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A parent education curriculum for families with an autism spectrum disorders child

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A PARENT EDUCATION CURRICULUM FOR FAMILIES WITH

AN AUTISM SPECTRUM DISORDERS CHILD

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A Project

Presented to the

Faculty of

California State University,

San Bernardino

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In Partial Fulfillment

of the Requirements for the Degree

Master of Arts

in

Psychology:

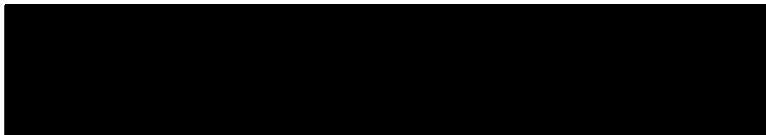Child Development

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by

Amber Marie Vela

December 2013

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Approved by:

Dr. Laura Kamptner, Chair, Psychology   Date   11-25-13

Dr. Eugene Wong

Dr. Kelly Campbell

ABSTRACT

Research has shown that families greatly benefit

from gaining knowledge in strategies that help nurture

and encourage the development of their Autism Spectrum

Disorder (ASD) children while addressing the impact of

ASDs on the family system immediately following the ASD

diagnosis. However, this information is not readily

available to families. This project provides a

comprehensive, parenting education program that focuses

on educating parents of young newly-diagnosed ASD

children about coordinated services, supporting the

family to promote the ASD child's growth and development,

and supporting the family system during the critical

early years. The program consisted of a month-long,

twice-weekly (1½ hour) sessions on seven topics including

what to expect after the diagnosis, understanding the ASD

child, how to parent an ASD child, how ASDs impact the

family system, treatment and intervention options,

negotiating the school system, and what resources are

available to families with an ASD child. Participants

included parents of newly-diagnosed ASD children between

the ages of 2-5 years. Professionals were also invited to

attend. Pre- and post-test assessments revealed that that

participants' level of parental confidence increased while levels of parental stress decreased slightly after the program. An additional benefit from the program was that professionals were able to expand their knowledge about ASDs.

ACKNOWLEDGMENTS

I owe my deepest gratitude to my project chair, Dr. Laura Kamptner, for her unsurpassed guidance and patience throughout my project. Her expertise was invaluable.

I would also like to thank my committee members, Dr. Eugene Wong and Dr. Kelly Campbell, for their constructive feedback and encouragement.

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Most importantly, I would like to thank my husband, Arturo "Kito" Vela, for his unconditional love and support. With the aid of his optimistic nature, I was able to fulfill my dreams.

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CHAPTER ONE

REVIEW OF THE LITERATURE

According to the Center for Disease Control and Prevention (CDC) website (n.d.), it is now estimated that 1 in 88 children in the United States are diagnosed with an Autism Spectrum Disorder. These disorders impact all racial, ethnic, and socioeconomic groups (Sicile-Kira, 2004). The impact of ASDs on the family system is profound, and most families feel overwhelmed.

Since early intervention is crucial for all family members when a child is diagnosed with an ASD, it is imperative for families to participate in an early intervention program that focuses on educating parents about coordinated services, supporting the family to promote the ASD child's growth and development, and supporting the family system during the ASD child's early years. The purpose of the current project is to provide families with a comprehensive parenting education program that focuses on educating and supporting parents of young newly-diagnosed ASD children.

Autism Spectrum Disorders

According to the CDC website (n.d.), Autism Spectrum

Disorders (ASDs) is an umbrella term that describes

multiple disorders including Autistic Disorder,

Asperger's Syndrome, Rett's Disorder, Childhood

Disintegrative Disorder, and Pervasive Developmental

Disorder, Not Otherwise Specified. ASDs are typically

diagnosable by observing several core deficits in shared

attention and regulation, engagement and relating,

purposeful emotional interactions, joint attention,

creativity, and logical thinking (Greenspan & Wieder,

2006). As stated by the Center for Disease Control and

Prevention website (n.d.), the symptoms of the core

deficits may include avoidance of eye contact, delayed

speech and language skills, obsessive interests, stemming

behaviors (e.g., hand flapping, body rocking, and

spinning in circles), unusual reactions to sound, taste,

smell, and texture, and difficulties in relating to or

understanding others' feelings. These core deficits and

related symptoms profoundly affect a child's health,

development, and functioning, and result in hardships in

movement, personal care, medical care, behavior

management, education, and relationships (Boulet, Boyle,

& Schieve, 2009; Greenspan, 2006; Rosa, Myers, Ditz, Willingham, & Greenburg, 2011). Behaviors typically associated with ASDs and so-called common symptoms present in one child may be absent in another. Parents of children who are newly diagnosed with ASDs can expect their child to exhibit various degrees of difficulties during interactions with the social and physical environment, during personal care activities, and when attempting to communicate with others.

The prevalence of Autism Spectrum Disorders (ASDs) appears to be on the rise in the United States, with males 4 to 5 times more likely than females to receive a formal ASD diagnosis (Sicile-Kira, 2004). As the rates of Autism Spectrum Disorders continue to increase, the importance of discovering the risk factors and raising awareness of the early signs of this disorder have become more urgent.

The financial impact of ASDs on society is vast. To date, the allocation of funding for autism research exceeds $81.3 million per year (Sicile-Kira, 2004). According to the CDC website (n.d.), medical expenditures for individuals diagnosed with ASDs are 4.1 to 6.2 times greater than for typically-developing individuals, and

enrollment costs for Medicaid programs average $10,709

per child per year. Additionally, the behavioral

intervention costs per child per year exceed $40,000 to

$60,000 (Sicile-Kira, 2004). Without costly early

intervention services, symptoms of ASDs may worsen,

resulting in even more costly treatment over the course

of a lifetime. The Autism Society (n.d.) estimates that

the lifetime cost of caring for an individual with an ASD

ranges from $3.5 to 5 million with the annual costs in

the United States currently totaling $90 billion. The

Autism Society (n.d.) projects that the costs may be

reduced by two-thirds with early diagnosis and

intervention.

Funding resources have allowed the Center for

Disease Control and Prevention to conduct one of the

largest studies to date on causal factors for ASDs (i.e.,

genetic, environmental, pregnancy, and behavioral

factors): the Study to Explore Early Development (SEED).

To date, research has found that ASDs are

neurologically-based, with genetics playing a major role

as children have been found to have an elevated risk for

ASDs when the parent or sibling has an ASD (Sicile-Kira,

2004). According to the Center for Disease Control and

Prevention website (n.d.), the SEED study has also found

that certain genetic and chromosomal conditions (e.g.,

chromosome 7q hot spot), differences in brain circuitry,

critical periods (i.e., phase in life that has heightened

sensitivity), and hormonal (e.g., serotonin) levels may

promote ASDs. Unfortunately, the exact causes of ASDs are

still intertwined in genetic and environmental

influences. Some evidence found by SEED suggests the

development of ASDs occurs before birth. According to

findings reported by the American Medical Association,

women who administer a folic acid supplement before

getting pregnant are approximately 40% less likely to

have a severely afflicted ASD child and 20% less likely

to have an ASD child (Suren et al., 2013). However, risk

factors of vaccines and infections must also be

considered, as well as possible environmental risk

factors (e.g., mercury toxicity, viral infections, lead,

and antimony and aluminum exposure) (Sicile-Kira, 2004).

The impacts of ASDs on the family system are

profound, and most families feel overwhelmed. Due to

related symptoms of the disorder, families may experience

additional stressors that are not usually present in

families of typically-developing children (e.g., lack of

flexibility in daily routines, perseverations, and socially inappropriate and maladaptive behaviors). These stressors are discussed in more detail below.

Challenges to Families with an Autism Spectrum Disorders Child

Studies have found that after receiving an ASD diagnosis, parents have a number of major concerns regarding the following: (1) what to expect after the diagnosis, (2) typical behaviors of ASD children, (3) negotiating the school system, (4) how ASDs impact the family system, (5) treatment and interventions options, (6) how to parent an ASD child, and (7) what resources are available to them (Greenspan & Wieder, 2006). Each of these is discussed in turn below.

What to Expect After the Diagnosis. After the diagnosis, parents can expect to experience grief and so they tend to benefit from sensitive social support (e.g., emotionally supportive professionals), clear diagnostic information and information about ASD services and funding (Sicile-Kira, 2004).

Parents typically experience a "grief cycle" after their child receives the initial diagnosis of an ASD (Sicile-Kira, 2004). The grief cycle includes feelings of

shock and disbelief, denial, anger or rage, confusion and
powerlessness, depression, guilt, shame or embarrassment,
fear and panic, bargaining, hope, isolation, and finally,
acceptance (Kubler-Ross, 1969). With ASD children,
parents often never resolve the grief cycle but do
eventually transition to the acceptance phase
(Sicile-Kira, 2004).

The impact of the grief cycle may vary as there are
individual differences in which stages are experienced
and how long each stage will last. Regardless of the
variability, progression through the stages of the grief
cycle is vital as research indicates that when a parent
is unable to utilize coping strategies early on, the
chances for successful child outcomes are substantially
lowered (Sicile-Kira, 2004). Progression in the grief
cycle can occur when parents accept that the "fantasy"
future and relationships they envisioned for their ASD
child will never be (i.e., parents letting go of their
shattered expectations). Additionally, parents can learn
to benefit from the grief cycle by positively channeling
their emotions to help themselves, their child, and their
families (Sicile-Kira, 2004).

<u>Typical Behaviors of Autism Spectrum Disorders</u>

<u>Children</u>. Studies suggest that parents of ASD children can benefit from information about the ASD child's development that will help them to decrease negative feelings towards the ASD child, help them be more proactive in the ASD child's life, and in turn help the ASD child (Sicile-Kira, 2004). Understandably, many parents exhibit difficulties in accepting the ASD diagnosis, and ultimately the child. However, research has found that parents who receive sensitive support at the time of the diagnosis of the disability are more likely to accept the child, and as a result are more likely to be less distraught, more considerate, and provide more positive care towards the child (Howe, 2006). Professionals can assist with the acceptance phase by providing a clear explanation of the nature and characteristics of the child's disability, and how it will likely influence the child's ability to communicate needs, emotions, and interactions (Howe, 2006). There are a number of typical ASD-related behaviors that parents may benefit from knowing about when their child is diagnosed. These include sensory issues, picky eating,

maladaptive behaviors, potty training, and the role of behaviors in communication.

Sensory issues may affect approximately 95% of children diagnosed with an ASD (Sheehan & DeOrnellas, 2011). These issues may arise from difficulties in processing the input and output of information. It has been suggested that children affected by ASDs are neurologically wired to respond differently to sensory stimuli (Sheehan & DeOrnellas, 2011). Researchers encourage parents to introduce stimuli with many sensory differences to the child to determine how the stimulus affects the child (Brookman-Frazee et al., 2006). By determining how a child responds to a stimulus, parents may be better suited to address sensory-related behaviors that arise in certain situations (e.g., the school environment, community outings, and medical appointments).

Most ASD children exhibit problems in processing auditory stimuli. However, problems with visual stimuli may also occur (Sheehan & DeOrnellas, 2011). There are four proposed sensory classifications: low-registration, sensation-seeking, sensory-sensitivity, and sensation-avoidant (Law et al., 2008). A child who has a

low registration is often unaffected by stimuli and may appear uninvolved in the world (Law et al., 2008). The sensation-seeking child's aim is to seek as much sensation as possible (Law et al., 2008). The sensory-sensitivity child is hyperactive and extremely distractible (Law et al., 2008), while the sensation-avoidant child exhibits behaviors that are aimed at decreasing the amount of stimuli coming into the child's system (Law et al., 2008). Symptoms of the sensory classifications may include evasion of auditory stimulation, no reaction or a strong reaction to touch, tactile sensitivities (e.g., child removing clothes), lack of eye contact (e.g., visual processing problem), and unusual body movements (Sicile-Kira, 2004).

Children diagnosed with an ASD may also exhibit sensory issues with food. Parents should note if the child exhibits symptoms of sensory overload such as eating foods of the same texture, smelling foods before eating, not eating foods that produce certain sounds, or eating only the exact same foods (Brookman-Frazee et al., 2006). These behaviors may be indicative of sensory processing issues or high sensory sensitivities. Experts suggest that parents should evaluate whether the child

has a sensory issue by documenting reactions and behaviors to food (Sicile-Kira, 2004). Once observations are reviewed and insights are obtained about the child's particular system, sensory integration therapy (e.g., children who are very sensitive to touch may go through a program that attempts to desensitize them by systematically brushing their bodies at regular intervals throughout the day) may be useful as it addresses the sensory interferences that prevent the child from enjoying meal times (Brookman-Frazee et al., 2006).

A child diagnosed with an ASD may also exhibit challenging behaviors related to food (e.g., avoiding or refusing foods of certain color, texture, or smell, or anxiety when an expected routine changes, and when a new food is introduced). If eating is an issue, it may be important for parents to discuss dietary concerns with the child's pediatrician and other related specialists (e.g., occupational and physical therapists) to rule out any physiological explanations for the behavior such as a gagging reflex, difficulty swallowing, or food allergies (Sicile-Kira, 2004).

There are other food-related issues that may cause stress for the family system. Parents of ASD children

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often complain about difficulties in establishing a routine for meal times, the child's inability to sit down and eat without assistance, and the child's overall nutritional balance (Boulet, Boyle, & Schieve, 2009; Brookman-Frazee et al., 2006). The primary recommendation from experts for parents is to not make food a big issue (Carothers & Taylor, 2004). Research suggests that parents should be flexible and provide the child with the opportunity to eat when hungry (Carothers & Taylor, 2004). In fact, parents should be creative with food so that it gains the child's attention (Sicile-Kira, 2004). Regarding the child's ability to participate in family meal time, the application of applied behavioral analysis (i.e., behavior modification techniques) may be appropriate if the child exhibits disruptive behaviors (Rosa et al., 2011).

The presence of maladaptive or inappropriate behaviors (e.g., irritability, non-compliance, aggression, property destruction, self-injury, and PICA) in Autistic Spectrum Disorders may often be attributed to the disorder's core deficits. As children with ASDs exhibit difficulties in understanding, expressing, and communicating feelings, behaviors may be viewed as a tool

to relay information to others. It is believed that the main purpose of ASD children's maladaptive behaviors is to release stress from sensory stimulation (Sicile-Kira, 2004) (i.e., their behaviors are reactions to sensory overload) (Sheehan & DeOrnellas, 2011).

It has been found that maladaptive behaviors are the primary source of stress for the family system (Schuengel et al., 2010; Singh et al., 2006). When these types of behaviors are exhibited, parents are often bombarded with emotions ranging from embarrassment to frustration. Most parents of children who are newly diagnosed with ASDs do not possess the knowledge to deescalate the situation, and they feel powerless when attempting to control their child (Singh et al., 2006). As such, parents may feel the urge to isolate the family system to prevent behaviors from occurring. Parents who are unable to deal with the typical problem behaviors tend to report the highest ratings of anxiety and depression (Singh et al., 2006). They may also experience feelings of loneliness as they are unable to participate in "normal" family activities (e.g., going on vacation, grocery shopping, eating out at restaurants, or visiting an amusement park) (Schuengel et al., 2010).

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If the ASD child's behaviors are severe enough to impact family functioning, experts suggest that parents seek treatment for the child such as applied behavioral analysis (ABA) in conjunction with a social and emotional component such as the DIR/floortime technique, which pursues the child's natural emotional interests while at the same time moving the child towards greater mastery of the intellectual, social, and emotional competencies, to promote and strengthen socially-appropriate behaviors (Greenspan & Wieder, 2006). Parents who are adequately trained to address behaviors in a warm, calm, and structured manner, and follow the ABA model, can reduce these maladaptive behaviors (Howe, 2006). By training parents to interact with their child using positive communication, parents can resolve the underlying culprits of the child's behavior.

Another challenging behavior that parents of ASD children may face is their child's inability to be potty trained: some children will master the skill quickly with minimal guidance, while others will need excessive assistance to make progress, if at all. Before parents initiate the potty training process, it is important to have the child evaluated to determine if there are any

physical characteristics that may hinder progress. If there are interfering deficits, seeking professional consultation and intervention may ease the stress of potty training.

It is recommended to take deficits into account when preparing for potty training (Boulet, Boyle, & Schieve, 2009). The most notable deficits may be child-related factors, developmental appropriateness, communication needs, sensory awareness, sensitivity to stimulation, preference for routine, motor planning difficulties, limited imitation and sequential learning, anxiety levels, and difficulties adjusting behaviors to fit to new contexts (Sheehan & DeOrnellas, 2011). When parents acknowledge their child's limitations, it may enable them to set realistic and obtainable goals for the child. Research has found that the use of picture schedules and social stories (i.e., materials used to describe an event or concept in terms of relevant social cues, viewpoints and common responses) ease the burden of potty training, and that teaching potty training skills in a natural environment is most effective (Boulet, Boyle, & Schieve, 2009; Carothers & Taylor, 2004). However, in order for the child to maintain and generalize this skill, it must

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be taught repeatedly by different individuals in varying contexts.

A third challenging behavior is that children with ASDs often exhibit extreme deficits in communication, and behaviors may stem from the child's inability to express his or her feelings (Sheehan & DeOrnellas, 2011). It may be helpful for parents to increase their child's communication skills by providing a framework for social interactions (Greenspan & Wieder, 2006). Initially, daily interventions may be as simple as using one-to-one interactions with the child and may become more complex as the circle of communication increases (Greenspan & Wieder, 2006). It has been proposed that the ASD child has to want to use words or gestures to share information (Greenspan & Wieder, 2006). When parents prompt and encourage the child to communicate either non-verbally or verbally, it may allow the child to connect emotional meaning to language. In turn, this may lessen the behaviors related to the ASD diagnosis as well as the later development of maladaptive behaviors. ASD children who are taught pragmatic language and social skills to deal with real life contexts tend to exhibit a deeper understanding of emotions (Sheehan & DeOrnellas, 2011;

Toth, Dawson, Meltzoff, Greenson, & Fein, 2007). By

utilizing this preventive communication approach, parents

may eliminate the formation of maladaptive behaviors.

Negotiating the School System. Another challenge for

parents is how they will determine their child's

educational needs. It is useful for parents to observe

and record their ASD child's learning abilities before

their child becomes eligible for school services

(Sicile-Kira, 2004). This may be done be observing how

their ASD child acts in different environments and how

their child relates to objects and people (Sicile-Kira,

2004). The following sections will review the critical

aspects of the school system.

Head Start and general school enrollment is often a

fearful obstacle for parents of ASD children as they are

typically ill-prepared to know what questions to ask. It

may be appropriate for parents to visit different schools

and classrooms and ask questions such as: How many

children are in a class? What is the ratio of staff to

children? Does the staff have appropriate skills and

access to training to help the child? What kinds of

experience do the school and the teacher have with

children with ASDs? What teaching methods and strategies

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specific to ASDs are the staff trained in? And is the school prepared to fit their system around the child (Sicile-Kira, 2004)? Also, parents would be helped by becoming familiar with the Individualized Education Program (IEP) process, their responsibility for child advocacy, and the established policies and procedures that regulate what and how services are implemented in the school environment.

The main objective of the IEP is to provide a disabled child with a Free Appropriate Public Education (FAPE). According to the U.S. Department of Education website (n.d.), the intention of an IEP is to assist children in reaching educational goals by describing how the child's disability affects the learning process and by identifying the supports and services needed to meet these objectives. The key components of the IEP include assessing the child in all areas related to the known disability, determining the child's ability to access the school curriculum, assessing how the disability affects the child's learning, developing objectives that correspond to the needs of the child, and choosing a placement in the least restrictive environment (Carothers & Taylor, 2004).

Participants in the IEP process include various professionals who provide services to the ASD child. The parent's role in the IEP process is to be an active participant. This can be done by requesting needed assessments in writing, obtaining assessments before the IEP meeting, considering full inclusion or increased integration, and making a list of points to discuss during the IEP meeting (Sicile-Kira, 2004). To increase IEP progression, parents must be well-informed about their child's particular disability, the policies and procedures of the local education system, and their rights under the state and federal law (Autism Society website, n.d.).

Parents can facilitate their ASD child's learning capability by disclosing pertinent information regarding their child's learning style. The parents' role is to be their child's advocate since they possess distinctive knowledge about their child's capabilities and needs. According to the U.S. Department of Education website (n.d.), it is the educator's responsibility to utilize strategies that work best for the child. However, it is the parent's responsibility to ensure that their child is receiving appropriate placement and has an opportunity to

participate in a "normal" school environment

(Sicile-Kira, 2004).

According to the U.S. Department of Education

website (n.d.), parents should become proficient about

how the Americans with Disabilities Act (ADA), the

Individuals with Disabilities Education Act (IDEA), the

Rehabilitation Act of 1973, Free Appropriate Public

Education, and the No Child Left Behind (NCLB)

legislation influence their ASD child's education. Each

Act prohibits discrimination of the basis of disability

status, and also provides individuals with disabilities

certain rights. The differences noted between the Acts

may be based on the funding source for services and

federal and/or state regulations.

How Autism Spectrum Disorders Impact the Family

System. The family system is profoundly impacted by an

ASD diagnosis. Families with an ASD child experience

greater disruptions, decreased spontaneity in daily

schedules, and greater burdens in work, home, and school

schedules (Larson, 2006). Coupled with the chronic

demands of the disability, the family system may be left

feeling exhausted, pessimistic, and at risk for burn-out

(Sicile-Kira, 2004). It has been found that parents who

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receive information about how typical family functioning

is affected (e.g., daily routines, parental stress,

marital dyad, respite care, and sibling relationships)

are more likely to exhibit acceptance of the ASD child

and to create flexibility in family routines

(Sicile-Kira, 2004).

First, the ASD child's inflexibility to deviate from

his or her own routine may create a barrier for typical

family routines (Larson, 2006). It has been found that

parental management of daily routines promotes positive

family functioning (Larson, 2006). It is the

responsibility of parents to provide a somewhat

predictable activity pattern to coordinate a reasonable

life for all family members. Parents should develop

functional routines that manage the demands presented by

the ASD child (e.g., difficulties in selecting and

tolerating clothing, bathing, showering and grooming,

toileting, completing chores, independently occupying

themselves, and taking medications) and that accommodate

to the needs of other family members (Larson, 2006).

Through the application of daily routines, parents can

coordinate family activities, maintain and strengthen the

family's cultural values, and provide continuity in daily life (Larson, 2006).

Second, parents of ASD children report more stress and depression than parents of typically-developing children (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). There is an urgent need to improve the parenting practices and stress management skills for these parents. The well-being of ASD children is significantly related to the well-being of their parents (Brookman-Frazee et al., 2006). Sources of stress for parents often include behaviors that are characteristic of the disorder such as the ASD child's disruptive behaviors of self-stimulation, inability to communicate effectively, and lack of social skills (Greenspan & Wieder, 2006). Parents also have to manage the child's inability to deviate from a routine, completing daily living activities, and the inability of their ASD child to occupy himself (Kersh et al., 2006). Parental stress is also predictive of the quality of the sibling relationship. When parental stress is high, typically-developing siblings report less satisfaction with their sibling relationships, as well as more negative behaviors directed towards their siblings with ASDs (Rivers & Stoneman, 2008). It has been found that

parental stress is related to lower self-esteem and higher depression in siblings (Rivers & Stoneman, 2008). Early intervention can reduce the negative effects of parental stress. Using treatment models that empower parents through role play, individualized consultation, and controlled learning environments can be both cost-effective and provide a coping mechanism for parents to manage family life (Law et al., 2009).

Third, parents of ASD children experience more discord in their intimate relationships, and are more likely to separate than parents of typically-developing children (Kersh et al., 2006). This is directly related to parents experiencing conflicting expectations in their roles as a partner and parent due to heightened caregiving responsibilities (Smith & Elder, 2010). Marital equality in parental responsibilities is important (Kersh, et al., 2006). It is helpful to discuss and decide on the division of responsibility and to consider how each parent's traits play out in their relationship and the family system as a whole (Greenspan & Wieder, 2006).

Parents must also realize that their relationship with each other is just as important as their

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relationship with their child. Parents need to establish a supportive marital relationship by regularly spending time alone with each other. This may provide parents the opportunity to regain intimacy within their relationship (Greenspan & Wieder, 2006).

Fourth, parents are responsible for providing a heightened level of care (e.g., stimulating social interaction, redirecting inappropriate behaviors, and monitoring daily living activities) for their ASD child. The decreased opportunity for personal time may put parents at risk for burn-out (Sicile-Kira, 2004). According to Inland Regional Center (n.d.) of Riverside and San Bernardino County, respite is a short period of relief for those who care for dependent individuals. It is designed to support and maintain the caregiving relationship, and to ensure the well-being of the care provider (M. Pounders, personal communication, October, 2012).

Parents may be weary of leaving their child in the care of a respite worker, but it is a necessary step to ensure that parents are taking care of themselves too (Greenspan & Wieder, 2006). When seeking respite services, it is best to locate an individual who has

previous experience working with ASD children. To locate the most qualified respite workers, it may be appropriate to place advertisements with local universities, teacher training colleges, other parents, and the newsletters of local ASD chapters (Sicile-Kira, 2004). The best practice for hiring respite workers is to develop a questionnaire for reviewing resumes, conducting telephone interviews, checking references, and completing face-to-face interviews (Sicile-Kira, 2004).

Finally, sibling relationships evolve through a dynamic interaction of social norms and biological factors (e.g., personality and health). It has been found that the quality of the sibling relationship in families with an ASD child is dependent on the child's temperament, persistence, family coping styles, and sibling perceptions (Smith & Elder, 2010). In particular, temperament affects sibling relationship quality such that typically-developing children who are more persistent have better relationships with the ASD sibling (Sage & Jegatheesan, 2010). If the typically-developing sibling exhibits high persistence, he is more likely to engage in repeated efforts to begin and reinstate social interactions (Rivers & Stoneman, 2008). This is

particularly important for the ASD child as the sibling

relationship provides opportunities to practice social

interactions in a natural setting (e.g., learning how to

play, share, listen, and react to social norms) (Rivers &

Stoneman, 2008). It has been found that

typically-developing siblings teach the ASD sibling the

importance of social skills in communication (Sage &

Jegatheesan, 2010). Most typically-developing siblings

are able to negotiate role relationships that accommodate

their sibling's disability and facilitate social

interactions (Stoneman, 2001).

The sibling relationship also has positive

influences for typically-developing siblings. The

relationship provides the chance for typically-developing

siblings to develop positive social skills, intelligence,

scholastic performance, and maturity level (Macks &

Reeve, 2007). However, negative side effects have also

been found. Typically-developing siblings often

experience a sudden change in family roles, a

restructuring of the family's activities, increased

responsibilities, different role expectations, loss or

lack of parental attention, feelings of guilt and shame,

and perplexity at the bizarre behavior that the ASD

sibling displays (Dyke, Mulroy, & Leonard, 2008; Macks & Reeve, 2007; Sage & Jegatheesan, 2010; Sheehan & DeOrnellas, 2011). These changes can be disastrous for typically-developing siblings' psychosocial and emotional well-being (Smith & Elder, 2010). It is important for parents to provide an age-appropriate explanation to typically-developing siblings as to why the ASD sibling may be treated differently, and why the changes in family functioning are necessary (Glasberg, 2000). It is also important for parents to provide plenty of opportunities for typically-developing siblings to discuss their feelings about their ASD sibling and empathize with them, and answer any questions they may have in a developmentally-appropriate manner (Greenspan & Wieder, 2006). When parents provide thorough explanations, greater sibling satisfaction and higher quality sibling relationships tend to occur (Rivers & Stoneman, 2008).

The quality of the sibling relationship is also influenced by the unique behaviors of the ASD sibling. Unfortunately, the deficits associated with ASDs (e.g., difficulties in understanding social cues) have been found to negatively impact the sibling relationship (Rivers & Stoneman, 2008). It is the parent's

responsibility to modify the ASD sibling's behaviors and offer ways to enhance the sibling relationship (Smith & Elder, 2010). Parental intervention can help ASD siblings take a more active role in play with typically-developing siblings, and this can lead to more cooperative behaviors between children (Sage & Jegatheesan, 2010). Parents can also encourage typically-developing siblings to use positive behaviors during interactions with the ASD sibling to elicit certain social skills that would benefit the sibling relationship (Knott, Lewis, & Williams, 2007). Parents can also strengthen interactions between siblings and the ASD child by spending time alone with the typically-developing sibling, and reminding them how much they are loved. Teaching typically-developing children how to interact with the ASD sibling, setting consequences for the ASD child, keeping lines of communication open, and allowing siblings to have a private, ASD-free zone are also ways that parents can increase the quality of the sibling relationship (Sicile-Kira, 2004).

Treatment and Interventions Options. Parents have also been found to benefit from knowledge about treatment and intervention options, e.g., behavioral,

socio-emotional, biomedical, and complementary and
alternative medicine (Howe, 2006). The ultimate goal of
treatment and intervention should be to alleviate
identified risks or problems, and to facilitate optimal
development (Greenspan & Wieder, 2006). The ideal program
for a young child may consist of a combination of methods
including applied behavioral analysis, the floor time
approach, a sensory integration program, nutrition and
supplements, and physical and occupational therapy to
improve motor skill development (Sicile-Kira, 2004).

Before a treatment or intervention plan is chosen,
screening of the child's social, intellectual, emotional,
and related motor and sensory functioning should be
completed (Greenspan & Wieder, 2006). Parents should also
analyze the impending risk for the child, the family, the
financial expenses of therapy, if the treatment can be
incorporated into an existing program, and the facts to
validate the method of treatment. If the treatment is ASD
specific, how the effectiveness will be measured, and the
track record of the provider of the treatment should also
be considered (Sicile-Kira, 2004). Recent research has
found that at least 70% of parents who have a child
diagnosed with an ASD have implemented some sort of

treatment or intervention ranging from gluten-free and casein-free diets to auditory integration therapy, music therapy, hyperbaric oxygen, and magnetic therapy, but all had stopped treatment due to ineffectiveness (Sheehan & DeOrnellas, 2011). The key for intervention and treatment is to find a method that is optimal for the particular child. It is important for parents to remember that the success of a given treatment or intervention method may be contingent on various factors including parental stress, economic status, parental psychopathology, and availability of time (Howe, 2006). Furthermore, there may be hindrances in applying interventions due to factors related to the child's disability, e.g., repetition needed, limited success achieved, and other demands on parental energy (Woolfson & Grant, 2006).

According to the Center for Disease Control and Prevention (CDC) website (n.d.), applied behavioral analysis (ABA) may include task analysis, discrete trial teaching, the Lovaas method, verbal behavior therapy, errorless learning (no-mistake learning), and rapid prompting method. These approaches teach children by eliciting responses through rigorous verbal, auditory, visual, and tactile triggers (Sicile-Kira, 2004). There

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is extensive research validating ABA approaches in regards to improvements in behavior management, task development, and academic achievement (Sicile-Kira, 2004). Operant conditioning treatment models are found to be successful in reducing behavioral excesses (e.g., aggression, non-compliance, hyperactivity, and conduct problems) and in improving communication and engagement with children, but only in a clinic environment (Brookman-Frazee, Stahmer, Baker-Ericzen, & Tsai, 2006). There are little to no generalizations to other contexts. It has been suggested that operant conditioning models need to develop a more naturalistic method for intervention that focuses on collaborations on all levels of programming, i.e., assessment, goal development, treatment, and delivery (Brookman-Frazee, Stahmer, Baker-Ericzen, & Tsai, 2006). Only minor improvements in social and emotional functioning have been found to be gained through ABA approaches (Greenspan & Wieder, 2006). For ABA approaches to be holistically successful there must be a social and emotional component that facilitates a continuous flow of interactions, and which also supports initiative and creativity (Greenspan & Wieder, 2006). Research states that behavioral approaches may

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experience heightened success if modeling, in-vivo
feedback, and coaching are provided, and are combined
with socio-emotional group support (Brookman-Frazee et
al., 2006).

In addition to behavioral interventions, there are
also social-emotional interventions. It is imperative to
improve the social and emotional awareness of children
diagnosed with Autistic Spectrum Disorders (Greenspan &
Wieder, 2006). Research has found that social deficits
identified early in life tend to become more prominent
later in life without successful intervention (Bass &
Mulick, 2007). The developmental individual-difference,
relationship-based (DIR) model has been found to improve
social and emotional intelligence by purposefully
encouraging ASD children to interact with others
(Greenspan & Wieder, 2006). The DIR model is based on the
idea that developmental progress can be made by following
the child's natural interests, and by discovering the
child's sensory and motor profile (Greenspan & Wieder,
2006). The model is not an exclusive intervention;
instead, it offers a methodical evaluation to create a
comprehensive program for ASD children that concentrate
on relationships, specific behaviors, and the creative

use of ideas (Greenspan & Wieder, 2006). The key element of the model is to tailor these interventions to the child and help the child build a healthy foundation for relating, communicating, and thinking (Greenspan & Wieder, 2006). Through its application, the DIR model promotes the development of social and emotional skills when applied in conjunction with other intervention approaches such as ABA and sensory integration therapy (Sicile-Kira, 2004).

DIR/Floortime utilizes naturalistic learning strategies (i.e., learning through interaction and discovery) that specifically address the core deficits (e.g., shared attention and regulation, engagement and relating, purposeful emotional interaction, shared problem solving, creating ideas, and logical thinking) as well as the surface behavioral problems of the disorder (e.g., disruptive social behaviors) (Greenspan & Wieder, 2006). As an intervention method, DIR/Floortime urges parents to expand on their child's interests in the world (i.e., assist the child in recognizing sights, sounds, smells, and other sensations outside of the child's body) and become part of that world (Greenspan & Wieder, 2006). When parents actively engage themselves in their child's

world, children with ASDs acquire various degrees of core strengths (Greenspan & Wieder, 2006).

In addition to DIR/Floortime intervention, social play is another intervention that promotes the development of social and emotional intelligence. Children diagnosed with ASDs tend to isolate themselves from others during social play (Bass & Mulick, 2007). Without intervention, these children may remain isolated from others, demonstrate few forms of spontaneous communication, exhibit inappropriate eye contact (e.g., avoidance of eye contact), and engage in recurrent peculiar behaviors when interacting with others. Deficits in social play may lead to pronounced impairments in reciprocal social interaction, communication, and imagination(Bass & Mulick, 2007).

Significant improvements in social play behaviors occur when an intervention such as the DIR model is implemented by siblings and/or peers (Bass & Mulick, 2007). Typically-developing siblings assist the ASD child by initiating, prompting, and reinforcing social interactions (Knott, Lewis, & Williams, 2007). Social skills training can also be facilitated by the use of social stories and social skill groups. Through their

actions, typically-developing siblings teach their ASD

sibling about social relationships and consequences of

the social choices they make (Bass & Mulick, 2007).

A third type of treatment intervention is

biomedical. While there is no biomedical cure for ASDs,

medications are available to alleviate related symptoms

of high energy levels, inability to focus, and depression

(e.g., Risperdal, Zyprexa, and Abilify). These

medications should only be used with moderate to severe

behavior problems that have not responded to behavioral

treatment alone (Sheehan & DeOrnellas, 2011).

Parents should be very cautious when choosing

biomedical services (Greenspan & Wieder, 2006). According

to the Center for Disease Control and Prevention website

(n.d.), it is vital for an ASD child to have a

comprehensive pediatric medical and neurological

evaluation, an extended sleep evaluation, and an

electroencephalography (EEG) to rule out possible

physiological causes for observed symptoms or behaviors.

Finally, there are also complementary and

alternative medicine treatments (CAM). According to the

National Center for Complementary and Alternative

Medicine website (n.d.), there are various types of CAM

treatments available such as natural products (e.g., herbal medicines), mind and body medicine (e.g., meditation), manipulative and body-based practices (e.g., spinal manipulation and massage therapy), and other practices such as magnet therapy and light therapy. The most popular CAM treatment among families is special diets (Sicile-Kira, 2004).

The safety and effectiveness of many CAM treatments are uncertain. CAM treatments are very controversial and there is little to no empirical evidence to support their claims. Current research from the Study to Explore Early Development (SEED) has found that as many as one third of parents of ASD children have tried a CAM, and up to 10% of the parents may be using potentially dangerous treatments.

The Autism Society (n.d.) indicates that many parents believe that diets reduce ASD symptoms without the hindrance of adverse side effects, costly implementation, or professional consultations. This anecdotal information should be evaluated thoroughly as many dietary treatments do not have the scientific support needed for widespread recommendation. Most research has noted there is no direct link between diet

and improvement in behavioral symptoms (Sheehan &
DeOrnellas, 2011). The most popular diets include the
gluten-free, casein-free (GFCF) diet, the anti-yeast
diet, the Feingold diet, and the Ketogenic diet. Diets
are uniquely designed to meet the needs of the
individual, ranging from gluten digestive difficulties to
reducing epileptic activity. Accordingly, improvements
observed in a specific child may not generalize to other
children. It is best to consult with the child's
pediatrician and dietician before considering a diet
approach.

How to Parent an Autism Spectrum Disorders Child. It
is imperative that parents of ASD children become
familiar with empirically-based information about
positive child guidance. It has been found that when
parents utilize supportive and
developmentally-appropriate child-rearing practices
(e.g., authoritative parenting styles), significant
improvements are gained in overall family functioning and
family synchrony (Law et al., 2008; Sicile-Kira, 2004).

Also, when parenting programs are tailored to the
specific needs of the family, healthy development of the
ASD child is more likely to occur (Law, Plunkett, Taylor,

& Gunning, 2008). Parents provide a gateway, through their parenting practices, for the family system to understand the ASD diagnosis. Parents' attitudes and expectations regarding the ASD diagnosis have the strongest bearing on how the family system adjusts (Rivers & Stoneman, 2008). Parents should utilize child guidance practices that are warm, synchronized with their child's specific abilities, and take individual differences into consideration (Law et al., 2008).

There are a vast number of parenting and child guidance methods available for parents to choose from. It has been found that sensitively-attuned parenting contributes to the well-being of children with disabilities (Schuengel et al., 2010; Woolfson & Grant, 2006). Parenting strategies that encourage independence in the ASD child and influence the child's behavior using a rational explanation that is sensitive to and facilitates the child's changing sense of self have been found to positively influence development (Bornstein & Lamb, 2011). These methods can be described as authoritative in nature, attachment parenting, or nurturing parenting (Singh et al., 2006). Parents who utilize these parenting styles set clear standards for

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their children, monitor their imposed limits, and allow

children to develop a sense of autonomy (Woolfson &

Grant, 2006). Parents are "in-tune" with their child,

express consistent and sensitive responsiveness, physical

and emotional availability, and are able to identify

their child's unmet needs and respond appropriately by

looking at the child's development and biology (Greenspan

& Wieder, 2006).

The most important step a parent can take after the

diagnosis of ASD is to interact with the child in a way

that promotes unconditional acceptance and harmony (i.e.,

a secure attachment) (Greenspan & Wieder, 2006). Research

shows that acceptance of the diagnosis allows a parent to

create a developmental pathway that produces positive,

bidirectional parent-child interactions (Singh et al.,

2006). This acceptance may be achieved by parents

changing their own behaviors by using "mind-mindfulness."

"Mind-mindfulness" may be described as a parent who

relates to events in the environment and has a clear,

serene mind that is focused on the present moment in a

tolerant manner (Singh et al., 2006). When parents

utilize "mind-mindfulness," it generates a harmony that

supports the child and increases parental satisfaction in

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parenting skills and interactions with the child (Singh et al., 2006).

Another challenge for parents early on is the responsibility to assist the child to talk, walk, and interact with others (Sheehan & DeOrnellas, 2011). Parents may utilize strategies aimed at increasing social communication and interactions with the child. This can be accomplished by providing opportunities to learn and practice social and emotional communication. A relationship-based model suggests that parents should provide an environment that is trusting, intimate, and warm (Greenspan & Wieder, 2006). It is vital for parents to provide a safe zone where the child can look, listen, pay attention to sights, sounds, smells, and other sensations outside of the child's body so that the child may make connections to the outside world (Greenspan & Wieder, 2006).

The utilization of the floor-time method may provide this safe zone. This method proposes that by following the child's lead, parents will find out what is important to the child, and will allow for social and emotional interactions to occur (Greenspan & Wieder, 2006).

Research has found that when interacting with an ASD child, parental sensitivity, emotional attunement, and responsiveness with a young child depends on the caregiver's ability to correctly identify, comprehend, and decipher the child's behavior, body language, facial expressions, and speech (Howe, 2006).

If there are difficulties with child-rearing practices, Parent-Child Interaction Training (PCIT) has been found to improve the quality of the parent-child relationship by changing parent-child interaction patterns (Law et al., 2008). Although this training was originally designed for typically-developing children with behavioral disturbances, it has recently been found to increase positive parent-child interactions with ASD children (Zisser & Eyberg, 2010). The main objective of the training is to empower parents to make changes that lead to a nurturing and secure relationship with their children, while increasing their child's prosocial behavior and decreasing negative behavior (Zisser & Eyberg, 2010). There are two basic interactions: Child Directed Interaction (CDI) and Parent Directed Interaction (PDI). Here, parents utilize the CDI strategy in play situations to strengthen their relationship with

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the ASD child, while the PDI strategy helps them learn
how to use specific behavior management techniques
(Lanier et al., 2011). It has been found that through the
use of extensive and repetitive affective social
exchanges between parents and ASD children (i.e.,
attachment parenting), children are able to compile an
understanding of how their own, and other people's minds,
perform at the emotional, intentional, and behavioral
level, and how these mental states influence social
interactions and relationships (Howe, 2006).

What Resources are Available to Families with an
Autism Spectrum Disorders Child. Research suggests that
the family system should receive social support from
community services after the diagnosis. This may include
parental coping support interventions and interventions
with parenting skills (Howe, 2006; Woolfson & Grant,
2006). These social support interventions may also
include components of networking with other families
affected by the diagnosis, connecting with research
organizations and advocacy groups, and parenting skills
training. Parents may also benefit from seeking advice
and reading accounts written by adults with ASDs, and
also by reading empirically-based academic journals.

Learning about the available services and funding that the ASD child may be eligible for may also be helpful since early intervention has been found to lessen the impact of ASDs (Sicile-Kira, 2004). The child's pediatrician may be an excellent source of information.

Summary and Purpose of Project

Current research acknowledges that there is a disparity in information that is provided to families of ASD children. Current parenting education programs offer families information about what ASDs are but largely fail to provide families with information about what to expect immediately following the ASD diagnosis (e.g., understanding the ASD child, how to parent an ASD child, parental stress, social support, and what resources are available to families). Additionally, these programs are not tailored towards young, newly-diagnosed ASD children. Parents of newly-diagnosed ASD children would benefit from professional input and individualization of information about ASDs (Keen et al., 2010; Todd et al., 2010). Specifically, families would greatly benefit from gaining knowledge in strategies that help nurture and encourage the development of their ASD children while addressing the impact of ASDs on the family system.

Therefore, the purpose of this project was to provide families with a comprehensive, parenting education program that focuses on educating parents of young newly-diagnosed ASD children about coordinated services, supporting the family to promote the ASD child's growth and development, and supporting the family system during the critical early years.

It was expected that this project would be a valuable asset to families with ASD children as it would help parents understand their ASD child by offering research-based information that other education programs have not provided.

While many education programs (e.g., Autism Parent Education Program, Family Service Agency, Center for Autism: Autism Education Series) help parents understand Autism Spectrum Disorders, including deficits in socialization, communication and behavior, and available interventions, they fail to address how ASDs impact the family system immediately following the diagnosis. Additionally, parent education classes (e.g., Star of CA: Behavioral and Psychological Services) often focus on behavior modification (e.g., applied behavioral analysis) and the skills necessary to effectively serve as an

interventionist and advocate for the ASD child, but they largely ignore the importance of the ASD child's socio-emotional development. This project can be beneficial to society as it can serve as a model intervention program for other agencies that serve families of ASD children.

CHAPTER TWO

METHODS

Overview

The purpose of this project was to design and implement a parenting program for families of young children who are newly diagnosed with Autism Spectrum Disorders (ASD). Parents attended a month-long, twice-weekly training titled "A Parent Education Curriculum for Families with Young ASD Children." The eight-session program focused on seven topics of information parents need after an ASD diagnosis.

The seven topics and course materials were developed after identifying discrepancies in academic research and existing parenting education programs. Topics were further developed after reviewing the recommendations made by parents of ASD children at Inland Regional Center, an agency that serves the developmentally disabled population in Riverside and San Bernardino County. The duration of the eight-session education program (e.g., each one and one-half hours, twice-weekly, for one month) was established after assessing the amount of time it would take to cover the information in each identified topic.

Table 1. Training Schedule

Session # 1	What to Expect after the Diagnosis/ Understanding the ASD Child: - Explanation of the "grief cycle." - Characteristics of ASDs - Maladaptive behaviors - Sensory-issues and sensory classifications - How to potty train an ASD child - Link between communication deficits and child behavior - Ideas to increase communication skills	Wk 1, Day 1
Session # 2	How to Parent an ASD Child (Part 1): - Attachment theory - Misconceptions of attachment in ASD children - Research on how parenting styles impact development	Wk 1, Day 2
Session # 3	How to Parent an ASD Child (Part 2): - Child guidance, why is it important? - Setting limits and gaining child cooperation - What to do when a child has a problem or need - Guidance tips (e.g., influencing development outcomes and managing behaviors in public) - Importance of ASD children's social and emotional development - Overview of early childhood development.	Wk 2, Day 3
Session # 4	How ASDs Impact the Family System (Part 1): - Parent stress - How daily routines assist in family management - The impact of an ASD diagnosis on the marital dyad - Respite care	Wk 2, Day 4

Session # 5	How ASDs Impact the Family System (Part 2): • How sibling relationships are affected by an ASD diagnosis • Why is it important for the ASD child to develop a high-quality sibling relationship? • Facilitating the development of the sibling relationship	Wk 3, Day 5
Session # 6	Treatment and Intervention Options: • Why early intervention is important • Why the identification of treatment goals and analysis of risks are important • Monitoring progress • Comprehensive review of treatment and intervention options available to children diagnosed with ASDs	Wk 3, Day 6
Session # 7	Negotiating the School System: • Comprehensive review of school requirements, legislation, and the IEP process.	Wk 4, Day 7
Session # 8	What Resources are Available to Families with an ASD Child	Wk 4, Day 8

At the beginning of the month-long program, parents completed the Parent Sense of Competence (PSOC) scale (Rogers & Matthews, 2004), the Parent Stress Index (PSI) (Abidin, 1997), and a background information form. After all sessions were completed, parents again completed the PSOC scale and Parent Stress Index (PSI), as well as a brief class evaluation form to assess the effectiveness

of this curriculum on improving parenting practices with ASD children.

Participants

A letter of approval was obtained from Inland Regional Center (Appendix A). Parents of young, newly-diagnosed ASD children were recruited with flyers posted in Inland Regional Center's Family Resource Center and Early Start Program, and were distributed to members of Institute of Child Development and Family Relations listserv at California State University, San Bernardino, and the Inland Empire Autism Society newsletter (Appendix B).

Professionals who gained access to the flyer and expressed interest in the program were also invited to attend. Formal demographic data that was professional specific (e.g., length of employment at agency, years of experience working with ASDs, etc.) was not collected as the program was designed for parents of ASD children.

A total of 7 participants responded and participated in the trainings. Two participants were parents of an ASD child; each had one child with an ASD between the ages of 3-5 years (M = 4 years) (one was female and the other

male). The parent participants' ages were 42 and 26 years old, and both were Hispanic females. Their educational background included one participant having a M.A. as the highest degree earned and the other participant completing some college/trade school. The remaining 5 participants were professionals. Their ages ranged from 24-45 years (M = 34.6); three were Hispanic, one was Caucasian, and one was African American. Two of the professional participants were care providers (e.g., they offer assistance in their home to ASD children) to a female ASD child between the ages of 3 and 4 years. The professional participants' educational backgrounds were diverse. One participant reported having an M.A., and four participants reported having a B.A. as the highest degree earned. Additionally, participants reported on the highest degree earned by the child's other biological parent, ethnicity of the ASD child, number of typically-developing children in the home, number of adults in the home, and the number of classes/orientations previously attended (see Table 2 for parents' and professionals' information).

Table 2. Participants' Background Information

| | Parents | | Professionals | | | | |
	1	2	1	2	3	4	5
Age	42	26	45	37	24	39	28
Highest Degree Earned	MA	College	MA	BA	BA	BA	BA
Highest Degree Earned by Other Parent	MA	High School	*NR	N/A	College	*NR	*NR
# of ASD Children/In Care	1	1	1	1	N/A	N/A	N/A
Age of ASD Child	4	5	3	4	N/A	N/A	N/A
Sex of ASD Child	F	M	F	F	N/A	N/A	N/A
Ethnicity of ASD Child	Asian	Hispanic	Other	AA	N/A	N/A	N/A
Number of Children in Home	3	0	2	3	0	0	0
Number of Adults in Home	2	2	2	1	1	3	1
# of Other Classes Attended	0	0	0	1	1	0	1

* Note: NR stands for Not Reported

Measures

The Parental Stress Index (PSI) and Parent Sense of Competence (PSOC) scales were chosen as measures since parental stress and parental sense of competency are contextual factors that directly influence the well-being of ASD children and their parents (Sheehan & DeOrnellas, 2011).

Parent Sense of Competence (PSOC) Scale

The Parent Sense of Competence (PSOC) scale (Appendix C) was used to assess parental confidence at the beginning and again at the end of the 4-week class. The PSOC scale was used to determine if the education program improved parental self-esteem, satisfaction in the parental role, parental efficacy, and interest in parenting. This 16-item Likert-type questionnaire measured parents' beliefs, values, and perceived skills regarding being a parent. It was originally developed by Gibaud-Wallston and Wandersman (1978) to measure distinct aspects of parenting self-esteem such as satisfaction in the parental role, parenting efficacy, and interest in parenting (Rogers & Matthews, 2004). PSOC items are phrased according to the individual completing the questionnaire (e.g., "If anyone can find the answer to what is troubling my child, I am the one"). Parents rated their extent of agreement with each item by circling a number that best matches what is accurate for them (1 = strongly disagree; 6 = strongly agree). Acceptable levels of internal consistency (range .75-.88) have been reported for the PSOC in a study by Gilmore and Cuskelly (2008).

Parent Stress Index

The Parent Stress Index (PSI) (Abidin, 1997)

(Appendix D) was used to evaluate the magnitude of stress

in the parent-child system. It was also used to evaluate

if participation in the education program reduced

parental stress. The 120 statement, self-report

questionnaire was used to identify parent-child problem

areas, and it focuses on three major domains of stress:

child characteristics, parent characteristics, and

situational/demographic life stress. The Child and Parent

domains are combined to form the Total Stress scale. The

Life Stress scale provided information about the amount

of parent stress caused by factors outside the

parent-child relationship. For each PSI statement (e.g.,

"My child smiles at me much less than I expected"),

participants were asked to focus on the child most

concerned with, and circle the response which best

represents their opinion. Based on data collected from a

sample of 534 mothers and 522 fathers, coefficient alphas

range from .78 to .88 for Child Domain subscales and from

.75 to .87 for Parent Domain subscales (Abidin, 1997).

Reliability coefficients for the two domains and the

Total Stress scale are .96 or greater, indicating a high

degree of internal consistency for these measures

(Abidin, 1997).

Background Information

A background information form (Appendix E) was used
to gather pertinent information about the participant's
age, sex, ethnicity, highest level of education attained,
the ASD child's other biological parent's education, the
number of children in the family diagnosed with an ASD
(including the children's age, sex and ethnicity), the
number of children without a disability (including the
children's age, sex, and ethnicity), the number of adults
in the home, and previous participation in
orientations/classes for parents of ASD children. The
background information form was completed during the
first class session.

Class Evaluation Form

A class evaluation form (Appendix F) was used to
assess the effectiveness of the parent training at the
end of the parenting class. Participants were asked to
provide feedback on the usefulness of the training, what
was the most and least valuable information learned from
the training, how the training can be improved, if the
information obtained will be used, and to what extent the

participant plans to incorporate the training into parenting practices.

Development of Project Materials
What to Expect After the Diagnosis/Understanding the Autism Spectrum Disorders Child

The outline for Session # 1, which covered What to Expect after the Diagnosis/Understanding the ASD Child, is provided in Appendix G-1. Research findings suggest that it is important for parents to become familiar with the "grief cycle" because getting emotional support and factual information helps parents cope after the diagnosis (Sicile-Kira, 2004). Therefore, participants were given general information describing the components of the "grief cycle" since it describes the emotions parents often feel after their child receives the initial diagnosis of an ASD (Appendix G-2).

Research findings suggest that parents who receive a thorough explanation of the nature and character of the child's disability, and how it will likely affect the child's ability to communicate needs, emotions, and interactions, are more likely to accept the child, and as a result are more likely to feel less distressed (Howe, 2006). Therefore, participants were provided with

diagnostic information about the nature and
characteristics of children diagnosed with ASDs. General
information describing Autistic Spectrum Disorders
(ASDs), e.g., definition, prevalence rates, causes and
risk factors, and the financial impact on society, were
also reviewed. Maladaptive or inappropriate behaviors
were then discussed (e.g., irritability, aggression,
non-compliance, property destruction, and self-injury).

Next, the link between communication deficits and
child behavior were reviewed. Participants were given
information about communication deficits in children with
ASDs and how behaviors may serve as a form of
communication. Since there is a considerable amount of
information in this session, some resources were not
covered, and were instead given to parents in the form of
handouts. Participants received a handout describing ways
to increase communication skills in ASD children (e.g.,
one-to-one interactions, scripting, and social stories)
(Appendix G-3). The topic of sensory-issues followed and
covered areas of auditory and visual stimuli, and ASD
sensory classifications. Participants were given a
handout discussing sensory-related issues with food
(Appendix G-4) and were also given an example of a

dietary log to assist in tracking food sensitivities
(Appendix G-5).

Potty training was then discussed, including
information regarding developmental appropriateness; and
the ASD child's communication needs, sensory awareness,
sensitivity to stimulation, preference for routines,
motor planning difficulties, anxiety levels, and
difficulties in adjusting behaviors to fit new contexts
was also reviewed. A handout with toilet training
recommendations were also given to participants (Appendix
G-6).

How to Parent an Autism Spectrum Disorders Child

The outline for Session #2, which covered How to
Parent an ASD Child, is provided in Appendix H-1.
Information on this topic was divided into two sessions.
Session Two included Part One of How to Parent an ASD
Child. Based on research findings, knowledge of
attachment theory is important as it describes the
conceptual framework for normative and individual
differences in caregiver-child interactions (Greenspan &
Wieder, 2006). Therefore, the topics of the session were
attachment theory and how attachment styles inform child
guidance practices. Parenting styles and the role of

mind-mindfulness was also discussed. The first part of the session provided participants with a review of the development of attachment, characteristics of attachment, and attachment statuses. Since there is a considerable amount of information in this session, some resources were given to participants in the form of handouts. Participants received a handout containing information about the developmental outcomes of attachment styles (Appendix H-2).

Based on research findings, it is important for parents to become knowledgeable and trained in positive child guidance skills because it contributes to the well-being of children with disabilities (Schuengel et al., 2010; Woolfson & Grant, 2006). Participants therefore received a handout reviewing Baumrind's parenting styles (e.g., authoritative, authoritarian, indulgent, and neglectful parenting) (Appendix H-3).

The concept of mind-mindfulness was discussed next. Studies show that parenting behaviors which encourage independence in the ASD child using rational explanations that are sensitive to and facilitate the child's changing sense of self (i.e., mind-mindfulness) positively influences development (Bornstein & Lamb, 2011).

Therefore, participants received information about mind-mindfulness.

The outline for Session # 3, which covered How to Parent an ASD Child, is provided in Appendix I-1. Session #3 included Part Two of How to Parent an ASD Child. Since there was a considerable amount of information in this session, some resources were given to participants in the form of handouts.

Since studies show that knowledge of child guidance skills informs parents of how to create an atmosphere that promotes their child's development (Woolfson & Grant, 2006), participants were provided with an explanations of child guidance including child guidance versus punishment (Appendix I-2), how to set limits and gain children's cooperation (Appendix I-3), and how to respond to a child when a problem or need is identified (Appendix I-4). Participants received guidance tips to increase developmental outcomes in the form of a handout (Appendix I-5). Participants also received a handout with parenting tips on how to manage behaviors (e.g., meltdowns) in public (Appendix I-6).

As ASD children exhibit deficits in social and emotional competence, the heightened importance of

promoting social and emotional development was reviewed.

Participants were given a handout with play ideas that

were aimed to promote social and emotional development in

ASD children (Appendix I-7).

Based on research findings, it is important for

parents to possess knowledge in developmental domains and

developmentally-appropriate child-rearing practices as

the quality of care a child receives is critical for

developmental outcomes (Law et al., 2008). Therefore, the

domains of child development were reviewed including

domains of social, emotional, language, physical, and

cognitive development. A handout of the relevant

developmental milestones from ages 1 to 5 years old was

also given to participants (Appendix I-8).

How Autism Spectrum Disorders Impact the Family

System. The outline for Session # 4, which covered How

ASDs Impact the Family System, is provided in Appendix

J-1. This topic was divided into two sessions: The first

part of How ASDs Impact the Family System reviewed topics

of parental stress, the importance of establishing daily

routines, the impact of an ASD diagnosis on the marital

dyad, and the importance of utilizing respite care.

Studies show that parents who receive information about

how parental stress can be managed through the implementation of daily routines are more likely to exhibit acceptance of the ASD child (Larson, 2006; Sicile-Kira, 2004). Therefore, parental stress was the first topic of the session. The sources of stress for parents were discussed next (e.g., characteristics of the disorder, including the ASD child's inability to deviate from routines, to complete daily living activities, and to have free-time). Daily routines were then reviewed as they relate to parental stress management. Since there was a considerable amount of information in this session, some resources were not covered, and were instead given to participants in form of handouts. A handout of a sample daily routine was given to participants to use as a reference when developing their own family routines (Appendix J-2). Studies show that the marital relationship is just as important as the relationship with the ASD child (Sicile-Kira, 2004). Therefore, the marital dyad was discussed next. It is important for parents to maintain the quality of their relationship as it has direct effects on the family system as a whole (Kersh et al., 2006), so the causes of marital discord (e.g., conflicting role expectations and heightened

caregiving responsibilities) were reviewed as well as the importance of marital equality and ways to maintain the intimacy of the marital relationship.

Respite care should also be utilized by the parents as it provides them with an opportunity for personal time and reduces the risk for burn-out (Sicile-Kira, 2004). Respite care was therefore reviewed as it is designed to maintain the parent-child relationship and the well-being of the parent. Handouts were given to participants with sample questionnaires designed for reviewing respite resumes, conducting telephone interviews, checking references, and completing face-to-face interviews (Sicile-Kira, 2004) (Appendix J-3). A listing of local respite providers was also given to participants (Appendix J-4).

The outline for Session #5, which covered How ASDs Impact the Family System, is provided in Appendix K-1. Session Five included the second part of How ASDs Impact the Family System. This session discussed sibling relationships. Studies show that it is important for the ASD child to establish high-quality sibling relationships as they provide the ASD child with opportunities to practice social interactions in a natural setting (e.g.,

learning how to play, share, listen, and react to social norms) (Rivers & Stoneman, 2008; Stoneman, 2001). It is therefore important for parents to learn about sibling relationships and encourage typically-developing siblings to use positive behaviors during interactions with the ASD sibling to elicit certain social skills that would benefit the sibling relationship (Knott, Lewis, & Williams, 2007). Thus, the importance of the sibling relationship for the ASD child was reviewed first. Participants were also given a family support tool kit explaining the sibling relationship (Appendix K-2) (Autism Speaks website, 2011). Parental responsibility for maintaining the sibling relationship (e.g., explaining the diagnosis, facilitating the development of the sibling relationship, modifying behaviors, and spending quality time alone with children) was also reviewed. Participants were given a handout explaining ways to facilitate the development of the sibling relationship (Appendix K-3).

The impact of the sibling relationship for typically-developing siblings and ASD siblings was reviewed next. Participants learned information about how associated behaviors of ASDs (e.g., deficits in social

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and emotional competence) impact the sibling relationship and the typically-developing siblings' development. Lastly, participants received a handout with ideas about spending time alone with typically-developing children (Appendix K-4).

Treatment and Intervention Options. The outline for Session #6, which covered Treatment and Intervention Options, is provided in Appendix L-1. Providing parents with information about intervention and treatment options is important as up to 10% of parents with ASD children may choose potentially dangerous treatments (e.g., secretin injections, nicotine patch therapy, and hyperbaric oxygen therapy) due to their lack of knowledge (Todd et al., 2010). Therefore, Session Six provided participants with information about the importance of early intervention, the identification of goals for treatment and intervention, and the analysis of risks before a treatment or intervention is chosen. Since there was a considerable amount of information in this session, some resources were given to participants in the form of handouts. Participants received a handout explaining the components of effective intervention programs (Appendix L-2). Next, information was provided to participants that

compared the components of the behavioral,

socio-emotional, biomedical, and complementary and

alternative medicine interventions and treatments

options. Detailed handouts reviewing applied behavioral

analysis (ABA) models (Appendix L-3), DIR/floortime,

social play, and social stories (Appendix L-4), and

specific biomedical (e.g., Risperdal, Zyprexa, and

Abilify) (Appendix L-5) and CAM treatments (e.g., special

diet) were also provided (Appendix L-6).

Studies show that parents who track their child's

progress increase the child's chances for developmental

progression, and they are in a better position to make

educated decisions regarding their child's treatments

(Brookman-Frazee et al., 2006; Sheehan & DeOrnellas,

2011). Therefore, participants were also given

information about how to develop a monitoring system to

track how each intervention or treatment option affects

their child (Appendix L-7). Participants received a copy

of the Autism Treatment Evaluation Checklist (ATEC) to

assist with evaluating treatment and interventions

(Appendix L-8).

Negotiating the School System. The outline for

Session # 7, which covered Negotiating the School System,

is provided in Appendix M-1. Research findings suggest that parents who are knowledgeable about special education components are better suited to make informed decisions regarding their child's future (Carothers & Taylor, 2004). Therefore, knowledge of school enrollment requirements, specifically Early Head Start and Head Start (e.g., regulations, guidelines, policies, and state/federal legislation), were discussed as this informed participants about how to choose a school environment that is optimal for their child's educational needs. Since there was a considerable amount of information in this session, some resources were given to parents in the form of handouts. Participants also received information about the specific legislation that impacts their child's educational rights (e.g., Americans with Disabilities Act, Individuals with Disabilities Education Act, Rehabilitation Act of 1973, Free Appropriate Public Education, and No Child Left Behind) (Appendix M-2). In addition, participants also received sample questions for assessing potential school environments (Appendix M-3) and information pertaining to parental educational rights (Appendix M-4). Participants also received information about the Individual Education

Plan (IEP) (Appendix M-5), an IEP checklist (Appendix

M-6), and a sample handout of the IEP (Appendix M-7).

What Resources are Available to Families. The

outline for Session #8, which covered What Resources are

Available to Families, is provided in Appendix N-1.

Studies show that parents' abilities to understand their

ASD child is heavily dependent on the support they

receive after the initial ASD diagnosis, and parental

knowledge and eventual parental participation in support

groups has been found to lessen the impact of ASDs on the

family system (Sicile-Kira, 2004). Therefore, Session

Eight provided participants with information about

available supports. Since there was a considerable amount

of information in this session, some resources were not

covered, and were instead given to participants in the

form of handouts. At the beginning of the session, the

Autism Research Institute was discussed. Participants

were given a handout with words of advice from Dr.

Edelson of the Autism Research Institute (Appendix N-2).

The components of Inland Regional Center's eligibility

criteria and services were reviewed next. Participants

were also given handouts explaining the services offered

by California State University, San Bernardino:

University Center for Developmental Disabilities

(Appendix N-3) and the Carolyn E. Wylie Center (Appendix

N-4).

Parents who are proactive in finding resources that

are available to their children, and who are advocates

for their children, have better family outcomes after the

diagnosis (Sicile-Kira, 2004). Therefore, participants

received information about local resources. Participants

were provided with a handout with contact information for

local support groups, research organizations, advocacy

groups, and foundation groups (Appendix N-5).

Studies show that parents of ASD children who

regularly attend counseling sessions that address topics

of raising a child with ASDs are better suited to care

for their children and have better family outcomes

(Woolfson & Grant, 2006). Therefore, participants

received information about counseling providers in the

local geographical area (Appendix N-6).

CHAPTER THREE

RESULTS

Pre- and Post-Assessments

Table 3 shows the data for the Parent Sense of Competence scale (Gibaud-Wallston & Wandersman, 1978) for the four participants: two were parents and two were professionals and care providers to ASD children. The three scoring ranges for parental-confidence were low (e.g., 16-50), moderate (e.g., 51-69), and high (e.g., 70-96). Results showed that, overall, participants were in the lower range of moderate parental-confidence ($\bar{x}$ = 52.25) for the pre-test scores; for the post-test items, participants were in the upper range of moderate parental-confidence ($\bar{x}$ = 68). The small sample size precluded calculation of alphas.

Table 3. Pre- and Post-Test Means for Parent Sense of

Competence (n = 4)

PSOC	Pre-test	Post-test
Problems of taking care of child are easily solved once you know how your actions affect your child, an understanding I have acquired.	3.75	5.25
Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age.	2.25	3.5
I go to bed the same way I wake up in the morning, feeling that I have not accomplished a whole lot	3	4.25
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.	4	5.25
My parent was better prepared to be a good parent than I am.	3	4
I would make a fine model for a new parent to follow in order to learn what he/she needs to know in order to be a good parent.	3.25	4.5
Being a parent is manageable, and any problems are easily solved.	2.25	3.25
A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one.	3	3.75
Sometimes I feel like I'm not getting anything done.	2.5	3.25
I meet my own personal expectations for expertise in caring for my child.	3	4.5
If anyone can find the answer to what is troubling my child, I am the one.	2.5	3
My talents and interests are in other others, not being a parent.	4	5.5
Considering how long I've been a parent, I feel thoroughly familiar with this role.	2.75	3.25
If being a mother of a child were only more interesting, I would be motivated to do a better job as a parent.	4.75	6
I honestly believe I have all the skills necessary to be a good parent to my child.	3.75	3.75
Being a parent makes me tense and anxious.	4.5	5
Total Score	52.25	68

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Table 4 shows the data for the Parent Stress Index scale (Abidin, 1997) for the three participants: two were parents and one who was a professional and care provider to an ASD child. Overall, results of Total Stress score showed that stress declined very slightly from pre-test ($\bar{x}$ = 311.3) to post-test ($\bar{x}$ = 302.9), which was in the expected direction. The small sample size precluded calculation of alphas.

Subscales of the Parent Domain were also compared. High scores on the Parent Domain suggest that the sources of stress may be related to dimensions of the parent's functioning (e.g., the presence of depression, the inability to fulfill parental responsibilities, parents who lack practical child development knowledge, or parents who possess a limited range of child management skills) (Abidin, 1997). The results of the Parental Domain subscales showed that for the various domains, pre- and post-test scores declined very slightly.

The Child Domain pre- to post-test scores remained relatively stable, with slight decreases noted in Child Reinforces Parent and Acceptability. However, Child

Demandingness scores slightly increased from pre-to post-test.

PSI items in the Life Stress Domain remained stable for pre- and post-test scores.

Table 4. Pre- and Post-Test Means for Parental Stress Index (n = 3)

PSI	Pre-test	Post-test
Parent Domain:		
Parent Competence (CO)	41	40.66
Parent Isolation (IS)	16.66	16.33
Parent Attachment (AT)	27.33	25.33
Parent Health (HE)	13.66	12
Parent Role Restriction (RO)	13	13.66
Parent Depression (DP)	30.66	29
Parent Spouse (SP)	17	16
Combined Score	189.31	182.98
Child Domain:		
Child Distractibility/Hyperactivity (DI)	21	21.66
Child Adaptability (AD)	25	25
Child Reinforces Parent (RE)	17.33	16.66
Child Demandingness (DE)	21	22
Child Mood (MO)	18.33	17.33
Child Acceptability (AC)	19.33	17.33
Combined Score	121.99	119.98
Life Stress	30	30
Total Stress Score	311.3	302.96

Class Evaluation Form

At the completion of the eight sessions,

participants responded to an evaluation survey of the

program.

The first question asked whether the program was

useful, and if so, why. All of the participants found the

program to be useful. They mentioned that they learned

new knowledge to apply to parenting practices with ASD

children, and that the information presented in the

course was useful because it provided examples on how to

understand and interact with ASD children.

Table 5. Was the Program Useful? Why or Why Not?

Participants	
P 1	"Yes, useful. I learned lots of good information from the presentations."
P 2	"Yes. It gave me information on how to interact with my child."
P 3	"Mostly. I learned about the most recent research."
P 4	"Yes. It gave me ideas on how to raise my ASD child and deal with problems."
P 5	"Yes. It gave an in depth understanding of autism and available resources."
P 6	"Yes. The sensory issues related to foods were interesting."
P 7	"Yes. I learned information about ASD's and how the diagnosis affects families."

The second question asked what participants felt was
the most important thing learned from the program.
Participants mentioned that learning about behaviors
related to ASDs, parenting behaviors, the sibling
relationship, and family dynamics were the most important
things they learned from the program.

Table 6. What is the Most Important Thing You Learned
from the Program?

Participants	
P 1	"Potty training, behaviors, parent stress resources."
P 2	"Dealing with behaviors."
P 3	"ASD information."
P 4	"Parenting behaviors."
P 5	"Early intervention, family stress, and sibling relationships."
P 6	"How the grief cycle relates to parenting."
P 7	"Family dynamics and how they play a large role in ASD outcomes."

The third question asked what they thought was the
least valuable part of the program. The majority of the
participants responded with N/A or that every part of the
program was valuable. However, two participants mentioned
that the information on mind-mindfulness and the grief

cycle were the least valuable because the participants

already possessed knowledge in these areas.

Table 7. What was the Least Valuable Part of the Program?

Participants	
P 1	"N/A"
P 2	"Grief cycle discussion."
P 3	"N/A"
P 4	"Information on mind-mindfulness."
P 5	"Every part of the training was valuable."
P 6	"It was all valuable."
P 7	"N/A"

The fourth question asked what they thought could be

added or changed to improve the program. Several

participants suggested adding sessions or lengthening

class times so that the information presented would be

less overwhelming. One participant suggested more real

life examples. Two other participants suggested that the

amount of handouts should be reduced.

Table 8. What do you Think can be Added or Changed to

Improve the Program?

Participants	
P 1	"Less handouts. Maybe condense information."
P 2	"Add more real life examples."
P 3	"Shorten sessions."
P 4	"Additional training and more in-depth coverage of the information."
P 5	"More time. The program is so intensive that it needs more time. The program can be divided in to two parts and taken at separate times."
P 6	"Possibly make the time longer and the days of attendance shorter."
P 7	"More sessions. Less handouts."

The fifth question asked whether they would use the information they learned from the program, and if so, why. All of the participants said they would use what they learned in the program. Participants mentioned that the program provided them with useful information that they could pass along to families and other individuals who are affected by ASDs.

Table 9. Will You Use the Information You Learned From
the Program? Why or Why Not?

Participants	
P 1	"Yes."
P 2	"Yes."
P 3	"Yes."
P 4	"Yes., when raising ASD child in my board and care."
P 5	"Yes. I am interested in working with families with ASD children."
P 6	"Yes. As a resource for families-pass along information."
P 7	"Yes. Pass information to parents within our agency."

The sixth question asked to what extent they planned
to incorporate the ideas/suggestions from the program
into your parenting practices. The mean response for this
item (1 = "not at all"; 7 = "definitely yes") was 5.71.

Overall, participants indicated that the program was
a positive experience. Many comments from the
participants expressed that they learned new techniques
that would help facilitate developmentally-appropriate
parenting practices for themselves and those families
affected by ASDs. Responses revealed that the
professionals were especially interested in learning more
so that they can pass information along to families.

Participants also indicated the training could be improved by lessening the amount of handouts (e.g., too much material covered in training), lengthening the duration of the sessions, and adding vignettes as examples.

<center>Parent Educator's Observations</center>

The parent educator found that the professionals who participated in this program were surprisingly unable to accurately identify risk factors for ASDs (e.g., observation of delayed social/emotional/cognitive development, loss of previously acquired skills, etc.) and that they possessed minimal knowledge regarding the development of ASD children. This is a major concern as professionals are often the first source of information for families of ASD children and it is difficult to ascertain how this lack of knowledge may influence family outcomes. Unexpectedly, the parents were more knowledgeable about the ASD-related topics discussed in the program than were the professionals. For example, the professionals were often bystanders and did not actively contribute to the conversations. Instead, they relied on the parents to provide input on ASDs even when their feedback would have been beneficial to the group (e.g., a

professional was certified in Applied Behavioral Analysis [ABA], a behavior management technique, and she failed to provide input during the topic discussion). The professionals were also unable to identify the networking agencies that serve children and families impacted by ASDs (in fact, most of them had no knowledge of the role of Inland Regional Center). Surprisingly, they also did not coordinate intervention services with other networking agencies.

Second, the parent educator also found that the overall relationship between the parents and professionals in the group was somewhat awkward; the professionals were uncomfortable during parent interactions. For example, the professionals often avoided contact with parents (e.g., they did not initiate conversations with parents and generally sat with other professionals during the program sessions). It appeared to the parent educator that at least for the professionals who participated in the program, they lacked hands-on experience or were not properly trained to interact with families.

Third, it was disclosed that the professionals did not work collaboratively with the parents of the children

they served. Based on conversations with the professionals during the program, it appeared that the professionals assumed the role of the expert and parents were not asked to provide input or feedback during the development of the ASD child's intervention. This is a bothersome observation because professionals are responsible for connecting families to resources and their lack of competence may affect the quality of services they provide.

Fourth, the interactions with the professionals in this group made the parent educator realize that the focus of intervention programs (i.e., where professionals were employed; County of San Bernardino and Inland Empire United Way) is on the ASD child alone and not the family system.

Fifth, the parent educator observed that professionals outnumbered parent participants in the program, even though it was advertised as a class for parents.

Overall, the results of implementing this intervention suggested that participants' level of parental confidence increased with a minimal impact on parental stress. It also appeared that the professionals

in the program lacked knowledge, training, and experience when dealing with children and families impacted by ASDs. The professionals seemed to recognize these disparities and sought out a means to increase their competencies by attending the parent-focused education program.

CHAPTER FOUR

DISCUSSION

The purpose of this project was to provide families with a comprehensive parenting education program that focused on educating parents of young newly-diagnosed ASD children about coordinated services, supporting the family to promote the ASD child's growth and development, and supporting the family system during the critical early years. The training served as a needed intervention for parents of newly-diagnosed ASD children as well as professionals in the field of developmental disabilities. Overall, the pre- and post-test results revealed that participants' level of parental confidence increased while parental stress levels decreased slightly. An additional benefit from the training was that the professionals' participants were able to expand their knowledge about ASDs.

Pre- and Post-Stress and Competency Measures

Results from the four participants who completed the Parent Sense of Competence Scale (Gibaud-Wallston & Wandersman, 1978) revealed that parental confidence increased slightly upon the completion of the parenting

education program. This finding may be attributed to the support (e.g., information about child guidance strategies and what to expect after an ASD diagnosis) that participants received from the program. Research suggests that ASD parents experience heightened levels of difficulties in the parenting role, conflicting expectations for their ASD children, and elevated stressors (e.g., child's disruptive behaviors, inability to communicate effectively, and lack of social skills) that directly impacts their confidence in parenting (Law et al., 2008; Greenspan & Wieder, 2006; Zisser & Eyberg, 2010). The presence this support system (e.g., parenting program) may have lessened the effect of these difficulties.

Results from the three participants who completed the Parent Stress Index (Abidin, 1997) revealed that parents of ASD children, particularly mothers, experienced a significant amount of stress (i.e., they reported high scores on PSI subscales). These results are consistent with findings by Sheehan and DeOrnellas (2011) and Kersh et al. (2006) who found that parents of ASD children report more stress and depression than parents of typically-developing children. The observation of high

scores on the PSI Parent Domain subscales may suggest

there is a potential dysfunction of the parent-child

system that is related to dimensions of the parent's

functioning (e.g., the presence of depression, the

inability to fulfill parental responsibilities, the lack

of practical child developmental knowledge or possessing

a limited range of child management skills) (Abidin,

1997). Post-PSI results revealed that potential

dysfunction of the parent-child system can be reduced by

expanding parental knowledge about ASDs immediately

following the diagnosis (e.g., child development

knowledge, ASD information, support groups, available

resources, etc.), and these results are consistent with

the findings made by Keen et al. (2010).

There were some trends that were apparent: PSI items

that focused on Parental Competence (e.g., parent who

lacks practical child development knowledge), Parental

Depression (e.g., parent who is withdrawn and unable to

act with assertiveness and authority towards the child),

Parental Isolation (e.g., parent who is socially isolated

from emotional support group), Attachment (e.g., parent

who does not feel emotional closeness to child), Health

(e.g., deterioration in parental health as a result of

parenting stress), and Spouse (e.g., parent who lacks the emotional and active support of the other parent in child management) decreased slightly after the parent training classes. PSI items that focused on Child Reinforces Parent (e.g., parent who does not experience child as source of positive reinforcement), Mood (e.g., child whose affective functioning shows evidence of dysfunction), and Acceptability (e.g., child possesses characteristics that do not match the expectations the parent has for the child) also decreased. In each case, the decreases may be a result of the intervention providing participants with the knowledge (e.g., what to expect after an ASD diagnosis) and resources (e.g., social support) to improve stress levels. This explanation is consistent with findings made by Woolfson and Grant (2006) which affirm that parental coping support interventions have a positive effect on stress management.

The items on the PSI that remained stable on the pre- and post-test assessments were related to Child Distractibility/Hyperactivity and Adaptability. In this case, no change as a result of the program may indicate that the children continued to display characteristics

associated with ASDs (e.g., over-activity, short attention span, failure to finish projects, restlessness, inability to adjust to change in environment, etc.) and the effect on parents remained constant.

The items on the PSI that increased on the post-test assessments were related to Child Demandingness and Parent Role Restriction. In this case, an increase as a result of the intervention may indicate that participants were made aware of the demands placed upon them by the ASD child (e.g., crying, frequently requesting help, behavioral problems) and it heightened their perception of how the child restricts their freedom and attempts to maintain their own identity. This is consistent with research by Larson (2006) which states that families impacted by ASDs often experience greater disruptions from child behaviors and have decreased opportunity for personal time.

These pre- and post-findings should be viewed cautiously, however, since the number of participants completing these measures was so small.

Class Evaluation

At the conclusion of the program, participants were asked six post-program assessment questions. Overall, participants gave positive feedback to the questions concerning the effectiveness of the program.

Positive feedback was received from the participants regarding the usefulness of the program. Parental participants conveyed the information was helpful in understanding their ASD child, and all of the professional participants expressed they would use the information in their professional endeavors.

The program supported parents by offering valuable information to help them understand their ASD child, i.e., information about coordinated services, supporting the family to promote the ASD child's growth and development, and supporting the family system during the ASD child's early years. Parent participants found that the techniques presented were useful tools for interacting with their children. The program demonstrated that parents benefited the most from gaining knowledge in specific areas such as how to deal with ASD-related behaviors, techniques for potty training, and resources to ease parental stress, which is consistent with

research by Keen et al. (2010) and Todd et al. (2010).

The program also provided insight on which areas parents

did not find beneficial, e.g., information about the

grief cycle, which is inconsistent with findings made by

Sicile-Kira (2004). It appeared that parents instead were

more concerned about their ability to manage daily life,

and they wanted to discover methods to help alleviate the

stressors that ASDs imposed on the family system.

This program also supported families by providing an

informal setting to ask questions and discuss concerns

regarding ASDs with other families impacted by the

diagnosis. Participants indicated that this opportunity

was useful because it provided access to a natural social

support system. Also, ASD-related information was

disseminated to parents in a way that allowed them to

understand the material and pass the information along to

other families, i.e., parents became a resource for

information. This was an important contribution because

parents are more likely to listen to other parents than

professionals (Sheehan & DeOrnellas, 2011).

Overall, the present program empowered parents by

equipping them with coping mechanisms to help them

decrease their negative feelings towards their ASD child,

help them become more proactive in the ASD child's life, and in turn help the ASD child (Sicile-Kira, 2004). The result of this empowerment will hopefully promote a nurturing and secure relationship with their ASD child (Zisser & Eybreg, 2010).

Professional participants indicated that the information about ASDs, parenting behaviors, early intervention, family stress, sibling relationships, the grief cycle, and how family dynamics play a large role in ASD outcomes were the most important things they learned from the program while the information on mind-mindfulness was the least valuable. It appeared that professionals benefited the most from information about how the ASD diagnosis impacted the family system. This makes sense as professionals typically do not have access to observe families and children in the home environment, and they may therefore be unfamiliar with what families experience on a daily basis.

Recommendations were made as to what the participants thought could be added or changed to improve the program. Most participants indicated that there was too much information to cover. The program should be adjusted to allow for a more in-depth review of the

material. Participants also suggested that the amount of handouts be decreased and to add real life examples to assist in grasping difficult concepts. Future programs should organize topics more efficiently (e.g., do not split topic into two sessions), condense the amount of handouts, and provide alternative visual and tactile stimulations. It may be beneficial to create pamphlets of materials that are provided to participants at the beginning of the program so that participants are well-prepared for discussions (e.g., questions, concerns, general input, elaborations, and illustrations). Real life examples should be added to facilitate the acquisition of difficult or abstract concepts. The vignettes would allow professionals and parents to evaluate how they would assist an ASD child. Future programs should also provide opportunities for role play/simulation. Also, programs should allow media to be introduced into the sessions (e.g., movies, clips, art, etc.) that is relevant to ASDs. These changes may support the development of new perspectives on the challenges faced by children with ASDs.

A recommendation was also made to include information that is geared towards training professionals

so that ASD related-information can be passed along to families. When the program is implemented again, there should be live and video observations of ASD children. This will provide professionals with a clearer picture of ASD children and how their characteristics impact the family system. By adding the observations to future trainings, participants will be given the necessary information to work with families impacted by ASDs.

Parent Educator's Observations

As mentioned previously, the professionals who participated in the program lacked basic knowledge regarding ASDs. It is unclear whether all professionals who assist families impacted by ASDs lack this knowledge or just the professionals who participated in the program. At any rate, it is imperative that professionals acquire knowledge about ASDs and developmentally-appropriate practices so that they can properly assist families impacted by the diagnosis. The current program provided this knowledge by equipping professionals with research-based ASD information (e.g., presentations, handouts, and feedback from discussions). The program also benefited professionals by providing

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them with the opportunity to apply the knowledge they
acquired at their places of employment. For example, a
professional was able to discuss the pros and cons of
behavioral, medical, and social/emotional interventions
for ASD children with a parent whereas before she lacked
knowledge in the area. When professionals are able to
provide a clear explanation of the nature and character
of the child's disability, acceptance of the child is
more likely to occur (Howe, 2006). The present program
also gave insight on how to best train professionals in
the field of developmental disabilities, i.e., provide
comprehensive, research-based information to agencies
that serve individuals and families with ASDs, identify
families in need of services, coordinate resources, and
provide ongoing staff development.

Second, an observation was made that participating
professionals felt awkward with the parents. The current
program did, however, help alleviate the somewhat awkward
relationship between parents and professionals because it
provided a hands-on approach for professionals to
rehearse the role of sensitive social support with the
participating parents. Professionals were able to
interact with parents during the sessions, and they

received constructive feedback on what worked (e.g., acknowledging that parents are a valuable source of information) and what did not (e.g., pacifying parents when a request was made).

The third observation was that professionals in the program appeared to not collaborate with the parents of ASD children they served. This oversight has been found to negatively impact the progress of interventions (Smith & Elder, 2010). It appeared that the program taught professionals how to successfully collaborate with parents since the professionals in this program realized that it is the parents that have spent the most time observing the child's behaviors, strengths, and challenges, and are therefore best suited to make recommendations for their child (Todd et al., 2010). The participating professionals learned that parental involvement in the child's program is very influential and can determine its success or failure. While the professional may develop the child's objectives, it is often the responsibility of the parent to ensure the child meets the objectives.

Fourth, it was observed that the focus of intervention programs is on the ASD child alone. This

approach has been stated in research to be ineffective in addressing problematic concerns (Todd et al., 2010), often leaving families with feelings of discontent. The results of the program suggest that professionals and agencies that serve ASD families need more training in incorporating the entire family system. The program provided the parent educator with insight on how to modify the focus of intervention programs to educate professionals on the importance of the entire family system, not just the ASD child. For example, if the ASD child is exhibiting difficulties in the sibling relationship, evaluations of the sibling and ASD child should be made to determine the problem is the result of an ASD characteristic or the sibling's apprehension to interact with the ASD child. Or, if the child displays problematic behaviors with parenting strategies (e.g., discipline or child guidance), the parent interaction style should be evaluated to determine the source of the problem.

Lastly, the fact that more professionals than parents attended this program suggests that there is a dire need for professionals, not just parents, to obtain information about ASDs. This can be achieved by offering

a program that is specifically designed to meet their need for knowledge while incorporating ways to disseminate ASD information to families.

Future Parent Classes

Future programs should make the following modifications to increase the program's effectiveness.

First, only mothers participated in the program even though fathers were active in the ASD child's life. Fathers should be encouraged to attend the program. Siblings also did not participate. ASDs have been shown to significantly impact the family system as a whole, and it would be optimal to include all family members in the educational program (Dyke et al., 2008).

Second, there were few participants who signed up for the parenting sessions. This may have been related to the time (e.g., 12:00 p.m.) of the sessions. Parents of ASD children are often unable to participate in interventions and classes due to full-time employment, child care concerns, and behaviors related to ASDs (e.g., ASD child's difficulties with changes in routine) (Todd et al., 2010). Future trainings should take these factors

into consideration by offering classes during the evening hours and providing child care.

The intent of future training programs should also be to advance professionals' knowledge about ASDs (e.g., ASD behaviors, diagnosis process, referrals for evaluations, and resources/services) and allow professionals to relay the information to parents/families of ASD children. In essence, professionals should become proficient enough to administer the parent education curriculum themselves.

In order to reap the benefits of a professional training program in ASDs, certain conditions are recommended:

First, support from local agencies should be solicited. By inviting the administration of surrounding family service agencies, perhaps professionals would get the support they need to gain access to ASD-related information. These agencies could also help professionals brainstorm on how to incorporate ASD-information into their agency's mission goals.

Second, future programs should have more emphasis placed on how professionals can identify families who are

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in need of parenting education services and the best way to coordinate services.

Third, future programs should discuss why it is important for professionals to possess the most up-to-date information about ASDs. Implementing an on-going staff development/training requirement may enable professionals to become valuable assets to the ASD community.

The overall effect of such a training program for both parents of ASD children and professionals who provide services for ASD children should be significant. Parents would have access to professionals who are proficient in ASDs and the process of navigating the support system. ASD children would benefit from the program through their parents acquiring the necessary skills from professionals to promote healthy child development and family functioning (Greenspan & Wieder, 2006).

Conclusions

Overall, the parenting education curriculum helped to increase parental competence with a minimal impact on parental stress. The curriculum also provided a

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much-needed education program not only for families but also for professionals. It was shocking that professionals outnumbered parents in the parenting education curriculum sessions; however, it became obvious that this program can serve as a model intervention program for other agencies that assist families of ASD children. With rates of ASDs increasing so dramatically, such programs should be readily available to professionals, as well as, parents.

APPENDIX A

LETTER OF APPROVAL FROM INLAND REGIONAL CENTER

June 4, 2013

Mary Pounders, Program Manager
Inland Regional Center
1365 S. Waterman Ave.
San Bernardino, CA
92408

Dear Institutional Review Board:

It is my understanding that Amber Vela will be recruiting participants from Inland Regional Center for a parenting program titled: "A Parent Education Curriculum for Families with Young ASD Children." Mrs. Vela has informed me of the design of the program as well as the targeted population.

I support this effort and will provide any assistance as necessary for the successful implementation of the program. If you have any questions, please do not hesitate to call. I can be reached at (951)826-2602.

Sincerely,

Mary Pounders
Program Manager, Inland Regional Center

APPENDIX B

FLYER

A Parenting Program for Parents of Newly-Diagnosed Autistic Spectrum Disorder Children

For Parents of Children Ages 2-5

Having a young newly diagnosed child with an Autistic Spectrum Disorder can be overwhelming for parents!

Come learn about the latest research to help you better understand your ASD child and learn ways to promote your child's development:

- What to expect after the ASD diagnosis
- Understanding the ASD child/Typical behaviors of ASD children
- How to parent an ASD child

- How ASDs impact the family system
- Treatment and intervention options
- Negotiating the school system
- What resources are available to families with an ASD child

Class Dates: Mondays and Wednesdays, August 19th-September 11th 2013 (Class duration of 4 weeks)

Time: 12:00pm to 1:30p

Location: Inland Regional Center- 1365 South Waterman Ave., San Bernardino, CA 92408

Presenter: Amber Vela, M.A. in Child Development, California State University, San Bernardino.

To Register and for further Information, contact Amber Vela at (951) 236-0965; amarien5@hotmail.com

APPENDIX C

PARENT SENSE OF COMPETENCE SCALE

Parenting Sense of Competence Scale

Please rate the extent to which you agree or disagree with each of the following statements.

Strongly Disagree	Somewhat Disagree	Disagree	Agree	Somewhat Agree	Strongly Agree
1	2	3	4	5	6

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 parent 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 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 was better prepared to be a good mother than I am.   1 2 3 4 5 6

6. I would make a fine model for a new mother to follow in order to learn what she 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 a bad one.   1 2 3 4 5 6

9. Sometimes I feel like I'm not getting anything done.   1 2 3 4 5 6

10. I meet by 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 being a parent.   1 2 3 4 5 6

13. Considering how long I've been a mother, I feel thoroughly familiar with this role.   1 2 3 4 5 6

Please rate the extent to which you agree or disagree with each of the following statements.

Strongly Disagree	Somewhat Disagree	Disagree	Agree	Somewhat Agree	Strongly Agree
1	2	3	4	5	6

14. If being a mother of a child were 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 to my child.   1 2 3 4 5 6

16. Being a parent makes me tense and anxious.   1 2 3 4 5 6

Reference: Gibaud-Wallston, J., & Wandersman, L. P. (1978) Developmental and utility of the Parenting Sense of Competence Scale. Paper presented at the annual meeting of the American Psychological Association, Toronto.

APPENDIX D

PARENT STRESS INDEX

Parenting Experiences

Child's gender: _____

Child's age: _____

Instructions:
On the PSI Answer Sheet, please write your name, gender, date of birth, ethnic group, marital status, child's name, child's gender, child's date of birth, and today's date. Please mark all your responses on the answer sheet.

This questionnaire contains 120 statements. Read each statement carefully. For each statement, please focus on the child you are most concerned about, and circle the response which best represents your opinion.

Circle the **SA** if you **strongly agree** with the statement.
Circle the **A** if you **agree** with the statement.
Circle the **NS** if you are **not sure**.
Circle the **D** if you **disagree** with the statement.
Circle the **SD** if you **strongly disagree** with the statement.

Example:
If you sometimes enjoy going to the movies, you would circle A in response to the following statement:

I enjoy going to the movies.   .   SA   A   NS   D   SD

While you may not find a response that exactly states your feelings, please circle the response that comes closest to describing how you feel. YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.

Circle only one response for each statement, and respond to all statements. DO NOT ERASE! If you need to change an answer, make an "X" through the incorrect answer and circle the correct response.

I enjoy going to the movies.   SA   A   NS   D   SD

	Strongly agree SA	Agree A	Not sure NS	Disagree D	Strongly disagree SD
1. When my child wants something, my child usually keeps trying to get it.	SA	A	NS	D	SD
2. My child is so active that it exhausts me.	SA	A	NS	D	SD
3. My child appears disorganized and is easily distracted.	SA	A	NS	D	SD
4. Compared to most, my child has more difficulty concentrating and paying attention.	SA	A	NS	D	SD
5. My child will often stay occupied with a toy for more than 10 minutes.	SA	A	NS	D	SD
6. My child wanders away much more than I expected.	SA	A	NS	D	SD
7. My child is much more active than I expected.	SA	A	NS	D	SD
8. My child squirms and kicks a great deal when being dressed or bathed.	SA	A	NS	D	SD
9. My child can be easily distracted from wanting something.	SA	A	NS	D	SD
10. My child rarely does things for me that make me feel good.	SA	A	NS	D	SD
11. Most times I feel that my child likes me and wants to be close to me.	SA	A	NS	D	SD
12. Sometimes I feel my child doesn't like me and doesn't want to be close to me.	SA	A	NS	D	SD
13. My child smiles at me much less than I expected.	SA	A	NS	D	SD
14. When I do things for my child, I get the feeling that my efforts are not appreciated very much.	SA	A	NS	D	SD

For statement 15, choose a response from choices 1 to 4 below.
15. Which statement best describes your child?
1. almost always likes to play with me
2. sometimes likes to play with me
3. usually doesn't like to play with me
4. almost never likes to play with me
For statement 16, choose a response from choices 1 to 5 below.
16. My child cries and fusses:
1. much less than I had expected
2. less than I expected
3. about as much as I expected
4. much more than I expected
5. it seems almost constant

	Strongly agree - SA	Agree - A	Not sure - NS	Disagree - D	Strongly disagree - SD
17. My child seems to cry or fuss more often than most children.	SA	A	NS	D	SD
18. When playing, my child doesn't often giggle or laugh.	SA	A	NS	D	SD
19. My child generally wakes up in a bad mood.	SA	A	NS	D	SD
20. I feel that my child is very moody and easily upset.	SA	A	NS	D	SD
21. My child looks a little different than I expected and it bothers me at times.	SA	A	NS	D	SD
22. In some areas, my child seems to have forgotten past learnings and has gone back to doing things characteristic of younger children.	SA	A	NS	D	SD
23. My child doesn't seem to learn as quickly as most children.	SA	A	NS	D	SD
24. My child doesn't seem to smile as much as most children.	SA	A	NS	D	SD

	Strongly agree - SA	Agree - A	Not sure - NS	Disagree - D	Strongly disagree - SD
25. My child does a few things which bother me a great deal.	SA	A	NS	D	SD
26. My child is not able to do as much as I expected.	SA	A	NS	D	SD
27. My child does not like to be cuddled or touched very much.	SA	A	NS	D	SD
28. When my child came home from the hospital, I had doubtful feelings about my ability to handle being a parent.	SA	A	NS	D	SD
29. Being a parent is harder than I thought it would be.	SA	A	NS	D	SD
30. I feel capable and on top of things when I am caring for my child.	SA	A	NS	D	SD
31. Compared to the average child, my child has a great deal of difficulty in getting used to changes in schedules or changes around the house.	SA	A	NS	D	SD
32. My child reacts very strongly when something happens that my child doesn't like.	SA	A	NS	D	SD
33. Leaving my child with a babysitter is usually a problem.	SA	A	NS	D	SD
34. My child gets upset easily over the smallest thing.	SA	A	NS	D	SD
35. My child easily notices and overreacts to loud sounds and bright lights.	SA	A	NS	D	SD
36. My child's sleeping or eating schedule was much harder to establish than I expected.	SA	A	NS	D	SD
37. My child usually avoids a new toy for a while before beginning to play with it.	SA	A	NS	D	SD

	Strongly agree - SA	Agree - A	Not sure - NS	Disagree - D	Strongly disagree - SD
38. It takes a long time and it is very hard for my child to get used to new things.	SA	A	NS	D	SD
39. My child doesn't seem comfortable when meeting strangers.	SA	A	NS	D	SD

For statement 40, choose from choices 1 to 4 below.

40. When upset, my child is:

1. easy to calm down
2. harder to calm down than I expected
3. very difficult to calm down
4. nothing I do helps to calm my child

For statement 41, choose from choices 1 to 5 below.

41. 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 42, choose from choices 1 to 5 below.

42. Think carefully and count the number of things which 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+

For statement 43, choose from choices 1 to 5 below.

43. When my child cries, it usually lasts:

1. Less than 2 minutes
2. 2-5 minutes
3. 5-10 minutes
4. 10-15 minutes
5. more than 15 minutes

	Strongly agree - SA	Agree - A	Not sure - NS	Disagree - D	Strongly disagree - SD
44. There are some things my child does that really bother me a lot.	SA	A	NS	D	SD
45. My child has had more health problems than I expected.	SA	A	NS	D	SD
46. As my child has grown older and become more independent, I find myself more worried that my child will get hurt or into trouble.	SA	A	NS	D	SD
47. My child turned out to be more of a problem than I had expected.	SA	A	NS	D	SD
48. My child seems to be much harder to care for than most.	SA	A	NS	D	SD
49. My child is always hanging on me.	SA	A	NS	D	SD
50. My child makes more demands on me than most children.	SA	A	NS	D	SD
51. I can't make decisions without help.	SA	A	NS	D	SD
52. I have had many more problems raising children than I expected.	SA	A	NS	D	SD
53. I enjoy being a parent.	SA	A	NS	D	SD
54. I feel that I am successful most of the time when I try to get my child to do or not do something.	SA	A	NS	D	SD
55. Since I brought my last child home from the hospital, I find that I am not able to take care of this child as well as I thought I could. I need help.	SA	A	NS	D	SD
56. I often have the feeling that I cannot handle things very well.	SA	A	NS	D	SD

For statement 57, choose from choices 1 to 5 below.
57. When I think about myself as a parent I believe:
1. I can handle anything that happens
2. I can handle most things pretty well
3. sometimes I have doubts, but find that I handle most things without any problems
4. I have some doubts about being able to handle things
5. I don't think I handle things very well at all
For statement 58, choose from choices 1 to 5 below.
58. 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
For questions 59 and 60, choose from choices 1 to 5 below.
59. What were the highest levels in school or college you and the child's father/mother have completed?
Mother:
1. 1st to 8th grade
2. 9th to 12th grade
3. vocational or some college
4. college graduate
5. graduate or professional school
60. Father:
1. 1st to 8th grade
2. 9th to 12th grade
3. vocational or some college
4. college graduate
5. graduate or professional school
For question 61, choose from choices 1 to 5 below.
61. How easy is it for you to understand what your child wants or needs?
1. very easy
2. easy
3. somewhat difficult
4. it is very hard
5. I usually can't figure out what the problem is

	Strongly agree - SA	Agree - A	Not sure - NS	Disagree - D	Strongly disagree - SD
62. It takes a long time for parents to develop close, warm feelings for their children.	SA	A	NS	D	SD
63. I expected to have closer and warmer feelings for my child than I do and this bothers me.	SA	A	NS	D	SD
64. Sometimes my child does things that bother me just to be mean.	SA	A	NS	D	SD
65. When I was young, I never felt comfortable holding or taking care of children.	SA	A	NS	D	SD
66. My child knows I am his or her parent and wants me more than other people.	SA	A	NS	D	SD
67. The number of children that I have now is too many.	SA	A	NS	D	SD
68. Most of my life is spent doing things for my child.	SA	A	NS	D	SD
69. I find myself giving up more of my life to meet my children's needs than I ever expected.	SA	A	NS	D	SD
70. I feel trapped by my responsibilities as a parent.	SA	A	NS	D	SD
71. I often feel that my child's needs control my life.	SA	A	NS	D	SD
72. Since having this child, I have been unable to do new and different things.	SA	A	NS	D	SD
73. Since having a child, I feel that I am almost never able to do things that I like to do.	SA	A	NS	D	SD
74. It is hard to find a place in our home where I can go to be by myself.	SA	A	NS	D	SD
75. When I think about the kind of parent I am, I often feel guilty or bad about myself.	SA	A	NS	D	SD

	Strongly agree - SA	Agree - A	Not sure - NS	Disagree - D	Strongly disagree - SD
76. I am unhappy with the last purchase of clothing I made for myself.	SA	A	NS	D	SD
77. When my child misbehaves or fusses too much, I feel responsible, as if I didn't do something right. ·	SA	A	NS	D	SD
78. I feel every time my child does something wrong, it is really my fault.	SA	A	NS	D	SD
79. I often feel guilty about the way I feel toward my child.	SA	A	NS	D	SD
80. There are quite a few things that bother me about my life.	SA	A	NS	D	SD
81. I felt sadder and more depressed than I expected after leaving the hospital with my baby.	SA	A	NS	D	SD
82. I wind up feeling guilty when I get angry at my child and this bothers me.	SA	A	NS	D	SD
83. After my child had been home from the hospital for about a month, I noticed that I was feeling more sad and depressed than I had expected.	SA	A	NS	D	SD
84. Since having my child, my spouse (or male/female friend) has not given me as much help and support as I expected.	SA	A	NS	D	SD
85. Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend).	SA	A	NS	D	SD
86. Since having a child, my spouse (or male/female friend) and I don't do as many things together.	SA	A	NS	D	SD
87. Since having a child, my spouse (or male/female friend) and I don't spend as much time together as a family as I had expected.	SA	A	NS	D	SD

	Strongly agree - SA	Agree - A	Not sure - NS	Disagree - D	Strongly disagree - SD
88. Since having my last child, I have had less interest in sex.	SA	A	NS	D	SD
89. Having a child seems to have increased the number of problems we have with in-laws and relatives.	SA	A	NS	D	SD
90. Having children has been much more expensive than I had expected.	SA	A	NS	D	SD
91. I feel alone and without friends.	SA	A	NS	D	SD
92. When I go to a party, I usually expect not to enjoy myself.	SA	A	NS	D	SD
93. I am not as interested in people as I used to be.	SA	A	NS	D	SD
94. I often have the feeling that other people my own age don't particularly like my company.	SA	A	NS	D	SD
95. When I run into a problem taking care of my children, I have a lot of people to whom I can talk to get help or advice.	SA	A	NS	D	SD
96. Since having children, I have a lot fewer chances to see my friends and to make new friends.	SA	A	NS	D	SD
97. During the past six months, I have been sicker than usual or have had more aches and pains than I normally do.	SA	A	NS	D	SD
98. Physically, I feel good most of the time.	SA	A	NS	D	SD
99. Having a child has caused changes in the way I sleep.	SA	A	NS	D	SD
100. I don't enjoy things as I used to.	SA	A	NS	D	SD

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For statement 101, choose from choices 1 to 4 below.		
101. Since I've had my child:		
1. I have been sick a great deal		
2. I haven't felt as good		
3. I haven't noticed any change in my health		
4. I have been healthier		
For statements 102 to 120, choose from choices Y for "Yes" and N for "No."	**YES**	**NO**
During the last 12 months, have any of the following events occurred in your immediate family?	Y	N
102. Divorce	Y	N
103. Marital reconciliation	Y	N
104. Marriage	Y	N
105. Separation	Y	N
106. Pregnancy	Y	N
107. Other relative moved into household	Y	N
108. Income increased substantially (20% or more)	Y	N
109. Went deeply into debt	Y	N
110. Moved to new location	Y	N
111. Promotion at work	Y	N
112. Income decreased substantially	Y	N
113. Alcohol or drug problem	Y	N
114. Death of close family friend	Y	N
115. Began new job	Y	N
116. Entered new school	Y	N
117. Trouble with superiors at work	Y	N
118. Trouble with teachers at school	Y	N
119. Legal problems	Y	N
120. Death of immediate family member	Y	N

Reference: Abidin, R. R. (1997). Parenting Stress Index: A measure of the parent-child
system. In *A book of resources* (pp. 277-291). Lanham, MD: Scarecrow Press, Inc.

APPENDIX E

BACKGROUND INFORMATION FORM

Background Information Form

Please Complete the Following:

1. Your age: _____ years

2. Your sex: _____ male _____ female

3. Your ethnicity: _____ Hispanic _____ African American
   _____ Asian _____ Caucasian
   _____ Other: _____

4. The highest level of education you have completed:
   _____ Did not complete high school
   _____ High school graduate
   _____ Some college or trade school
   _____ Graduated with a Bachelor's degree
   _____ Some graduate school
   _____ Graduate or professional degree

5. The highest level of education your child's other biological parent has completed:
   _____ Did not complete high school
   _____ High school graduate
   _____ Some college or trade school
   _____ Graduated with a Bachelor's degree
   _____ Some graduate school
   _____ Graduate or professional degree

6. Number of children diagnosed with an ASD? _____
   a. Age: _____
   b. Sex: _____
   c. Ethnicity: _____

7. Number of children without a disability? _____
   a. Age: _____
   b. Sex: _____
   c. Ethnicity: _____

8. Number of adults living in the home? _____

9. Have you previously attended classes or orientations for parents of ASD children?
   _____ yes _____ no

Developed by Amber Vela

APPENDIX F

CLASS EVALUATION FORM

Class Evaluation Form   code number: _____

1. Was the program useful? Why or why not?

2. What is the most important thing you learned from the program?

3. What was the least valuable part of the program?

4. What do you think can be added or changed to improve the program?

5. Will you use the information you learned from the program? Why or why not?

6. To what extend to you plan to incorporate the ideas/suggestions from the program into your parenting practices? **(circle one)**

    Not at all   Definitely Yes
        1   2   3   4   5   6   7

Developed by Amber Vela

APPENDIX G

WHAT TO EXPECT AFTER THE DIAGNOSIS AND

UNDERSTANDING THE AUTISM SPECTRUM

DISORDERS CHILD

Overview/Outline: What to Expect after the Diagnosis/Understanding the ASD Child

Purpose:

It has been found that parents benefit from knowledge about managing their emotions after the ASD diagnosis. Therefore, the components of the "grief cycle" will be discussed. Parents of ASD children benefit from information about their ASD child's development that helps them to decrease negative feelings towards the ASD child, helps them be more proactive in the ASD child's life, which in turn helps the ASD child. Knowledge of the nature and characteristics of ASDs also influences a parent's ability to accept the ASD child. Therefore, parents will receive information about formal definitions, prevalence rates, etc. Parents will also learn about typical and atypical behaviors in ASD children and the link between communication and behaviors. Parents will learn strategies to increase their ASD child's communication skills. Parents will also learn about sensory-issues and sensory classifications so that they are able to provide a comfortable environment for their ASD child. Parents will learn techniques to potty-train their ASD child.

Objectives:

- Acquire knowledge about the grief cycle
- Acquire knowledge about ASDs
- Acquire knowledge about maladaptive or inappropriate behaviors
- Acquire knowledge about the link between communication deficits and ASD child behavior
- Learn strategies to increase communication skills
- Acquire knowledge about sensory-issues
- Learn strategies to potty-train an ASD child

What to Expect after the Diagnosis
    I.   The Grief Cycle (G-2)

        Understanding the ASD Child
    I.   Introduction to ASD Diagnostic Information
           A. Nature of disability
           B. Characteristics of disability
           C. Typical behaviors
           D. Repetitive behaviors
           E. Formal definition
           F. Prevalence rates
           G. Suspected causes and risk factors
           H. Impact on society

II.   Maladaptive and Inappropriate Behaviors
    A. Irritability
    B. Aggression
    C. Non-compliance
   D. Property destruction
    E. Self-injury

III.   Communication Deficits and Child Behaviors
    A. Deficits in communication skills
    B. Ways to increase communication skills and decrease behaviors (G-3)
        1. One-to-one interactions examples
        2. Scripting examples
        3. Social stories examples

IV.   Sensory-Issues
    A. Auditory and visual stimuli
    B. Sensory classifications
        1. Low-registration
        2. Sensation-seeking
        3. Sensory-sensitivity
        4. Sensation-avoidant
    C. Food (G-4)
    D. Dietary log (G-5)

V.   Potty-Training
    A. Reasons ASD children exhibit difficulties
    B. Techniques for potty-training (G-6)

The Grief Cycle

I. What is the grief cycle?
    A. Reaction to the ASD diagnosis
    B. Stages of grief cycle

Adapted from Kubler-Ross, 1969
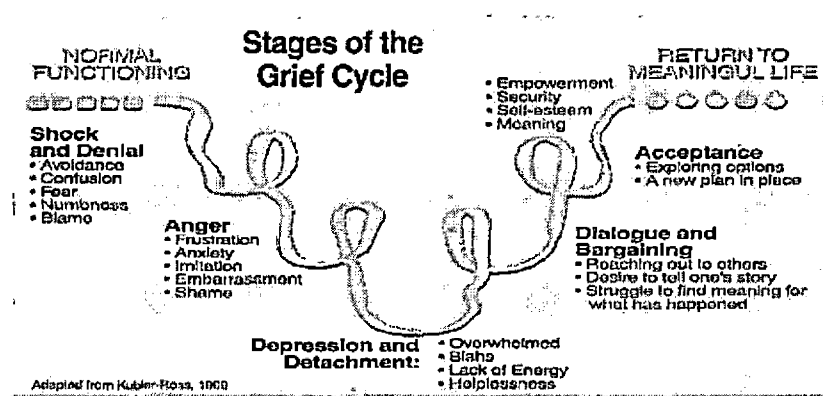
C. Examples of feelings
    1. Shock and disbelief (e.g., "How can this be happening to my child?")
    2. Denial (e.g., "He will grow out of this" or "I can fix this.")
    3. Anger or rage (e.g., "We do not deserve this.")
    4. Confusion and powerlessness (e.g., "I cannot do things I normally do for my family.")
    5. Depression (e.g., "I feel overwhelmed with sadness," or I find myself crying a lot.")
    6. Shame or embarrassment (e.g., "What will my family and friends think of my child.")
    7. Isolation (e.g., "I have never felt so alone" or "no one understands the situation.")
    8. Fear and panic (e.g., "Who will take care of my child if I am unable to.")
    9. Acceptance (e.g., "My family will be okay.")
D. Characteristics of the cycle
    1. Common problem of the cycle is that individuals may become stagnant in one stage
    2. Individuals may also regress to earlier cycles if stage was not completely resolved
    3. It is acceptable to move between the feelings or stages of the grief cycle however there should be a clear progression towards a resolution

Reference:
Kübler-Ross, E. (1969). On Death and Dying, Routledge. ISBN: 0-415-04015-9

Increasing Communication Skills in ASD Children

II. Emotions are natural and powerful
    A. Parents must accept the reactions and acknowledge their feelings so that they are able to move forward and begin advocating for their ASD child

I. Carol Gray: Social Stories
    A. http://www.thegraycenter.org/social-stories/what-are-social-stories

II. What are Social Stories? (Gray, 2004)
    A. Describes a situation, skill, or concept in terms of relevant social cues, perspectives, and common behavior responses in a specifically defined style and format.
    B. Included in the story are:
        1. Who is involved
        2. What happens
        3. When the event takes place
        4. Why it happens
        5. How it happens
        6. Illustrates social rules or concepts
    C. Developed using age-appropriate levels and formats.

III. 10 Defining Criteria (Gray, 2004)
    A. Meaningfully shares social information with an overall patient and reassuring quality
    B. Introduction clearly identifies topic, body adds detail, and conclusion reinforces and summarizes the information
    C. Describes the setting or context, time-related information, relevant people, important cues, basic activities, behaviors or statements, and the reasons behind them
    D. Written from a first person perspective, as though the child is describing the event
    E. Uses positive language with positive responses
    F. Comprised of descriptive sentences
        1. Objective
        2. Perspective
        3. Cooperative
        4. Directive
        5. Affirmative
        6. Control
    G. Matches ability and interests of audience
    H. Formula
    I. Uses illustrations that are meaningful
    J. Title meets applicable social story criteria

IV.   Examples of Social Stories
          A. Social Story from Sandbox Learning
               1. www.sandbox-learning.com
          B. http://youtu.be/Jfq6S6FOQCk

V.   What are Scripts? (Greenspan & Wieder, 2006; Sheehan & DeOrnellas, 2011)
          A. Guide to teach communication skills during real-life situations
               1. Pre-taught language for specific situations
          B. Practice of a variety of communicative functions within a natural context
          C. Simple, structured way to carry out a conversation(initiate, maintain, and terminate)
               1. Involves conversation starters, responses, and ideas to connect conversations ,or change the topic
          D. Sequences of messages for conversations rather than wants and needs
          E. Provides structure and takes guess work out of interaction and provides ASD children with opportunities to communicate beyond responding and requesting.

VI.   Examples of Scripting for Social Interactions

Formal:

ASD Child: Hello Mr.

Smith.

Adult: Hi Johnny, how are

you?

ASD Child: Fine. Thanks

for asking. How are you?

Adult: Great. It was nice to

see you.

ASD Child: Have a nice

day.

Adult: You too. Bye

Casual:

Peer: Hey, how's it going?

ASD Child: Pretty good.

How about you?

Peer: Great, I'm on my way

to class.

ASD Child: Me too. See

you later.

Peer: Okay, bye.

VII. How to Write a Script for Play: www.autism-society.org
    A. Select a child to play with
        1. Begin meaningful conversation by selecting partner to interact with
    B. Determine reason for playing
        1. Child understands purpose of interacting with partner
    C. Identify other child's interest
        1. Ensure conversation is meaningful for both
    D. Select topic of planned conversation
        1. Child chooses topic or theme
    E. Develop script initiation and expected response
        1. Lists with anticipated responses and questions
    F. Select best setting to initiate conversation
        1. Select natural setting where conversations take place
    G. Rehearse the script

VIII. Positive Contributions for Development (Greenspan & Wieder, 2006; Sheehan & DeOrnellas, 2011)
    A. Social Stories
        1. Teaches ASD children what to expect in certain situations and settings.
        2. Provides framework for how to act.
        3. Can be written for any age or situation and photos or pictures can be used.
    B. Scripting
        1. Teaches ASD child short social interactions to have with others.
        2. Can write and practice the script and include the child in the writing of the script if possible.
        3. Teaches children the idea of social and verbal exchange

References:

Autism Society website. (n.d.). http://www.autism-society.org/living-with-autism/lifespan/infants-toddlers/

Gray, C. (2004). Social stories 10.0: The new defining criteria & guidelines. *Jenison Autism Journal, 15*, 1-16.

Greenspan, S. & Wieder, S. (2006). *Engaging Autism: Using a floortime approach to help children relate, communicate, and think.* Cambridge, MA: Da Capo Press.

Inland Regional Center website. (n.d.). http://www.inlandrc.org

Sheehan, B., & DeOrnellas, K. (2011). *What I wish I'd known about raising a child with Autism.* Arlington, TX: Future Horizons.

Skills sheets by sandbox learning. (2004). Retrieved from http://www.sandbox-learning.co

Sensory Issues Related to Food

I.   Behaviors Related to Food
    A. Avoiding or refusing foods of certain color, texture, or smell
    B. Anxiety when an expected meal routine changes
    C. Anxiety when a new food is introduced

II. Meal Times
    A. Parents of ASD children often complain about difficulties in establishing a routine for meal times, the child's inability to sit down and eat without assistance, and the child's overall nutritional balance
    B. Experts suggest that parents should be flexible and provide the child with the opportunity to eat when hungry (Boulet, Boyle, & Schieve, 2009; Brookman-Frazee et al., 2006).
        1. Do not force the child to sit down and eat

III. Using Utensils
    A. Scaffolding and social modeling
        1. Show child how to eat with utensils
    B. Applied behavioral analysis
        1. You tube video **http://youtu.be/pOAivs58SOU**
        2. Teach task
            ▪ Put spoon in child's hand
            ▪ Use food that is easy to transfer from spoon to mouth
        3. Generalization of task
            ▪ Can also practice other items that require fine motor coordination (e.g., coloring, brushing hair, etc.)
        4. Reinforce positive behavior
        5. Praise child for success
    C. If necessary, adaptive feeding equipment is available
        1. You tube video **http://youtu.be/VR_clnzwVhg**

IV. The Responsibility of Parents
    A. If eating is an issue, it may be important for parents to discuss dietary concerns with the child's pediatrician and other related specialists (e.g., occupational and physical therapists) to rule out any physiological explanations for the behavior such as a gagging reflex, difficulty swallowing, or food allergies (Sicile-Kira, 2004).
    B. Experts suggest that parents should evaluate whether the child has a sensory issue by documenting reactions and behaviors to food (e.g., food log) (Sicile-Kira, 2004).

V. Recommendations From Research
    A. The primary recommendation from experts for parents is to not make food a big issue (Carothers & Taylor, 2004).
    B. Remember the texture and appearance of food are as important as the taste of food for the ASD child (Sheehan & DeOrnellas, 2011)
    C. If looking to branch out, start with fruit
    D. Use whole food supplementation
    E. Desensitization
        1. Associate new things with positive things
        2. Slowing introduce new foods to children (e.g., introduce an apple for a snack every day at the same time of day for two weeks)
            ▪ Work with one food and one attribute at a time, it may take months to years to introduce a new food or texture
        3. Allow the child to build tolerance of food
        4. Parents should be creative with food so that it gains the child's attention (Sicile-Kira, 2004)
    F. Changing the environment
        1. Change in diet if behaviors are indicative of physiological explanations
    G. Allow the child to become part of the meal process (Boulet, Boyle, & Schieve, 2009)
        1. Choosing food
        2. Assisting with preparing food
        3. Make a big deal out of feeding the child the food he or she picked out

VI. Reading Recommendations
    A. Deceptively Delicious By Jessica Seinfeld

References:

Boulet, S. L., Boyle, C. A., & Schieve, L. A. (2009). Health care use and health and functional impact of developmental disabilities among US children, 1997-2005. Retrieved from http://archpedi.ama-assn.org.cgi/content/full/163/1/19

Carothers, D. E., & Taylor, R. L. (2004, Summer). How teachers and parents can work together to teach daily living skills to children with Autism. *Focus on Autism and Other Developmental Disabilities, 19,* 102-104.

Sheehan, B., & DeOrnellas, K. (2011). *What I wish I'd known about raising a child with Autism.* Arlington, TX: Future Horizons Sicile-Kira, C. (2004). *Autism spectrum disorders: The complete guide to understanding autism, asperger's syndrome, pervasive developmental disorder, and other ASDs.* New York, NY: The Berkley Publishing Group.

Dietary Log

Meal	Time	Reaction

Meal	Time	Reaction

Meal	Time	Reaction

Meal	Time	Reaction

Developed by Amber Vela

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A Parent's Guide: Toilet Training

I. Paraphrased from Autism Speaks Toilet Training Guide

II. **Toileting training can be challenging for children** with autism spectrum disorders (ASD). There are many reasons why it can take a long time. Many children with ASD learn to use the toilet at a late age. Most children with ASD learn to urinate and have bowel movements in the toilet later than other children.

III. Each child with an ASD is different. Children with ASD have some common problems that can make toileting hard. Knowing about these problems can help you come up with different ways to meet your child's needs. Here are some ideas to think about:
   A. *Physical*: There may be a physical or medical reason for toileting difficulties. Discuss these issues with your child's pediatrician.
   B. *Language*: Children with ASD have trouble understanding and using language. Do not expect a child with autism to ask to use the toilet.
   C. *Dressing*: Some children with ASD have difficulty pulling their pants down or pulling them back up.
   D. *Fears*: Some children with ASD are afraid of sitting on toilet seats or hearing toilets flush. Getting used to the toilet by using a visual schedule and making it part of the routine can make it less scary.
   E. *Body cues:* Some children with ASD may not be aware that they need to go or that their clothes are wet or soiled.
   F. *Need for sameness (aka routine)*: Many children with ASD already have their own ways of urinating and having bowel movements. Learning new ways to toilet may be hard.
   G. *Using different toilets:* Some children with ASD learn a toileting routine at home or school, but have a hard time going in other places such as public restrooms.

IV. "Trip Training" or "Schedule Training" helps children learn toileting skills without placing other demands on them. Adults set the schedule and help train the child's body to follow the schedule.
   A. Sit for 6. Set a goal for 6 toilet sits per day. At first, trips will be short (as little as 5 seconds per trip), with one longer trip each day to work on bowel movements. Over time, toilet sits can be long (e.g., up to 10 minutes). Setting a timer can be a helpful way to let your child know when the toilet sit can end. Your child also is allowed to get up from the toilet immediately if s/he urinates or has a bowel movement. Boys are taught to sit on the toilet to urinate until they regularly have bowel movements on the toilet.

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B. Don't Ask. Tell. Do not wait for children to tell you they need to use the bathroom or say "yes" when asked if they need to go. Tell them it is time for a toilet trip.

C. Schedule. Make toilet trips part of your everyday life. Plan toilet trips around your usual routine. Stick with the same times of the day or the same daily activities.

D. Communicate. Use the same simple words, signs or pictures during each trip. This helps a child learn toileting language.

E. Keep Trying. They say it takes 3 weeks to make a habit. Once you outline the routine and methods, keep working towards the same goal for 3 weeks.

F. Make a Visual Schedule. Pictures may help you children know what to expect during toilet trips. Take pictures of items in your bathroom. Place pictures in order on a piece of paper to show your child each step of the toilet trip.

G. Identify Rewards. Make a list of your child's favorite things, like food, toys, and videos. Think of which ones will be easiest to give your child as soon as he/she urinates or has a bowel movement in the toilet.

V. Tips to Increase Toileting Success

A. **For 3- "typical" days, document your child's routine.** To help you write your child's toileting program, track how long it takes between when your child drinks and when he or she is wet. Checking your child's diaper frequently for wetness (e.g., every 15 minutes) will help you decide when to schedule toilet trips.

B. **Consider your child's diet.** Dietary changes, such as increasing the fluids and fiber your child eats and drinks, may help your child feel the urge to use the toilet.

C. **Make small changes in daily habits.** Dress your child in easy-to-remove clothing. Change your child as soon as he or she becomes wet or soiled. Change diapers in or near the bathroom. Involve your child in the cleanup process.

D. **Have your child put waste from the diaper in the toilet when possible.** This will also help your child understand that waste goes in the toilet. Have your child flush the toilet and wash hands after each diaper change.

E. **Make sure toilet trips are comfortable.** Your child should be comfortable while sitting on the toilet. Use a smaller potty seat and/or provide a footstool. If your child will not sit on the toilet, work on sitting before beginning a toilet training program.

F. **Think about your child's sensory needs.** If your child does not like certain sounds, smells, or things he or she touches in the bathroom, change these as much as you can.

G. **Have many pairs of underwear ready.** During toilet training it is important for children to wear underwear during the day. They need to feel when they are wet. Your child may wear rubber pants or a pull-up over underwear if necessary. Diapers or pull-ups may be used when your child is sleeping or is away from the home.

H. **Use a visual schedule.** Pictures showing each step of the "potty routine" may help your child learn the routine and know what will happen. During toilet trips, show your child the visual schedule you have created. Label each step as you go along.

I. **Use rewards.** Give your child a reward *immediately* after he or she urinates or has a bowel movement in the toilet. The more quickly you reward a behavior, the more likely that behavior will increase. Toileting rewards are special. Rewards used for toileting should *only* be used for toileting.

J. **Practice in different bathrooms.** Using different bathrooms helps your child know he or she can use different toilets in different places.

Reference:

Autism Speaks website. (2011). http://www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits#toilettraining

APPENDIX H

HOW TO PARENT AN AUTISM SPECTRUM DISORDERS CHILD

How to Parent an ASD Child (Part 1)

Purpose:

Attachment theory describes the conceptual framework for normative and individual differences in parent-child interactions based on parents' attachment parenting style and their child's attachment status. Therefore, parents will learn about attachment research including child attachment statuses. Parents will also learn about misconceptions in ASD children's attachment styles. Parenting behaviors influence ASD children's growth. Therefore, parents will learn about how parenting styles and parenting behaviors impact development. Parents will also be given an introduction to the role of mind-mindfulness.

Objectives:

- Acquire knowledge about attachment theory and attachment in ASD children
- Acquire knowledge about attachment misconceptions in ASD children
- Acquire knowledge about parenting behaviors

How to Parent an ASD Child (Part 1)
- I. Attachment Theory
  - A. Attachment styles outcomes (H-2)
    1. Secure
    2. Insecure-avoidant
    3. Insecure-ambivalent
    4. Disorganized

- II. Misconceptions of attachment in ASD children

- III. Parenting Behaviors
  - A. Baumrind's styles of parenting(H-3)
  - B. Mind-Mindfulness

Outcomes for Attachment Styles

I. Secure Children Learn:
    A. Their needs will be met
    B. Can explore the world with confidence and autonomy knowing that parents are available when needed
    C. Can influence others and be successful in the world since parents provided scaffolding needed for task mastery
    D. Can engage in reciprocal interactions with others
    E. Can meet their own needs
    F. Can be empathetic towards others
    G. Are socially competent and are worthy of positive and trusting social interactions
    H. Can regulate their emotions themselves
    I. Are competent, lovable, cooperative, and capable

II. Insecure-Avoidant and Insecure-Ambivalent Children Learn:
    A. Cannot get their needs met because parents did not meet them
        1. Develop defensive strategies that compromise exploration
        2. Are not confident and autonomous
            ▪ Being alone triggers fear that their care and protection will be unavailable or inconsistent should they feel afraid
    B. Believe efforts will be unsuccessful for their efforts to influence their parents have failed
    C. Cannot regulate their emotions for parents did not provide scaffolding
    D. Do not expect to be successful in getting their needs met

III. Disorganized Children Learn:
    A. To develop any strategy that reduces terror, including distraction, dissociation, and/or aggression or withdrawal, for their parents are frightening to them
    B. To avoid intimacy in relationship
        1. Experienced danger and confusion in their first relationship
    C. To become vigilant and distrustful of others
    D. To passively accept what others give
        1. Have no power to affect their world
    E. How to get what they need in any way possible
        1. Have to fend for themselves

Reference:
Wetherby, A., Brosnan-Maddox, S., Peace, V., & Newton (2008). Validation of the infant toddler checklist as a broadband screener for autism spectrum disorders from 9 to 24 months of age. *Autism Journal*, 12-487.

APPENDIX I

HOW TO PARENT AN AUTISM SPECTRUM DISORDERS

CHILD (PART 2)

Overview/Outline: How to Parent an ASD Child (Part 2)

Purpose:
Knowledge of child guidance skills allows parents to create an atmosphere that promotes their ASD child's development. Therefore, parents will learn about child guidance: including how to set limits and gain children's cooperation, and what to do when a child has a problem or need. Parents will also receive guidance tips on how to support their child's development and how to manage their child's behaviors in public. It is important for parents to understand developmental growth patterns to be able to support their ASD child in various developmental domains. Parent will learn the importance of play for ASD children's social and emotional development. Developmental domains such as social, emotional, language, physical, and cognitive development will also be covered.

Objectives:
- Acquire knowledge about child guidance
- Learn strategies to set limits and gain the ASD child's cooperation
- Learn strategies to respond when an ASD child has a behavior in public
- Learn strategies to promote optimal child development
- Learn strategies to promote social and emotional development in ASD children through play
- Acquire knowledge about child development domains

IV. Introduction to Child Guidance
    A. Guidance vs. punishment (I-2)
        1. Punishment
        2. Guidance
    B. Setting Limits, Gaining Cooperation (I-3)
    C. How to React to a Child When a Problem or Need is Identified (I-4)

V. Guidance Tips (I-5)
    A. Parenting tips for managing behaviors in public (I-6)

VI. Importance of ASD Child's Social and Emotional Development
    A. Ideas for play aimed to promote social and emotional development (I-7)

VII. Impact of Parenting Skills on Child Development
    A. Introduction to Child Development: 1 to 5 Years Old (I-8)
        1. Social
        2. Emotional
        3. Language/Communication
        4. Physical
        5. Cognitive

Child Guidance (Kamptner, 2012)

1. Guidance: Optimal for Child Development
   a. Modeling appropriate behaviors and positive attitudes
      i. Teaches coping mechanisms
   b. Being clear about the rules and being consistent in applying them
   c. Providing opportunities for the child to learn guidelines for acceptable behavior
   d. Recognizing child's feelings when discussing their inappropriate behavior
   e. Help children to "brainstorm" to solve problems and make choices
      i. Promotes self-esteem
      ii. Teaches problem solving skills

2. Punishment: Detrimental for Child Development
   a. Subjecting children to cruel or severe punishment
      i. Humiliation
      ii. Verbal abuse
      iii. Neglect
   b. Use of corporal punishment
      i. Spanking
   c. Deprivation of child's needs
      i. Meals and snack times
   d. Control child actions to motivate the child to become more compliant with parents authority and demands

Setting Limits and Gaining Cooperation (Kamptner, 2012)

1. Always intervene immediately if the child is in danger of hurting self, others, or objects
   a. Sometimes it is hard to know exactly when to step in and set a limit. This is a helpful guideline

2. What we say and how we say it to children matters
   a. The specific words we use when talking to children affects their development especially their social skills, their sense of self-worth, overall mental health, and their compliance/cooperation

3. Always provide reasons and explanations for setting limits and asking children to do something
   a. Not only does this increase children's compliance, but it supports their brain, cognitive, social, language, and emotional development

4. Meeting children's basic psychological needs decreases the number of behavior problems you will have with you children
   a. The more warm, sensitively-attuned, and responsive parents are to their child, and the more time and attention parents give their child, the fewer child behavior problems there will be
   b. Children will also be more compliant

5. Plan ahead to prevent problems
   a. Some problems can be taken care of by planning again, changing routines, or changing the environment
      i. Instead of telling child "no" and "do not touch that"→childproof the home
      ii. If morning are hectic→get clothes and lunches made the night before
      iii. If going to the store→discuss buying versus looking day

Reference:
L. Kamptner, personal communication, October, 2012.

8-Step Program for Limiting Setting When a Child is Behaving Dangerously or Aggressively (Greenspan & Wieder, 2006)

I.   Increase your affect and your vocal tone to get the child's attention

II.   Add, almost simultaneously, limit-setting gestures, such as holding your hand up to indicate "stop" or "whoa" or shaking your head "no."

III.   Use tactile support, if needed, by holding the child's hand or providing firm gentle pressure to the child's body to get the child to pay attention and inhibit their action.

IV.   Then try to distract the child with something that will satisfy their physical impulse. If the child wants to squeeze something, instead of squeezing the cat, the child can squeeze a Nerf ball. Or if the child wants to hit, maybe the child can take a foam bat and hit the couch instead of the caregiver.

V.   If these steps haven't kept the child from getting out of control, the caregiver will have to contain the child physically. The principle is to use the minimal amount of containment needed to curb the worrisome behavior.
    A. Hold child from behind in a bear hug, gently and firmly to give the sensory support and help the child organize, or maybe move rhythmically with the child while holding their hands
    B. Goal is to keep the child contained until the child can relax
    C. If cannot relax, take him to a safe place where the child can have space to unwind
    D. Main point is to create a calming, containing situation for the child according to the child's individual needs

VI.   After the child is calm, the caregiver can discuss the situation.
    A. What happened?
    B. Why did that occur?
    C. Careprovider should understand the situation from the child's perspective and then solve the problem with the child
        1. What can we do next time to handle the situation without hitting-using words instead (or symbols if non-verbal)

VII.   Next, consider the appropriate consequence if the child has done this action before. **But never isolate the child. Isolation will be counterproductive to the child's development.**
    A. Consequences should be determined in advance so that the child and caregiver know what to expect
        1. Might be useful to post in public view in the home

VIII. The ongoing goal is to help the child improve a two-way communication by using gestural interactions (e.g., child can shake fists or say "I'm mad" instead of becoming physically assaultive)

Reference:

Greenspan, S. & Wieder, S. (2006). *Engaging Autism: Using a floortime approach to help children relate, communicate, and think.* Cambridge, MA: Da Capo Press.

When a Child has a Problem/Need (Kamptner, 2012)

I. Feelings are important!
   A. Children's feelings are very important. In fact, research shows that the MOST important thing in parenting, for the child, is to "feel felt"—which means that the parent needs to recognize and respond appropriately to the child's internal emotional state (Siegel & Bryson, 2012).
   B. A child's emotions come "first", which means that before a child can learn, pay attention, or listen to reasoning, their emotions need to be recognized and responded to by caring adults.

II. When a child's feelings are acknowledged and responded to by a parent, the child:
   A. feels understood
   B. feels important and valued as a person
   C. learns to identify his/her feelings
   D. develops a positive self-esteem
   E. gets their basic (psychological) needs met
   F. is able to develop an emotionally- close relationship with the parent
   G. is better adjusted

III. By contrast, when a child's feelings are ignored by a parent, the child:
   A. develops feelings of shame
   B. develops feelings of distress, which cause her brain to release the stress hormone cortisol (which negatively affects brain development)
   C. doesn't get their basic (psychological) needs met
   D. is unable to develop an emotionally-close relationship with the parent

IV. Very young children (esp. age 0-3 yrs.) have BIG EMOTIONS. Children are right-brain dominant during the early years of life; the right side of the brain specializes in emotions and not verbal/reasoning skills. This means that very young children, especially 0-3 yrs., easily become flooded by strong, intense emotions. (It isn't until the early childhood years that the left side of the brain, with its verbal/reasoning capabilities, comes online) (Siegel & Bryson, 2012).

V. All feelings are acceptable: don't tell a child not to feel a certain way- children feel what they feel. (Of course, they may not be allowed to "act" on those feelings!)

VI. Remember common origins of children's problems, such as:
   A. A basic (psychological need) is not met (e.g., for warm, sensitive, responsive parenting; time and attention from parents; etc.)
   B. A basic physical need is not met (e.g., child is hungry, tired, becoming ill)
   C. Parents have unrealistic expectations of the child
   D. Use of an authoritarian parenting style at home
   E. Upsetting circumstances at home

Exercise: What feelings do children often have to deal with?

What feelings are especially hard for children to deal with?

Do YOU let your feelings show or do you try to hide them?

Do you give your children permission to express their feelings?

Reference:
L. Kamptner, personal communication, October, 2012.

When the Child Has a Problem/Need
(i.e., child is crying, upset, angry, frustrated, etc.) (Kamptner, 2012)

Exercise: How do you like people to respond to you when you are upset about something?

When children get upset, the most important thing for parents to do is to acknowledge the child's feelings and "join" with the child, i.e., sense what the child is feeling and respond in a caring and empathic way. When a child is upset, logic and reasoning don't work.

I. REFLECTIVE LISTENING:

"Reflective listening" is a verbal response by the parent to the child that is used when the child has a problem/need (e.g., upset, angry, frustrated, crying, etc.). The parent attempts to put into words what she thinks the child is feeling. Acknowledging and naming the child's internal, emotional state helps to calm the child's strong emotions.

Our usual tendency is to either ignore what a child is feeling or to just jump in to try to "fix" the child's problem. Reflective listening, by contrast, lets a parent acknowledge and respond to the child's feelings. After child is calmed and comforted, THEN the conversation turns to brainstorming for possible solutions:

(SIEGEL: CONNECT & REDIRECT; NAME IT TO TAME IT)

There are two parts to reflective listening statement:

A. The reflective listening phrase:
   1. Start with a "door opener" : "You seem...", "It sounds like..."
   2. Then add a feeling word: "...angry... "...frustrated."
B. The problem-solving steps: Once you have accurately identified what the child is feeling, explore with the child what caused the problem and then brainstorm on possible solutions. You can do this with a child who is at least 2 or 2 1/2 yrs. old.
   1. Identify the problem: explore with the child what happened to make her feel this way (e.g., "Can you tell me what happened?"). Mirror back to her what you hear her saying to make sure you understand what happened.
   2. Brainstorm with your child on possible solutions
   3. Decide with the child which solution to try out
   4. Check back with child to see if solution worked (and if need be, try a different solution)

Don't dominate the conversation, and don't blame or criticize the child. Let the child do most of the talking.

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(With preverbal infants and young toddlers: verbalize out loud what you think your child is feeling--this helps little ones learn the names of the feelings they have, and they'll respond to the emotional tone of your voice. And since you can't engage in joint problem-solving, you do the problem-solving for them and verbalize what you are doing out loud to them!)

Sometimes there isn't a solution to the child's feelings (e.g., a preschooler is sad because dad just left on a business trip). In this case it helps the child just to have their real feelings (e.g., anxiety, sadness) acknowledged and responded to by the parent.

Don't dish out platitudes. Simply telling a child to "cheer up", "things will get better", or "I had it a lot tougher when I was a kid" isn't reflective listening, and it communicates to the child are simply dismissing their feelings.

Remember that all feelings are acceptable. Children can't always act on their feelings, but every child has a right to feel what they feel.

"Mirroring": is a good technique to get a child to open up (especially if you aren't quite sure how child is feeling). Simply "mirror" back to child what they said in a questioning tone of voice:

> Child: "I never want to see Sheena again!"
>
> Parent: "You never want to see Sheena again?"
>
> Child: "No—she invited everyone in the class to her birthday party except me!"

Once you have an idea of what the problem is you can proceed with reflective listening and the problem-solving steps. This is also a "door opener", i.e., an invitation to the child to open up and say more.

Benefits of using reflective listening: Reflective listening promotes the development of an emotionally-close relationship between parent and child as well as the social, language, emotional, and cognitive development of a child. In addition, it:

- helps children feel understood and valued; that someone "gets them"
- helps children learn the right words for their feelings
- validates the child as well as the child's feelings
- helps children develop a positive self-esteem
- improves children's communication and social skills, and helps them understand others
- improves children's problem-solving abilities
- increases children's empathy for others

II. WHEN A CHILD IS STRUGGLING WITH SOMETHING: Try saying, "Can I help you?" This lets child know you are available to help if they would like help.

When we just step in to help without asking, this can send the message that we think they are incapable of succeeding on their own).

III. <u>MOVE IT</u>! Moving the body helps to change a child's emotional states. Engage in reflective listening with a child first! As your child gets older, help him learn that strong emotions often don't last long, and that moving one's body can help change their emotional state!

IV. <u>WHEN A CHILD HAS HAD AN ESPECIALLY UPSETTING/FRIGHTENING EXPERIENCE</u>: TALK about upsetting, frightening, and traumatic experiences with kids. Helping a child retell the story of a frightening/upsetting experience over and over allows the child's brain to make sense out of what happened to them. Putting these upsetting memories into words helps to "tame" these frightening thoughts for children. Also, when parents can fill in the gaps in a child's memory, it can change the child's memory of the upsetting event.

(SIEGEL: REWIND & REMEMBER)

(By contrast, sleep disturbances, debilitating phobias, etc. result when kids are unable to make sense of painful memories)

V. <u>ESPECIALLY FOR INFANTS AND TODDLERS</u>:

- Determine their real needs before performing caregiver tasks (e.g., don't assume a young child need a diaper change just because they may be fussy)
- When a toddler is trying to tell you something that you don't understand, say "Can you show me?"
- Try distracting your child from something in order to prevent a potential problem or meltdown (e.g., distracting your child in the grocery cart to look at some of the cereals in order to avoid looking at the toys on the other side of the aisle). This works up to about age 3.
- Many older infants and young toddlers go through a period when they will NOT sit down or allow themselves to be confined (e.g., by a seatbelt, in a stroller, in a grocery cart). This is normal! If you have a young child who is going through this phase, try to do your errands when you can leave them at home with someone else—this will pass.

References:
Gordon, 2000; Ginott, 2003; Shonkoff & Phillips, 2000; Siegel & Bryson, 2012

Toddlers (1 to 3 Years)
(Kamptner, 2012)

<u>Guidance tips</u>

- Pick your battles—this is a time when parents and young children can get into many conflicts. Choose the 2 or 3 most important rules to enforce (e.g., intervene if child is about to hurt self, others, or materials/ equipment) and let the rest go.
- Plan something positive to do every day, especially outside of the house: an outing to the park, a picnic, etc.
- Always supervise closely. Do not <u>ever</u> leave a toddler unsupervised for even a minute. Adults are responsible for keeping a toddler physically safe. You cannot rely on telling a toddler something (e.g., "don't go into the street") and expecting them to "obey". They are unable to control their impulses.
- Toddlers often go through a stage where they won't sit down (often around 18 mos. of age or so --in a car seat, stroller, high chair, shopping cart, etc. This is normal and part of their strong desire to be physically involved with the environment. It's best to just leave them with another adult when you must go out
- Use environmental/preventive means to head off potential problems For example, don't rely on telling a toddler to stay off the stairs; instead, block it off with a safety gate
- Don't misinterpret toddlers' behavior as "spite" or an act of rebellion; look at the activity from the toddler's perspective: spilling juice is a cool science experiment in gravity!
- Plan to have 20-30 minutes of floortime daily with toddler
- Keep play dates at home short
- Toddlers won't sit still for a regular meal. So instead, let them feed themselves foods they can eat with their fingers—even standing up if needed—6 or so mini meals throughout the day.
- Blocks, sand, mud, finger-paint, playdoh, and dumping activities are great activities for this age
- Give 2 choices when you can: "Do you want peas or beans for dinner?" This supports the toddler's strong need for autonomy at this age.
- Give toddlers a real job to do. They want to help, and can do such simple tasks like putting the napkins out for dinner, dusting, sweeping.
- Give toddlers a warning of an upcoming transition—they are very rigid and have a difficult time making transitions
- Support toddlers in their desire to learn self-help skills (brushing teeth, getting dressed, etc.)

- Most toddlers will bite another child or you at some point—NEVER BITE THEM BACK to "show them what it feels like". Instead, get down to their eye level and say, "Biting hurts. You may not bite". And then work with them to find the source of their frustration/anger.
- Stay out of battles with toddlers regarding food, potty training.
- Talk to toddlers! Give simple reasons and explanations for things.
- Read interactive books to toddlers— reading books also at bedtime helps establish a routine and it provides them with time to wind down
- Toddlers love their routines; these give them a sense of security
- Emotions come first with toddlers (as at all other ages)—attend to their emotions; reflect their feelings back to them. Provide correct words for their emotions.
- Get down to the toddler's eye level when you talk to her.
- Toddlers are SUPPOSED to want/demand parents' full attention, especially when you are talking on the phone or visiting in person with someone!
- As toddlers give up naps, they will sleep better/longer at night. There is a lot of individual variation as to when she may give up naps—it may be anytime between 18 mos.- 3+ yrs.
- Toddlers will transition from crib to toddler bed sometime between 18 mos. – 3 yrs. As soon as toddler can climb out of bed, it's time to move them (for safety's sake) to a toddler bed!

Early Childhood (3 to 5 Years)
(Kamptner, 2012)

<u>Guidance Tips</u>

- Read, read, and read to children!
- Talk with children about what's going on, explaining how the world works to them
- Parents/caregivers need to be active social coaches for child: talk with child about what to do when; why they should do "XX"; what behaviors are expected when; etc.
- Use environmental/preventive means to head off potential problems
- Try to have 20-30 minutes of floortime daily with child
- Support them in their desire to learn self-help skills (brushing teeth, getting dressed, etc.)
- Bedtime/sleep: give child time to wind down; give child plenty of individual attention before bedtime (so bedtime isn't the only time of the day when the child gets the parent solely to themselves); have a regular bedtime routine (bath, story, drink of water, etc.)
- Bad dreams/nightmares fairly common: make sure child doesn't observe upsetting situations, family violence, and violent TV shows/movies.
- Child's biggest fear: abandonment by loved ones
- Mealtime tips: give child choices when you can; remove plate after a period of time; give child small portions; involve child in making it. Allow child to stop eating when child is full.
- Competitive games and team sports are inappropriate for this age (due to child's egocentrism)
- Spend time playing with child: studies show that the more play periods parents have with child, the better the child's social and emotional development—and the better they will get along with others
- Tips for visits to doctor, dentist, hair salon, new babysitter, and new school/teacher: discuss with child and role-play beforehand!
- When you take young children on outings or to restaurants: pack a travel bag with toys, books, and snacks to help keep her occupied!
- No more than 30 minutes of appropriate children's TV per day (e.g., Sesame Street)

Reference:

L. Kamptner, personal communication, October, 2012.

Parenting Tips for Managing Child Behaviors in Public

I. Behaviors are often caused by external factors that can be solved by calm, responsive, and creative caregivers

II. Child is less likely to misbehave intentionally than typically-developing children
   A. Know your child
      1. Sensory-classifications (e.g., sensitive to sound or light)
   B. Modify your expectations
      1. Start with smaller goals that are compatible with your ASD child's abilities (e.g., instead of expecting the child to sit through a full dinner at a restaurant , allow your child to sit still for three minutes, eat using a fork, etc.)
   C. Modify the environment
      1. Safety is key
   D. Consider the possible sources of behavior
      1. Most ASD children crave or over-respond to sensory input and behaviors may be a reaction to too much or too little sensory input.
      2. Observe your child to figure out what may be triggering behaviors
   E. Remove overwhelming sensory input
      1. Avoid
      2. Consider using ear plugs or distracting objects
   F. Provide sensory input
      1. Weighted vests or quilts
      2. If can withstand touch, provide bear hugs
   G. Look for positive outlets for unusual behaviors (e.g., while child may spin in the grocery store it may be useful to let the child twirl on a tire swing)
   H. Enjoy your child's successes
   I. Worry less about others' opinions
      1. Remember your child has an ASD; he is not intentionally being embarrassing!

III. Meltdowns
   A. Physical aggression is most dangerous part of meltdown
      1. Caregiver must ensure his/her safety during the meltdown
      2. Caregiver must then ensure the safety of the child
         1. Often unaware of the harm they can cause and are not in control of their emotions
         3. Least importantly, caregivers should worry about the safety of the property

B. Tips for managing child behaviors:
1. Discover what your child's triggers are
2. Be aware of triggers and the environment and manipulate those triggers so they cause the child less distress
3. Work to eliminate or reduce those triggers to the point where they will only anger the child
4. Teach the child to manage his or her emotions (e.g., social stories)

C. Caregiver responsibilities:
1. Model calm behaviors during meltdown so child can follow cues
2. Be ready to provide instructions to the child, verbally and/or physically, to a place when the child can safely calm down
   1. Instructions should be very simple (e.g., "go to your safe spot")
      a. Safe spot can be previously identified
3. If unable to redirect child, caregiver should just watch the child and allow for the meltdown to pass
4. Restraint should only be used as the last resort
   1. Should not jeopardize child's safety

Reference:
Sicile-Kira, C. (2004). *Autism spectrum disorders: The complete guide to understanding autism, asperger's syndrome, pervasive developmental disorder, and other ASDs*. New York, NY: The Berkley Publishing Group.

Promoting Social and Emotional Development

Ideas for Play

I. The mentioned activities follow the DIR/Floortime approach
    A. For more information about the DIR/Floortime approach
        1. Read: Engaging Autism by Stanley Greenspan and Serena Wieder (2006)
    B. The purpose of the play activities is to facilitate acquisition of core deficits observed in ASD children (e.g., shared attention and regulation, engagement and relating, purposeful emotional interactions, shared problem-solving, creating ideas, and logical thinking) by:
        1. Expanding on the child's interest and becoming part of the child's world
        2. Engaging the child by following the child's lead to find out what is important to the child
        3. Increasing circles of communication
    C. Allows the ASD child to look and listen, pay attention to sights, sounds, smells, and other sensations outside of the child

II. Review Greenspan & Wieder's (2006): Key Questions for Parents and Other Caregivers to Ask (document attached)

III. Play Activities
    A. To improve shared attention and regulation skills
        1. Look and Listen Game:
            - Face the child, smile, and talk to the child using slow animated faces to the right and left to capture the child's attention for a few seconds
        2. Soothe Me Game:
            - Soothe the child in a rhythmic way and touch the child's head, arms, legs, tummy, back, feet, and hands in a lullaby rocking motion
    B. To improve engagement and relating skills
        1. Smiling Game:
            - Use words and funny faces to entice the child to smile broadly or produce other pleased facial expressions (e.g., wide eyes)
        2. "Dance with Me" Sound and Movement Game:
            - Inspire the child to make sounds and move his or her limbs in rhythm with your voice
    C. To improve purposeful emotional interactions
        1. Funny Sound, Face, and Feeling Game:
            - Note the sounds and facial expressions the child naturally uses to express joy, annoyance, surprise, and

mirror these sounds and facial expressions back to the child in a playful way to try and get a response in return

    2. Circle-of-Communication Game:
- Create back-and-forth interactions with child (e.g., child touches parent's face, parent squeals)
  - a. Each time the child follows his interests he is closing the circle of communication

D. To improve shared problem-solving skills

    1. Working-Together Game:
- Note the child's natural interests in various toys and create a problem he or she needs your help to solve around that favorite toy

    2. Copycat Game:
- Copy the child's sounds and gestures
- See if the child will mirror your funny faces, sounds, and movements
- Eventually add words if appropriate

E. To improve creating ideas skills

    1. Let's Chitchat Game:
- Promote the use of words by elaborating on the child's responses to see how many circles of communication are possible

    2. Let's Pretend Game:
- Encourage the child's imagination by setting a familiar stage during pretend play then introduce new plot twists.
- Periodically summarize the action and encourage the child to move the drama along

F. To improve logical thinking skills

    1. Director Game:
- See how many plot shifts or new story lines the child can initiate in make-believe games together (e.g., what can we do next?)

    2. "Why Should I" Game:
- When child wants the parent to do things, the parent will gently tease the child with "why should I" to see how many reasons the child can give the parent

IV. For Additional Play Ideas
    A. Read: Early Intervention Games by Barbara Sher (2009).

Reference:

Greenspan, S. & Wieder, S. (2006). *Engaging Autism: Using a floortime approach to help children relate, communicate, and think.* Cambridge, MA: Da Capo Press.

Developmental Milestones and Key Needs for Toddlers (1 to 3 Years)
(Kamptner, 2012)

I. <u>Developmental Milestones</u>:

<u>Physical growth</u>:

- Large muscle skills (e.g., walking, running) are much better than small muscle skills (e.g., writing with a pencil) throughout the toddler and preschool years (especially for boys)
- Likes to push big toys around, carry, and dump things
- Is constantly on the move; doesn't sit still (due to brain immaturity)
- Is too busy to sit down to eat
- Usually can run, climb up stairs beginning around 18+ mos.
- Jumps, climbs, rides trike around 3+ yrs.
- Sleep: 10-15 hrs. in a 24 hr. period (i.e., 2-3 hrs. of daytime sleep in 1-2 naps and 8-13 hrs. of nighttime sleep with awakenings)

<u>Brain development</u>:

- Is right-brain dominant (which means she has BIG EMOTIONS)
- Very short attention span; inability to sit still; is very impulsive
- After about 2 or 2-1/2 yrs., less likely to awaken at night
- Potty training linked to brain development: average ages for girls is 1 to 3+yrs; average age for boys is 3-1/2 yrs

<u>Cognitive development</u>:
- Is very curious and driven by impulse
- Has an intense interest in learning about world
- Has a very limited understanding of the world: has a hard time distinguishing between fantasy and reality; thinks if something moves, it's alive; may worry about going down drains, toilet; & worries about physical harm to self (e.g., blood oozing out, body parts coming apart)
- Is egocentric
- Has emotionally-based thinking
- Interprets things literally
- Has a poor understanding of numbers, time, size, causality, and space
- Observes and imitates others
- Develops intention/goal-oriented behavior
- Likes to explore properties and functions of objects

Language development:

- Very rapid language growth (vocabulary, syntax, grammar, etc.), especially after 18 mos.
- At 2 years: typically speaks in 2-word phrases ("Mommy go") to express a complete thought
- At 3 years: typically speaks in 3-word/full sentences
- 2-3 yrs: asks questions, talks about experiences, talks to self
- Limited ability to speak clearly but understands much more
- Limitations in language ability often cause frustrations (esp. 18mos.+)
- Makes lots of grammatical errors (never correct child's mistakes; instead, mirror back to them the correct way to say something)
- If you don't understand what a toddler is saying, say "Can you show me?"
- Likes "interactive" books (i.e., books with flaps to open, buttons to push, things to feel)

Social development/play:

- Does not share because is still very egocentric
- Doesn't know socially-acceptable ways of doing things; needs patient adult guidance
- Is very possessive of toys, of primary caregiver's attention, etc.
- Enjoys being around others but will often treat others as objects (poking, hitting, pushing)
- Engages in solitary, onlooker, or parallel play
- Is "wired" to seek/be target of attention by caregivers
- Imitates peers and parents
- Pretend play begins 18-24 mos.
- Engages in onlooker, parallel, or solitary play as a young toddler; older toddlers may begin engaging in interactive play (3yrs+)
- Play helps toddlers manage stress

Emotional development:

- May lash out physically when frustrated. (Physical activities can help diffuse strong emotions)
- Fluctuates between autonomy and seeking independence
- Very strong emotions but little/no coping ability
- Is very rigid
- Confused by emotions of others (e.g., distress); will often get caregiver to help another young child in need
- Uses comforting objects (e.g., blanket, stuffed animal) for soothing and coping with separation
- Has very limited ability to cope so is dependent on primary caregivers for calming, soothing, comforting ("emotional regulation")
- Begins to show empathy for others
- Typically experiences separation anxiety

II. Key needs of toddler:

- Parents providing warm, sensitively-attuned, responsive caregiving.
- Parents supporting toddlers' need for autonomy (while keeping them safe); child's strong drive toward autonomy may begin as early as 12-13 mos. Parent-child relationship must change as child has more freedom to move about on own.
- Parents understanding that meltdowns are normal at this age and are due to brain immaturity and that when they occur, toddlers should be comforted, not ignored
- Parents keeping toddlers safe (as they have no sense of what's safe and what's not safe)
- Parents talking to, reading books to, and playing with the toddler
- Parents providing the toddler with an emotionally-positive environment
- Parents using positive and supportive guidance, not punishment
- Parents providing toddlers with experiences with both the physical and social environments
- Parents spending 20-30 minutes of floortime daily with child

Recommended books— Toddler development:

Allen, K. & Markotz, L. (2010). *Developmental profiles*.

Altmann, T. (2006). *The wonder years*. (American Academy of Pediatrics)

Davies, D. (2011). *Child development*.

Fromberg, D. & Beren, D. (2006). *Play from birth to twelve*.

Gonzalez-Mena, J. & Eyer, J. (2004). *Infants, toddlers, and caregivers*.

Ames & Ilg (19XX). *Your 2 year old, Your 3 year old*.

Eisenberg, A. (1996). *What to expect in the toddler years*.

Grille, R. (2008). *Heart-to-heart parenting: Nurturing your child's emotional intelligence from conception to school-age.*

Lieberman, A. (1995). *The emotional life of the toddler*.

Miller, K. (2005). *Ages and stages: Developmental descriptions and activities- birth through 8 years of age.*

Segal, M. (1998). *Your child at play: One to two years: Exploring, learning, making friends, and pretending.*

Segal, M. (1999). *Your child at play: Two to three years: Growing up, language, and imagination.*

Shatz, M. (1994). *A toddler's life.*

Developmental Milestones and Key Needs for Early Childhood (3 to 5 Years)
(Kamptner, 2012)

I. Developmental Milestones

Physical growth:

- Gross motor skills (e.g., running, climbing) are far better than fine motor skills (e.g., using a pencil). Girls are often better at fine motor skills than boys through the early elementary years. Give BIG crayons, pencils, markers, puzzle pieces, building materials
- Gaining more control over bodies
- Growth slows down after age 3
- Still cannot sit still/pay attention for long periods of time
- Improving ability to control impulses
- Sleep: **10-13 hrs. in a 24 hr. period** (i.e., up to 2 hrs. of daytime sleep and 8-11 hrs. of nighttime sleep with awakenings). Preschoolers typically go to bed between 7-9 pm and get up between 6-8 a.m. Daytime naps become shorter with age and are typically given up sometime between 2-5 yrs of age. When naps are given up, children will sleep better and longer at night, and will go to bed earlier.

Brain development:

- Left brain comes online ±3 yrs of age (when children start asking "why?")
- Continued short attention span
- Continued inability to sit still and concentrate for long periods of time. (As the left side of the brain matures throughout the early elementary school years, children will be able to increasingly sit and focus their attention).
- Potty training linked to brain development: average ages for girls are 1 to 3+yrs; average age for boys is 3-1/2 yrs.
- The typical age of reading readiness, which is dependent on brain maturation, is 6+ yrs. Writing follows (and also depends on maturation of the left side of the brain)

Cognitive development:

- Thinking is rigid, inflexible, prelogical, literal, concrete, egocentric, emotion-based, and distorted
- Limited understanding of how the real world works
- Often reverses cause and effect
- Poor understanding of numbers, time, size, causality, and space
- Difficulty distinguishing between fantasy and reality
- Thinks if something moves, it's alive.
- Games with rules & sharing things with others don't work well since still egocentric

- begins to be able to follow a few simple rules with reminders/reinforcement (4-6 yrs)
- Height of fantasy, make-believe
- Doesn't understand that things remain the same even though their outward appearance changes (i.e., lacks "conservation")
- Difficulty following complex story lines
- Tends to put events together in time and space as cause-effect relationship (e.g., eat ice cream→ gets sick)
- Interested in where babies come from
- Doesn't understand that some aspects of self are unchangeable
- Cannot retell an event with the listener's perspective in mind (due to egocentrism)

Language development:

- Typically speaks in full sentences by age 3
- Speech becomes clearer
- Vocabulary at age 3: 1000 words, increasing by 50 words per month 3-6 yrs.
- Uses out-loud self-talk in directing own behavior and during play
- Understands more than they can speak
- Makes a lot of grammatical errors. (Never correct child's mistakes; instead, mirror back to child the correct way to say something).
- Stuttering is fairly common and usually disappears after a short time
- Loves books (so read to child every day)!

Social development:

- Does not share well—continues to be fairly egocentric. (Focus should instead be on "taking turns")
- Peers become more important
- May engage in interactive social play at around age 3 (depends on language ability), and cooperative play toward the end of the preschool years
- Social skills develop through play and interactions with peers – and with patience positive/supportive adult guidance
- Doesn't know socially-acceptable ways of doing things; needs patient adult support and guidance (i.e., "social coaching")
- Increasingly uses language to interact with peers and deal with conflicts
- Friendships are based on common play interests (4-6 yrs.)

Emotional development:

- Can better identify different emotions (IF parents label and discuss and child's feelings/emotions with them)
- Many fears persist (e.g., abandonment, haircuts, doctors, dentists, etc.)
- Senses right vs. wrong but may confuse the "truth"
- Is interested in own birth story

- Thinks of self in mostly physical, concrete, external ways
- Still often has separation issues; may be attached to a treasured possession (e.g., blanket, teddy bear) to help with separation. As memory and sense of time improves (4-6 yrs.), can cope better with separations
- Increasing empathic reactions toward others (3-6 yrs)
- Guilt develops (4-6 yrs.)
- Cannot emotionally tolerate "losing" at a game

Play

- Helps child explore reality, social roles, manage stress/fears, and master the environment
- Allows child to practice new cognitive skills (e.g., cause-effect thinking)

II. Key needs of Preschoolers:

- Warm, sensitively-attuned, responsive caregiving (i.e., a secure attachment)
- Support for their increasing need to venture out into the world
- Support and positive guidance for their developing social skills
- A safe and emotionally-positive environment
- Parents/caregivers who talk to, read books to, and play with them
- Parent/caregiver support of and involvement in their play
- Parents/caregivers who act as interpreters of the world for them
- Parents/caregivers who use positive and supportive guidance, not punishment
- Regular floortime sessions (20-30 minutes) with parents/caregivers

Recommended books/selected references— early childhood:

Allen, K. & Markotz, L. (2010). *Developmental profiles.*

Altmann, T. (2006). *The wonder years.* (American Academy of Pediatrics)

Fromberg, D. & Beren, D. (2006). *Play from birth to twelve.*

Ames & Ilg (19XX). *Your 3 year old, Your 4 year old, Your 5 year old*

Elkind, D. (1987). *Miseducation: Preschoolers at risk.*

Elkind, D. (2007). *The power of play.*

Fraiberg, S. (1996). *The magic years: Understanding and handling the problems of early childhood.*

Grille, R. (2008). *Heart-to-heart parenting: Nurturing your child's emotional intelligence from conception to school-age.*

Hendrick, J. & Weissman, P. (2010). *The whole child.*

Miller, K. (2005). *Ages and stages: Developmental descriptions and activities- birth through 8 years of age.*

Segal, M. (1999) *Your child at play: Three to five years: Conversation, creativity, and learning letters, words, and numbers.*

Developmental Milestones: Caring For Your Baby and Young Child Birth to Age Five

I. **Your Child at 1 Year**
   A. **Act early if your child:**
      1. Doesn't crawl
      2. Can't stand when supported
      3. Doesn't search for things that she sees you hide.
      4. Doesn't say single words like "mama" or "dada"
      5. Doesn't learn gestures like waving or shaking head
      6. Doesn't point to things
      7. Loses skills he once had

II. **Your Child at 18 Months**
   A. **Act early if your child:**
      1. Doesn't point to show things to others
      2. Can't walk
      3. Doesn't know what familiar things are for
      4. Doesn't copy others
      5. Doesn't gain new words
      6. Doesn't have at least 6 words
      7. Doesn't notice or mind when a caregiver leaves or returns
      8. Loses skills he once had

III. **Your Child at 2 Years**
   A. **Act early if your child:**
      1. Doesn't use 2-word phrases (for example, "drink milk")
      2. Doesn't know what to do with common things, like a brush, phone, fork, spoon
      3. Doesn't copy actions and words
      4. Doesn't follow simple instructions
      5. Doesn't walk steadily
      6. Loses skills she once had

IV. **Your Child at 3 Years**
   A. **Act early if your child:**
      1. Falls down a lot or has trouble with stairs
      2. Drools or has very unclear speech
      3. Can't work simple toys (such as peg boards, simple puzzles, turning handle)
      4. Doesn't speak in sentences
      5. Doesn't understand simple instructions
      6. Doesn't play pretend or make-believe
      7. Doesn't want to play with other children or with toys
      8. Doesn't make eye contact
      9. Loses skills he once had

V. Your Child at 4 Years
  A. Act early if your child:
  1. Can't jump in place
  2. Has trouble scribbling
  3. Shows no interest in interactive games or make-believe
  4. Ignores other children or doesn't respond to people outside the family
  5. Resists dressing, sleeping, and using the toilet
  6. Can't retell a favorite story
  7. Doesn't follow 3-part commands
  8. Doesn't understand "same" and "different"
  9. Doesn't use "me" and "you" correctly
  10. Speaks unclearly
  11. Loses skills he once had

VI. Your Child at 5 Years
  A. Act early if your child:
  1. Doesn't show a wide range of emotions
  2. Shows extreme behavior (unusually fearful, aggressive, shy or sad)
  3. Unusually withdrawn and not active
  4. Is easily distracted, has trouble focusing on one activity for more than 5 minutes
  5. Doesn't respond to people, or responds only superficially
  6. Can't tell what's real and what's make-believe
  7. Doesn't play a variety of games and activities
  8. Can't give first and last name
  9. Doesn't use plurals or past tense properly
  10. Doesn't talk about daily activities or experiences
  11. Doesn't draw picture
  12. Can't brush teeth, wash and dry hands, or get undressed without help
  13. Loses skills he once had

VII. For more information, go to www.cdc.gov/concerned or call 1-800-CDC-INFO

Reference:
Adapted from *Caring for your baby and young child: Birth to age 5*, 5th ed., edited by Steven Shelov and Tanya Remer Altmann © 1991, 1993, 1998, 2004, 2009 by the *American academy of pediatrics and bright futures: Guidelines for health supervision of infants, children, and adolescents*, 3rd ed., edited by Joseph Hagan, Jr., Judith S. Shaw, and Paula M. Duncan, 2008, Elk Grove Village, IL: American Academy of Pediatrics.

APPENDIX J

HOW AUTISM SPECTRUM DISORDERS IMPACT

THE FAMILY SYSTEM

Overview/Outline: How ASDs Impact the Family System (Part 1)

Purpose:

Knowledge of source of parental stress is important as the well-being of ASD children is significantly related to the well-being of their parents. Therefore, parents will learn how to identify and manage parental stress. It is also important for parents to manage family functioning as ASD children's inflexibility to deviate from their own routine often creates a barrier for typical family routines. Therefore, parents will learn how to develop and implement daily routines. Parents of ASD children also experience more discord in their intimate relationships and are more likely to separate as a result of the ASD diagnosis. This significantly impact ASD children's developmental outcomes. Therefore, it is important to identify the causes of marital discord. Parents will learn strategies to maintain the intimacy of their relationship. Parents of ASD children often experience heightened caregiving responsibilities and as a result may be at risk for burn-out. Therefore, parents will learn how to request and utilize respite care.

Objectives:

- Acquire knowledge about parental stress
- Learn strategies for family management
- Acquire knowledge of the impact of an ASD diagnosis on the marital dyad
- Acquire knowledge about respite care

I. Parental Stress
   A. Sources of parental stress
   B. Stress alleviation techniques

II. Family Management
   A. Important for family dynamics
   B. Daily routines (J-2)
   C. Challenges of daily routines
   D. Benefits of daily routines

III. Marital Dyad
   A. Marital discord
      1. Causes
      2. How to decrease discord?
   B. How to maintain the relationship?

IV. Respite Care
   A. What is respite care?
   B. Benefits of utilizing respite
   C. How to request respite?
   D. How to choose a respite provider? (J-3)
   E. Listing of providers (J-4)

Example of Schedule

EARLY MORNING SCHEDULE—

7:30 - 8:15 a.m. - Youngster and parent prepare for breakfast.

8:15 - 8:45 a.m. - Breakfast and clean-up: As youngster finishes breakfast, he reads books or listens to music until free play begins.

MORNING SCHEDULE—

8:45 - 9:00 a.m. - Sharing time: Conversation and sharing time; music, movement, or rhythms; finger-plays.

9:00 - 10:00 a.m. - Free play: Youngster selects from one of the interest areas: art, blocks, library corner, table toys, house corner, sand and water.

10:00 - 10:15 a.m. - Clean-up: Youngster puts away toys and materials; as he finishes, he selects a book to read.

10:15 - 10:30 a.m. - Story time: The length of story time should vary with the age of the youngster.

10:30 - 10:50 a.m. - Snack and preparation to go outdoors.

10:50 - 11:45 a.m. - Outdoor play: Youngster selects from climbing activities, wheel toys, balls, hoops, sand and water play, woodworking, gardening, and youngster-initiated games.

11:45 - 12:00 noon - Quiet time: Youngster selects a book or listens to tapes.

LUNCH AND REST—

12:00 - 12:45 p.m. - Prepare for lunch, eat lunch, and clean up: As youngster finishes lunch, he goes to the bathroom and then read books on his bed in preparation for nap time.

12:45 - 1:00 p.m. - Quiet activity prior to nap: Story, song by parent, quiet music, or story record.

1:00 - 3:00 p.m. - Nap time: As youngster awakens, he reads books or plays quiet games such as puzzles or lotto on their cots (kids who do not sleep or who awaken early are taken into another room for free play with books, table toys, and other quiet activities).

AFTERNOON SCHEDULE--

3:00 - 3:30 p.m. - Snack and preparation to go outdoors.

3:30 - 4:30 p.m. - Outdoor play: Youngster selects from climbing activities, wheel toys, balls, hoops, sand and water play, woodworking, gardening, and youngster-initiated games.

4:30 - 5:15 p.m. - Free play: Youngster selects from art (activity requiring minimal clean-up time), blocks, house corner, library corner, and table toys.

5:15 - 6:00 p.m. - Clean-up: After snack, parent plans quiet activities such as table toys; songs, finger-plays, or music; stories; and coloring. Older kids might help parent prepare materials for the next day.

**Remember routines can be changed to include various activities such as school attendance, social activities, and going on vacations.

Reference:

Example of schedule. (2012). Retrieved from
http://www.myaspergerschild.com/2009/12/examples-of-schedules-for-aspergers.html

Creating Daily Routines (Larson, 2006)

I.   Step One: Analyze the Day
     A. Complete a time study
        1. Look for problem times
        2. Think about how the schedule can be structured to eliminate problems related to behavior, stress, fatigue, hunger, and disorganization

II.   Step Two: Brainstorm Expectations
     A. Focus on balance of activities and rest for the family
     B. Take an honest look at both parents and child needs

III.   Step Three: Write it Down
     A. Get a poster board and marker
        1.Write the schedule down for all to see
        2.Post it in the kitchen
     B. Inform the family that the routine will be followed from now on
     C. Expect opposition but stand firm

IV.   Step Four: Follow the Schedule for a Week
     A. Check the schedule often
     B. Let it guide your days
     C. Make sure the children follow it
        1.Remind them if necessary

V.   Step Five: Tweak the Schedule
     A. After the first week
        1.Look to see if the schedule is working and how the schedule needs changing
     B. Make changes to the schedule
        1.Write it on a new poster board
     C. Follow the schedule until it is natural for the family to do so

References:

Example of schedule. (2012). Retrieved from
     http://www.myaspergerschild.com/2009/12/examples-of-schedules-for-
     aspergers.html

Larson, E. (2006). Caregiving and Autism: How does children's propensity for
     routinization influence family participation in family activities? *Occupation,
     Participation, and Health, 26,* 69-79.

Respite Provider (Sicile-Kira, 2004)

I. How to Hire a Respite Provider
   A. Look for someone with experience
   B. Or someone you trust who is a good candidate for training in applied behavior analysis

II. Where to Place a Respite Advertisement
   A. Typically hire respite workers through an agency
   B. To hire directly
      1. Place ads in newsletter of local chapter of ASD support group
      2. Colleges
      3. Universities

III. What to Put in the Advertisement
   A. Write exactly what you are looking for
      1. Experience (necessary or not)
      2. Training (available or not)
      3. Amount of hours needs per week
      4. Hourly rate (to be discussed)
   B. Describe your child
      1. Personality
      2. Likes and dislikes
      3. What child responds to

IV. Looking Over a Resume
   A. Does the person have work experience?
   B. Has she held job responsibilities before?
   C. Has she had a regular work schedule?
   D. Has she worked with children of the same age group as your child?
   E. What has she been studying at college and what kind of work has she done?

V. Questions to Ask on the Phone
   A. Has she worked with children before? What age group?
   B. Has she ever babysat before or spent a lot of time around children?
   C. How many siblings does she have, and what is her position in her family?
   D. Why is she interested in working with your child?
   E. How long can she commit to working with your child?
   F. Can she provide any work references? Is she has no work references, how about personal references?
   G. Is she willing to submit to fingerprinting?

VI.   Questions to Ask a Person Named as a Work Reference
       A. How long did the applicant work for them?
       B. Is she dependable, reliable, and trustworthy?
       C. Was she on time or late often?
       D. Did she often call in sick?
       E. Was she good at working independently and as part of a team?
       F. Was she flexible and able to learn and do the job the way the employer
           wanted?
       G. Did she take constructive criticism well?
       H. Did she show a creative streak?
       I. What were her most positive attributes, and least positive?
       J. Would they recommend her for the position you have in mind?

VII.   Face-to-Face Interviews
       A. What did she like about the jobs she has had in the past?
       B. What does she hope to pursue as a career?
       C. Why does she want the position with your child?
       D. How long can she commit for?
       E. What schedule constraints does she have?
       F. Does she have any questions for you?
       G. Bring your child into the interview
           1. Does the applicant try to make contact with your child?
           2. Does she appear respectful of your child?
           3. What kind of approach does she have?
           4. You know your child. Does it appear that your child likes the
               person?

Reference:
Sicile-Kira, C. (2004). *Autism spectrum disorders: The complete guide to
    understanding autism, asperger's syndrome, pervasive developmental
    disorder, and other ASDs*. New York, NY: The Berkley Publishing Group.

Respite Providers Contact Information

Provider	Address	City	Telephone
Accent Care Inc.	6840 Indiana Ave. Ste. 275	Riverside, CA 92506	951-778-8985
ACN Health Care Providers	35325 Date Palm Dr., Ste. 152-B	Cathedral City, CA 92234	760-202-1888
Cambrian Homecare	27994 Bradley Rd.	Sun City, CA 92586	877-390-4300 951-301-4300
Desert Arc	73255 Country Club Drive	Palm Desert, CA 92260	760-346-1611
Extra Help at Home, Inc.	9045 Haven Ave., Ste. 100	Rancho Cucamonga, CA 91730	909-581-0900
Inland Respite Inc.	10800 Hole Ave.	Riverside, CA 92501	951-353-1261
Shella Care Management, Inc.	29800 Bradley Rd. #102	Sun City, CA 92586	951-723-8460
We Care 4 You, LLC	23493 Crest Forrest Dr.	Crestline, CA 92325	909-338-0448
In-Roads Creative Programs, Inc.	7955 Webster St., Ste. 14	Highland, CA 92346	909-864-1551
Maulin Home Care Services Inc.	1004 W. Foothill Ste. 201	Upland, CA 91786	909-946-9600

LVN/RN/Health Care Agencies

Allcare Health Services Inc.	360 S. Milliken Ste. F & G	Ontario, CA 91761	909-390-5772
Bayada Home Health Care	1832 Commerce Center Ste. B	San Bernardino, CA 92408	909-890-2286
Best Home Health Care Inc.	1630 E. Francis St Ste. K	Ontario, CA 91761	909-923-9303
Team Nurses Home Health Services Inc.	1815 N. D St.	San Bernardino, CA 92405	909-881-5953
Premier Healthcare Service, LLC	650 E. Hospitality Ste. 10	San Bernardino, CA 92408	909-890-0448
24-Seven Homehealth Inc.	2050 N. Garey Ave. Ste. 3	Pomona, CA 91767	909-593-0900

APPENDIX K

HOW AUTISM SPECTRUM DISORDERS IMPACT THE

FAMILY SYSTEM (PART 2)

Overview/Outline: How ASDs Impact the Family System (Part 2)

Purpose:

The sibling relationship is important as it provides opportunities for the ASD child to learn and practice social interactions in a natural setting. It also teaches ASD children the importance of social skills in communication. Therefore, parents will learn strategies to facilitate the development of the sibling relationship. Parents will also learn about ASD- related impairments that can impact the sibling relationship. It is the parents' responsibility to supervise the sibling relationship. Therefore, parents will learn strategies to assist typically-developing siblings in forming and maintaining the sibling relationship. Parents will also learn how to spend quality time alone with typically-developing children.

Objectives:

- **Acquire knowledge about sibling relationships**
- **Learn strategies to facilitate the development of sibling relationships**

I. Sibling Relationship
    A. Discuss the importance of sibling relationship for the ASD child
        1.High-quality relationship
    B. Discuss the impact of ASDs on the sibling relationship
        1.ASD impairments
        2.Typically-developing sibling
    C. Discuss parental responsibility for sibling relationships
        1.Explain the diagnosis
            - A Sibling's Guide to Autism-Autism Speaks Family Support Tool Kit (K-2)
        2.Facilitate the development of the sibling relationship (K-3)
        3.Modify ASD sibling's behavior
        4.Spending time alone with the typically-developing sibling (K-4)

A Sibling's Guide to Autism (Autism Speaks Inc., 2011)

I. Learning that your brother or sister has autism can be a very difficult experience. You may have noticed behaviors that upset you, and hearing the word "autism" might be confusing for you. During this time, your life and that of your family may feel different than they were before this happened. You may be worried about how this will affect the future. Sometimes you may worry about how your family will cope.

II. **It's okay to have feelings about having a brother or sister with autism, but it doesn't help to keep those feelings to yourself. Remember your mom and dad may be having similar feelings, and it's important to share with them what's going on with you.**

III. **Some things you may be having trouble with:**
   A. Understanding why your brother or sister acts in what seems to you to be strange ways.
   B. Feeling like your brother and sister gets more time and attention from your parents than you do.
   C. Feeling embarrassed about your brother or sister's behaviors when you are with friends or out in the community, like at a store where other people may stare at you or react negatively.
   D. Not knowing how to play with your brother and sister.

IV. **Some questions you may have:**
   A. Will I get to spend alone time with my mom or dad? Do they still care about me?
   B. How much time do I have to play with my brother? What can we do that he or she will like?
   C. How can I explain my brother or sister's behavior to my friends?
   D. Why doesn't my brother or sister have to do chores and other things around the house like I have to do?

V. **Since your sibling was diagnosed with autism what's different for you?**
   1._____
   2._____
   3._____
   4._____

Do you have questions that no one has been able to answer yet?
   1._____
   2._____
   3._____
   4._____

VI. **How You can Help**

    A. Your relationship with your brother or sister is very important. So it makes sense that you will want to spend time together, and for you both to feel comfortable and safe when you are playing.

    B. There may be times that your brother or sister does something suddenly or in an unusual way that can cause you to feel frustrated and upset. Ask your parents about activities that you and your brother or sister can do together. It is important for you to know the best ways to interact with your sibling.

    C. **Things to ask your parents about before you start to play with your brother or sister:**

        1._____

        2._____

        3. _____

VII. Finding an activity you can do with your brother or sister will allow you to have fun and enjoy each other's company.

    A. **Some activities you may enjoy doing with your brother or sister:**

        1. Playing a board game or working on a puzzle.

        2. Playing an interactive video game.

        3. Playing a physical game, like tag or jumping on a trampoline.

    B. Your brother or sister is still your sibling, so it's important to have a good relationship. Together as a family, you can figure out ways to make sure everyone is happy!

    C. **What activities can you and your sibling do together?**

        1._____

        2._____

Reference:
Autism Speaks website. (2011). http://www.autismspeaks.org/family-services/tool-kits/family-support-tool-kits#siblings

Recommendations for Facilitating the Development of the Sibling Relationship

I.   Provide plenty of opportunities for typically-developing children to…
     (Greenspan & Wieder, 2006)
     A. Discuss their feelings about their ASD sibling
         i.   Empathize with them
         ii. Answer any questions they may have in a
              developmentally-appropriate manner

II. Facilitate as much interactions between typically-developing siblings and the
     child with ASD as possible
     A. Model to children how to interact with each other
     B. Through play activities
         i.   Scavenger hunt
         ii. Duck duck goose

III. Strengthen interactions between typically-developing siblings and the ASD
     child by… (Sicile-Kira, 2004)
     A. Spending time alone with typically-developing children
     B. Reminding typically-developing children how much they are loved
     C. Teaching typically-developing children how to interact with the ASD
         sibling
     D. Setting consequences for the ASD child
     E. Keeping lines of communication open

IV. Allowing typically-developing siblings to have a private, ASD-free zone
     A. Play dates with peers without sibling
     B. Area in home that ASD sibling is not allowed

V.   Enroll typically-developing child in support group for siblings of children with
     ASDs
     A. Local autism chapter will have information

Reference:
Greenspan, S. & Wieder, S. (2006). *Engaging Autism: Using a floortime approach to
     help children relate, communicate, and think.* Cambridge, MA: Da Capo Press.

Recommendations for Quality Time with Typically-Developing Children (Sicile-Kira, 2004)

I. Each parent should spend at least half an hour a day with the typically-developing child
    A. Activities should be appropriate to child's age
    B. Allow the time to be purely enjoyable
    C. Let the child be the center of attention
    D. Do whatever the child wants to do
    E. Do not allow the focus to shift to the child with ASDs

II. Show the child he or she is valued and loved

III. Be emotionally available to typically-developing children so they can discuss their feelings
    A. Emphasize and validate their feelings

IV. Establish play dates for typically-developing children without ASD child
    A. ASD-free zones

Reference:

Sicile-Kira, C. (2004). *Autism spectrum disorders: The complete guide to understanding autism, asperger's syndrome, pervasive developmental disorder, and other ASDs*. New York, NY: The Berkley Publishing Group.

APPENDIX L

TREATMENT AND INTERVENTION OPTIONS

Overview/Outline: Treatment and Intervention Options

Purpose:

Parents who possess knowledge about treatment and intervention options increase their ASD child's chances for developmental progression and are better suited to make educated decisions regarding their child's treatments. Therefore, parents will receive a comprehensive review of treatment and intervention options available. Parents will also receive information about effective early intervention programs. Lastly, parents will learn the steps to take to ensure optimal developmental progressions are made.

Objectives:

- **Learn how early intervention impacts developmental outcomes**
- **Learn why screening of ASD child's current level of development is important for the development of intervention objectives**
- **Learn components of effective early intervention programs**
- **Learn the importance of completing an analysis of risks before an intervention is chosen**
- **Acquire knowledge about treatment and intervention options**
- **Learn strategies to monitor intervention and treatment progress**

I. Early Intervention
    A. Purpose of intervention or treatment
    B. Importance of participation
    C. Impact on ASD child developmental outcomes
    D. Components of effective intervention program (L-2)

II. Importance of Screening ASD Child's Current Level of Development

III. Risk analysis of intervention or treatment for
    A. Child
    B. Family

IV. Intervention and Treatments Available
    A. Behavioral (L-3)
        1. Applied behavioral analysis (ABA)
    B. Socio-Emotional (L-4)
        1. Developmental individual-difference, relationship (DIR/Floortime)
        2. DIR/Floortime promoting health development using the model
        3. Social play
        4. Social stories
    C. Biomedical (L-5)
        1. Medications
    D. Complementary and Alternative Medicine (CAM) (L-6)
        1. Special diets

V. Monitoring Strategies (L-7)
    A. Autism Treatment Evaluation Checklist (ATEC) (L-8)

Components of Effective Early Intervention Programs

I.   According to the National Institute of Mental Health, intensive early intervention programs can significantly improve cognitive and language skills in young children with ASDs.

II.   The most effective features of early intervention programs include:
- A. Start as soon as the child has been diagnosed with an ASD
- B. Provide focused and challenging learning activities at the proper developmental level for the child for at least 25 hours per week and 12 months per year
- C. Have small classes that allow the child to have one-on-one time with the therapist or specialist and small group learning activities
- D. Have special training for parents and families
- E. Encourage activities that include typically-developing children, as long as such activities help meet a specific learning objective
- F. Measure and record each child's progress and adjust the intervention program as needed
- G. Provide a high degree of structure, routine, and visual cues (e.g., posted activity schedule and clearly defined boundaries) to reduce distractions
- H. Guide the child in adapting learned skills to new situations and settings and maintain the learned skills
- I. Uses a curriculum that focuses on
    1. Language and communication
    2. Social skills (e.g., joint attention)
    3. Self-help and daily living skills (e.g., dressing and grooming)
    4. Research-based methods to reduce challenging behaviors (e.g., aggression and emotional outbursts)
    5. Cognitive skills (e.g., pretend play and perspective taking)
    6. Typical school-readiness skills (e.g., letter recognition and counting)

Reference:
http://www.nimh.nih.gov/health/publications/a-parents-guide-to-autism-spectrum-disorder/how-is-asd-treated.shtml

Behavioral Treatment and Interventions (www.cdc.org)

I. Behavioral
    A. Applied Behavioral Analysis
        1.Based on the assumption that all learned behaviors have an antecedent (i.e., what happened before the behavior was exhibited), and a consequence (i.e., what happened after the behavior was exhibited) and that all such behavior is shaped by the consequences of our actions.
        - Therefore are motivated to repeat that behavior
        2. Specific skills are taught by breaking them into small steps, teaching each step one at a time, building on the previous one.
        3.Successful in academic, self-help skills, speech and language, and socially appropriate behaviors.
        4.Terms in ABA:
        - Task analysis
            a. Analyzing a task or skill that needs to be taught, by indentifying each step of the skill, and which steps the person needs to learn (i.e., analyze the sequence of the task).
        - Discrete trial training
            a. Systematic method that consists of a request, the child's response, and the consequence to that response; a short pause and then the next trial. Each trial is discrete (i.e., separate) so it is clear what is being requested of the child.
        - The Lovaas Method
            a. Intensive ABA program that is aimed at preschool children
        - Errorless learning (no-mistake learning)
            a. Parents or professional prompt a new behavior, physically motoring the student if necessary. The prompts are gradually removed so that the behavior will eventually occur simply in response to a request or other cue.

II. To locate board-certified providers, go to the Behavioral Analyst Certification Board's website (www.bacb.com).

Reference:
Center for Disease Control and Prevention website. (n.d.). Retrieved June 29, 2012 from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm

Socio-Emotional Treatment and Interventions (Greenspan & Wieder, 2006)

I.   Socio-Emotional
   A. Developmental, Individual-Difference, Relationship-Based DIR/Floortime Model
      1. Aims to build healthy and meaningful relationships and abilities following the natural emotions and interests of the child
      2. Fosters improvements in communication, thinking, language, and others social skills, and seeks to reduce atypical behaviors through play.
      3. Four objectives:
- Encourage attention and intimacy
- Two-way communication
- Encourage expression and the use of ideas and feelings
- Logical thought

      4. Handout-outline of the DIR approach to evaluation and intervention

   B. Social play
      1. Promotes appropriate behaviors by initiating, prompting, and reinforcing social interactions in a natural setting
      2. Teaches children about social relationships and the consequences of the social choices they make

   C. Social stories
      1. Promotes desired social behavior by describing social situations and appropriate social responses through the written word.
- Created with the learn, who takes an active role in developing the story
- Social stories have descriptive sentences about the setting, characters, and their appropriate feelings and thoughts, and give direction in regard to the appropriate responses and behaviors.

II. Suggested Readings
   A. The child with Special Needs: Encouraging Intellectual and Emotional Growth by Stanley I. Greenspan and Serna Wieder

   B. The Boy Who Loved Windows: Opening the Heart and Mind of a Children Threatened with Autism by Patricia Stacey

Reference:
Greenspan, S. & Wieder, S. (2006). *Engaging Autism: Using a floortime approach to help children relate, communicate, and think*. Cambridge, MA: Da Capo Press.

Promote Healthy Development using the DIR/Floortime Model

Your Child's Developmental Goal	What You Can Do to Help
Stage One Being Calm and Interested in All the Sensations of the World	Help your baby look, listen, begin to move, and calm down.
Stage Two Falling in Love	Woo your baby into engaging with you with pleasure and delight
Stage Three Becoming an Intentional Two-Way Communicator	Follow your baby's lead and challenge him/her to exchange gestures and emotional signals with you about his/her interests
Stage Four Learning to Interact to Solve problems and Discover a Sense of Self	Become an interactive partner with your toddler as he/she learns to use a continuous flow of gestures with you to pursue his/her interests and meet his/her needs
Stage Five Creating Ideas	Enter your child's make-believe world as a character in his/her dramas. Engage him/her in long conversations about his/her interests, desires, and even his/her complaints
Stage Six Building Bridges Between Ideas	Challenge your child to connect his/her ideas together by seeking his/her opinion, enjoying his/her debates, and enlarging his/her pretend dramas.

Reference: Greenspan S.I. (2000). Building Healthy Minds: The Six Experiences that Create Intelligence and Emotional Growth in babies and Young Children. Da Capo Press, Perseus Books Group, MA, USA, 2000

Biomedical Treatment and Interventions

I.   Biomedical
    A. The individuality of each patient is the first consideration in the medical treatment options.
    B. Patient is the expert and expresses responses to tests and treatments which guides further understanding of the options

II. Pharmacotherapy
    A. No medications that can cure ASDs or event treat the main symptoms
    B. A child with ASD may not respond in the same way to medications as typically-developing children
        1.Keep a record of how child reacts to medication
    C. Medications available that can help with related symptoms
        1.Antipsychotic
            ▪ Reduce aggression and other serious behavior problems
            ▪ Can reduce repetitive behaviors, hyperactivity, and attention problems
        2.Antidepressant
            ▪ Treat depression and anxiety
            ▪ Can help control aggression and anxiety
        3.Stimulant
            ▪ Treat hyperactivity
    D. All medications carry a risk of side effects

III. Suggested Readings
    A. Essential Psychopharmacology by S.M. Stahl
    B. Autistic Spectrum Disorders: Understanding the Diagnoses and Getting Help by Mitzi Waltz
    C. http://www.nimh.nih.gov/health/publications/a-parents-guide-to-autism-spectrum-disorder/how-is-asd-treated.shtml

Reference:

http://www.nimh.nih.gov

Complementary and Alternative Medicine (CAM) Treatment and Interventions

I.   Complementary and Alternative Medicine (CAM)-Special Diets
    A. Word of caution
        1. Beware of anecdotal information from other parents
    B. Types:
        1. Mercury detoxification treatment (chelation)
        2. Vitamin B6 and magnesium
        3. Dimethylglycine (DMG)
        4. Fatty acids
        5. Sulphate ions
        6. Enzymes
        7. Secretin
        8. Intravenous immunoglobulin (IVIG) therapy
        9. Magnetic therapy
        10. Auditory integration
    C. Special diets
        1. Gluten-free, Casein-free (GFCF) diet eliminates dietary intake of naturally occurring proteins gluten and casein.
            ■ Developed for individuals who have allergies or a toxic response to gluten or casein.
            ■ There is a subset of individuals with ASD who also have celiac disease (immune-mediated, chronic, multisystem disorder) which is triggered by gluten ingestion.
            ■ Use of diet is not harmful to child
        2. Anti-Yeast diet is intended to inhibit overgrowth of Candida yeast and eliminates intake of yeast products.
            ■ May be helpful for ASD child with an overgrowth of yeast in the system.
            ■ Symptoms of yeast overgrowth include gastrointestinal distress, headaches, skin rashes, irritability, confusion, and hyperactivity.
            ■ Use of diet is not harmful to child
        3. Feingold diet removes artificial coloring, flavorings, salicylates, and some preservatives from diet.
            ■ Use of diet is not harmful to child
        4. Ketogenic diet is a high-fat, adequate-protein, low-carbohydrate diet.
            ■ Designed for people who experience seizures.
            ■ Can be harmful to child. Diet should not be implemented without supervision of neurologist and dietician.

Reference:

http://www.nimh.nih.gov

Monitoring Strategies (Sicile-Kira, 2004)

I. Maintain Records
    A. Order full medical, mental health, therapy files from any professionals the child has seen so it can be reviewed from time to time.
    B. Cross reference the files to gather "forgotten" information
    C. Start a detailed medical and behavioral, intertwined history
    D. Immunization history
    E. Growth chart

II. Observe and Record Child's Abilities
    A. Senses and perception
    B. Movement
    C. Self-concept and independence
    D. Communication
    E. Thinking skills
    F. Social relationships

III. Observe and Document Child's Learning Style
    A. Noisy vs. quiet environment
    B. Group vs. individual
    C. Organized vs. messy
    D. Verbal vs. picture
    E. Work consistently vs. frequent breaks

Reference:

Sicile-Kira, C. (2004). *Autism spectrum disorders: The complete guide to understanding autism, asperger's syndrome, pervasive developmental disorder, and other ASDs*. New York, NY: The Berkley Publishing Group.

Sample: Autism Treatment Evaluation Checklist

Autism Treatment Evaluation Checklist (ATEC)
Bernard Rimland, Ph.D. and Stephen M. Edelson, Ph.D.
Autism Research Institute
4182 Adams Avenue, San Diego, CA 92116
fax: (619) 563-6840; www.autism.com/ari

Project/Purpose

Scores:	I	II	III	IV	Total

This form is intended to measure the effects of treatment. Free scoring of this
form is available on the Internet at: www.autism.com/atec

Name of Child _____ _____ ☐ Male   Age _____
  Last   First   ☐ Female   Date of Birth _____
Form completed by: _____ Relationship: _____ Today's Date _____

Please circle the letters to indicate how true each phrase is:

I. Speech/Language/Communication: *[N] Not true   [S] Somewhat true   [V] Very true*

N S V 1. Knows own name
N S V 2. Responds to 'No' or 'Stop'
N S V 3. Can follow some commands
N S V 4. Can use one word at a time (No!, Eat, Water, etc.)
N S V 5. Can use 2 words at a time (Don't want, Go home)

N S V 6. Can use 3 words at a time (Want more milk)
N S V 7. Knows 10 or more words
N S V 8. Can use sentences with 4 or more words
N S V 9. Explains what he/she wants
N S V 10. Asks meaningful questions

N S V 11. Speech tends to be meaningful/relevant
N S V 12. Often uses several successive sentences
N S V 13. Carries on fairly good conversation
N S V 14. Has normal ability to communicate for his/her age

II. Sociability: *[N] Not descriptive   [S] Somewhat descriptive   [V] Very descriptive*

N S V 1. Seems to be in a shell – you cannot reach him/her
N S V 2. Ignores other people
N S V 3. Pays little or no attention when addressed
N S V 4. Uncooperative and resistant
N S V 5. No eye contact
N S V 6. Prefers to be left alone

N S V 7. Shows no affection
N S V 8. Fails to greet parents
N S V 9. Avoids contact with others
N S V 10. Does not imitate
N S V 11. Dislikes being held/cuddled
N S V 12. Does not share or show
N S V 13. Does not wave 'bye bye'

N S V 14. Disagreeable/not compliant
N S V 15. Temper tantrums
N S V 16. Lacks friends/companions
N S V 17. Rarely smiles
N S V 18. Insensitive to other's feelings
N S V 19. Indifferent to being liked
N S V 20. Indifferent if parent(s) leave

III. Sensory/Cognitive Awareness: *[N] Not descriptive   [S] Somewhat descriptive   [V] Very descriptive*

N S V 1. Responds to own name
N S V 2. Responds to praise
N S V 3. Looks at people and animals
N S V 4. Looks at pictures (and T.V.)
N S V 5. Does drawing, coloring, art
N S V 6. Plays with toys appropriately

N S V 7. Appropriate facial expression
N S V 8. Understands stories on T.V.
N S V 9. Understands explanations
N S V 10. Aware of environment
N S V 11. Aware of danger
N S V 12. Shows imagination

N S V 13. Initiates activities
N S V 14. Dresses self
N S V 15. Curious, interested
N S V 16. Venturesome - explores
N S V 17. "Tuned in" — Not spacey
N S V 18. Looks where others are looking

IV. Health/Physical/Behavior:

Use this code: [N] Not a Problem   [MO] Moderate Problem
[MI] Minor Problem   [S] Serious Problem

N MI MO S 1. Bed-wetting
N MI MO S 2. Wets pants/diapers
N MI MO S 3. Soils pants/diapers
N MI MO S 4. Diarrhea
N MI MO S 5. Constipation
N MI MO S 6. Sleep problems
N MI MO S 7. Eats too much/too little
N MI MO S 8. Extremely limited diet

N MI MO S 9. Hyperactive
N MI MO S 10. Lethargic
N MI MO S 11. Hits or injures self
N MI MO S 12. Hits or injures others
N MI MO S 13. Destructive
N MI MO S 14. Sound-sensitive
N MI MO S 15. Anxious/fearful
N MI MO S 16. Unhappy/crying
N MI MO S 17. Seizures

N MI MO S 18. Obsessive speech
N MI MO S 19. Rigid routines
N MI MO S 20. Shouts or screams
N MI MO S 21. Demands sameness
N MI MO S 22. Often agitated
N MI MO S 23. Not sensitive to pain
N MI MO S 24. "Hooked" or fixated on certain objects/topics
N MI MO S 25. Repetitive movements (stimming, rocking, etc.)

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APPENDIX M

NEGOTIATING THE SCHOOL SYSTEM

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Overview/Outline: Negotiating the School System

Purpose:

Parents must be knowledgeable about their child's specific disability, their rights under the federal and state law, and the policies and procedures of the local education agency. Parents who are knowledgeable in special education components are better suited to make informed decisions regarding their ASD child's future. Therefore, parents will learn about the process of school enrollment, state and federal legislation that impacts their ASD child, and the role of the Individual Education Plan (IEP).

Objectives:

- **Acquire knowledge about Early Head Start and Head Start**
- **Acquire knowledge about legislation that impacts ASD children's education**
- **Learn strategies to assess potential school environments**
- **Acquire knowledge about the Individual Education Plan (IEP)**

I. Early Head Start and Head Start
    a. Purpose
    b. Enrollment requirements

II. Legislation (M-2)
    a. Americans with Disabilities Act (ADA)
    b. Individuals with Disabilities Education Act (IDEA)
    c. Rehabilitation Act of 1973
    d. Free Appropriate Public Education (FAPE)
    e. No Child Left Behind Act of 2001

III. Assessing Appropriateness of School Environment
    a. Determining your child's educational needs
    b. Questions to ask when assessing schools and classrooms (M-3)
    c. Advocating throughout the Special Education Process
    d. Parental education rights (M-4)

IV. Individual Education Plan (IEP)
    a. IEP review (M-5)
    b. IEP checklist (M-6)
    c. Sample IEP (M-7)
    d. Role of parents as advocates

Legislation Overview

I. American with Disabilities Act (ADA)
   A. Prohibits discrimination of the basis of disability by any state or local government entities, including public school districts
   B. Guarantees that school districts who receive public accommodations provide services for individuals with disabilities

II. Individuals with Disabilities Act (IDEA)
   A. Guarantees a basic foundation of opportunity for the disabled child consisting of specialized instruction and related services which are individually designed to provide education benefit
   B. IDEA ensures that all individuals have access to a "free and appropriate education (FAPE)"
      i. Public schools are required to make education available to all children with disabilities
   C. Requires that an Individual Education Plan (IEP) be written according to the needs of the disabled child who meets eligibility requirements under the IDEA and state regulations
      i. Services available as specified in the IDEA may include speech therapy, occupational or physical therapy, interpreters, medical services, orientation and mobility services, parent counseling and training to aid in the implementation of the IEP, psychological or counseling services, recreation services, rehabilitation, social work services, and transportation

III. Rehabilitation Act of 1973
   A. Bans discrimination by the state or local recipients of federal assistance on the basis of disability
   B. Prevents exclusion from participation in the state public education programs
   C. Requires that a school district develop a plan for the disabled child extending authorizations of grants for vocational rehabilitation, supported employment, independent living, and client assistance services with special emphasis on services provided to the most severely disabled
   D. Administered by the Rehabilitation Services Administration

IV. Free Appropriate Public Education (FAPE)
    A. An education right of children with disabilities that is guaranteed by the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act (IDEA)
    B. Education services must be provided at the public expense, under public supervision and direction, and without charge to parents except for fees that are charged to all students
    C. FAPE is a program tailored to the specific child and is designed to meet the child's unique needs by providing access to the general curriculum
        i. Concurrently meets grade-level standards established by the state, and from which the child receive educational benefits
    D. FAPE requires schools to provide students with an education which includes specialized instruction and related services that prepares the child for further education, employment, and independent living

V. No Child Left Behind (NCLB) Act of 2001
    A. Guarantees aid to programs for disadvantaged students
    B. Designed to provide incentives to school districts that exhibit progress for students with disabilities
    C. NCLB and IDEA work together to provide both individualized instruction and school accountability for students with disabilities
        i. Law specifically forbids schools and states from excluding students with disabilities from accountability systems, and all students must participate in tests that accurately gauge their progress
        ii. Tests give parents and educators valuable information to target the areas in which the child needs help
    D. NCLB increases school districts accountability by monitoring the effectiveness of interventions offered by the Individual Educational Plan (IEP)
    E. Provides alternative options for schools that are not meeting the needs of the disabled population

References:

http://www.ada.gov/
http://idea.ed.gov/
http://www.ncld.org/parents-child-disabilities/idea-guide/overview-idea-parent-guide
http://www2.ed.gov/policy/speced/reg/narrative.html
http://www.ed.gov/

Questions to Ask When Assessing Schools and Classrooms (Sicile-Kira, 2004)

I. How many children are in a class?

II. What is the ratio of staff to children?

III. Does the staff have appropriate skills and access to training to help my child?

IV. Are there any specialist resources (e.g., behavioral consultant)?

V. What kind of experience do the school and the teacher have with children with ASDs?

VI. What teaching methods and strategies specific to ASDs are the staff trained in?

VII. Is the school prepared to fit the systems around the child rather than being concerned about how a child will fit into the school system (e.g., flexibility in rules)?

VIII. Ask specific questions about the teacher's experience with and knowledge of ASDs

IX. Ask about teaching aids or support staff functional knowledge of teaching methods

Reference:

Sicile-Kira, C. (2004). *Autism spectrum disorders: The complete guide to understanding autism, asperger's syndrome, pervasive developmental disorder, and other ASDs*. New York, NY: The Berkley Publishing Group.

Parents' Educational Rights

I.   Parents' Rights
- A. To obtain independent educational evaluations (IEE)
- B. To receive prior written notice any time the school district plans to evaluate the student, schedules an meeting where decisions will be made about the student's eligibility or educational placement or refuses to evaluate or change the student's plan or placement
- C. To consent to evaluations and to the school providing special education services
- D. To have access to their child's educational records
- E. To present and resolve a complaint through the due process complaint and state compliant process including the time period parent have in which to make a complaint, how the school district or state may resolve the complaint, the difference between the due process and state complaint procedures, the availability of mediation services, and the student's educational placement while the complaint is being resolved
- F. To state level appeals of decisions made in due process hearings (if applicable in that state)
- G. To bring civil actions against the school district or state, including the time period in which to file such actions
- H. To reimbursement of attorney fees under specific circumstances

Reference:
http://www.ncld.org/parents-child-disabilities/idea-guide/chapter-4-procedural-safeguards-understanding-exercising-your-legal-rights?start=1

Individual Education Plan (IEP)

I. An IEP must be developed within 30 days of eligibility determination and then must be reviewed annually as long as the student continues to be eligible for services
   A. Special education and related services cannot begin until an IEP has been developed

II. Scheduling the IEP
   A. School districts are required
      i. To provide advanced notice of the meeting to ensure parents have the opportunity to attend
      ii. To schedule the meeting at a mutually agreed upon time and place
      iii. Provide alternative ways of meeting (e.g., conference calls and video conferencing)

III. Meeting Notice
   A. School must provide written notice of every proposed IEP meeting
      i. Purpose of meeting
      ii. The time and location of meeting
      iii. Who will attend
      iv. Inform of rights to bring other individuals to IEP meeting
   B. Who Attends IEP Meetings?
      i. The IEP team consists of
         1. The students parents
         2. Regular education teacher of the student
         3. Special education teacher or provider
         4. Representative of the school district who is qualified to provide instruction and knowledgeable about the general education curriculum and is knowledgeable about the school districts resources
         5. An individual who can interpret the instructional implications of evaluation results (e.g., school psychologist)
         6. Any individuals who have knowledge or special expertise regarding the child (e.g., speech pathologist, occupational therapist, private tutor)
         7. When appropriate, the student

IV. Developing the IEP
    A. Consideration factors
        i. The strengths of the child
        ii. Parents concerns for improving child education
        iii. The results of the child's initial evaluation or most recent evaluation
        iv. The academic, developmental, and functional needs of the child
            1. Can include social skill development, behavioral problems, and attention issues
    B. Special factors
        i. Positive behavioral interventions and strategies to address a child's behavior that disrupts learning or that of others
            1. Functional behavioral assessment and behavior intervention plans
        ii. Language and communication factors
        iii. Need for assistive technology
    C. Present level of performance (PLOP)
        i. Develop a statement describing child's present level of academic and functional performance
        ii. Includes information on how the child's disability affects involvement and progress in the general education curriculum
        iii. Establishes a baseline that will be used to develop the IEPs measurable annual goals
    D. Measurable annual goals
        i. Goals designed to meet the child's needs as a result of the disability
        ii. Goals enable the child to be involved in and make progress in the general education curriculum
        iii. Goals must be measurable and related directly to the information in the PLOP
    E. Short-term objectives
        i. Measurable intermediate steps between the baseline (as described in the PLOP) and the annual goal
    F. Progress reporting
        i. IEP team will describe child's progress towards meeting the annual goals in measurable terms
            1. May be provided quarterly

G. Services/programs
  i. IEP team will develop a statement about the specially designed instruction, related services, and supplementary aids and services that will be provided to the child
  ii. Proposed services must enable the child to:
    1. Advance appropriately toward reaching the annual goals
    2. Be involved in and make progress in the general education curriculum, extracurricular and other nonacademic activities
    3. Be educated and participate with children who do not have disabilities
  iii. Must include specific information
    1. Dates (e.g., service will begin and end)
    2. Frequency (e.g., how often service will be provided)
    3. Location (e.g., where service will be provided)
    4. Duration (e.g., the period of time each service will be provided)
H. Participation in general education
  i. IEP team must describe how much time the child will spend outside the regular education classroom and away from students who do not have disabilities
    1. Requirement is designed to protect the child's right to be educated in the least restrictive environment
I. Accommodations and assessment participation
  i. IEP team will develop a statement about any individual accommodations that the child should use when taking assessment or tests as required by NCLB

V. Finalizing the Initial IEP
  A. Signatures serve as informed consent for the school to begin to provide special education services to the child
    i. May take IEP home to review before signing
      1. Can disagree in part or in full to IEP components
  B. Services should begin as soon as the IEP is finalized

VI. Changing an IEP
   A. IDEA provides parents and school the ability to make changes
      i. Can amend or change the IEP without holding another meeting of the full team
      ii. Revisions to a current IEP can be made
         1. All members of the IEP team must be made aware of the changes and their responsibility in implementing the changes

VII. Access to IEPs
   A. Highly confidential information
   B. IEP is accessible to each person responsible for its implementation

VIII. Annual IEP Review
   A. Focus on
      i. Any lack of expected progress towards the annual goals as well as progress in the general education curriculum
      ii. Results of reevaluations conducted
      iii. Information that provided about the child
      iv. Any additional information such as the child's performance on state and district assessments
      v. General education teacher must participate in the review and revision of the IEP
   B. Signing annual IEPs
      i. Parents are not required to sign annual IEPs
      ii. Parents can withdraw their consent for services at any time

IX. When You Move
   A. IDEA ensures that the child's special education program continues without interruption when moving to a new district either within the same state or to another state
   B. Transfer of records

Reference:
http://www.ncld.org/parents-child-disabilities/idea-guide/chapter-7-individualized-education-programs-ieps-developing-your-childs-education-plan

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IEP Checklist for Parents

☐Yes	☐No	Is the information in your child's present level of performance (PLOP) clearly stated and supported with objective information and assessment or evaluation data, such as information from standardized testing, curriculum based measurements or performance on district or state-wide assessments?
☐Yes	☐No	Does the present level of performance (PLOP) section of the IEP contain information about the academic, developmental and functional needs of your child?
☐Yes	☐No	Are your concerns and expectations for your child included in the present level of performance (PLOP) section of the IEP?
☐Yes	☐No	Are your child's annual goals clearly stated and can they be measured?
☐Yes	☐No	Knowing the effects of your child's disability, do the annual goals directly relate to your child's needs as stated in the present level of performance (PLOP)?
☐Yes	☐No	Is the specific way(s) to master the annual goals clearly stated?
☐Yes	☐No	Is the method(s) to monitor and evaluate your child's progress toward the annual goals clearly stated?
☐Yes	☐No	Does the IEP indicate the amount of time your child will spend in general education?
☐Yes	☐No	Are the special education services and related services recommended for your child supported by scientific research that supports their effectiveness? If not, what evidence has the school provided to indicate that the services and instructional methods proposed for your child have been found to be effective for children with similar learning difficulties and of similar age?
☐Yes	☐No	Does the IEP state who will be responsible for implementing the services listed?
☐Yes	☐No	Are the appropriate related services addressed on the IEP?
☐Yes	☐No	Do you know how the IEP content will be communicated and shared with the staff responsible for their implementation?

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☐ Yes	☐ No	Are all of the appropriate accommodations listed?
☐ Yes	☐ No	Does the IEP indicate how your child will participate in state and district testing?
☐ Yes	☐ No	Have any potential consequences of your child's assessment participation been explained to you? Have you discussed whether your child may or may not be allowed to move on to the next grade or graduate with a regular diploma?

Reference:

http://ncld.org

Sample IEP

STUDENT PROFILE

In determining both eligibility and need for special education services or programs, the IEP team must consider each of the following:

Describe student's strengths and interests: Memo" « ①   ②

Describe parent concerns for enhancing student's education: Memo" « ②

Address progress on IEP goals and objectives (attached). ③   ☐ N/A – This is an initial IEP

Memo" «

Consider academic/pre-academic achievement results on most recent state- and/or district-wide assessments.

Memo" «   ④

PRESENT LEVEL OF ACADEMIC ACHIEVEMENT AND FUNCTIONAL PERFORMANCE (PLAAFP)

After reviewing the results of an initial evaluation or the most recent reevaluation of the student and the student's progress in the general education curriculum, describe the student's present level of academic achievement and functional performance.

Memo" « ⑤

BASELINE DATA	IMPACT AND RESULTING NEEDS
In area(s) of need, report baseline data with same-age peer comparison, such as curriculum-based assessments, studentwork, teacher observations, parent input, and other data scores that have been collected over time. Explain how student accesses or makes progress in general education curriculum based on grade level content standards for the grade in which student is enrolled or would be enrolled based on need; or appropriate activities for preschool children.	In area(s) of need, describe how the student's academic, developmental, and functional levels impact involvement and progress in general education curriculum (or age-appropriate activities for preschool children) and resulting needs.
Reading: ☐ Not applicable Memo" « ⑥	Impact: Memo" « ⑦ Resulting Needs: Memo" «
Mathematics: ☐ Not applicable Memo" « ⑧	Impact: Memo" « ⑨ Resulting Needs: Memo" «
Written Expression: ☐ Not applicable Memo" « ⑩	Impact: Memo" « ⑪ Resulting Needs: Memo" «

TRANSITION ASSESSMENT

Age-appropriate related to training, education, employment, and independent living skills.

☐ Not applicable

Memo" « ⑫	Impact: Memo" « ⑬ Resulting Needs: Memo" «

COMMUNICATION / SPEECH & LANGUAGE

Articulation, language development, augmentative communication, etc.

☐ Not applicable

Memo" « ⑭	☐ Language needs for students with limited English proficiency were considered. Other Communication / Language Needs: Impact: Memo" « ⑮ Resulting Needs: Memo" «

SOCIAL-EMOTIONAL / BEHAVIORAL

Behavior that impedes student's learning or the learning of others, positive behavioral supports, strategies, etc.

☐ Not applicable

Memo" « ⑯	☐ Positive behavior interventions, supports, and other strategies for behaviors impeding learning were considered. Other Social/Behavioral Needs: Impact: Memo" « ⑰ Resulting Needs: Memo" «

PERCEPTION / MOTOR / MOBILITY - Gross and fine motor coordination, balance, and limb/body mobility.

☐ Not applicable

Memo" « ⑱	Impact: Memo" « ⑲ Resulting Needs: Memo" «

ADAPTIVE / INDEPENDENT LIVING SKILLS

Skills for academic success and independent living (where appropriate).

☐ Not applicable

Memo" « ⑳	Independence Level: ☐ Full ☐ Functional ☐ Supported ☐ Participation Impact: Memo" « ㉑ Resulting Needs: Memo" «

MEDICAL

Health, vision, hearing, or other physical/medical issues.

☐ Not applicable

Memo" « ㉒	☐ Language/communication needs for student who is deaf/hard of hearing were considered. ☐ Braille instruction for student who is visually impaired/blind was considered. ☐ Other medical needs: Impact: Memo" « ㉓ Resulting Needs: Memo" «

ASSISTIVE TECHNOLOGY

If previously assigned, indicate low-/tech/high-tech supports, devices, etc.

APPENDIX N

WHAT RESOURCES ARE AVAILABLE TO FAMILIES WITH

AN AUTISM SPECTRUM DISORDERS CHILD

Overview/Outline: What Resources are Available to Families with an ASD Child

Purpose:

Parents' abilities to understand their ASD child is heavily dependent on the support they receive after the initial ASD diagnosis. To lessen the impact of ASDs on the family system, it is important for parents to participate in ASD support groups. It is also important for parents to learn about the available services and funding that the ASD child may be eligible for. Therefore, parents will learn about local supports, services, and funding.

Objectives:

- **Acquire knowledge about available support and resources**

I. Importance of Social Support
    A. Autism Research Institute
        i. Words of advice from Dr. Edelson (N-2)

II. Role of Inland Regional Center (IRC)
    A. Eligibility
    B. Available services

III. Support Services
    A. California State University, San Bernardino: University Center for Developmental Disabilities (N-3)
    B. Carolyn E. Wylie Center (N-4)

IV. Support Groups (N-5)
    A. Advocacy groups
    B. Research organizations

V. Counseling Providers (N-6)

Words of Advice from Stephen M. Edelson, Ph.D.

Over the past 30 years I have been fortunate to conduct research in several areas of autism and to collaborate with many of the leading pioneers, including biomedical (Bernard Rimland), behavior/education (Ivar Lovaas), and sensory (Temple Grandin, Guy Berard, Lorna Jean King, Melvin Kaplan, Helen Irlen). These experiences have helped me broaden my understanding of what can be done to help these individuals.

One of the most difficult and stressful times for a family is when they first learn that their child has autism. Parents are then faced with a critical and life-determining question: What should I do to help my child? The decision on which treatments to implement (and not to implement) will likely determine the child's prognosis. I have outlined the steps that I would take if I were a parent of an autistic child.

Action Plan

First, I would read the paper Advice for Parents of Young Autistic Children, written by Drs. Jim Adams, Bernard Rimland, Temple Grandin and myself.

Second, I would write to the Autism Research Institute (ARI, 4182 Adams Ave., San Diego, CA 92116; fax: 619-563-6840) and request their free parent packet. The packet contains a wealth of information that describes ways to understand and to treat many problems associated with autism. It includes a sample issue of the quarterly ARI newsletter, the Autism Research Review International (ARRI). Subscribing to the ARRI is the best way to keep informed ($18/year).

I would also contact the local chapter of the Autism Society of America (ASA) in my area. The autism chapter will likely provide valuable resources and contact numbers in the community and throughout the state. In addition, I would attend at least one parent support group to see what they have to offer. ASA maintains a listing of most autism chapters throughout the country (toll-free: 800-3-AUTISM).

Important note: Before contacting my health insurance carrier, I would first read the policy. Many policies do not cover treatment services for autistic individuals. These insurance companies may reimburse therapies if the therapy is not specifically aimed at treating autism and if the insurance company is not aware that the child has autism. For example, if the child has a speech problem, the insurance company may pay for speech therapy.

Intervention. There are two major approaches that I would pursue simultaneously; and the earlier these interventions are started, the better the child's prognosis. The first approach involves determining whether the child has health problems. These problems may include a critical need for essential vitamins and minerals (e.g., vitamin B6 with magnesium, DMG, vitamins A and C), gastrointestinal problems (e.g., leaky gut, yeast overgrowth, viral infection), high levels of heavy metals and other toxins (e.g., mercury, lead), food sensitivities and allergies, and more. The majority of autistic individuals have one or more of these problems.

An evidence-based combined approach to autism addresses both medical and educational issues. ARI distributes a diagnostic and treatment book titled Autism: Effective Biomedical Treatments (2005, Supplement update 2007). A list of practitioners who understand and know how to treat such medical conditions can be obtained from ARI. Of the many treatments described in the book, I would first give the child vitamin B6 with magnesium, then dimethylglycine (DMG), and then the gluten-/casein-free diet. I would also read Dr. James Adams' 28-page paper titled Biomedical Treatment Summary.

Comment on drugs. Some pediatricians prescribe drugs to autistic children even though the Food and Drug Administration has not approved any drugs for treating autism. Additionally, almost every drug has harmful side effects. I sometimes hear reports of some benefit with Risperdal, Prozac, and Ritalin. However, it is very likely that even greater improvements will occur following other, non-drug, biomedical treatments. See Parent Ratings.

If the child talks very little or not at all, I would have the child tested to see if he/she has seizures. Seizure activity may affect speech production. An electroencephalogram (EEG) measures brain wave activity, and it may be able to detect seizure activity. If the child does have seizures, I would use non-toxic nutritional supplements to treat the seizures, such as vitamin B6 and DMG.

The second approach is behavior/education. Applied behavior analysis (ABA) is a well-documented and effective teaching method for many autistic children. This method involves 1-on-1 instructional sessions and utilizes educational tasks that have been developed specifically for autism. Teaching Individuals with Developmental Delays: Basic Intervention Techniques, written by O. Ivar Lovaas, is an excellent resource and describes, in detail, how to implement this method. If my child had a limited verbal skills, I would look into the Rapid Prompting Method.

After the biomedical and behavior/education interventions are well underway, I would direct my attention to the child's sensory problems. Many autistic individuals suffer from a hypersensitive or hyposensitive sensory system. These problems may involve hearing (e.g., sound sensitivity, appears to be deaf), vision (e.g., light sensitivity, visual attention problems), tactile (e.g., sensitivity to touch, insensitivity to pain), vestibular (e.g., craves or resists certain movements, such as swinging), proprioceptive (e.g., excessive jumping), smell (e.g., sensitivity or insensitivity to odors), and taste (e.g., picky eater, pica behavior). There are several interventions that can reduce or eliminate many of these problems, such as Auditory Integration Training (hearing), vision training and the Irlen lenses (vision), and sensory integration (vestibular/tactile/proprioceptive).

The three treatment approaches outlined above complement one another. Autistic individuals often become more attentive and more motivated to learn soon after treating their biomedical and sensory problems. A child may do well with only one these approaches, but the combination can lead to amazing results and even recovery for some children.

The next step. It is also worth looking into other interventions for autism, such as structured teaching, social stories, Relationship Development Intervention (RDI), the Greenspan method, Picture Exchange Communication System (PECS), and Grodin's relaxation/visual imagery techniques.

Family issues. Raising an autistic child can be very stressful to the entire family. Siblings sometime feel ignored because so much of the parents' attention is directed toward the autistic child. Divorce is quite common among families with an autistic child. Additionally, relatives and close friends may distance themselves. It is important to be aware of these dangers and address them if they should occur.

Finally, it is important to be a strong advocate for the child. Many professionals are aware of the symptoms associated with autism. However, they do not know how to treat them. Information is a powerful tool. I would keep all of the child's documents and diagnostic test results in one well-organized folder. Whenever possible, I would provide relevant articles and other informational materials to therapists and other professionals who work with the child. Like many other parents of autistic children, I would likely wind up teaching professionals how to work with the child.

It is important to realize that autism is treatable, and there are many resources available, such as books, newsletters, Internet websites, and conferences. I would start with the following resources:

Additional Recommended Readings
I consider the ones listed below as 'starter' books:
Gerlach, E.K. (2003). Autism Treatment Guide. Second Edition. Arlington, TX: Future Horizons.
Hamilton, L.M. (2000). Facing Autism. Colorado Springs, CO: Waterbrook Press.
Biomedical Approach
McCandless, J. (2007). Children with Starving Brains: A Medical Treatment Guide for Autism Spectrum Disorder. Paterson, NJ: Bramble Books.
Seroussi, K. (2000). Unraveling the Mystery of Autism and Pervasive Developmental Disorder. New York: Simon & Schuster.
Behavior/Education
Leaf, R., & McEachin, R. (1999). A Work in Progress: Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism. New York: DRL Books.
Lovaas, O.I. (2002). Teaching Individuals with Developmental Delays: Basic Intervention Techniques. Austin, TX: Pro Ed.

Reference:
Autism Research Institute. (2012). Words of Advice from Stephen M. Edelson.
        Retrieved from http://www.autism.com/index.php/understanding_advice

University Center for Developmental Disabilities

The University Center for Developmental Disabilities (UCDD) subscribes to a philosophy of positive behavioral interventions. Such interventions are intended to promote the dignity of each consumer and be as non-invasive as possible. UCDD believes that all consumers have the ability to increase their independence and maturity. To accomplish this goal, UCDD utilizes Functional Analysis to understand the structure and function of challenging behaviors in order to teach new or replacement behaviors as effective alternatives to the identified problem behaviors.

The University Center for Developmental Disabilities provides a program for children with autism within San Bernardino and Riverside counties. This program was developed as a collaboration between the Inland Regional Center (IRC) and California State University, San Bernardino (CSUSB) to serve children with autism and other pervasive developmental disabilities and their families. The program is designed to complement existing programs by providing supplemental support services.

Services include direct instruction to children to increase socialization, communication and appropriate behaviors, support activities for parents and siblings, instruction for improved parenting, and activities to enhance the cooperation of schools and agencies that serve children enrolled in Center programs.

The UCDD program is an individually designed, intense, one-to-one behavioral intervention. UCDD programs are supported by faculty and a professional staff of more than one hundred trained teachers, counselors, and psychologists. Treatment strategies are research based and represent best practices. A Re-directive technique, which includes an effective system of behavioral intervention that uses a low level of intrusion and positive reinforcement, is a primary treatment strategy at UCDD.

Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) principles are also used with some of the children at the Center. TEACCH's structured teaching caters to the child's visual processing strengths by organizing the physical structure of the environment. Picture schedules may be posted and other casual cues employed to increase the child's skills. Structured activities are designed to foster independent functioning.

The Picture Exchange Communication System (PECS) is also used with some of the children at the Center. PECS is a communication training program designed to help children with autism acquire functional, symbolic communication skills. Children using PECS are taught to give a picture or icon of a desired item or activity to their teacher or parent in exchange for the item. Initiated, symbolic communication is taught using PECS system. Verbal cues are paired with the PECS icons and the use of spoken language is also reinforced.

An intensive one-to-one instructional design is used with the children enrolled in the UCDD program. In each two and one half hour session, children will work with their teacher to increase communication, socialization and appropriate behaviors.

Initial goals often include increasing a child's ability to attend to prefer a non preferred activities, increasing a child's ability to transition between activities and increasing compliance. Increased interaction skills and increased receptive and expressive communication skills are targeted across activities.

Children typically attend the UCDD program for one session per week for approximately two years. Programming may also include more frequent participation in Center programming and work within the home or school environment, based on the child's individual needs.

Parent training and support groups are an integral part of the UCDD programming. Parents of children attending the supplemental program at UCDD are required to participate in UCDD's parent support groups. These support groups are run by a UCDD counselor. While many parents are initially focused on their child's needs and programming when the family enters the Center program, the parent support group often becomes the aspect of the UCDD program that parents later report as having the most impact and benefit to their family. Parents participate in a weekly informational and support group for parents led by an UCDD counselor. Parent group objectives include: increased parenting skills, knowledge of effective behavioral techniques, and reduction in feelings of isolation.

More than one hundred and thirty families attend weekly sessions on the campus of CSUSB and approximately sixty five families attend sessions at UCDD's satellite program in Palm Desert. The program operates in San Bernardino Monday through Thursday evenings from 6:00 – 8:30 p.m. and Saturday mornings from 9:00 – 11:30 a.m. The program operates in Palm Desert Monday through Thursday evenings from 6:00 – 8:30 p.m.

Families are referred to the UCDD program by their Regional Center case manager. Each child referred to the program will receive a two part assessment, home and Center based, from UCDD staff. Parents can obtain additional information about the program or can schedule an appointment to visit the center by calling 909-537-5495.

UCDD Contact Information
Phone: 909-537-5495
760-341-2883 ext. 75495
Fax: 909-537-7002

Reference:
California State University, San Bernardino website. (2013). University Center for Developmental Disabilities. Retrieved from http://icdfr.csusb.edu/ucdd/

Carolyn E. Wylie Center

Provide intensive one-to-one behavior modification and early intervention for children 18 months to 12 years of age by using an integrated and comprehensive intervention model based on the principles of behavior analysis and the concept of individualization. Believe intervention must target *every area* of impaired functioning, including communication, social, play, motor, cognitive, academic, attention, executive functioning, and adaptive skill.

The Autism Program's Approach

Approach is an integrated educational and therapeutic program which combines evidence-based practices and current research with clinical best practices to address deficits in all domains, including communicative, behavioral, cognitive, social, emotional, play, sensory and academic. Recognize that spectrum disorders require an integrated approach that simultaneously focuses on all of these areas. Through the use of behavior analysis, structured learning, visual communication systems and Floor Time; individualize each child's program to fit their needs. Look to build on the child's strengths while helping to minimize areas of delay or deficiencies.

The Clinic Setting

The Clinic features child–friendly classrooms and therapy rooms in a welcoming, nurturing environment. Attending the clinic allows children to participate in social groups, play with peers and make friends while highly qualified interventionists guide positive interactions and shape appropriate behaviors.

Clinic Includes:

Sensory Room

Motor Room

Circle Time Area

Snack Area

Along with several individualized work rooms

Staff maintains a 1 to 1 ratio with each child in order to facilitate the highest level of learning and intervention

The clinic is unique in that if offers children the opportunity to receive

 Occupational Therapy

 Sensory Integration Therapy

 Speech and Language Therapy through the Wylie Center's Medical Therapies Department

Clinic Location

Wylie Center

4164 Brockton Avenue

Riverside, CA 92501

First Floor

Hours of Operation

Monday – Friday

8:00am-6:00pm

Please Contact For More Information

(951) 683 5193 ext. 331

(951) 683 6019 fax

autismclinic@wyliecenter.org

Reference:
Carolyn E. Wylie Center Website. (n.d.). Retrieved from
http://www.wyliecenterautism.org

Resources

Organization	Purpose	Address	Telephone Number	Website
Autism Speaks	Funding research into causes, prevention, treatments, and a cure for autism, and advocating for the needs of individuals with autism and their families	5455 Wilshire Boulevard, Suite 2250 Los Angeles, CA 90036	(323) 549-0500	http://www.autismspeaks.org
A.W.A.R.E.	Free support, information, and resources for Barstow families raising children with Autism Spectrum Disorders		Amber Woods (760) 910-1023	
Coachella Valley Autism Society	Education about Autism and network with parents and professionals	77564B Country Club, Suite 363 Palm Desert, CA 92211	(760) 772-1000 (760) 779-0012	http://www.autism-society.org
Early Start Family Resource Network (ESFRN)	Provides no cost information to families of children with disabilities	1425 S. Waterman Avenue San Bernardino, CA 92408	(800) 974-5553	
East Valley Support Group	Support group	Unity Church of Yucaipa 359393 Avenue E Yucaipa, CA 92399	Cheryl (909) 496-7884 Raquel (909) 238-0469	
Easter Seals	Provides local services that promote equality, dignity, and independence for children with disabilities	1450 University Avenue Suite F-2 Riverside, CA 92507	(951) 248-4874	
Easter Seals	Provides local services that promote equality, dignity, and independence for children with disabilities	241 East Ninth Street San Bernardino, CA 92410	(909) 888-4125	

FETA Support Group	Group to help gain knowledge on the IEP process	Peppermint Ridge 825 Magnolia Avenue Corona, CA 92879	Valeria Aprahamian (909) 841-2600	http://www.vaspe d@sbcglobal.net
First 5 Riverside	Programs center on affordable child care, early education, and health care	2002 Iowa Avenue, Suite 100 Riverside, CA 92507	(951) 248-0014	First5@rccfc.org
Inland Empire Autism Society	Be the resource of the entire autism community in education, advocacy, services and support.	2276 Griffin Way, Suite 105-194 Corona, CA 92879	(909) 204-4142 x339 (909) 220-6922	http://www.ieauti sm.org
Inland Regional Center: Family Helpline	Assist families with general questions regarding child development, communication, parenting skills and attachment problems		(866) 475-1411 Hours: Monday-Fri day, 8:00a to 8:00p	
Inland Regional Center: Father's Network	Support group for fathers of children with disabilities		(909) 890-4782	ircfathersnetwk@ yahoo.com
Inland Regional Center: Moms Supporting Moms	Support group for mothers of children with disabilities		(909) 890-4781	
H.E.A.R.T.S.	Support group	Loma Vista Middle School Library 11050 Arlington Avenue Riverside, CA 92505	Dennis Findly (909) 417-6769	denisfindly@yah oo.com
Parent Support Group	Support group for school age children with disabilities	Maple Street Education Center 550 W. Maple Street Ontario, CA 91762	Karen Laureta or Isabel Schaper (909) 983-1222	

Talk About Curing Autism (TACA)	Provides information, resources, and supports to families	3070 Bristol Street, Suite 340 Costa Mesa, CA 92626	(949) 640-4401	http://www.tacanow.org
TACA	Parent support group	10777 Civic Center Drive Rancho Cucamonga, CA 91730		Porterof5@gmail.com
Temecula Autism Aspergers Group – TAAG	Group discussions and helpful workshops			http://temeculapost.com/taag

Developed by Amber Vela

Websites for ASD Information

Organization	Website
Autism Cares	http://www.autismcares.org
Autism Research Institute-Autism is Treatable	http://www.autismresearchinstitute.com
Autism Society Inland Empire	http://www.ieautism.org
Centers for Disease Control and Prevention	http://www.cdc.gov
Data Accountability Center	http://www.ideadata.org
National Association for the Dually Diagnosed	http://www.thenadd.org
National Autism Center	http://www.nationalautismcenter.org
National Center for Biotechnology Information	http://www.ncbi.nih.gov
National Dissemination Center for Children with Disabilities	http://www.nichcy.org
Organization for Autism Research	http://www.researchautism.org

Developed by Amber Vela

Foundations

Foundation	Website
Doug Flutie Jr. Foundation for Autism	http://dougflutiejrfoundation.org
Dan Marino Foundation-Opening Doors	http://www.danmarinofoundation.org
Talk About Curing Autism	http://tacanow.org/about-taca/family-scholarship-program/

Developed by Amber Vela

Counseling Providers

I. Family Service Agency (FSA)
   A. Website: http://familyservicerivaca.org
   B. Center for Family and Community Services
      1. Offers services of parenting classes and individual, couples, and family therapy
      2. Location:
         472 N. Arrowhead Ave.
         San Bernardino, CA
         92401
         (855) 372-4968

   C. Executive Headquarters
      21250 Box Springs Road Suite 212
      Moreno Valley, CA
      92557
      (951) 686-1096

II. County of San Bernardino Department of Behavioral Health
   A. Provides screenings and referrals to the entire system of care including fee-for-service, contract and department of behavioral health providers.
   B. Website: http://www.sbcounty.gov.dbh
   C. Telephone Number: (909) 381-2420

III. The Community Counseling Center-Department of Psychology of CSUSB
   A. Provides low-cost counseling services
   B. Telephone Number: (909) 537-5569

IV. Catholic Charities-Counseling Services
   A. Provides individual, couple, and family counseling services, and parent education.
   B. Website: http://www.ccsbriv.org/home.html
   C. Location:
      1441 North D Street
      San Bernardino, CA
      92405
      (909) 763-4970
      (951)801-5282

V.   Loma Linda University Marital and Family Therapy Clinic
       A. Provides individual, couples, and family therapy, and parenting groups
       B. Location:
          164 West Hospitality Lane Suite 15
          San Bernardino, CA
          92408
          (909) 558-4934

VI.   Bilingual Family Counseling Service, Inc.
       A. Provides individual, family, and couples counseling
       B. Location:
          317 West F St.
          Ontario, CA
          91762
          (909) 986-7111

REFERENCES

Abidin, R. R. (1997). Parenting Stress Index: A measure of the parent-child system. In *A book of resources* (pp. 277-291). Lanham, MD: Scarecrow Press, Inc.

ADA.gov United States Department of Justice Civil Rights Division. (n.d.). http://www.ada.gov

Autism Research Institute. (2012). http://www.autism.com/index.php/understanding_advice

Autism Society website. (n.d.). http://www.autism-society.org/living-with-autism/lif espan/infants-toddlers/

Autism Speaks website. (2011). http://www.autismspeaks.org/family-services/tool-kit s/family-support-tool-kits#siblings

Bornstein, M. H., & Lamb, M. E. (2011). *Developmental science* (6th ed.). New York, NY: Psychology Press.

Boulet, S. L., Boyle, C. A., & Schieve, L. A. (2009). Health care use and health and functional impact of developmental disabilities among US children, 1997-2005. Retrieved from http://archpedi.ama-assn.org.cgi/content/full/163/1/ 19

Brookman-Frazee, L., Stahmer, A., Baker-Ericzen, M. J., & Tsai, K. (2006, December). Parenting interventions for children with autism spectrum and disruptive behavior disorders: Opportunities for cross-fertilization. *Clinical Child and Family Psychology Review, 9*, 181-196.

California State University San Bernardino Institute for Child Development & Family Relations. (n.d.). http://icdfr.csusb.edu/ucdd/

Carolyn E. Wylie Center For Children. Youth, & Families. (n.d.). http://www.wyliecenterautism.org/

Carothers, D. E., & Taylor, R. L. (2004, Summer). How teachers and parents can work together to teach daily living skills to children with Autism. *Focus on Autism and Other Developmental Disabilities, 19,* 102-104.

Center for Disease Control and Prevention website. (n.d.). Retrieved June 29, 2012 from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm

Dyke, P., Mulroy, S., & Leonard, H. (2008). Siblings of children with disabilities: Challenges and opportunities. *Acta Paediatrica, 98,* 23-24. doi:10.1111/j.1651-2227.2008.01168.x

ED.gov U.S. Department of Education. (2013). http://www2.ed.gov/policy/speced/reg/narrative.html

ED.gov U.S. Department of Education. (n.d.). http://idea.ed.gov/

ED.gov U.S. Department of Education. (n.d.). http://www.ed.gov/

Gibaud-Wallston, J., & Wandersman, L. P. (1978). Development and utility of the Parenting Sense of Competence Scale. Paper presented at the annual meeting of the American Psychological Association, Toronto.

Gilmore, L., & Cuskelly, M. (2009). Factor structure of the parenting sense of competence scale using a normative sample. *Child Care Health Department, 35,* 48-66. http://dx.doi.org/10.1111/j.1365-2214.2008.00867.x

Glasberg, B. A. (2000). The development of siblings' understanding of autism spectrum disorders. *Journal of Autism and Developmental Disorders, 30,* 143-155. doi:0162-3257/00/0040-0143518.00/0

Gray, C. (2004). Social stories 10.0: The new defining criteria & guidelines. *Jenison Autism Journal, 15,* 1-16.

Greenspan, S. & Wieder, S. (2006). *Engaging Autism: Using a floortime approach to help children relate, communicate, and think*. Cambridge, MA: Da Capo Press.

Howe, D. (2006). Disabled children, parent-child interaction and attachment. *Child and Family Social Work, 11,* 95-106.

Inland Regional Center website. (n.d.). http://www.inlandrc.org

Karst, J. S., & Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review, 15,* 247-277. doi:10.1007/s10567-012-0119-6

Keen, D., Couzens, D., Muspratt, S., & Rodger, S. (2010). The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence. *Research in Autism Spectrum Disorders, 4,* 229-241. doi:10.1016/j.rasd.2009.09.009

Kersh, J., Hedvat, T. T., Hauser-Cram, P., & Warfield, M. E. (2006, December). The contribution of marital quality to the well-being of parents of children with developmental disabilities. *Journal of Intellectual Disability Research,* 883-893. doi:10.1111/j.1365-2788.2006.00906.x

Knott, F., Lewis, C., & Williams, T. (2007). Sibling interaction of children with autism: Development over 12 months. *Journal of Autism Developmental Disorder, 37,* 1987-1995. doi:10.1007/s10803-006-0347-z

Kubler-Ross, E. (1969). *On Death and Dying*. Routledge: .

Lanier, P., Kohl, P. L., Benz, J., Swinger, D., Moussette, P., & Drake, B. (2011). Parent-child interaction therapy in a community setting: Examining outcomes, attrition, and treatment settings. Research on Social Work Practice

Larson, E. (2006). Caregiving and Autism: How does children's propensity for routinization influence family participation in family activities? *Occupation, Participation, and Health, 26,* 69-79.

Law, J., Plunkett, C., Taylor, J., & Gunning, M. (2008, December 7). Developing policy in the provision of parenting programmes: Integrating a review of reviews with the perspectives of both parents and professionals. *Child: care, health and development, 35,* 302-312. doi:10.1111/j.1365-2214.2009.00939.x

Macks, R. J., & Reeve, R. E. (2007). The adjustment of non-disabled siblings of children with autism. *Journal Autism Development Disorder, 37,* 1060-1076. doi:10.1007/s10803-006-0249-0

Mandell, D. S., & Salzer, M. S. (2007). Who joins support groups among parents of children with autism? *Autism, 11,* 111-122. doi:10.1177/1362361307077506

My Asperger's Child. (2012). http://myaspergerschild.com

National Center for Complementary and Alternative Medicine website. (n.d.). Retrieved June 06, 2012 from http://nccam.nih.gov/health/whatiscam

National Center for Learning Disabilities. (n.d.). http://www.ncld.org/types-learning-disabilities

Rivers, J. W., & Stoneman, Z. (2008). Child temperaments, differential parenting, and the sibling relationships of children with autism spectrum disorder. *Journal Autism Developmental Disorder,* 1740-1750. doi:10.1007/s10803-008-0560-z

Rogers, H., & Matthews, J. (2004). The parenting sense of competence scale: Investigation of the factor structure, reliability, and validity for an Australian sample. *Australian Psychologist, 39,* 88-96.

Rosa, S. D., Myers, J. B., Ditz, L., Willingham, E., & Greenburg, C. (2011). *Thinking person's guide to Autism: What you really need to know about Autism: from Autistics, parents and professionals* (1st ed.). Redwood City, CA: Deadwood City Publishing.

Sage, K. D., & Jegatheesan, B. (2010, June). Perceptions of siblings with autism and relationships with them: European Americans and Asian American sibling draw and tell. *Journal of Intellectual & Developmental Disability, 35,* 92-103. doi:10.3109/13668251003712788

Schuengel, C., Kef, S., Damen, S., & Worm, M. (2010, March). People who need people: Attachment and professional caregiving. *Journal of Intellectual Disability Research, 54,* 38-46. doi:10.1111/j.1365-2788.2009.01236.x

Sheehan, B., & DeOrnellas, K. (2011). *What I wish I'd known about raising a child with Autism.* Arlington, TX: Future Horizons.

Sicile-Kira, C. (2004). *Autism spectrum disorders: The complete guide to understanding autism, asperger's syndrome, pervasive developmental disorder, and other ASDs.* New York, NY: The Berkley Publishing Group.

Singh, N. N., Lancioni, G. E., Winton, A. S., Fisher, B. C., Wahler, R. G., McAleavey, K.,...Sabaawi, M. (2006, Fall). Mindful parenting decreases aggression, noncompliance, and self-injury in children with autism. *Journal of Emotional and Behavioral Disorders, 14,* 169-177.

Skills sheets by sandbox learning. (2004). Retrieved from http://www.sandbox-learning.com

Smith, L. O., & Elder, J. H. (2010). Siblings and family environments of persons with autism spectrum disorder: A review of the literature. *Journal of Child and Adolescent Psychiatric Nursing, 23,* 189-195. doi:10.1111/j.1744-6171.2010.00240.x

Stoneman, Z. (2001). Supporting positive sibling relationships during childhood. *Mental Retardation and Developmental Disabilities Research Reviews, 7*, 134-142.

Suren, P., Roth, C., Bresnahan, M., Haugen, M., Hornig, M., Hirtz, D.,...Smith, G. D. (2013, February 13). Association between maternal use of folic acid supplements and risk of autism spectrum disorders in children. *The Journal of the American Medical Association, 309*, 570-577. http://dx.doi.org/doi:10.1001/jama.2012.155925

Todd, S., Bromley, J., Ioannou, K., Harrison, J., Mellor, C., Taylor, E., & Crabtree, E. (2010). Using group-based parent training interventions with parents of children with disabilities: A description of process, content, and outcomes in clinical practice. *Child and Adolescent Mental Health, 15*, 171-175. doi:10.1111/j.1475-3588.2009.00553.x

Toth, K., Dawson, G., Meltzoff, A. N., Greenson, J., & Fein, D. (2007). Early social, imitation, play and language abilities of young non-autistic siblings of children with Autism. *Journal of Autism Developmental Disorder, 37*, 145-157. doi:10.1007/s10803-006-0336-2

U.S. Department of Education website. (n.d.). http://www.ed.gov

Wetherby, A., Brosnan-Maddox, S., Peace, V., & Newton (2008). Validation of the infant toddler checklist as a broadband screener for autism spectrum disorders from 9 to 24 months of age. *Autism Journal*, 12-48.

Woolfson, L., & Grant, E. (2006). Authoritative parenting and parental stress in parents of pre-school and older children with developmental disabilities . *Child-Care, Health & Development, 32*, 177-184.

Zisser, A., & Eyberg, S. M. (2010). *Treating oppositional behavior in children using parent-child interaction therapy* (2nd ed.). New York: Guilford: In A. E. Kazdin & J. R. Weisz.