facial expressions, like smiling or frowning

Language/Communication

- Begins to babble
- Babbles with expression and copies sounds he hears
- Cries in different ways to show hunger, pain, or being tired

Cognitive (learning, thinking, problem-solving)

- Lets you know if she is happy or sad
- Responds to affection
- Reaches for toy with one hand
- Uses hands and eyes together, such as seeing a toy and reaching for it
- Follows moving things with eyes from side to side
- Watches faces closely
- Recognizes familiar people and things at a distance

Movement/Physical Development

- Holds head steady, unsupported
- Pushes down on legs when feet are on a hard surface
- May be able to roll over from tummy to back
- Can hold a toy and shake it and swing at dangling toys
- Brings hands to mouth
- When lying on stomach, pushes up to elbows

Act Early by Talking to Your Child's Doctor if Your Child:

- Doesn't watch things as they move
- Doesn't smile at people
- Can't hold head steady
- Doesn't coo or make sounds
- Doesn't bring things to mouth
- Doesn't push down with legs when feet are placed on a hard surface
- Has trouble moving one or both eyes in all directions

Tell your child's doctor or nurse if you notice any of these signs of possible developmental delay for this age, and talk with someone in your community who is familiar with services for young children in your area, such as your state's public early intervention program. For more information, go to www.cdc.gov/concerned or call 1-800-CDC-INFO.

Adapted from *CARING FOR YOUR BABY AND YOUNG CHILD: BIRTH TO AGE 5*, 14th Edition, edited by Steven Shelov and Tanya Remer Altmann © 1991, 1993, 1994, 2004, 2009 by the American Academy of Pediatrics and *BRIGHT FUTURES: GUIDELINES FOR HEALTH SUPERVISION OF INFANTS, CHILDREN, AND ADOLESCENTS*, Third Edition, edited by Joseph Hooper, Jr., Judith S. Shew, and Paula M. Surocky, 2004, St. Louis, Mo: Elsevier, © American Academy of Pediatrics. This milestone checklist is not a substitute for a standardized, validated developmental screening tool.

www.cdc.gov/actearly | 1-800-CDC-INFO



Learn the Signs. Act Early.

Your Baby at 6 Months



Child's Name _____

Child's Age _____

Today's Date _____

How your child plays, learns, speaks, and acts offers important clues about your child's development. Developmental milestones are things most children can do by a certain age.

Check the milestones your child has reached by the end of 6 months. Take this with you and talk with your child's doctor at every visit about the milestones your child has reached and what to expect next.

What Most Babies Do at this Age:

Social/Emotional

- Knows familiar faces and begins to know if someone is a stranger
- Likes to play with others, especially parents
- Responds to other people's emotions and often seems happy
- Likes to look at self in a mirror

Language/Communication

- Responds to sounds by making sounds
- Strings vowels together when babbling ("ah," "eh," "oh") and likes taking turns with parent while making sounds
- Responds to own name
- Makes sounds to show joy and displeasure
- Begins to say consonant sounds (jabbering with "m," "b")

Cognitive (learning, thinking, problem-solving)

- Looks around at things nearby
- Brings things to mouth
- Shows curiosity about things and tries to get things that are out of reach
- Begins to pass things from one hand to the other

Movement/Physical Development

- Rolls over in both directions (front to back, back to front)
- Begins to sit without support
- When standing, supports weight on legs and might bounce
- Rocks back and forth, sometimes crawling backward before moving forward

Act Early by Talking to Your Child's Doctor if Your Child:

- Doesn't try to get things that are in reach
- Shows no affection for caregivers
- Doesn't respond to sounds around him
- Has difficulty getting things to mouth
- Doesn't make vowel sounds ("ah", "eh", "oh")
- Doesn't roll over in either direction
- Doesn't laugh or make squealing sounds
- Seems very stiff, with tight muscles
- Seems very floppy, like a rag doll

Tell your child's doctor or nurse if you notice any of these signs of possible developmental delay for this age, and talk with someone in your community who is familiar with services for young children in your area, such as your state's public early intervention program. For more information, go to www.cdc.gov/concerned or call 1-800-CDC-INFO.

Adapted from Caring for Your Baby and Young Child: Birth to Age 5, Fifth Edition, edited by Steven Shelov and Tanya Reamer Altman © 1991, 1993, 1998, 2004, 2009 by the American Academy of Pediatrics and BRIGHT FUTURES: GUIDELINES FOR HEALTH SUPERVISION OF INFANTS, CHILDREN, AND ADOLESCENTS, Third Edition, edited by Joseph Hagan, Jr., Judith S. Shaw, and Paula M. Duncan, 2000, Elk Grove Village, IL: American Academy of Pediatrics. This milestone checklist is not a substitute for a standardized, validated developmental screening tool.

www.cdc.gov/actearly | 1-800-CDC-INFO



Learn the Signs. Act Early.

Your Baby at 9 Months



Child's Name _____

Child's Age _____

Today's Date _____

How your child plays, learns, speaks, and acts offers important clues about your child's development. Developmental milestones are things most children can do by a certain age.

Check the milestones your child has reached by the end of 9 months. Take this with you and talk with your child's doctor at every visit about the milestones your child has reached and what to expect next.

What Most Babies Do at this Age:

Social/Emotional

- May be afraid of strangers
- May be clingy with familiar adults
- Has favorite toys

Language/Communication

- Understands "no"
- Makes a lot of different sounds like "mamama" and "babababab"
- Copies sounds and gestures of others
- Uses fingers to point at things

Cognitive (learning, thinking, problem-solving)

- Watches the path of something as it falls
- Looks for things he sees you hide
- Plays peek-a-boo
- Puts things in her mouth
- Moves things smoothly from one hand to the other
- Picks up things like cereal o's between thumb and index finger

Movement/Physical Development

- Stands, holding on
- Can get into sitting position
- Sits without support
- Pulls to stand
- Crawls

Act Early by Talking to Your Child's Doctor if Your Child:

- Doesn't bear weight on legs with support
- Doesn't sit with help
- Doesn't babble ("mama", "baba", "dada")
- Doesn't play any games involving back-and-forth play
- Doesn't respond to own name
- Doesn't seem to recognize familiar people
- Doesn't look where you point
- Doesn't transfer toys from one hand to the other

Tell your child's doctor or nurse if you notice any of these signs of possible developmental delay for this age, and talk with someone in your community who is familiar with services for young children in your area, such as your state's public early intervention program. For more information, go to www.cdc.gov/concerned or call 1-800-CDC-INFO.

The American Academy of Pediatrics recommends that children be screened for general development at the 9-month visit. Ask your child's doctor about your child's developmental screening.

Adapted from Caring for Your Baby and Young Child: Birth to Age 5, Fifth Edition, edited by Steven Shelov and Tanya Renner Abrams © 1991, 1993, 1998, 2004, 2009 by the American Academy of Pediatrics and Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, Third Edition, edited by Joseph Hagan, Jr., Judith S. Shaw, and Paula M. Duncan, 2008, 5th Green Village, IL: American Academy of Pediatrics. This milestone checklist is not a substitute for a standardized, validated developmental screening test.

www.cdc.gov/actearly | 1-800-CDC-INFO



Learn the Signs. Act Early.

Your Child at 1 Year



Child's Name _____

Child's Age _____

Today's Date _____

How your child plays, learns, speaks, and acts offers important clues about your child's development. Developmental milestones are things most children can do by a certain age.

Check the milestones your child has reached by his or her 1st birthday. Take this with you and talk with your child's doctor at every visit about the milestones your child has reached and what to expect next.

What Most Children Do at this Age:

Social/Emotional

- Is shy or nervous with strangers
- Cries when mom or dad leaves
- Has favorite things and people
- Shows fear in some situations
- Hands you a book when he wants to hear a story
- Repeats sounds or actions to get attention
- Puts out arm or leg to help with dressing
- Plays games such as "peek-a-boo" and "pat-a-cake"

Language/Communication

- Responds to simple spoken requests
- Uses simple gestures, like shaking head "no" or waving "bye-bye"
- Makes sounds with changes in tone (sounds more like speech)
- Says "mama" and "dada" and exclamations like "uh-oh!"
- Tries to say words you say

Cognitive (learning, thinking, problem-solving)

- Explores things in different ways, like shaking, banging, throwing
- Finds hidden things easily
- Looks at the right picture or thing when it's named
- Copies gestures
- Starts to use things correctly; for example, drinks from a cup, brushes hair
- Bangs two things together
- Puts things in a container, takes things out of a container
- Lets things go without help
- Pokes with index (pointer) finger
- Follows simple directions like "pick up the toy"

Movement/Physical Development

- Gets to a sitting position without help
- Pulls up to stand, walks holding on to furniture ("cruising")
- May take a few steps without holding on
- May stand alone

Act Early by Talking to Your Child's Doctor if Your Child:

- Doesn't crawl
- Can't stand when supported
- Doesn't search for things that she sees you hide.
- Doesn't say single words like "mama" or "dada"
- Doesn't learn gestures like waving or shaking head
- Doesn't point to things
- Loses skills he once had

Tell your child's doctor or nurse if you notice any of these signs of possible developmental delay for this age, and talk with someone in your community who is familiar with services for young children in your area, such as your state's public early intervention program. For more information, go to www.cdc.gov/concerned or call 1-800-CDC-INFO.

Adapted from Caring for Your Baby and Young Child: Birth to Age 5, Fifth Edition, edited by Steven Shelov and Tanya Farmer Altmann. © 1991, 1993, 1996, 2004, 2009 by the American Academy of Pediatrics and SMART PUPPETS: GUIDELINES FOR HEALTH SUPERVISION OF INFANTS, CHILDREN, AND ADOLESCENTS, Third Edition, edited by Joseph Hagan, Jr., Judith S. Shaw, and Paula M. Duncan, 2008, Elk Grove Village, IL: American Academy of Pediatrics. This milestone checklist is not a substitute for a standardized, validated developmental screening tool.

www.cdc.gov/actearly | 1-800-CDC-INFO



Learn the Signs. Act Early.

Your Child at 18 Months (1½ Yrs)



Child's Name _____

Child's Age _____

Today's Date _____

How your child plays, learns, speaks, and acts offers important clues about your child's development. Developmental milestones are things most children can do by a certain age.

Check the milestones your child has reached by the end of 18 months. Take this with you and talk with your child's doctor at every visit about the milestones your child has reached and what to expect next.

What Most Children Do at this Age:

Social/Emotional

- Likes to hand things to others as play
- May have temper tantrums
- May be afraid of strangers
- Shows affection to familiar people
- Plays simple pretend, such as feeding a doll
- May cling to caregivers in new situations
- Points to show others something interesting
- Explores alone but with parent close by

Language/Communication

- Says several single words
- Says and shakes head "no"
- Points to show someone what he wants

Cognitive (learning, thinking, problem-solving)

- Knows what ordinary things are for; for example, telephone, brush, spoon
- Points to get the attention of others
- Shows interest in a doll or stuffed animal by pretending to feed
- Points to one body part
- Scribbles on his own
- Can follow 1-step verbal commands without any gestures; for example, sits when you say "sit down"

Movement/Physical Development

- Walks alone
- May walk up steps and run
- Pulls toys while walking
- Can help undress herself
- Drinks from a cup
- Eats with a spoon

Act Early by Talking to Your Child's Doctor if Your Child:

- Doesn't point to show things to others
- Can't walk
- Doesn't know what familiar things are for
- Doesn't copy others
- Doesn't gain new words
- Doesn't have at least 6 words
- Doesn't notice or mind when a caregiver leaves or returns
- Loses skills he once had

Tell your child's doctor or nurse if you notice any of these signs of possible developmental delay for this age, and talk with someone in your community who is familiar with services for young children in your area, such as your state's public early intervention program. For more information, go to www.cdc.gov/concerned or call 1-800-CDC-INFO.

The American Academy of Pediatrics recommends that children be screened for general development and autism at the 18-month visit. Ask your child's doctor about your child's developmental screening.

Adapted from Caring for Your Baby and Young Child: Birth to Age 5, Fifth Edition, edited by Steven Shelov and Tanya Renner Altmann © 1991, 1993, 1996, 2004, 2009 by the American Academy of Pediatrics and Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, Third Edition, edited by Joseph Hagan, Jr., Judith S. Shaw, and Paula M. Duncan, 2005, Elk Grove Village, IL: American Academy of Pediatrics. This milestone checklist is not a substitute for a standardized, validated developmental screening tool.

www.cdc.gov/actearly | 1-800-CDC-INFO



Learn the Signs. Act Early.

Your Child at 2 Years



Child's Name _____

Child's Age _____

Today's Date _____

How your child plays, learns, speaks, and acts offers important clues about your child's development. Developmental milestones are things most children can do by a certain age.

Check the milestones your child has reached by his or her 2nd birthday. Take this with you and talk with your child's doctor at every visit about the milestones your child has reached and what to expect next.

What Most Children Do at this Age:

Social/Emotional

- Copies others, especially adults and older children
- Gets excited when with other children
- Shows more and more independence
- Shows defiant behavior (doing what he has been told not to)
- Plays mainly beside other children, but is beginning to include other children, such as in chase games

Language/Communication

- Points to things or pictures when they are named
- Knows names of familiar people and body parts
- Says sentences with 2 to 4 words
- Follows simple instructions
- Repeats words overheard in conversation
- Points to things in a book

Cognitive (learning, thinking, problem-solving)

- Finds things even when hidden under two or three covers
- Begins to sort shapes and colors
- Completes sentences and rhymes in familiar books
- Plays simple make-believe games
- Builds towers of 4 or more blocks
- Might use one hand more than the other
- Follows two-step instructions such as "Pick up your shoes and put them in the closet."
- Names items in a picture book such as a cat, bird, or dog

Movement/Physical Development

- Stands on tiptoe
- Kicks a ball
- Begins to run

- Climbs onto and down from furniture without help
- Walks up and down stairs holding on
- Throws ball overhand
- Makes or copies straight lines and circles

Act Early by Talking to Your Child's Doctor if Your Child:

- Doesn't use 2-word phrases (for example, "drink milk")
- Doesn't know what to do with common things, like a brush, phone, fork, spoon
- Doesn't copy actions and words
- Doesn't follow simple instructions
- Doesn't walk steadily
- Loses skills she once had

Tell your child's doctor or nurse if you notice any of these signs of possible developmental delay for this age, and talk with someone in your community who is familiar with services for young children in your area, such as your state's public early intervention program. For more information, go to www.cdc.gov/concerned or call 1-800-CDC-INFO.

The American Academy of Pediatrics recommends that children be screened for general development and autism at the 24-month visit. Ask your child's doctor about your child's developmental screening.

Adapted from Caring for Your Baby and Young Child: Birth to Age 5, Fifth Edition, edited by Steven Shiller and Tanya Remer Abowitz © 1991, 1993, 1994, 2004, 2009 by the American Academy of Pediatrics and Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, Third Edition, edited by Joseph Hagan, Jr., Judith S. Shaw, and Paula M. Duncan, 2008, Elk Grove Village, IL: American Academy of Pediatrics. This milestone checklist is not a substitute for a standardized, validated developmental screening tool.

www.cdc.gov/actearly | 1-800-CDC-INFO



Learn the Signs. Act Early.

Your Child at 3 Years



Child's Name _____

Child's Age _____

Today's Date _____

How your child plays, learns, speaks, and acts offers important clues about your child's development. Developmental milestones are things most children can do by a certain age.

Check the milestones your child has reached by his or her 3rd birthday. Take this with you and talk with your child's doctor at every visit about the milestones your child has reached and what to expect next.

What Most Children Do at this Age:

Social/Emotional

- Copies adults and friends
- Shows affection for friends without prompting
- Takes turns in games
- Shows concern for a crying friend
- Understands the idea of "mine" and "his" or "hers"
- Shows a wide range of emotions
- Separates easily from mom and dad
- May get upset with major changes in routine
- Dresses and undresses self

Language/Communication

- Follows instructions with 2 or 3 steps
- Can name most familiar things
- Understands words like "in," "on," and "under"
- Says first name, age, and sex
- Names a friend
- Says words like "I," "me," "we," and "you" and some plurals (cars, dogs, cats)
- Talks well enough for strangers to understand most of the time
- Carries on a conversation using 2 to 3 sentences

Cognitive (learning, thinking, problem-solving)

- Can work toys with buttons, levers, and moving parts
- Plays make-believe with dolls, animals, and people
- Does puzzles with 3 or 4 pieces
- Understands what "two" means
- Copies a circle with pencil or crayon
- Turns book pages one at a time
- Builds towers of more than 6 blocks
- Screws and unscrews jar lids or turns door handle

Movement/Physical Development

- Climbs well
- Runs easily
- Pedals a tricycle (3-wheel bike)
- Walks up and down stairs, one foot on each step

Act Early by Talking to Your Child's Doctor if Your Child:

- Falls down a lot or has trouble with stairs
- Drools or has very unclear speech
- Can't work simple toys (such as peg boards, simple puzzles, turning handle)
- Doesn't speak in sentences
- Doesn't understand simple instructions
- Doesn't play pretend or make-believe
- Doesn't want to play with other children or with toys
- Doesn't make eye contact
- Loses skills he once had

Tell your child's doctor or nurse if you notice any of these signs of possible developmental delay for this age, and talk with someone in your community who is familiar with services for young children in your area, such as your local public school. For more information, go to www.cdc.gov/concerned or call 1-800-CDC-INFO.

Adapted from Caring for Your Baby and Young Child: Birth to Age 5, Fifth Edition, edited by Steven Shelov and Tanya Remar Altmann © 1997, 1993, 1998, 2004, 2009 by the American Academy of Pediatrics and BRIGHT FUTURES: GUIDELINES FOR HEALTH SUPERVISION OF INFANTS, CHILDREN, AND ADOLESCENTS, Third Edition, edited by Joseph Hagan, Jr., Judith S. Shaw, and Paula M. Duncan, 2009, Elk Grove Village, IL: American Academy of Pediatrics. This milestone checklist is not a substitute for a standardized, validated developmental screening tool.

www.cdc.gov/actearly | 1-800-CDC-INFO



Learn the Signs. Act Early.

Centers for Disease Control and Prevention. (2016). Developmental milestones.

Retrieved from <https://www.cdc.gov/ncbddd/actearly/milestones/index.html>

APPENDIX J
APPLIED BEHAVIOR ANALYSIS HANDOUT

Applied Behavior Analysis (ABA)

Autism Speaks Autism Treatment Network (ATN) now has a tool kit to help parents work with their children's applied behavior analysts. (Learn more and download it [here](#).) Although the tool kit was developed with children and teens in mind, it also contains helpful information for those wanting to better understand and support ABA therapy for an adult with autism.

Behavior analysis is a scientifically validated approach to understanding behavior and how it is affected by the environment. In this context, "behavior" refers to actions and skills. "Environment" includes any influence – physical or social – that might change or be changed by one's behavior.

On a practical level, the principles and methods of behavior analysis have helped many different kinds of learners acquire many different skills – from healthier lifestyles to the mastery of a new language. Since the 1960s, therapists have been applying behavior analysis to help children with autism and related developmental disorders.

What is Applied Behavior Analysis?

Behavior analysis focuses on the principles that explain how learning takes place. Positive reinforcement is one such principle. When a behavior is followed by some sort of reward, the behavior is more likely to be repeated. Through decades of research, the field of behavior analysis has developed many techniques for increasing useful behaviors and reducing those that may cause harm or interfere with learning.

Applied behavior analysis (ABA) is the use of these techniques and principles to bring about meaningful and positive change in behavior.

As mentioned, behavior analysts began working with young children with autism and related disorders in the 1960s. Early techniques often involved adults directing most of the instruction. Some allowed the child to take the lead. Since that time, a wide variety of ABA techniques have been developed for building useful skills in learners with autism – from toddlers through adulthood.

These techniques can be used in structured situations such as a classroom lesson as well as in "everyday" situations such as family dinnertime or the neighborhood playground. Some ABA therapy sessions involve one-on-one interaction between the behavior analyst and the participant. Group instruction can likewise prove useful.

How Does ABA Benefit Those with Autism?

Today, ABA is widely recognized as a safe and effective treatment for autism. It has been endorsed by a number of state and federal agencies, including the U.S. Surgeon General

and the New York State Department of Health. Over the last decade, the nation has seen a particularly dramatic increase in the use of ABA to help persons with autism live happy and productive lives. In particular, ABA principles and techniques can foster basic skills such as looking, listening and imitating, as well as complex skills such as reading, conversing and understanding another person's perspective.

More information about behavior analysis and ABA is available at the websites of the [Association of Professional Behavior Analysts](#), the [Association for Behavior Analysis International](#) and the [Behavior Analyst Certification Board](#).

What Does Research Tell Us About ABA and Autism?

[A number of completed studies](#) have demonstrated that ABA techniques can produce improvements in communication, social relationships, play, self care, school and employment. These studies involved age groups ranging from preschoolers to adults. Results for all age groups showed that ABA increased participation in family and community activities.

A number of peer-reviewed studies have examined the potential benefits of combining multiple ABA techniques into comprehensive, individualized and intensive early intervention programs for children with autism. "Comprehensive" refers to interventions that address a full range of life skills, from communication and sociability to self-care and readiness for school. "Early intervention" refers to programs designed to begin before age 4. "Intensive" refers to programs that total 25 to 40 hours per week for 1 to 3 years.

These programs allow children to learn and practice skills in both structured and unstructured situations. The "intensity" of these programs may be particularly important to replicate the thousands of interactions that typical toddlers experience each day while interacting with their parents and peers.

Such studies have demonstrated that many children with autism experience significant improvements in learning, reasoning, communication and adaptability when they participate in high-quality ABA programs. Some preschoolers who participate in early intensive ABA for two or more years acquire sufficient skills to participate in regular classrooms with little or no additional support. Other children learn many important skills, but still need additional educational support to succeed in a classroom.

Across studies, a small percentage of children show relatively little improvement. More research is needed to determine why some children with autism respond more favorably to early intensive ABA than others do. Currently, it remains difficult to predict the extent to which a particular child will benefit.

In [some studies](#), researchers compared intensive ABA with less intensive ABA and/or other early intervention or special education programs for children with autism. Generally, they found that children who receive intensive ABA treatment make larger

improvements in more skill areas than do children who participate in other interventions. In addition, the parents of the children who receive intensive ABA report greater reductions in daily stress than do parents whose children receive other treatments.

ABA and Adults with Autism

A number of [recent studies](#) confirm that ABA techniques are effective for building important life skills in teens and adults with autism. Many comprehensive autism support programs for adults employ and combine ABA techniques to help individuals transition successfully into independent living and employment. However, the benefits of intensive ABA programs remain far less studied in teens and adults than they have been with young children. This is a research area of particular interest to Autism Speaks and its supporters.

What Does ABA Intervention Involve?

Effective ABA intervention for autism is not a "one size fits all" approach and should never be viewed as a "canned" set of programs or drills. On the contrary, a skilled therapist customizes the intervention to each learner's skills, needs, interests, preferences and family situation. For these reasons, an ABA program for one learner will look different than a program for another learner. That said, quality ABA programs for learners with autism have the following in common:

Planning and Ongoing Assessment

- * A qualified and trained behavior analyst designs and directly oversees the intervention.
- * The analyst's development of treatment goals stems from a detailed assessment of each learner's skills and preferences and may also include family goals.
- * Treatment goals and instruction are developmentally appropriate and target a broad range of skill areas such as communication, sociability, self-care, play and leisure, motor development and academic skills.
- * Goals emphasize skills that will enable learners to become independent and successful in both the short and long terms.
- * The instruction plan breaks down desired skills into manageable steps to be taught from the simplest (e.g. imitating single sounds) to the more complex (e.g. carrying on a conversation).
- * The intervention involves ongoing objective measurement of the learner's progress.
- * The behavior analyst frequently reviews information on the learner's progress and uses this to adjust procedures and goals as needed.
- * The analyst meets regularly with family members and program staff to plan ahead, review progress and make adjustments as needed.

ABA Techniques and Philosophy

- * The instructor uses a variety of behavior analytic procedures, some of which are directed by the instructor and others initiated by the learner.
- * Parents and/or other family members and caregivers receive training so they can support learning and skill practice throughout the day.
- * The learner's day is structured to provide many opportunities – both planned and naturally occurring - to acquire and practice skills in both structured and unstructured situations.
- * The learner receives an abundance of positive reinforcement for demonstrating useful skills and socially appropriate behaviors. The emphasis is on positive social interactions and enjoyable learning.
- * The learner receives no reinforcement for behaviors that pose harm or prevent learning.

What Kind of Progress Can Be Expected with ABA?

Competently delivered ABA intervention can help learners with autism make meaningful changes in many areas. However, changes do not typically occur quickly. Rather, most learners require intensive and ongoing instruction that builds on their step-by-step progress. Moreover, the rate of progress – like the goals of intervention – varies considerably from person to person depending on age, level of functioning, family goals and other factors.

Some learners do acquire skills quickly. But typically, this rapid progress happens in just one or two particular skill areas such as reading, while much more instruction and practice is needed to master another skill area such as interacting with peers.

Who Is Qualified to Provide ABA Intervention?

Just as a medical treatment program should be directed by a qualified medical professional, ABA programs for learners with autism should be designed and supervised by qualified professionals, which include either licensed clinical psychologists with training in applied behavior analysis or behavior analysts, who are [board certified](#) with supervised experience providing ABA treatment for autism or who can clearly document that they have equivalent training and experience.

Because of the huge demand for ABA intervention for autism, many individuals and programs now claim to provide ABA. Some are private practitioners or agencies that offer services in a family's home. Others operate private schools. And still others provide consultation services to public schools.

Unfortunately, some who claim to offer ABA lack the field's established minimum requirements in education and practical experience. Family members, teachers and others involved in developing an individual's therapy and support program should keep the following in mind when choosing an ABA program or practitioner:

Always check credentials of those who claim to be qualified in behavior analysis. For example, for licensed clinical psychologists, you should inquire about the level of training in behavioral interventions for autism, including training in applied behavior analysis. For behavior analysts, you should determine whether the person has been credentialed with the [Behavior Analyst Certification Board](#) or the [Association of Professional Behavior Analysts](#). These professionals often supervise other people, including paraprofessionals, who will be working directly with your child. Thus, it is important that you feel confident that the licensed clinical psychologist or behavior analyst is providing regular supervision to anyone working directly with your child.

Parents, guardians and other care givers should monitor the program by observing sessions and participating in training sessions and consultations.

For more information and resources related to autism, please see our [Treatment overview](#), [Video Glossary](#), [FAQs](#) and special sections on [Symptoms](#), [Diagnosis](#), [Learn the Signs](#), [Your Child's Rights](#), [Asperger Syndrome](#) and [PDD-NOS](#). We also offer a number of resource-packed tool kits for free download ([here](#) and [here](#)). They include our [100 Day Kit](#) for families who have a child recently diagnosed with autism. These resources are made possible through the generous support of our families, volunteers and other donors.

Autism Speaks. (2017). Applied behavior analysis (ABA). Retrieved from

<https://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba>

APPENDIX K
FACTS ABOUT AUTISM HANDOUT

Facts About ASD

Autism spectrum disorder (ASD) is a [developmental disability](#) that can cause significant social, communication and behavioral challenges. There is often nothing about how people with ASD look that sets them apart from other people, but people with ASD may communicate, interact, behave, and learn in ways that are different from most other people. The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged. Some people with ASD need a lot of help in their daily lives; others need less.

A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called autism spectrum disorder.

Signs and Symptoms

People with ASD often have problems with social, emotional, and communication skills. They might repeat certain behaviors and might not want change in their daily activities. Many people with ASD also have different ways of learning, paying attention, or reacting to things. Signs of ASD begin during early childhood and typically last throughout a person's life.

Children or adults with ASD might:

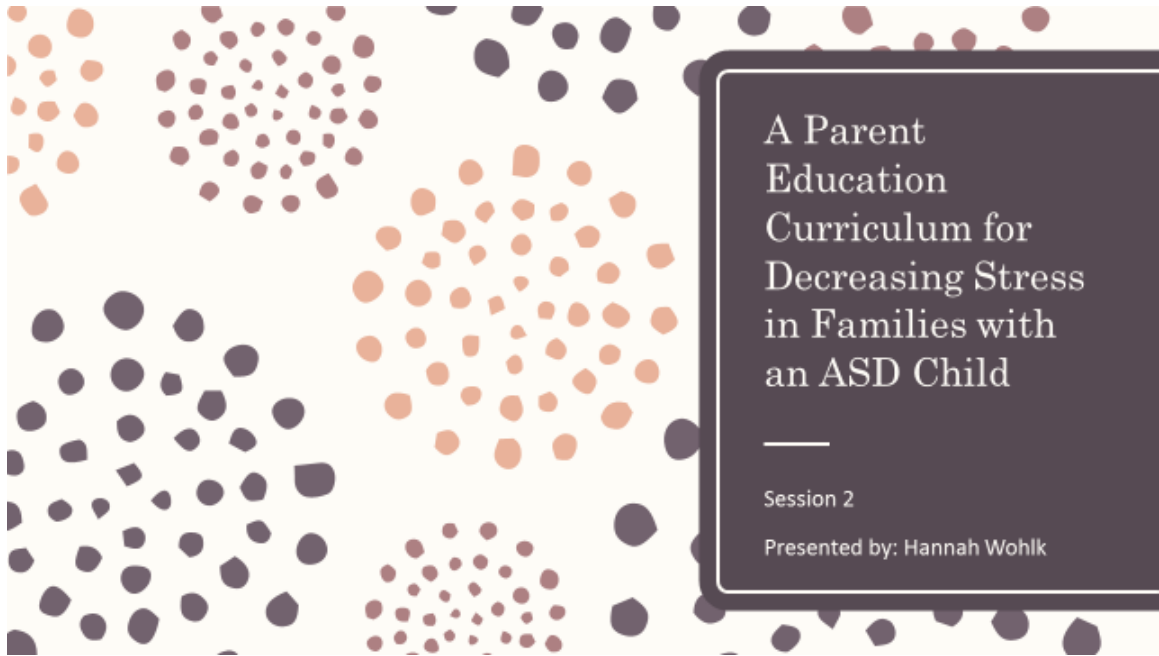
- not point at objects to show interest (for example, not point at an airplane flying over)
- not look at objects when another person points at them
- have trouble relating to others or not have an interest in other people at all
- avoid eye contact and want to be alone
- have trouble understanding other people's feelings or talking about their own feelings
- prefer not to be held or cuddled, or might cuddle only when they want to
- appear to be unaware when people talk to them, but respond to other sounds
- be very interested in people, but not know how to talk, play, or relate to them

- repeat or echo words or phrases said to them, or repeat words or phrases in place of normal language
- have trouble expressing their needs using typical words or motions
- not play “pretend” games (for example, not pretend to “feed” a doll)
- repeat actions over and over again
- have trouble adapting when a routine changes
- have unusual reactions to the way things smell, taste, look, feel, or sound
- lose skills they once had (for example, stop saying words they were using)

Centers for Disease Control and Prevention website. Retrieved June 19, 2016.

<http://www.cdc.gov/ncbddd/autism/data.html>

APPENDIX L
SESSION 2 POWERPOINT



A Parent Education Curriculum for Decreasing Stress in Families with an ASD Child

Session 2

Presented by: Hannah Wohlk

Welcome Back!

- Lack of community support
- Strain on the couple relationship
- Financial strain
- Discussion
- Stress relief activity



Session 2

I. Community Support

- Feelings of not enough support from family or peers
 - Emotional
 - Physical
- Physical demands parents/families experience
 - Daily tasks
 - *Going to store*
 - *Going to school*



Community Support continued

- Emotional
 - Availability of peers or family to talk
 - *Listen/hear them out/vent*
- May exhibit avoidance behaviors
 - Isolation from child if stress levels are too high

Why Is This Stressful?

- Feeling like there is no one there to help them
- Feeling as though there is no one to listen
- Feeling as though they are alone in this journey
- Confused
- Having questions, needing answers and not receiving what they need

What Helps?

- Community programs
- Talking to parents who are experiencing the same types of emotions
- Talking to parents who are raising a child with autism themselves
 - May have similar experiences
 - Share stories and what has worked for them in the past
 - May have other resources themselves to share

What Helps? continued

- Having support from other family members
- Knowing they are not alone!!

Community Support Groups in the I.E.

- <http://www.ieautism.org/children/support-groups-all-disabilities/>

II. Couple Relationship

- Raising a child with autism can likely put a strain on the parents' relationship
- Foundation of a strong and healthy marriage is rooted in
 - Communication
 - Flexibility
 - Intimacy
 - Commitment
 - Shared resources
- These components can be compromised when raising a child with autism
- Divorce rates are higher in families with a child with autism

Why Is This Stressful?

- Parents have to dedicate a significant amount of time to their child
 - Creating a successful learning environment
 - Making sure they are safe and healthy
- Time spent with spouse becomes limited
 - Creates distance between partners
- Financial burdens and decisions that must be made
- Intimacy and communication can be diminished

What Helps?

- Having high levels of positive affect
- Happiness
- Joy
- *Decreases parental stress*
- *Increases marital satisfaction*
- Activity
- Respite care
 - Spend time together outside the home
- Having planning skills
- Optimism
 - Daily optimism exercises as a couple

Respite Care Facilities in the I.E.

- <http://www.ieautism.org/children/respice/>



Daily Positive Affect

- Becoming financially stable
- Support systems
- Maintaining a daily routine
- Be consistent with discipline
- Answer questions when they come up
- Treat your child like a child
- No more “guilt” in your vocabulary
- Take time for your children
- Take time for yourself
- Stay positive

III. Financial Strain

- Expenses for families of children with autism can be 3-10x more annually than when raising a typically developing child/children
- These expenses are can be direct costs from many different sources
- Early intervention/therapy
- Medications
- Medical expenses
 - *Healthcare*
- Becoming a single income household
- Specialized childcare
- Education

Why Is This Stressful? Early intervention/therapy

- These costs can be out of pocket for families if insurance does not cover therapy, medication, etc.
- Early intervention, such as ABA, is not always covered for families by their insurance

Why Is This Stressful? Early intervention/therapy

- ABA/early intervention in the long run has been shown to be highly beneficial for the child, therefore although these expenses can be out of pocket, it is important for families to consider this option for their children
- Can be up to \$30,000 a year for this type of 1:1 therapy

Why Is This Stressful?

Early intervention/therapy con't.

-
- Other therapies such as sensory integration therapies are important to pay for as well due to the benefits for the child
 - Horse therapy
 - Music therapy
 - Finding therapy that is accommodating and works well with the child is also a stressful aspect

Why Is This Stressful?

Medication

-
- Medications are sometimes prescribed to children with autism to manage some of the symptomologies or autism
 - Behavioral symptoms
 - *SIBS, aggression, sleeping difficulties*
 - Medications that cover behavioral symptomologies are likely not covered by insurances
 - Although there are community funded programs to help parents and families in this situation, there are likely long waiting lists

Why Is This Stressful? Medical/health expenses

- Medical and health expenses have been shown to be one of the most stressful aspects in regards to financial strain
- Health and medical expenses can be up to \$12,000 annually
- More doctor and physician visits are necessary for families raising a child with autism, when compared to a family raising a typically developing child/children

Why Is This Stressful? Single income household

- Families may decide that having one parent stop working may be best for the child and the family as a whole
 - One income household
- Other families may find it better to both work part time jobs rather than a full time job

Why Is This Stressful? Specialized childcare

- Both indirect and direct costs
- Direct
 - Hiring someone to take care of the child while parents are working
 - *More attention needed, childcare may be required for a longer period of time*
 - Taking the child to a child care center/facility
 - *Childcare providers likely not trained in working with children with autism*
 - Travel costs

Why Is This Stressful? Specialized childcare cont.

- Indirect costs
 - Having to stay at home in order to care for the child
 - *May mean having to leave a job*

Why Is This Stressful?

Education and special education

-
- These costs are substantially higher as well
 - Child's needs may not be met through the school staff
 - May have to hire outside help
 - *Interventionists*
 - *Therapists*
 - Speech and occupational therapy are likely available through the school district

Why Is This Stressful?

Education and special education

-
- If the therapies are not available or can not be obtained through the school, parents likely have to look into therapy outside of the school setting which is costly

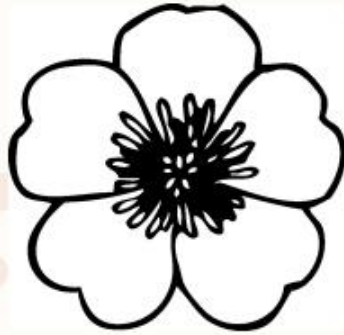
What Helps?

- In some cases, federal programs can help alleviate some costs for families raising children with autism
- Enrolling children in the programs that they are qualified for can alleviate stress and financial burdens
- Knowing what your child qualifies for
- Using resources that are provided
- <http://www.ieautism.org/children/financial-assistance/>

Discussion

- What did you find to be beneficial for you in regards to getting support from the community?
- Did you and your family do anything different than what was mentioned in the slides to alleviate some of the financial strain?
- What works best for you when it comes to get quality time with your spouse and family as a whole?

Activity



- On each petal, write something positive about your child or your relationship with your child
- Once you're done, color in the petals
- Next, turn the page over and write a letter to your child, telling them what they mean to you and how they have influenced and changed your life for the better

**"IF THEY CAN'T
LEARN THE WAY
WE TEACH, WE
TEACH THE WAY
THEY LEARN."**

DR. O. IVAR LOVAAS

ANDNEXTCOMESL.COM

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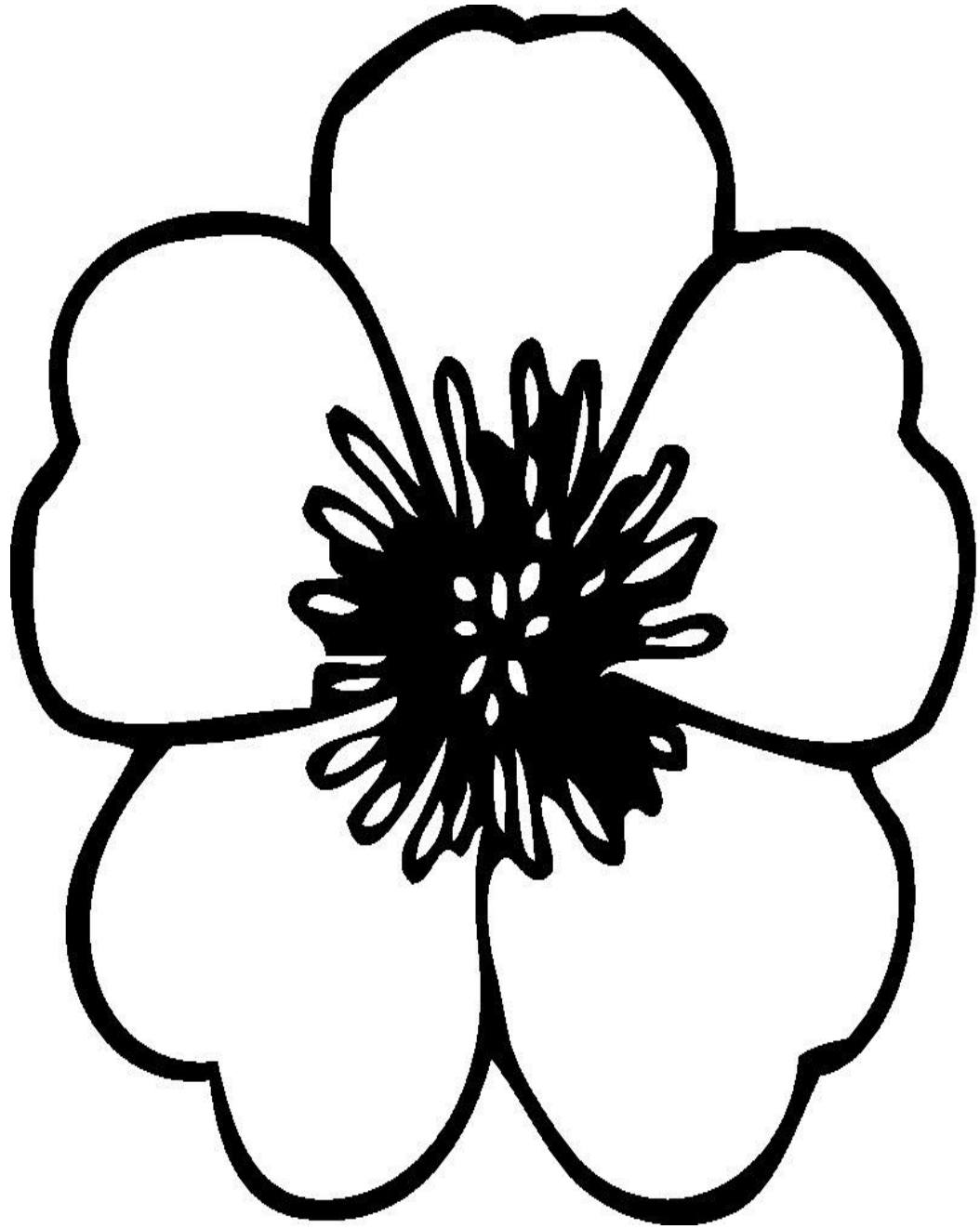
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Financial strain

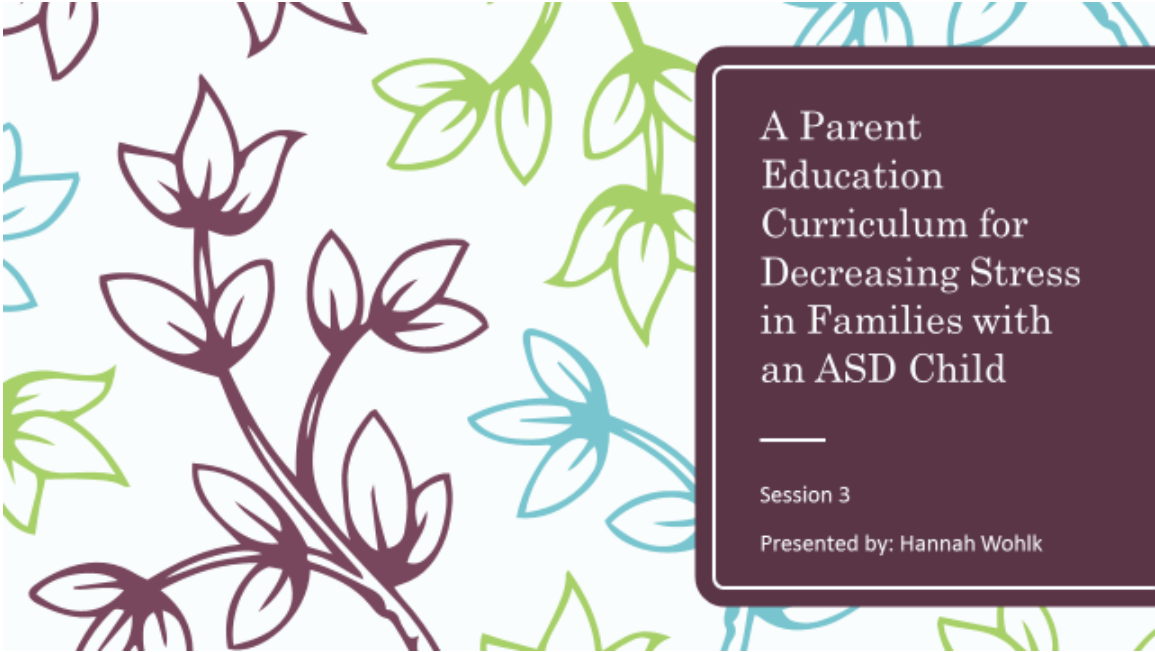
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APPENDIX M

SESSION 2 STRESS RELIEF ACTIVITY HANDOUT



APPENDIX N
SESSION 3 POWERPOINT



A Parent Education Curriculum for Decreasing Stress in Families with an ASD Child

—
Session 3

Presented by: Hannah Wohlk



Good evening!

- Managing maladaptive behaviors
- Regulatory problems
- Communication between parent and child
- Parent perception of competency
- Discussion
- Stress relief activity



I. Managing Maladaptive Behaviors

- Maladaptive behaviors are defined as non-productive behaviors that are used in order to convey a message
- They can be exhibited in many different forms and differ from child to child
- The more common maladaptive behaviors are
 - Self injurious behaviors (SIBs)
 - Self-stimulatory behaviors (SSBs)
 - Aggression
 - *Destructive towards self, others, or property*
 - *Use to escape certain situations*



Why Is This Stressful?

- SIBs in particular are stressful for families
 - Harmful to self
 - Destructive in nature
 - Safety of child is at risk
 - *If injury to head, can cause regression due to traumatic tissue damage*
 - Interference with social and/or learning situations



Why Is This Stressful? continued

- SSBs are stressful in that they
 - Interfere with appropriate play
 - *Further interferes with social interaction*
 - Bring about unwanted attention
 - Interrupts learning
 - *Can interfere with getting the child mainstreamed at school*



Why Is This Stressful?

- Distracting to child and/or peers
- Distracting in stores, movie theatres, restaurants, etc.
- Typically deemed socially-inappropriate
 - *May cause hesitation in bringing child out in public*
 - Fear of causing a scene in public



Why Is This Stressful? continued

- Aggression can be exhibited by a child as well when they are experiencing a situation in which they are trying to escape or feel overwhelmed
- Rather than using language, the child may resort to aggression in order to let a parent or family member know that they are upset (if they are unable to express that distraught in a more productive or appropriate way)
- Aggression is both physically and emotionally stressful for parents and family members



What Helps?

- Identifying the function of the behavior is one way parents can help decrease the frequency of the behavior and further, decrease the stress that it creates for parents
- Learning and understanding the function of a particular behavior can help parents better respond to a behavior and possibly eliminate the behaviors altogether



What Helps?

- There are four functions of behavior
 - Sensory
 - Escape
 - Attention Seeking
 - Tangible
 - (*Access or denied access to*)
 - <http://www.educateautism.com/behavioural-principles/functions-of-behaviour.html>
- Functions of behavior - Handout



ABC Data

- A: Antecedent
- B: Behavior
- C: Consequence
- Discuss situations you've experienced



What Helps? continued

- Support from spouse or other family members has shown to reduce stress that stems from maladaptive behaviors
- Learning adaptive behaviors
- Creating opportunities to teach more functional and appropriate ways to teach the child how to express their wants and needs before resorting to aggression or other maladaptive behaviors
- Further supports the idea of identifying the function of the behavior



II. Regulatory Problems

- Children can experience difficulties in
 - Sleeping
 - *Lack of sleep*
 - *Difficulty falling asleep/restlessness*
 - *Fussiness*
 - Eating: being particular about what they eat
 - *Smell/texture sensitivities*
 - *Food refusal*
 - *Only eating particular foods (food selectivity)*
 - *Possibility of becoming overweight*



Regulatory Problems

- Emotional
- *Lack the capacity for problem solving*
- *Destructive/impulsive*
- *Inability to relax*



Why Is This Stressful?

- The health and safety of the child directly impacted
- Lack of nutrients
- Possibility of becoming overweight
- There may more additional services/therapy needed to address the needs of a particular child
- Lack of sleep for the child can lead to lack of sleep for the parents and other family members



Why Is This Stressful?

- Increase in maladaptive behaviors due to lack of sleep
- More time may have to be allocated to helping the child during meal times
- Parents may be unable to relax since more attention needs to be focused on the child during particular events
- Children may need help coping with particular emotions
- Lack of functional language may lead to the child expressing their needs through tantrums and/or meltdowns



What Helps?

- Support from the family and community has been shown to decrease stress in families
- There are resources and services out there that can help aid in the child's particular problems areas
- Sleeping difficulties
 - Doing activities before sleep
- Eating difficulties
 - Premack principle (first, then) strategy
 - Non removal of spoon (more intrusive)
 - Appearance of certain foods
- Emotional regulation
 - Understanding the function of a particular behavior in order to replace the impulsive behavior
 - Teaching adaptive behaviors



Books on Regulatory Problems

- Sleeping difficulties
- [Solving Sleep Problems in Children with Autism Spectrum Disorders: A Guide for Frazzled Families](#) by Terry Katz and Beth Ann Malow
- [Sleep Difficulties and Autism Spectrum Disorders: A Guide for Parents and Professionals](#) by Kenneth J Aitken
- [Sleep Well on the Autism Spectrum: How to Recognise Common Sleep Difficulties, Choose the Right Treatment, and Get You or Your Child Sleeping Soundly](#) by Kenneth J Aitken
- For more information on how to help with your child's sleeping difficulties: <https://www.autismspeaks.org/family-services/health-and-wellness/sleep>



Books continued

- Eating difficulties
- [Special-Needs Kids Eat Right: Strategies to Help Kids on the Autism Spectrum Focus, Learn, and Thrive](#) by Judy Converse
- [Special Diets for Special Kids, Two](#) by Lisa Lewis
- [Just Take a Bite: Easy, Effective Answers to Food Aversions and Eating Challenges!](#) by Lori Ernsperger and Tania Stegen-Hanson
- [Mealtime and Children on the Autism Spectrum: Beyond Picky, Fussy, and Fads](#) by Marci Wheeler (online article)
- [ASD The Complete Autism Spectrum Disorder Health and Diet Guide: Includes 175 Gluten-Free and Casein-Free Recipes](#) by R. Smith



Books continued

- Emotional regulation
- [Self-Regulation Interventions and Strategies: Keeping the Body, Mind & Emotions on Task in Children with Autism, ADHD or Sensory Disorders](#) by Teresa Garland
- For more information on books in a specific area, go to the Autism Speaks website
- <https://www.autismspeaks.org/family-services/resource-library/books>



In Addition...

- For more sensory products to try with your child, visit -
- <https://www.nationalautismresources.com/calming-products/>
- <https://funandfunction.com/>



III. Communication Between Parent and Child

- Some children have difficulties expressing their needs with functional language
- Can cause frustration between parent and child, when the child's needs are not met
- Children may feel as though their parents are not dependable
- Increase in maladaptive behaviors
 - Can be harmful to self and others
- Poor eye contact
- Social impairments



Why Is This Stressful?

- Sometimes the way children with autism expressed their needs is not easily understood by parents and other family members
- Making it difficult to have their child's needs met
- Potential to create distrust between child and parent
 - Can compromise the relationship



Why Is This Stressful?

- Missed milestones in regards to language acquisition
 - Can cause a setback at school
 - More services for speech may be necessary
- Increase in the use of maladaptive behaviors in order to communicate needs
 - Can be harmful to parent/family member/self



Why Is This Stressful?

- Typically, dialogue between child and parent is a foundation for learning
- When there is a lack of that expressive language and communication skills, there is likely no initiation and drive to learn more
 - Unlikely to take advantage of natural learning opportunities
 - Can create a barrier for advancing in school
 - Later on in life, it can be difficult to get a job as well



Why Is This Stressful?

- Poor eye contact can hinder advancing in the classroom setting
- Difficulty in school can lead to educational setbacks
- Parents want the best for their child, especially in regards to education
 - *Any setback can be stressful or frustrating*



Why Is This Stressful?

- Socially, the inability to communicate also can refer to the child's inability to understand social cues, and gather information on body language/gestures
- Not being able to communicate with peers or have the drive to engage with similar aged peers has been found to be one of the most stressful for parents
 - Can further isolate the child



What Helps?

- Since oftentimes children are left to express their needs in other ways ...
 - Maladaptive behaviors
 - *Tantrums*
 - *Aggression*
 - *Crying*
- ... parents can decrease stress levels and benefit from understanding the function of a particular behavior



What Helps?

- Recognizing the signs and seeing what the child needs before the behavior occurs also helps
 - Can help parents understand their child's needs and wants
 - Can likely eliminate some of the problem behaviors that children are exhibiting
 - *ABC Data*

What Helps?

- In addition to recognizing the maladaptive behaviors as the child's way to communicate their needs, teaching the child replacement behaviors can be helpful
 - Sign language
 - PECs
 - *Picture exchange communication system*
 - Technology
 - Spoken language

What Helps?

Baby Sign Language

www.babysignlanguage.com



What Helps?

PECs



- <http://www.pecsusa.com/pecs.php>

What Helps?

Proloquo2Go

- <http://www.assistiveware.com/product/proloquo2go>



What Helps?

Facilitation of language

- Help your child facilitate language by beginning with imitation of simple sounds
- Once imitation of simple sounds is learned, begin by working on tougher sounds
- Begin to add more syllables
- In addition, practicing oral motor activities helps with muscle movement in the mouth
- Labeling everything



IV. Parent Perception of Competency

- The stress that parents face on a daily basis and the parent's perception of their ability to manage their child's behaviors can directly impact stress level
- Parents who feel more confident and able to manage have lower levels of stress, whereas parents who feel as though they are unable to handle the behaviors have higher levels of stress
- If parents perceive their child as unhappy, there are higher levels of stress
 - Parents may feel as though it is their fault
- Self fulfilling prophecy



What Helps?

- Parents who get more involved in their child's therapy feel more competent
- Getting involved with the school and their child's teachers and education team
- Understanding and using the tools to replace maladaptive behaviors
- Perceiving the maladaptive behaviors as their way to communicate



Ways to Get Involved

- Listen in on your child's therapy session
- Learn the terminology that your child's therapist/teachers are using
- Participate in therapy
- Ask what you can do outside of school/therapy sessions
- Determine functions of your child's behaviors
- ASK QUESTIONS! 😊



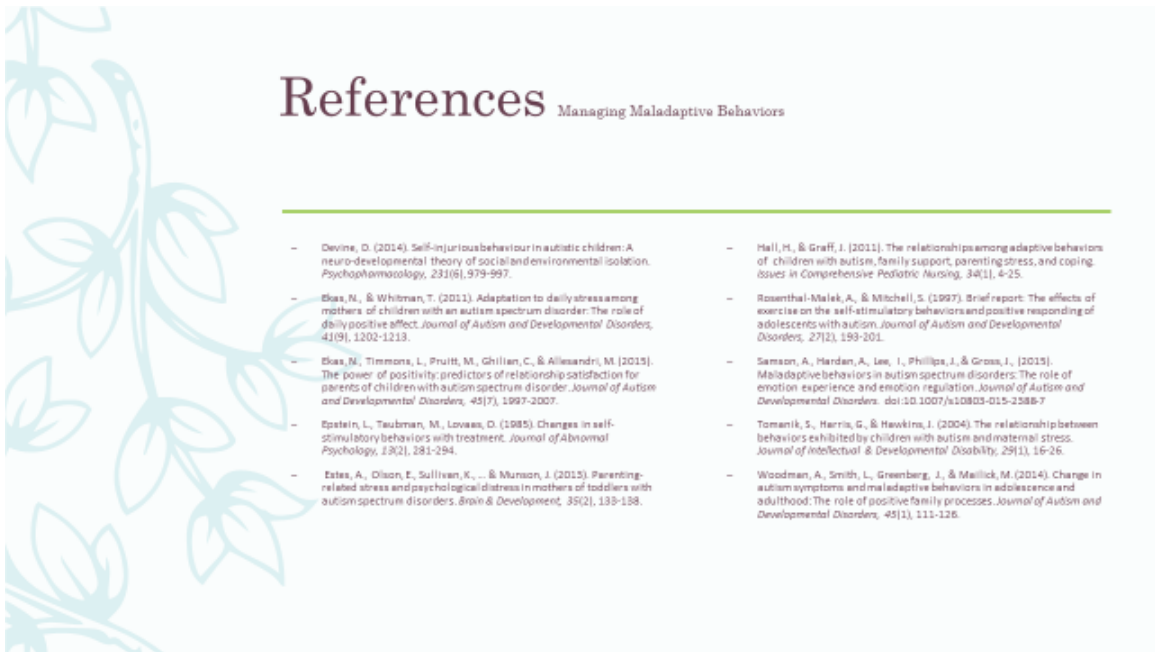
Discussion

- Are there any maladaptive behaviors that your child exhibits that you could potentially examine with ABC data?
- What difficulties do you experience with your child's communication skills? What helps you communicate better with them?
- Personally, do you think examining your child's behaviors and determining the function will help you and your child?



Activity

- Speak a "stress-free" language or have an "optimistic explanatory style"
- Write about three things that happened to you today, or within the past few days, and change the way you viewed the situation
 - Ex: "I sat in traffic today on my way to work" → "I made it to work safely and I was able to hear another one of my favorite songs on the radio"



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Communication Problems Between Child and Parent

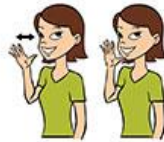
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APPENDIX O
BABY SIGN LANGUAGE HANDOUT



mom



dad



sister



brother

Baby Sign Language...

Baby Sign Language...



grandma



grandpa



aunt



uncle



eat



drink

Baby Sign Language...

Baby Sign Language...



milk



water



more



all done



apple



cereal



happy



I love you

Baby Sign Language...

Baby Sign Language...



book



bear



hurt



bed



dog

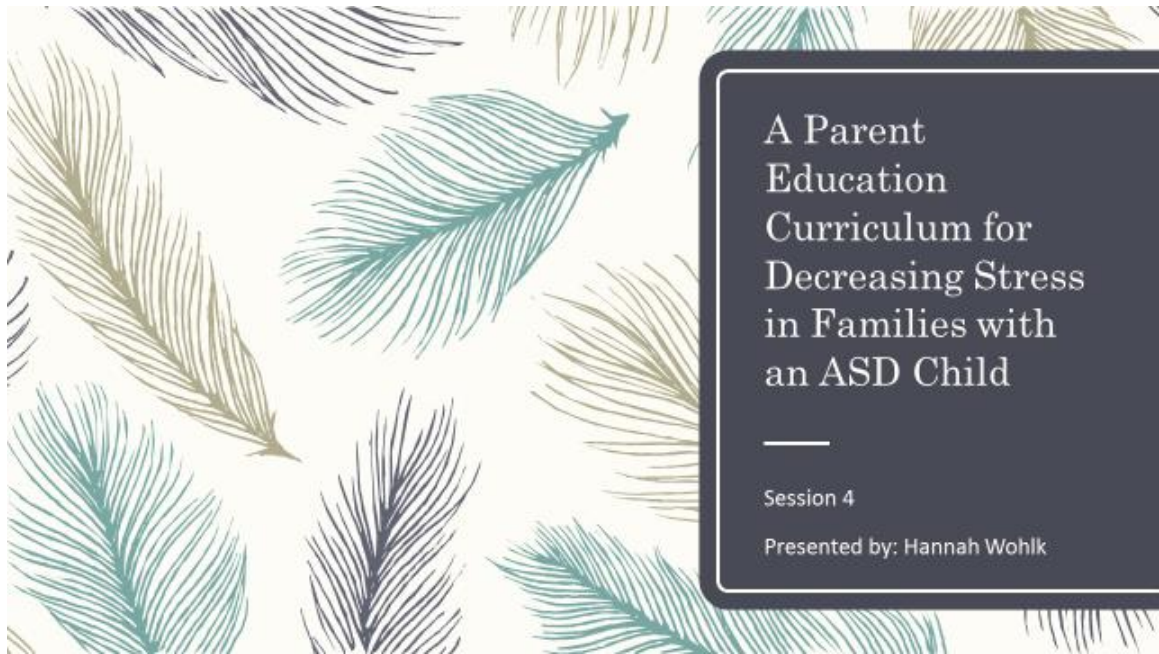


cat

Baby Sign Language. (2017). Baby sign language quick start. Retrieved from

<http://www.babysignlanguage.com/basics/>

APPENDIX P
SESSION 4 POWERPOINT



Good evening!

- Ambiguity of child's future
- Future of family as a whole
- Discussion
- Post-assessment
- Stress relief activity



I. Ambiguity of Child's Future

- What does my child's future hold?
- This question is different depending on the family
 - Dependency of care
 - *May lack the skills needed for daily functioning*
 - Holding a job, making their own food, daily hygiene tasks
 - *May become a physical burden for parents*



Why Is It Stressful?

- As the children grow up and enter the adult world, parents fear that their son or daughter may require full time care
- Becomes difficult for parents have their own job
- Leisure activities may suffer, social life



II. Future of Family as a Whole

- Future considerations families must discuss
 - What is the best option for work for us?
 - *Do I change jobs? Do I leave my current job and stay home?*
 - Do we want to have another child?
 - *Heritability rates are higher in children with siblings with autism*



Why Is It Stressful?

- These are big questions that families must discuss
- The decisions they make as a family are life changing
- It is a lot of responsibility
- The likelihood of the next child having autism increases if there is a sibling with autism



What Helps?

- Research has shown that personality characteristics can aid in decreasing stress for parents
 - Hopefulness
 - Optimism
- Daily positive affect
 - Having positive experiences with child
 - Exhibiting positive emotions
- These types of emotions and characteristics can serve as protective factors



Just a Reminder...

- Becoming financially stable
- Support systems
- Maintaining a daily routine
- Be consistent with discipline
- Answer questions when they come up
- Treat your child like a child
- No more "guilt" in your vocabulary
- Take time for your children
- Take time for yourself
- Stay positive



Discussion

- What do you feel like has helped you focus on creating a successful environment for your child?
- Has your family had to make any difficult decisions since the diagnosis? What helped you cope?



Activity Mindfulness Training

- Mindfulness is focusing on the present moment and accepting it
- Mindfulness is now becoming more researched and studies have shown that it is a key element in happiness
- Mindfulness improves
 - Well-being
 - Physical health
 - Mental health
- Activity
- www.helpguide.org
- <http://www.mindful.org/meditation/mindfulness-getting-started/>



Assessment

- Post-training assessment
- Class evaluation
- Take your time and be honest!
- Thank you!!





Thank you!



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APPENDIX Q
INFORMED CONSENT



College of Social and Behavioral Sciences
Department of Psychology

Informed Consent

The parent education program you are invited to participate in is for parents raising a child with an autism spectrum disorder. The current project is being conducted by Hannah Wohlk, M.A. candidate in Child Development, under the supervision of Dr. Laura Kamptner, Department of Psychology, California State University, San Bernardino.

Participation consists of attending a 4-session course that will provide information about autism, stressors families experience when raising a child with autism, and strategies that can be used in order to manage/cope with the stress. Each session will last two hours. In addition, during the first session, you will be asked to fill out some paperwork for us including some background information and items asking about your role as a parent and your stress level. At the end of the last session, we will have similar questions for you to respond to (including a class evaluation form).

Participation is completely voluntary and you may discontinue at any time without penalty. Information collected on the questionnaires will be completely anonymous and will take approximately 15 minutes at the beginning and at the end of the 4-session course. No names or other identifying information will be associated with your data.

This study entails no foreseeable risks beyond those of daily life, and may provide direct educational benefits to participating parents. Parents will learn about autism as a whole, discuss stressors that may be experienced when raising a child with autism, and also learn ways to manage and cope with the daily stress.

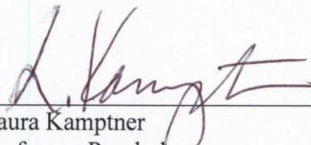
This study has been approved by the Department of Psychology Institutional Review Board Sub-Committee of the California State University, San Bernardino, and a copy of the official Psychology IRB stamp of approval should appear on this consent form.

The results of this project will be reported in Hannah Wohlk's Master's thesis, and will be made available to interested participants. Results will be available after January 2018 from Dr. Laura Kamptner, Department of Psychology at (909)537-5582.

If you have any questions or concerns about participants' rights, please contact Dr. Kamptner. You may also contact the University Institutional Review Board (CSUSB) if you have any concerns. Thank you for your participation.

Sincerely,

Hannah Wohlk
M.A. candidate, Child Development



Laura Kamptner
Professor, Psychology

Consent Agreement:

I acknowledge that I have been informed of, and understand the true nature and purpose of this study, and I freely consent to participate. I acknowledge that I am at least 18 years of age.

Please indicate your desire to participate by placing an "X" on the line below.

Participant's X _____

Date _____

CALIFORNIA STATE UNIVERSITY			
PSYCHOLOGY INSTITUTIONAL REVIEW BOARD SUB-COMMITTEE			
APPROVED	2/12/17	VOID AFTER	2/12/18
IRB #	H-17W1-05	CHAIR	<i>John B. Clay</i>

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