

FATHERS RAISING A CHILD WITH AUTISM SPECTRUM DISORDER:
DEVELOPMENT OF A FATHER TRAINING COURSE

A Paper
Submitted to the Graduate Faculty
of the
North Dakota State University
of Agriculture and Applied Science

By

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In Partial Fulfillment of the Requirements
for the Degree of
MASTER OF SCIENCE

Major Department:
Human Development and Family Science

May 2010

Fargo, North Dakota

North Dakota State University
Graduate School

Title

Fathers Raising a Child with Autism Spectrum Disorder:

Development of a Father Training Course

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ABSTRACT

Stokesbary, Camie Johanna, M.S., Department of Human Development and Family Science, College of Human Development and Education, North Dakota State University, May 2010. *Fathers Raising a Child with Autism Spectrum Disorder: Development of a Father Training Course*. Major Professor: Dr. Sean Brotherson.

The purpose of this paper was to review research on the issue of fathers raising a child diagnosed with Autism Spectrum Disorder (ASD) and outline the development of a father training course for such families. The paper reviewed a framework for supporting a child with developmental needs, examined literature on parenting children diagnosed with Autism Spectrum Disorder, and highlighted the benefits of parental training courses and their potential value for parents who have children with developmental needs. The training course was developed in a four-part series and was designed to address paternal concerns, provide resources and answer questions that fathers have while raising a child with ASD. The training course model is designed to be an hour and a half long for four weeks, and the course modules include: (1) The Definition of Autism and Getting Past the Diagnosis; (2) The Key to Family, Sibling, and Peer Relationships; (3) Finding a Good Educational Fit for Your Child; and (4) Additional Information for Fathers to Know About Raising a Child with ASD.

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CHAPTER 1

INTRODUCTION

Children are being diagnosed with autism spectrum disorder (ASD) at a greater rate than ever before (Wing & Potter, 2002). The Centers for Disease Control and Prevention (CDC) now estimates that approximately one percent of American children, or one in 110 children, are identified as having an autism spectrum disorder. It is further reported that ASD is diagnosed for one in 70 boys, while the ratio is only one in 315 girls, suggesting boys are up to four times more likely to be diagnosed with ASD. Ongoing research indicates that there has been a 600 percent increase over the last 20 years in the number of children annually diagnosed with autism. This pattern suggests that there are 750,000 children in America alone who have an autism spectrum disorder (Centers for Disease Control and Prevention, 2009). Although earlier diagnosis by professionals, improved diagnostic criteria, and an expansion of those included on the autism spectrum accounts for some of the increase in numbers, it does not account for all of it (Centers for Disease Control and Prevention). However, it is unknown precisely why ASD diagnosis rates continue rising. Increasing the knowledge of parents who raise children with ASD may aid them in their parenting strategies and have a positive effect on their child's developmental journey (Zimmerman, 2008).

Children with ASD present their families with a unique challenge because of challenging characteristics and behaviors that are typical of their disorder. Some of the characteristics and behaviors typically associated with ASD include lack of communication

skills, inappropriate social interaction, repetitive behaviors or interests, and eccentric body movements (National Institute of Mental Health (NIMH), 2004). These characteristics and behaviors, along with the intensive and time-consuming responsibilities of caring for a child with ASD, often place a large amount of stress on the parents as well as other family members (Simmerman & Blacher, 2001). Tomanik, Harris and Hawkins (2004) explained that parents may feel stress due to not being able to give their child what the child wants (due to communication difficulties), not being able to understand their wants and needs, or because of difficulties in figuring out how to deal with their child's harming and/or abusive behaviors. These demands upon the parents may result in feelings of depression, role restriction, or conflict with their spouse. Tomanik et al. (2004) explained that interventions with parents and children may lower the levels of maladaptive behaviors in children with autism, and this may help to foster adaptive functioning and consequently help to reduce stress levels for the parents. Parents who face challenging situations benefit from interventions that assist them in understanding options in parenting, managing child behavior and feeling social support from others (Campbell & Palm, 2004).

While support groups and other parenting interventions are increasingly common for families and children with developmental needs, mothers tend to utilize and experience these resources more commonly than fathers. Support groups for families in such circumstances often attract mothers only, or at least primarily, which is why support sessions intended for fathers or paternal training opportunities may be important. As Turbiville and Marquis (2001) explained, a father's involvement in support programs for children with disabilities has shown to be beneficial to the child, the father, and other

family members. Although support for families with children with autism is increasing, it is important to consider additional training and services to be available for fathers (Auer, 2006). Ketzner (2007), writing in an article for the Indiana Resource Center for Autism, stated it simply: “What About the Dads?” Turbiville and Marquis (2001) found that children were more likely to finish school and were higher-achieving given even minimal participation in school activities by their fathers. Further potential benefits of parent trainings for fathers that have been reported included renewed parental confidence and reduced stress levels (McConachie & Diggle, 2006).

The purpose of this paper was to develop a parent training program specifically for fathers who have a child with ASD. This paper outlined the framework of bioecological theory and its application for an individual with ASD, the stress that is involved in raising a child with ASD, and what resources and support are currently available to families, specifically fathers. Further, the paper described how having a child with ASD can add stress to a family unit, and how father involvement and collaboration is important for successful parenting of a child with developmental needs. This paper proposed the development of a parent training program directed towards fathers of a child diagnosed with ASD. This four-week training course is designed especially for fathers of children with ASD, to encourage paternal involvement, increase knowledge and skills in the area of fathering a child with ASD, have the opportunity to ask questions concerning parenting a child with ASD, and supply additional resources for future reference and consultation.

CHAPTER 2

LITERATURE REVIEW

This chapter gives an overview of research on fathers raising a child diagnosed with Autism Spectrum Disorder (ASD). First, a theoretical perspective using Bronfenbrenner's (1979) human ecology model is discussed regarding where parents, specifically fathers, and external supports fit in the framework of supporting a child with developmental needs. Next, research concerning the definition and scope of developmental needs in children, and specifically autism, is addressed. The next portion explores research on the role that fathers play in parenting a child with developmental needs. Lastly, parent training courses for parents raising children with developmental needs are considered, as well as the value of a training course for fathers who are raising a child with autism.

Human Ecology Theory and Children with Developmental Challenges

One of the most influential and comprehensive frameworks to address human development is human ecology theory as outlined by Bronfenbrenner (1979). This framework is also known as bioecological theory and is useful in putting forth a theoretical context outlining the support network for a child with developmental needs. White and Klein (2008) explained that the objective of bioecological theory is to consider the environment as the primary context for understanding an individual's past, present, and future. Bronfenbrenner's (1979) bioecological model is based on both environmental influences and nature in shaping human development (White & Klein, 2008). A child born with developmental needs will be shaped by the unfolding pattern of individual

development and supporting environmental influences. The different levels of an individual's environment impact the support extended to someone who experiences greater developmental needs, such as children with autism.

Bronfenbrenner (1979) explained the bioecological system consists of four levels: micro-system, mesosystem, exosystem and macrosystem. These differing levels of the human environment impact a child with developmental needs both directly and indirectly. For a child with developmental challenges, the microsystem includes the settings and relationships in which the individual experiences his or her everyday routine, and so this could include family members, school, therapy, day care, or caregivers. In addition, therapists and doctors who a child may see on a regular basis would also be included in his or her microsystem.

In Bronfenbrenner's bioecological model, the mesosystem is another environmental influence that is vitally important for children who have a developmental challenge. The mesosystem is the setting of how a child's microsystems interact together in relationship to the child. Individuals, values, and supports within the microsystem are critical for the growth of a child, but they are also influenced by the interactions between these elements in the microsystem. Parents, caregivers, teachers, doctors, siblings, extended family, and others must all be able to cooperate and discuss the most beneficial way to help the child succeed. Not only do parents need to work together to co-parent a child with developmental needs, it is essential that families work together and collaborate with the school system, therapists, and doctors to be successful in raising a successful and healthy child (Shore & Restelli, 2006). Family support and other supportive elements are also

important for parents and siblings, as well as the developmentally challenged child, to grow and experience life more functionally and successfully.

The exosystem that surrounds a child with developmental needs includes the systems that the child is not directly touched by, but which do have an impact on the child. The exosystem includes the parent's workplace, the neighborhood they live in, and even extended family members (Bronfenbrenner, 1979). An example of how a child's exosystem may have an effect on a child would be the amount of stress that a parent may bring home from work and the impact that it has on his or her children. This example of stress is especially important for a family that includes a child with a developmental challenge. As Tomanik, Harris, and Hawkins (2004) explained, parents and caregivers who raise children with a disability typically carry with them a significant amount of stress. Financial strains may also come into play in the exosystem, as difficulties in the economic arena can impact the family and the developing child. For families raising children with a developmental challenge, financial issues may often arise that increase stress and affect available resources (Shore & Restelli, 2006). When families are struggling with financial problems, parents may be unable to afford medicine, therapies, or additional resources for their family and children, and this can have a large impact on the well-being of their children. The exosystem influences on a developing child illustrate that factors outside the immediate setting can interact and affect individuals within the broad context of human ecology.

Finally, the macrosystem involves the broad institutional patterns of a culture, and can include religion, laws, ethnicity and many other aspects of the social environment (White & Klein, 2008). The macrosystem affects a child with disabilities because laws,

government, the economy and other large-scale systems all play a role and influence a child's development, whether positively or negatively. For example, government entities may be in control of providing and supporting research funding regarding developmental needs for children. Cultural values that are commonplace in a specific society may influence parenting styles which, in turn, affects a child. These four levels of environmental context in human ecology theory illustrate that all parts of a system, whether it be particular family members, care professionals, laws, values, or culture, all play an important role in an individual's developmental process. This pattern of multiple influences at different levels within the framework of human ecology provides a meaningful context for framing the influences on a person's journey of development, whether the individual has developmental challenges or not.

Understanding Children with Developmental Needs and Autism Spectrum Disorder

The science of human development has identified patterns of "normative" or expected behavior on a developmental timeline in areas such as physical, cognitive, and social-emotional development. The definition of a child who may experience developmental challenges is one who does not meet the expected developmental milestones by a certain time period (Boyse, 2009). However, considering the large number of different developmental concerns that may exist for an individual, it is difficult to define an individual as developmentally challenged without considering many different factors. A few of the different types of developmental concerns identified in research on human development include: lack of functioning or deficits in cognitive skills, communication

skills, social skills, emotional skills, and fine and gross motor skills (physical). Typically, there are concerns related to an individual's functioning, skills, or behavior in one or more of these areas of development. More specifically, these concerns may include Attention-Deficit Disorder (ADD), Attention-Deficit Hyperactivity Disorder (ADHD), bipolar disorder, Down's syndrome, cerebral palsy, mental retardation or impairment, learning disabilities, and autism spectrum disorder, just to name a few (Boyse, 2009).

According to the Centers for Disease Control and Prevention (2007), autism is one of the most common Pervasive Developmental Disorders (PDD), having an effect on an estimated one in 110 children. The Autism Society of America (2008) has explained that Autism Spectrum Disorder (ASD) is a "complex developmental disability" that usually is diagnosed during the first three years of a child's life. ASD detrimentally affects the normal functioning of the brain, leading to reduced social interaction and difficulties in communication and daily functioning. Autism is a spectrum disorder, meaning that all individuals diagnosed with the condition have a unique personality and possess their own range of differing characteristics. Thus, there is no child with autism who would possess or exhibit the exact same characteristics as another child with autism, although similarities can and often do exist (Autism Society of America, 2008).

There are more children diagnosed with autism every year, both in the United States and across the world. The increased rate of diagnosis for ASD results in more parents who are experiencing the unique challenge of raising a child with autism than ever before (Simmerman & Blacher, 2001). As discussed in a *New York Times* article, parents, as well as experts, have sought out possible explanations for the increase in the diagnosis of

autism, including: genetics, birth injuries, childhood immunizations, increase in public awareness, and refined diagnostic procedures in the medical and educational community. As Blakeslee (2002) stated, “none of these factors could explain an increase of the magnitude reported there—more than tripled from 1987 to 1998.” It is possible that there is not just one cause of autism, but instead there may be several different factors that are related to having an autistic condition (Shore & Restelli, 2006).

The environment and genetics are two critical factors that may have a relationship to the diagnosis of autism in a child. Wing and Potter (2002) explained that genetic factors alone are not likely to account for the rise in the number of autism cases diagnosed within the last two decades. Environmental factors need to be considered as well. These authors went on to state that environmental factors can include diet, pollutants, antibiotics, allergies, vaccines, and traces of neurotoxins that may be present in preservatives and vaccines. Most importantly, Wing and Potter (2002) made it clear that much of the reported rise in the diagnosis of autism is likely due to changes in the diagnostic criteria and the greater amount of awareness among the general public, professionals, and parents. The critical scientific question is whether or not there has actually been a genuine rise in the number of children being diagnosed with autism spectrum disorder or whether the increased rate of diagnosis is due to more public awareness and related factors. Also, if there has been a genuine increase in the rate of autism, how large is it and is it still continuing? These and additional questions remain to be further explored in research related to autism in children.

Parent and Family Support in Raising Children with Autism Spectrum Disorder

Support and resources for children with developmental challenges, as well as their families, are critical for both the child and family to improve their life experiences together. Considering that parents who are raising a child with a disability experience high levels of distress, often referred to as child-related stress or caretaking burden (Simmerman & Blacher, 2001), there is a need for parental support. For example, parents raising a child with ASD will need to attain a clear understanding of their child's developmental condition and tendencies so that they can work toward meeting their child's developmental needs. Further, they may also benefit from caregiving guidance or assistance with their child, as well as social support.

Once a parent has been told his or her child has been diagnosed with ASD, it can be a very difficult time that often challenges a person's physical health, mental and emotional health, and overall well-being. Dealing with the diagnosis process can be emotionally draining. The diagnosis of ASD in a child can cause the family to experience many additional pressures, issues, and decisions to make (Shore & Restelli, 2006). Coming to terms with your child being diagnosed with ASD typically involves a period of bereavement and accepting the fact that life may never be the same, that this can be a life-changing and momentous event, and family members need to work through it over time (Shore & Restelli).

Many families attempt to deal with the daily stressors of raising a child with ASD internally by seeking social support or using particular coping strategies (Dunn, Burbine,

Bowers, & Tantleff-Dunn, 2001). Studies show that parents who use coping strategies that generally focus on problem-solving and social support are seen to report more positive adjustment outcomes (Glidden, Billings, & Jobe, 2006). Many times family members will exhibit unhealthy coping strategies and withdraw or remove themselves from their social network if they lack professional support. Dunn et al. (2001) explained that it is important for families to use coping strategies such as positive reappraisal, social support and confrontive coping. Dunn et al. (2001) also found that often parents of a child with ASD will invoke fantasizing and hoping for miracles as a way to cope with their child's disorder. Dunn et al. (2001) explained that social supports are crucial in reducing the amount of stress in parents who are raising a child with ASD. It was also found that positive social supports relate strongly to having fewer marital conflicts and decreased isolation within the family when raising a child with a disability (Dunn et al., 2001).

One focus of intervention in working with autistic children has been on encouraging appropriate social behaviors and ignoring inappropriate behaviors (Seung, Ashwell, Elder & Valcante, 2006). This process is enhanced by including family members, especially parents, in understanding and facilitating such an approach in the home environment. This approach not only enhances a clinically based intervention program but can also contribute another environment where appropriately trained social behaviors can be generalized, such as at home. This approach can also give the parents a sense of involvement with their child's learning and a clear understanding of the intervention that is going on with their child in other social environments (Seung et al., 2006).

Due to the intensive nature of dealing with a child with developmental challenges, formalized means for social support to families are often needed and may include parent support groups, professional support, or parent education. Shore and Restelli (2006) suggested that parent support groups for adults raising a child with developmental challenges can have a positive impact for those who attend. For example, peers within a support group may not have all of the answers needed, but they may be experiencing similar struggles and successes. Support group members are also available to offer feedback and listen to daily challenges (Shore & Restelli, 2006). Shore and Restelli (2006) also explained that the camaraderie that occurs within support groups can reduce the feelings of isolation that individuals may be feeling. There are a couple different types of parent support groups that exist, including face-to face, Internet-based, clinical, and/or one-on-one support groups. There is substantive evidence that social support may actually buffer the impact of a child with disabilities on the parents (Simmerman & Blacher, 2001).

Research literature suggests that parents of autistic children face a variety of challenging issues as parents. Brobst, Clopton, and Hendrick (2009) explained that parents of children diagnosed with ASD experience more extreme child behavior problems, greater parenting stress, and tend to be less satisfied with their relationship. In order to assist parents in changing their negative stress experiences and accessing positive supports, professionals such as doctors, therapists, counselors, family support specialists, and others need to provide guidance in the area of dealing with daily stresses. Professionals are often able to teach parents how to care for their child and manage their child's maladaptive behaviors in an effective way. Using community professionals with expertise to teach and

mentor parents in working with their autistic children may also be an approach to help reduce stress felt by parents overall. These and other approaches to providing parents of autistic children with needed social support are important to consider. In particular, perhaps greater emphasis should be given to fathers in this social support process.

The Role of Fathers in Raising Autistic Children

In research and practice with families and autism, much of the research has focused on mothers, as they are often the ones to assume the primary role in raising the children. This pattern is often the case whether or not there is a child with a disability involved in family life (Simmerman & Blacher, 2001). Considering the number of children who are entering early intervention systems, there is a need to better understand the experiences of families who are raising children diagnosed with ASD (Davis & Carter, 2008). More specifically, there is value in understanding the experience of fathers and mothers together in raising children with ASD and how each parent plays an important role in the process.

In recent years there has been an increased focus on father involvement and child development, particularly in regard to raising children with special needs (Lamb & Billings, 1997). Elder, Valcante, Won, and Zylis (2003) reported that fathers can be critically important in the development of children who are diagnosed with ASD. These authors reported that fathers who are more involved with their families often report less amounts of stress within the family, as well as more positive family well-being (Elder et al., 2003). In addition, while it has been suggested that mothers experience greater stress than fathers when it comes to raising a child with autism, some recent evidence has

indicated that mothers and fathers of children with ASD report comparable levels of stress (Davis & Carter, 2008).

One study that researched father involvement in families with a young child with a disability found that satisfaction with the father's amount of involvement contributed to higher marital adjustment and to lower child-rearing burdens (Simmerman & Blacher, 2001). Such findings have implications for intervention programs that should involve fathers, both separately as well as with a spouse or significant other. Such research suggests that collaboration between mothers and fathers is crucial for the success of raising a child with developmental challenges, including autism. In raising an autistic child, parents must cope personally with the challenges as well as minimize stress by working together (Davis & Carter, 2008). Further research has found that challenges in the relationship between a mother and the father are a source of significant stress for the mother (Yamada et al., 2007). It is important for interventions and programs to increase the levels of confidence and competence that fathers feel in the father-child relationship. It is also critical that fathers have support systems in their families, health care systems, and communities that support, encourage, and reward positive father-child relationships (Elder et al., 2003). Another study has indicated that increasing fathers' competence levels and knowledge regarding autism is important because this can promote feelings of parental self-efficacy and reduce stress (Kuhn & Carter, 2006).

The involvement of fathers in the lives of children also appears to have important consequences for autistic children and their functioning. Typically developing children who are raised in a household in which their fathers are involved are reported to be less

likely to experience depression and more likely to finish their educations (Seung et al., 2006). Also, fathers who are involved with a special needs child reported higher feelings of parental competence and marital satisfaction than fathers who are not involved at home (Seung et al., 2006). Finally, it has also been found that actively involved fathers not only show an increase in their own feelings of self-worth, but such involvement often helps their children to have better life outcomes (Seung et al. 2006).

As Brotherson and Dollahite (1997) explained, fathers who are able to show support towards their child, embrace their child in a loving home despite a diagnosis of concern, and provide their child with supportive relationships make a meaningful difference in their child's growth and experience. They further noted that whether it is "rearranging a work schedule [or] changing bedpans for an ill child," fathers of special needs children make a difference through "the creative exercise of a father's abilities to love and respond to a child's needs and desires" (1997, p. 104). Ricci and Hodapp (2003) suggested there is increasing recognition that father involvement is connected to a child's well-being, cognitive growth, and social competence. These findings provide a foundation for understanding the need for positive paternal involvement in a child's life and giving support to men in seeking responsible involvement.

Need for a Parental Training Course for Fathers

As a review of the literature suggests, paternal involvement is typically important and beneficial in the development of a child. There is not a great deal of research on fathers who are either raising a child with ASD or helping to raise a child with ASD. However, the existing research suggests there is value in giving support to father involvement with

autistic children, and that fathers may benefit from a parent training course designed to facilitate such involvement.

Children with autism often exhibit deficits in social interaction and communication; however, with intervention it has been shown that improvements to communication deficits and social interaction challenges are possible (Seung et al., 2006). Research by Seung et al. (2006) has indicated that parent-centered training programs assist with improving children's social-communicative skills for those diagnosed with ASD. Seung et al. (2006) also explained that even if children with autism attend communication intervention from a speech and language pathologist in a clinic or classroom setting, their research supports parent training as a supplementary intervention method for assisting children with autism. Such research provides solid evidence that parent programs are needed and can be a significant benefit among parents who are raising a child with autism.

Parent training programs are often used to treat children with disruptive behaviors. Such programs can be helpful for parents raising children with a variety of developmental challenges, including ADD, ADHD, bipolar disorder, Down's syndrome, PDD, cerebral palsy, mental impairment, learning disabilities, and ASD. Most often the focus of parent training programs has been for mothers; fewer than 15% of fathers have been involved in parent trainings and treatment support. However, it is almost universally assumed that the involvement of fathers in parent training programs will improve treatment outcomes for children (Bagner & Eyberg, 2003). Bagner and Eyberg (2003) reported that when fathers are encouraged and given the opportunity to participate (meaning that trainings are scheduled when fathers are able to attend), fathers were likely to attend trainings at an

equal rate to that of their child's mother. Participation in such programs may not always be possible for fathers, as clinics and agency settings often do not allow for evening and weekend scheduling of such support efforts. Yet, it is important, if possible, for families to attend parent trainings together so that there is consistency between the parents during the treatment process to improve treatment outcomes (Bagner & Eyberg, 2003; Turbiville & Marquis, 2001).

Seung et al. (2006) explained that for the most part it is mothers who are being trained in parent training programs and not the fathers. Even in training that includes both parents, it is often the mothers who are left to train the fathers (Seung et al., 2006). Parent training and support is beneficial because there is evidence that it can reduce parenting stress for mothers and fathers raising children with a disability (Davis & Carter, 2008). Baker-Ericzen, Brookman-Frazee, and Stahmer (2005) stated that there is evidence that parental stress can both have an influence on the effectiveness of intervention programs as well as be influenced by interventions. Parent education programs have been shown to increase a child's communication skills and also facilitate a decreased amount of parental stress. Parent training programs that intervene with families raising a child with ASD are those that teach parents naturalistic strategies to increase communication and lower child behavioral problems (Baker-Ericzen et al., 2006).

McConachie and Diggle (2007) have noted that potential benefits of parent training programs include increased parental skills, renewed confidence, and reduced stress for parents as well as for the children. These authors also indicated that group training for parents which includes new skills has been shown to enhance mutual support between the

two parents. Comprehensive programs for young children with ASD clearly involve parents in applying the strategies that are taught to assist children in their developmental journey (McConachie & Diggle, 2007). McConachie and Diggle (2007) described characteristics of useful intervention programs with parents and typically they involve parents in managing behaviors and promoting positive communication skills, are non-intensive, and utilize teaching within everyday situations. Such approaches hold significant promise as a supplemental method in aiding parents of children with ASD to gain new knowledge and skills, work toward a positive and mutually supportive relationship in their efforts, and lower parental stress levels.

Programs designed to instruct parents in knowledge and skills for raising a child with ASD must consider how to reach out and involve parents in the learning process. Lieb (1991) described adult education and reported that adults are goal-oriented and self-directed learners. Most adults who enroll for a course have already thought about what they are hoping to gain from the experience. Further, being a self-directed learner entitles them to be free to direct themselves. It is important for program facilitators or educators to encourage active participation and get the participants' perspectives of what they hope to learn (Lieb, 1991). Turbiville and Marquis (2001) found that fathers tend to participate in programs that provide information regarding their child's needs, such as how to facilitate a child's developmental and educational progress. Research has also shown that fathers are more likely to engage in training courses and activities that do not interfere with their work schedules (Turbiville & Marquis, 2001). This pattern is consistent with Bagner and Eyberg's (2003) observation that programs ought to be offered at times that avoid conflicts

with fathers' work schedules. Thus, programs are more likely to achieve success with fathers as they consider the time schedules of fathers and emphasize learning objectives that are consistent with fathers' interests in facilitating a child's progress and meeting essential needs (Bagner & Eyberg, 2003; Lieb, 1991; Turbiville & Marquis, 2001).

Considering the value of both parents in raising children and the somewhat limited outreach to fathers of children with ASD, there is definite value in developing additional approaches to working with fathers of autistic children. Clearly, a parent training course for fathers who are raising a child with ASD would be beneficial. In this project, I developed a parent training course which addressed primary paternal concerns for fathers raising a child diagnosed with ASD and provided answers to questions that they may have. This course is designed to encourage and support the involvement of fathers with their children, emphasize positive father-child interactions, and provide additional resources for fathers to utilize in their parenting efforts.

CHAPTER 3

DEVELOPMENT OF PARENT TRAINING COURSE

This section of the paper describes the development of a training course for fathers of a child with ASD. Development of such a parent training option is meant to emphasize the importance of father involvement with children who have been diagnosed with ASD and encourage their participation with that child. Issues outlined in this section include objectives of a parent training course for fathers, target audience, course design and content, review of materials, and evaluation tools for such a course.

Training Course Development

This project envisions development of a training course for fathers as a practical educational tool for reaching fathers who are raising a child diagnosed with ASD. The course has not been designed as an exhaustive approach to parenting a child with ASD, but instead focuses on key aspects of raising a child with ASD which should familiarize fathers with essential information, provide social support and highlight important resources. This series of four training sessions contains research-based information designed to actively engage fathers in the life and development of their child who has been diagnosed with ASD. The training course is intended for use by resource centers, autism centers, support groups, and other community entities as an educational tool for fathers raising a child with ASD.

The development and usage of parent training is an increasingly useful tool in parent education with families who have a special needs child (McConachie & Diggle,

2007). Specifically, parent education approaches that target fathers and father figures have more appeal to men and allow a focus on their particular issues and concerns (Brotherson, 2007). Doherty (1995) developed the “levels of family involvement model” that describes a range of interventions with families ranging from minimal resources (Level 1) to intensive therapeutic assistance (Level 5). Among the differing levels in the framework, a Level Four intervention consists of a “brief focused intervention” that involves “a planned effort to help the parent [with] a troublesome parenting problem [or] a broader family interaction pattern” and it specifically identifies “families with special needs” (Doherty, 1995, p. 355). Utilizing the Levels of Family Involvement model as a framework for developing this planned program, a brief and intensive educational effort with fathers and their families would be considered a Level Four intervention (Doherty, 1995).

Doherty, Kouneski, and Erickson (1998) suggest that a well-designed intervention in support of fathers and their families should involve a wide range of factors which reflect the comprehensive influences on fathering. A few recommendations to generate an effective program include: target all domains of fathering, promote the well-being of mothers and the co-parental relationship, involve employment dimensions, train staff to promote responsible fathering, involve other fathers, and promote a caring, committed, and collaborative relationship between mothers and fathers (Doherty et al., 1996). These are just a few suggestions, however there are others that are designed to promote and encourage a positive and effective father training course for fathers with children (Brotherson, 2007).

Turbiville and Marquis (2001) found that fathers were more likely to participate in programs that involved their family members. Considering this training course is focused on fathers and their involvement with family members, the conceptual plan for the training course is to create a “family night” where families are invited to participate as a family, or at least the parents with the autistic child. The training course would offer a meal and/or activity for fathers and their children, as well as other family members, to participate in before the informational session of the night is conducted. A break-out session would then provide the information to fathers specifically, while children and other family members were engaged in a continuing activity. This environment would invite the participation of fathers and encourage quality time to be spent between fathers, the child with ASD, and other family members. So, all four sessions would consist of this broader family context combined with a specific informational session for fathers during each session. Only the material related to the informational session for fathers has been developed for this paper.

The objectives of the training course that was developed to support fathers in raising a child with ASD are as follows:

- Offer a safe environment for fathers and their partners to feel comfortable and learn in a positive setting;
- Encourage fathers to engage in conversations, ask questions, and learn honest information from other fathers as well as professionals;
- Create an atmosphere where men can feel support and become comfortable in discussing difficult topics, such as the diagnosis of ASD for a child;

- Provide information on key aspects of ASD, useful parenting approaches, and key resources in dealing with this parental experience.

Training Course Participants

This training course is targeted to include fathers and father figures, such as boyfriends, grandfathers, uncles, etc., in families that are raising a child diagnosed with ASD. Family members including the diagnosed child and others will also be invited to attend all four sessions and participate in the “family night” portion of the program. This course is geared towards fathers of children ages two (or time of diagnosis) to age six. The training course would be available to autism centers, community education programs, early childhood programs, and school systems that wish to implement a training course for fathers who are raising a child diagnosed with ASD.

Training Course Design and Content

Each individual training session highlights a key topic related to raising a child with ASD and addresses questions and concerns that fathers may have. The training course as currently designed includes four sessions. Topics selected for the training course are as follows.

Week 1: Defining Autism and Moving Beyond the Diagnosis. The discussion for this first week focuses on the characteristics and behaviors associated with autism in children, as well as tips to move beyond the diagnosis of ASD in raising a child. The session will also address how fathers and mothers may differ when accepting the diagnosis that a child has ASD.

Week 2: The Key to Family, Sibling and Peer Relationships. This week's discussion relates to the relationships that the autistic child has with his or her family, siblings and peers. This week will further emphasize the importance of quality father-child relationships. It will focus on encouraging efforts to build relationship connections through shared time and activities. This week also will offer a variety of suggestions and resources to help fathers, family members, siblings and peers connect with a child with ASD.

Week 3: Finding a Good Educational Fit for Your Child. The session discussion during the third week explores differing interventions and therapies, as well as working for a child with ASD to receive a good education. A major concern of fathers that will be addressed includes financial issues regarding medications, therapies, and additional costs of raising a child with ASD. The financial element of providing for a child's education and therapy is included here because the costs for raising an ASD child are often substantial and the responsibility for providing financial support is a common concern of fathers.

Week 4: Additional Information to Know in Parenting a Child with ASD. This week's session provides a chance for participants to ask questions and pursue answers. The session will include a panel of experienced fathers of children with ASD and community professionals with ASD expertise such as teachers, doctors, special education teachers, and therapists. This session will allow fathers to ask direct questions and receive answers from other fathers and professionals. Handouts with additional resources will also be available.

Each of the training sessions focuses on a central topic combined with supporting research, ideas and activities. Each session is designed to facilitate three outcomes. First, to familiarize participants with a key topic of concern that fathers of children with ASD often

have and to answer related questions. Second, to encourage fathers to be involved with their child in a positive and interactive manner. Third, to collaborate with their spouse or other parent, doctors, teachers, and the child to develop the best outcomes for their child.

As with any educational program, the number and variety of topics for the training course were limited only because of time and the need to keep the training course manageable. It is anticipated that other topics could be included in the training course, either by adding additional weeks or extending the amount of time designated for the current sessions. Such additional topics could include behavioral challenges, nutrition and eating problems, safety of the child, the transition to adulthood and other issues. However, the current design of the training course is to maintain a focus on aspects of interest to fathers of children diagnosed with ASD at a young age and major concerns and questions of fathers.

Each week participants will have the opportunity to ask questions, express concerns, and interact with other fathers who may be experiencing similar situations. Each week will also include a focused “take-home” hand-out, as well as a list of resources. The activities included on the “take-home” hand-outs include an activity to do with the child, a spouse or partner, and a self-reflective activity involving oneself. At the beginning of the next session, some follow-up time will be dedicated to discussing how the “take-home” activity went for fathers. Resources related to fathering a child with ASD will also be available for participants to take following each session. These resources will provide additional reading and support for fathers who are looking for further information on fathering a child diagnosed with ASD.

This educational training course will be offered as a pilot program to various entities that may be interested in a program for fathers who are raising a child diagnosed with autism. The goals associated with developing this pilot program include three specific items. The first goal of the program is to make information on raising a child with ASD more readily available. Next, a goal of the program is to offer educational programming that is targeted at meeting the needs of fathers who are raising a child with autism. Finally, a goal of the program is to help fathers and their families who participate to understand that father involvement is highly important and can be beneficial in raising a child with ASD.

The training course format for the fathering course focuses on several criteria. It is geared to a specific audience: fathers of children who have been diagnosed with autism. The presentation materials are intended to be informative and engaging. A personal goal sheet will be collected during the first series to gain an understanding of what participants are hoping to get out of the course (see Appendix 7). Also, the course format could reasonably be offered during the evening and this pattern would allow for more participants to attend. The content is intended to be appealing and understandable to a wide range of educational levels. Fathers will be able to access this training course through a variety of community programs and agencies upon its completion and distribution.

Training Course Review

Two community professionals with expertise in autism spectrum disorder, and two fathers who are raising a child diagnosed with ASD, will review and provide feedback on the training course as part of the process of its development. Recommendations made by these persons upon review will be incorporated, and revisions will be made before the

training course is considered ready to be presented in an educational setting. This review process will enhance the accuracy of the information provided in the presentation materials and will help to ensure the usefulness of the training course for fathers of children with ASD. Although incorporation of the review suggestions will not take place as part of completing this paper, it is important to outline the process that will occur as the materials are prepared for educational usage.

Training Course Evaluation

The training course format is intended to be an effective parent education tool. One method of determining whether the course meets its objectives is to conduct an evaluation of how the training course is utilized and the resulting impacts on those who have participated. A sample evaluation tool was developed and includes the following dimensions:

- Characteristics of population using the training course - This information focuses on gathering demographic characteristics to understand who is using the training course and potential differences based upon participant characteristics.
- Usage of the training course information - This information addresses how the training course information is being used. For example, it includes questions about information taken away from the course, who the participant shares the information with, and if activities and ideas have been applied to their father-child relationship.
- Usefulness of the training course - This information seeks to understand how participants value the training course and how they compare it to other sources of information.

- Impacts of the training course - This information assesses course impact related to the knowledge, confidence, skills and behavior of participants. The course evaluation tool includes questions to reflect how the course impacts the fathers who participate.

Studies of parent education program and training courses report that they often have beneficial impacts on the father, the mother, the child, and other members of the family (Turbiville & Marquis, 2001). Developing a sample evaluation tool to be used with this program allows future users of the educational material to assess how it is being used and its possible impacts.

In the sample evaluation included with this educational program, both a pre-test and a post-test form are included so that information could be gathered from participants before and after the program. The evaluation design suggested would include administering the forms directly before and after the program has been completed. Additionally, the post-test form could be utilized in short-term follow-up evaluation efforts, so that fathers might be asked to complete the form again two or three months following completion of the course. Since this educational program has been designed as a preliminary introduction to raising a child with ASD for fathers, the focus of the sample evaluation tool provided is on how fathers perceive the educational experience, its value and perceived impacts. This focus does not exclude the possibility of a larger evaluation effort that would address perceived impacts on the entire family, including the mother, child with ASD, and siblings, but the primary target of this sample evaluation is the father himself.

CHAPTER 4

OVERVIEW OF THE TRAINING COURSE

This section provides a brief overview of the planned training course for fathers who are raising a child diagnosed with ASD. It also furnishes a conceptual outline of each specific session of the training course. The actual content of each training course series is included in the appendices.

General Overview of the Parent Training Course

This parent training course was developed to inform fathers of different concepts and resources that may be helpful while raising a child with autism. This training course is intended to give research-based information to fathers that promotes learning about autism and actively engaging with one's child. The course gives the opportunity to participate in a family night as parents and children, as well as gain specific information regarding topics such as moving beyond the diagnosis, building parent-child relationships, finding options for education and therapy, and accessing additional resources that fathers may be interested in.

This four-session training course is intended for use by resource centers, autism centers, support groups, and other community entities as an educational tool for fathers raising a child with ASD. These avenues of education can help to facilitate the adoption and implementation of the training course so that fathers of children diagnosed with ASD can be supported.

Conceptual Outline of the Training Course

Each session in the course is designed to provide research-based information to fathers with a child diagnosed with ASD. The conceptual outlines for each specific training course session are highlighted below.

Session One: Defining Autism and Moving Beyond the Diagnosis

Training Course Goal. The goal of session one is to provide a clear definition of autism and how to effectively engage the topic and move beyond the news of the child's diagnosis. The session introduces the topic of autism and addresses a variety of ways that parents can understand the issue, assist their child and work through the child's diagnosis of ASD (for a copy of the session outline see Appendix 1).

Key Concepts. The key concepts addressed in this session include behaviors and characteristics associated with autism in children, tips to move beyond the child's diagnosis and become more informed, and possible differences between how mothers and fathers may cope with the diagnosis.

Methods. The material in this course session may be used as the basis for class discussion during a fathering class in various settings. It may also stand alone as an educational resource to be read and shared as fathers see fit. Sharing of information could take place with a partner, a spouse, in the workplace, with friends and relatives, or in support groups.

Parent Take-Home Handout. A take-home handout for parents is provided with additional information regarding the acceptance of a child's diagnosis. There is also a reminder of the question that each father should reflect on for the week, as well as a

suggested activity for the father and child to take part in together during the week. Included in the hand-out is a list of additional readings for adults and children, as well as helpful websites.

Resources. This session offers additional websites and books for fathers to refer to in their learning process. A learning section titled “Ten Things to Do after a Diagnosis” is featured in this session. Additional resources used in writing the content of the training course are also listed. Included in this session is a handout with recommendations of adult books, children’s books, and websites for fathers to learn from.

Series Two: The Key to Family, Sibling and Peer Relationships

Training Course Goal. The goal of this session is to increase parental knowledge of ways to promote positive parent, sibling and peer relationships with an autistic child (for a copy of the session outline see Appendix 2).

Key Concepts. The key concepts addressed in this session focus on effective ways to build family, sibling and peer relationships while managing an ASD child’s behavior. The topic of dealing with the stress of social activities, as well as tips for parents to create positive relationships with their child, is addressed. Outcomes for siblings and how to promote effective relationships between siblings is also touched on in this session. Also, ways to include your child with ASD in community events and promote relationships with peers is discussed.

Methods. The material in this course session may be used as the basis for class discussion during a fathering class in various settings. It may also stand alone as an educational resource to be read and shared as fathers see fit. Sharing of information could

take place with a partner, a spouse, in the workplace, with friends and relatives, or in support groups.

Parent Take-Home Handout. Each parent is provided with a take-home sheet that identifies additional information, tips and activities for the father to engage in with his child. This sheet provides additional ways for fathers to engage with their child in appropriate activities. It also addresses concerns when engaging your child in a social activity. A reminder of the reflective question and the father-child activity to take part in during the week is also included. Included in the hand-out is a list of additional readings for adults and children, as well as helpful websites.

Resources. Additional web sites are listed, as well as games, songs, and activities to connect with your child. Included in this session is a handout with recommendations of adult books, children's books, and websites for fathers to learn from. Resources used in writing this session of the training course are also listed.

Series Three: Finding a Good Educational Fit for Your Child

Training Course Goal. The goal of this session is to assist fathers in becoming aware of additional therapies offered to children with autism, to learn the importance of early intervention, and to identify ways that parents can work with a child's school and IEP. Also, a major concern for most fathers addressed in this session is how to pay for needed therapy and education (for a copy of the session outline see Appendix 3).

Key Concepts. Key concepts addressed in this session include: the importance of early intervention; explanation of laws that will impact a child's education; your child's individualized education plan (IEP) and the importance of IEP meetings; how to work with

the school and supporting a child's IEP while at home; and ways to financially afford the best services for your child and what to do if you are unable to afford extra therapies and early intervention.

Methods. The material in this course session may be used as the basis for class discussion during a fathering class in various settings. It may also stand alone as an educational resource to be read and shared as fathers see fit. Sharing of information could take place with a partner, a spouse, in the workplace, with friends and relatives, or in support groups.

Parent Take-Home Handout. The parent handout for this session addresses how to pay for the interventions to benefit a child with ASD, and also the effectiveness of early intervention. The handout further includes a reminder of the reflective question and the father-child activity that parents are encouraged to engage in during the week. Included in the hand-out is a list of additional readings for adults and children, as well as helpful websites.

Resources. This session includes a handout with recommendations of adult books, children's books, and websites for fathers to learn from. Resources used in writing this session of the training course are also listed.

Series Four: Additional Information to Know in Parenting a Child with ASD

Training Course Goal. The goal of this final session is to give fathers the opportunity to ask professionals, teachers, doctors, and other fathers whatever questions they may still have and would like to discuss (for a copy of the session outline see Appendix 4).

Key Concepts. Several different concepts can be addressed in this final session. The information that may be provided in the session will likely differ depending on which professionals are chosen for participation on the panel. Additionally, having fathers of children with ASD on the panel allows for receiving information from men who are experiencing similar situations in their parenting, and this may be useful and informative for participants.

Methods. The material in this course session may be used as the basis for class discussion during a fathering class in various settings. It may also stand alone as an educational resource to be read and shared as fathers see fit. Sharing of information could take place with a partner, a spouse, in the workplace, with friends and relatives, or in support groups.

Parent Take-Home Handout. The parent take-home handout for this session includes additional resources which include: websites, journals, magazines, and support group recommendations. Included in the hand-out is a list of additional readings for adults and children, as well as helpful websites.

Resources. This session includes a handout with recommendations of adult books, children's books, and websites for fathers to learn from. The weekly handout also includes several different resources for fathers.

Program Leader's Guide

A brief program leader's guide was developed and organized in a format appropriate for peer educators. The guide information includes the target audience, the estimated time that will be needed, the goals of the training course, what preparation and

supplies will be needed, the objectives of the training course, and a short explanation regarding the use of the presentation materials (see Appendix 5).

Extended Program Leader's Guide

An extended program leader's guide was also developed to furnish a more in-depth explanation of the training course. The extended program leader's guide offers a more extensive profile of the training course. The extended guide includes an outline of the training course, the suggested format of the course, and suggestions regarding how to use the training course. It also encompasses what to do prior to teaching the course, what to do while teaching the course, and how to utilize the sample evaluation that is included (see Appendix 6).

Evaluation Materials

The sample evaluation included with the course includes a pre-test form and a post-test form. The evaluation forms are intended to gather information regarding participant demographic characteristics, how participants plan to use information from the training course, and perceived impacts on participant knowledge, awareness of resources, and support. The pre-test form would be given prior to the start of the training course. The post-test form would be given at the conclusion of the training course.

Summary

The training course outlined in this chapter comprises the essential content of the training course for fathers raising a child diagnosed with ASD. Each course session was prepared with a goal, a specific content idea, and methods to assist professionals who are using the information provided, including activities and resources. As professionals present

this information to fathers who are raising a child with ASD, fathers will be provided with ideas, activities and resources which are meant to help fathers become more confident and informed while raising a child with ASD.

CHAPTER 5

DISCUSSION

Considering the increase in the numbers of children diagnosed with ASD, the provision of education, awareness and support is essential for families who are raising a child with ASD. Families who are raising children with ASD face multiple challenges and stressors. Research has indicated that parents who are presented with such challenges benefit from interventions that assist them in understanding parenting options, effectively managing child behaviors, and feeling social support from others.

Support groups for parents raising children with special needs commonly attract mothers who are the primary caregivers who experience and utilize support groups. Support groups and parent training programs are becoming more common today. However, additional services need to be offered to fathers raising children with ASD. Fathers who take part in parental training programs tend to express a sense of renewed confidence and lower stress levels (McConachie & Diggle, 2007). As support groups or parent education courses can be an important resource for fathers, the design and implementation of a parent training course for fathers raising children with ASD is a positive and needed objective.

This training course will offer fathers an opportunity to have their questions and concerns answered and gain a social support network with other participants. In addition, it will assist them in learning about additional resources and recommendations that will help them father their child with ASD in a healthy and positive manner. The training course has been designed to create an environment where fathers feel comfortable and are encouraged

to explore their questions and concerns. The training course is intended to be presented in a manner that is easy to understand and includes educational materials for fathers that are simple to read and apply.

In addition to the benefits that may directly accrue to fathers and their children with ASD, development of such a parent training course offers the opportunity to learn more about educational supports for families raising a child with autism. Research on fathers and raising autistic children is minimal and such a course would enable the opportunity for further research with men and their families. Further research on how to support fathers raising autistic children and the value of educational support mechanisms can strengthen efforts to furnish a healthy and positive future for families raising children with special needs.

We do not yet have the answers to cure ASD. However, we do have answers regarding how to create positive and healthy relationships between a father and his child. Education and awareness is a vital key to these positive relationships. It is anticipated that participation in the parent training course will be a positive influence in the lives of at least some fathers, their children, and the entire family.

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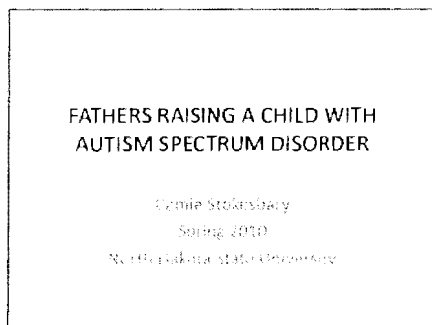
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APPENDIX 1

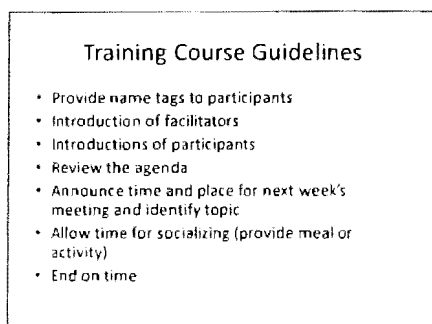
TRAINING COURSE SESSION ONE

Slide 1



Introduce yourself and welcome the participants.

Slide 2



As families arrive, provide name tags to all participants including partners, wives, significant others, and children.

Introduce the facilitators and explain the goals of the session.


When the break-out session with fathers begins, have fathers introduce themselves and encourage them to give their story, age of their child, age of child's diagnosis, why they are attending, and/or what they hope to get out of the session.

At the end of the session remind participants of next week's location and topic. It is important to end on time, as families are busy and schedules are very important!

Slide 3

Week 1

The Definition of Autism and Getting Past the
Diagnosis



Tonight we are going to discuss the definition of autism and how to help accept the diagnosis.

Slide 4

Lesson Objectives

- To understand the definition of Autism Spectrum Disorder (ASD)
- To learn what professionals currently know about Autism
- Identify what we can do after the diagnosis

Go through the objectives so participants can form some expectations for learning and discussion during the session.

Slide 5

Autism is...

- Autism is a biologically based developmental disorder that impairs an individual's ability to communicate, build relationships, and relate appropriately to the environment.
- Occurs: Infancy to early preschool

Autism is often diagnosed in infancy or during the early preschool years.

Slide 6

What We Know

- Autism is a developmental disability which is brain based.
- Autism is found in every country, every ethnic group, and every socioeconomic status.
- Autism is diagnosed four times more in boys than girls.
- Early intervention is critical for children with autism.

There are a few key things that professionals agree on when it comes to autism spectrum disorder. These items are a few facts that are widely agreed on in the professional community.

Slide 7

**10 Things to do after a
Diagnosis of ASD**

1. Learn as much as you can
2. Network with other families
3. Test, test, test
4. Investigate financial aid
5. Consider lifestyle changes
6. Set up educational and behavioral programs in your home
7. Begin therapies
8. Address your child's diet
9. Don't give up
10. Relax

It is very important to identify practical steps you can take following a child's diagnosis with autism. The 10 things identified in this list will allow you to let life move forward, educate yourself and others, take the steps that are needed in the treatment process, and work on coming to terms with the diagnosis.

Slide 8

1. Learn as much as you can

- Many autism organizations
 - Autism Society of America (ASA)
 - Unlocking Autism (UA)
 - Autism Research Institute (ARI)
 - Cure Autism Now (CAN)
- Additional resources
 - Websites
 - Books
 - Magazines
 - Research journals

Additional resources will be provided on your "take-home" handout sheet.

Don't spend too much time online. It is important to find a balance between researching and networking, but most of all, remember the most important thing is to spend time with your family.

Slide 9

2. Network with other families

- Autism community
- Autism conferences
- Support-group meetings

Other families who are dealing with raising a child with autism may be the best support system. Try to make it to conferences or support groups, as people that you meet in those settings may be very helpful. Families who are raising a child with autism understand the challenges and stresses, can provide a network of support, and may be able to connect you with needed resources.

Slide 10

3. Test, test, test

- Be open to new technologies and ideas
- All treatments do not work for all



It is okay to try several different approaches in assisting your child. Getting a baseline assessment of where your child is developmentally in key areas can assist you in what type of therapies and treatment will be most effective for you and your child. Work on being prepared, organized, informed, and ready to communicate with your doctors.

Slide 11

4. Investigate financial aid

- A free and appropriate education for every child with a disability is guaranteed under the federal Individuals with Disabilities Education Act (IDEA).
- Health insurance will sometimes cover the cost of medical tests used in the diagnostic process and the cost of prescription medication, but it will not pay for behavioral or other types of therapy for autism.
- Out of pocket costs often include: doctor or therapy services, prescription and non-prescription drugs, and medical interventions.
- Seek financial counseling and planning.

Under the IDEA Act a child is guaranteed free education. This education may be appropriate but is it the most ideal or what may be best for your child? Therapy and intervention for your child can be very costly, considering the extensive amount of time that is needed. Therapy could cost up to 30,000 dollars a year so it is helpful to investigate available sources of financial aid in providing for your child's treatment and needs.

Slide 12

5. Consider lifestyle changes

- Resignation from job or working from home
- Decreased work hours
- Home schooling
 - Due to inadequate public education
- Relocation
 - Moving in with extended family for support

Often child care workers are not trained to work with special needs children. The lack of resources for supporting special needs children in child care may cause families to decrease work hours or a parent may even quit their job to care for their child. Has anyone experienced any of these situations? Would anyone be willing to share their experiences or insights?

Slide 13

6. Set up educational and behavioral programs in your home

- Can become very costly
- May work for stay at home parents
- May have a toll on the entire family

We will discuss how to pay for additional therapies in the third session. It is important to remember that having a child with ASD does have an impact on the entire family. We will also discuss this topic in more depth next week.

Slide 14

7. Begin therapies

- What is most effective?
 - ABA (Applied Behavior Analysis)
 - TEACCH (Treatment and Education of Autistic and Communication Handicapped Children)
 - RDI (Relationship Development Intervention)
 - Speech and language therapy
 - Several others
- How many hours are needed?
 - 25-40 hours
- Where should I turn to for therapy?
 - Schools
 - Autism Centers

There are many questions when debating therapy and early intervention for children with autism spectrum disorder (ASD). However, it is known that early intervention is critical for young children. Hours of intervention varies across participants; however, 66% of families reported receiving less than the recommended 25 hours per week of services per child (National Research Council, 2001).

Controlled trials have shown ABA therapy to be effective for improving social skills and language when provided for at least 25-40 hours per week for 2 years (Lord & McGee, 2001). Efficacy is greatest when behavioral interventions are used early, but improved skills have been reported with older kids (McClanahan, MacDuff, & Krantz, 2002; Weiss & Harris, 2001).

The communities in which children are diagnosed vary in their ability to meet the needs of people with ASD (Shattuck & Grosse, 2007). Local school districts vary in their ability to provide appropriate educational programs for children with ASD (Mandell & Palmer, 2005; Palmer et al., 2005).

Slide 15

8. Address your child's diet

- A child's digestive system is important. Understand that the food that you feed your child can directly affect what happens in his or her brain.
- Benefits of using autism diets for your child can include:
 - Improved digestion
 - Reduced gastrointestinal pain
 - Less rash or eczema
 - Physical pain relieved
 - Aggressive behavior ceases
 - Language skills increase
 - Ability to focus & cognitive readiness
 - Sleeping through the night
 - Increased eye contact
 - Easier toilet training

Along with specific diets, including supplements, vitamins and/or minerals with your child's diet may also result in significant positive differences for your child.

Some families find diet and drug therapy helps reduce undesirable behavior and increase attention span, sometimes quite dramatically. Others do not find meaningful differences. Each child will respond differently to such treatments.

Slide 16

9. Don't give up

- Everything takes time!
- Educate yourself

Be patient. Discovering which treatments work best for your child can take time.

Learn about your loved one's condition, as information is empowering.

Slide 17

10. Take care of yourself

- Remember to take time for yourself
- Watch for signs of depression
- Be good to yourself
- When people offer to help, accept!
- Seek support
- Relax
 - Yoga
 - Meditation
 - Journaling
 - Prayer

If you are raising a child with ASD, you're doing a very hard job and you deserve some quality time or respite time, just for you. Watch for signs of depression or other illnesses and get help when you need it. Also, provide support to a spouse or significant other so they can get needed rest. It is important to know that you are not alone, seek support from other caregivers, and most importantly take time to relax!

Slide 18

How do fathers and mothers differ?


- There have been contradictory findings regarding which parent experiences more stress while raising a child with ASD. Some report that mothers do, while others report that both parents experience equal levels of parental stress.
- Reasons for differences could include:
 - Mothers may spend more time with the child diagnosed with ASD.
 - Or, for example: Maybe a father's way of coping with their child's behavior problems is by avoiding their child and engaging in other activities
- Both mothers and fathers report bringing different coping strategies to the co-parental relationship
- What are some differences you may have seen between your partner and yourself?

Hastings et al. (2005) show that there may be differences between mothers and fathers and the way they cope with the diagnosis.

Slide 19

Take home activity


- Reflect: How have you dealt with the news of your child's diagnosis? Are you moving forward? If not, how can you?
- Father-Child Activity: Make a meal or snack with your child, let your child help:
 - breakfast waffles
 - make cupcakes
 - home made pizza
 - pack a picnic



Slide 20

Looking ahead...

- Next Week
 - The Key to Family, Sibling, and Peer Relationships



Slide 21

Resources

For Adults

- The Autism Sourcebook: Everything You Need to Know About Diagnosis, Treatment, Coping, and Healing. By Karen Silk Sakorn
- The Autism Answer Book: More Than 300 of the Top Questions Parents Ask. By William Stillman
- The Autism Book: Answers to Your Most Pressing Questions. By S. Joanna Rubledo & Dawn Kern Kucharski
- Diagnose Autism: How What? By Lawrence Kaplan and Jay Burstein

For Children

- Video: Autism: Being Friends
- The Mystery of the Special Kid. By Jose Santomauro & Jose Santomauro

Web Sites

- [http://www.news.wisc.com/article.php?id=555931/](http://www.news.wisc.com/article.php?id=555931)
An Autism Diagnosis: Coping, Assistance & Tips for Kids to Move Forward
- <http://www.writinginacardinaljackets.com/2009/06/04/>
Facing Life With Autism: 1500+ Stories and Advice for the Un-Prepared Families

Additional resources are available that can help in becoming informed. Books for adults, children's books, and websites can be helpful. The video, *Autism: Being Friends*, is from Indiana's Resource Center for Autism, and it is geared towards awareness to use with children. Refer to your weekly handout for a list of additional resources.

Additional Resources - Week 1

For Adults

- *The Autism Sourcebook: Everything You Need to Know About Diagnosis, Treatment, Coping, and Healing.* By Karen Siff Exkorn
- *The Autism Answer Book: More Than 300 of the Top Questions Parents Ask.* By William Stillman
- *The Autism Book: Answers to Your Most Pressing Questions.* By S. Jhoanna Robledo & Dawn Ham-Kucharski
- *Diagnosis Autism: Now What?* By Lawrence Kaplan and Jav Burstein
- *Playing by the Rules: A Story about Autism.* By Dena Luchsigner

For Children

- Video: *Autism: Being Friends.*
- *The Mystery of the Special Kid.* By Josie Santomauro
- *Autism through a Sister's Eyes.* By Emily Hecht

Web Sites

- <http://www.newswise.com/articles/view/555932/>
 - An Autism Diagnosis: Coping, Acceptance & Times Are Key to Moving Forward
- <http://www.wrightslaw.com/info/autism.lessons.lrnd.pdf>
 - Learning to Live With Autism: Lessons Learned and Advice for Newly Diagnosed Families

Parent Handout - Week 1

Defining Autism and Moving Beyond the Diagnosis

Accepting the Label: Autistic

It may be difficult to accept that your child is autistic. You must understand how to treat your child's condition rather than focus on labels. However, it is important for you to recognize that this label is very important for two reasons.

- This label can be your ticket to community, school, and medical services.
- When you accept the label given to a person you care about, that means that you are able to recognize that help is needed and is on the way.

Stages of Grief

You may experience these in order, jump from stage to stage, be stuck in a stage, or skip a stage entirely. That is okay, grief does not follow a predictable path.

- *Shock*: Right after the diagnosis you may be stunned and confused.
- *Sadness and Grief*: It may be necessary to mourn the hopes and dreams that you may have had for your child, but then move on. Feeling sad is okay, and it is important to express feelings of sadness when comfortable.
- *Anger*: Anger is normal. Anger is an expected reaction for the feelings of loss and stress of the diagnosis.
- *Denial*: You may experience feelings of refusing to believe this is happening to your child. Don't be critical of yourself; denial is a way of coping.
- *Loneliness*: Feelings of isolation and loneliness may be source of many factors such as feelings of having no one to turn to, or lack of time for other relationships.
- *Acceptance*: Ultimately, you will accept the diagnosis. However, accepting your child's diagnosis may take time, so be patient.
- http://www.autismspeaks.org/docs/family_services_docs/100day2/Family_Version_2_0.pdf

HOMEWORK REMINDER

- Reflect: How have you dealt with the news of your child's diagnosis? Are you moving forward? If not, how can you?
- Father-Child Activity: Make a meal or snack with your child, let your child help:
 - Make breakfast waffles, cupcakes, homemade pizza, or pack a picnic.

APPENDIX 2

TRAINING COURSE SESSION TWO

Slide 1

**FATHERS RAISING A CHILD WITH
AUTISM SPECTRUM DISORDER**

man: b.k.m. @e
p: 604.271.1117
www.fatherhood.com

Introduce yourself and welcome the participants.

Slide 2

Recap

- **Reflect:** How have you dealt with the news of your child's diagnosis? Are you moving forward? If not, how can you?
- **Father-Child Activity:** Make a meal or snack with your child, let your child help.
 - breakfast waffles
 - make cupcakes
 - home made pizza
 - pack a picnic
- Experiences or insights to share?

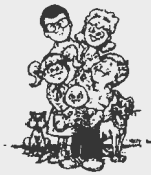
Have participants introduce themselves.

To begin, recap the previous week's session. Ask participants if they were able to reflect on the question: How have you dealt with the news of your child's diagnosis? If so, does anyone care to explain their response?

What were some of the special activities that parents were able to take part in with their child. Did any differ from what you would "normally" do during the week?

Slide 3

Week 2
The Key to Family, Sibling and Peer Relationships



Tonight we are going to discuss how we can increase positive relationships between you and your child. We will also look at ways to provide positive relationships with other siblings, extended family, and peers.

Slide 4

Lesson Objectives

- Increase your knowledge of ways to promote positive relationships with your child
- Provide you with tips for engaging in a positive relationship with your child
- Learn ways to promote healthy sibling and peer relationships
- Learn ways to deal with the stress of social activities and your child with Autism

Explain the objectives so participants can form some expectations for learning and discussion during the session.

Slide 5

Relationship tips for you, the parent

- Encourage communication
- "Here and Now"
 - "First this, then that" statements
- Comprehension
- Loose structure
- Guiding rather than pushing
- Focus on your child, not others
- Team effort
 - Teachers, therapists, doctors, friends, and family
- Education

Communication with a child could include sign language, pictures, words, or gestures.

It is important to break down simple instructions. For example, in a situation where you are going to the park a break-down like this may be beneficial: 1. Get dressed, 2. Go to car, 3. Stop at store, 4. Go to the park.

Children may understand even if they are unable to communicate with you. Talk with them rather than about them.

Remember to keep to your schedule; however, it is important for your schedule to not be too rigid. Explore how many changes in his or her schedule your child can tolerate.

Use preferred items to motivate your child.

Learn as much as you can - you are your child's biggest advocate.

Slide 6

Sibling relationships

- Some siblings may be at a greater risk for poor outcomes such as emotional and behavioral problems
 - Depression
 - Over-responsibility
 - Withdrawn
 - Siblings can learn compassion, maturity, and social skills from being a sibling of a child with ASD
- Get siblings involved.
- It is important for professionals and teachers to be aware of these family matters and act accordingly.
- Overall, siblings report a positive relationship between the child with ASD and themselves.
- Conversations with siblings (depending on their age)
 - Informing your other children about autism
 - It's okay to say, "We don't know yet", when a child asks, "Why?"

It is important to express to each child in the family that they are valued. Such efforts help to decrease the likelihood of overcompensating to make parents feel better, or minimize a sibling's efforts to gain attention due to feeling insufficient attention.

Positive affect among sibling has been predicted by greater parental support.

Slide 7

Peer relationships

- Children with ASD may have poorer quality friendships and tend to be more lonely than children without a clinical diagnosis; however, it is suggested that peer support is important to individuals with ASD.
- How to include your child into the community
 - Special Olympics
 - Girl/Boy scouts
 - Support groups
 - Day treatment centers
 - Groups for children with ASD
 - Any other ideas?

Considering peer support has been found to be important to people with ASD. It is important to get your child involved in order to develop quality peer relationships.

Slide 8

Social activities

- Strategies to help your child cope while being in public
 - Know your child
 - Try to minimize difficult situations and scenarios according to your child's past behaviors.
 - Plan ahead
 - Keep errands short, anticipate problems and plan ahead for dealing with them.
 - Use pictures
 - Take pictures of your frequent stops and show these to your child so he or she knows what to expect.

Do you struggle with taking your child to a baseball game, the mall, or even out to eat? These tips may be helpful for the next time you try to get out of the house. Problem behaviors by a child and tantrums can be embarrassing, frustrating, and uncomfortable for the entire family.

Slide 9

Social activities (continued)

- Keep your child busy
 - Bring toys or activities for your child to be doing, give him or her a "job" while on your outing (such as finding something on the grocery list).
- Provide praise
 - Encourage positive behaviors and when you see them provide praise, the more you give the more you get!
- Practice and be realistic
 - Practice outings, ease into new situations and places, and try to end the outing on a positive note
- Don't give up!
 - One outing may be fine while another may be a total bust, keep trying, the more you get out there the more comfortable you and your child will become.

Slide 10

Take Home Activity

- Reflect: What are ways that you and your family can strengthen your relationship with your child?
- Father-Child Activity: Participate with your child in something he or she may not have had the chance to do . . . they could enjoy it!
 - Art class
 - Sports game
 - Go skating or swimming
 - Visit the library
 - Other ideas?



Hand out the take-home sheet. The activities identified here can help to develop parent-child relationships, and friendships with peers as well.

Slide 11

Looking ahead...

- Next week
 - Finding a good educational fit for your child and how to pay for it.



Slide 12

Resources

- For Adults**
- *Playing, Laughing and Learning With Children on the Autism Spectrum: A Practical Resource of Play Ideas for Parents and Caregivers* By Julie Moore
 - *Me, My Brother and Autism* By A. C. Pflaum
 - *Understanding Sam and Asperger's Syndrome* By Carabella van Nieuwen
 - *Playing by the Rules: A Story about Autism* By Dana Luchinger
 - *Autism through a Sister's Eyes* By Emily Hechi
 - *More Than Words: Helping Parents Promote Communication and Social Skills in Children with Autism Spectrum Disorder* By Ren Susman
 - *Your Special Grandchild* By Joyce Santomaso
- For Children**
- *A is for Autism: It is for Friend: A Kid's Book on Making Friends with a Child Who Has Autism* By Joanna L. Keating-Welton
 - *The Autism Acceptance Book* By Ellen Sahn
 - *Buster and the Amazing Daisy Adventures with Asperger Syndrome* By Nancy Ogas
- Websites**
- http://www.kidstake.com/research_Activities_for_Autistic_Kids
- Preschool Activities for Autistic Kids
 - <http://www.tehmittautism.com/abbysautismforumwithautism/communication/communication.asp>
- Taking Your Child Out and About - From a Parent's Perspective

Additional resources will also be provided on your take-home sheet this week.

Additional Resources - Week 2

For Adults

- *Playing, Laughing and Learning With Children on the Autism Spectrum: A Practical Resource of Play Ideas for Parents and Carers.* By Julia Moor
- *More than Words: Helping Parents Promote Communication and Social Skills in Children with Autism Spectrum Disorder.* By Fern Sussman
- *Your Special Grandchild.* By Josie Santomauro

For Children

- *A Is for Autism, F Is for Friend: A Kid's Book on Making Friends with a Child Who Has Autism.* By Joanna L. Keating-Velasco
- *The Autism Acceptance Book.* By Ellen Sabin
- *Buster and the Amazing Daisy: Adventures with Asperger Syndrome.* By Nancy Ogaz
- *Me, My Brother and Autism.* By A. C. Phalon
- *Understanding Sam and Asperger Syndrome.* By Clarabella van Niekerk

Websites

- [http://autism.lovetoknow.com/Preschool Activities for Autistic Kids](http://autism.lovetoknow.com/Preschool%20Activities%20for%20Autistic%20Kids)
 - Preschool activities for children with Autism
- <http://www.rethinkautism.com/aboutautism/LivingWithAutism/CommunityAssimilation.aspx>
 - Taking Your Child Out and About - From a Parent's Perspective
- http://www.autism-society.org/site/PageServer?pagename=life_home
 - Life with Autism, family issues, and additional resources

Parent Handout - Week 2

The Key to Family, Sibling and Peer Relationships

Autistic Children and Making Connections

- Children who have Autism simply play in a different way. It is important for parents and caregivers to engage in the child's interests and sensory needs, as this can make critical emotional connections. No two children on the autism spectrum are exactly alike, and neither are their interests or needs.
- When engaging your child in an activity it is important to address:
 - Participants- who else is participating? Be aware of the other children in the group.
 - Activity level- What type of activity is it? Is the child able to complete it individually or will he/she need assistance?
 - Potential problems- Are there any potential problems that might occur? What is the noise level? Is there physical contact involved? Will it be stressful for the child?

Appropriate Activities for Your Child

- Matching
 - Shapes
 - Colors
 - Letters
- Sensory toys/bins
 - Rice
 - Water
 - Beans
- Games
 - Simon Says
 - Songs (Ring Around the Rosie, Farmer and the Dell)
 - Catch
 - Guess Who?
 - I Spy

Playing games and doing activities with your child can increase socialization with non-autistic children and are a fun way to interact and connect with your child.

Top 10 Ways to Spend Quality Time with Your Kids

- 1. Tell them a Story
 - 2. Plan a picnic
 - 3. Take a vacation
 - 4. Turn off the TV
 - 5. Hold a family night
 - 6. Grow a garden
 - 7. Eat meals together
 - 8. Help with homework
 - 9. Enjoy the weather on a walk
 - 10. Take a car ride together
-
- http://fatherhood.about.com/od/activities/tp/quality_time.htm

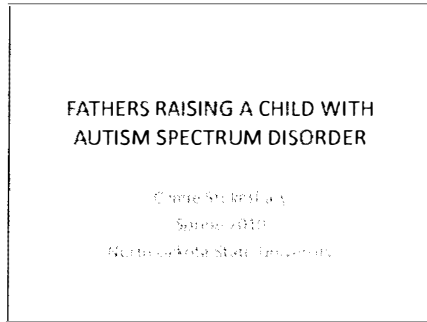
HOMEWORK REMINDER

- Reflect: What are ways you and your family can strengthen your relationship with your child?
- Father-Child Activity: Participate with your child in something he or she may not have had the chance to do:
 - Art class
 - Sports game
 - Go skating or swimming
 - Visit the library
 - Other activities

APPENDIX 3

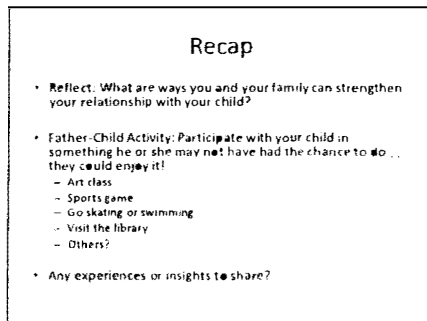
TRAINING COURSE SESSION THREE

Slide 1



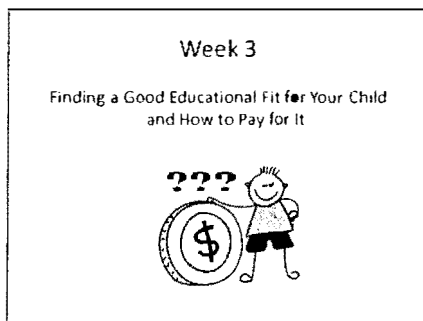
Introduce yourself and welcome the participants. Have participants introduce themselves again.

Slide 2



So what did you do? Were you and your child able to enjoy a father-child activity? What were some of the challenges, if any?

Slide 3



Tonight we are going to discuss how to find a good educational fit for your child. We will also discuss therapy opportunities and how to pay for them.

Slide 4

Lesson Objectives

- Become aware of additional therapies offered to children with Autism
- Learn the importance of early intervention
- Identify ways to work with your child's school
- And, think about ways to pay for it all

Explain the objectives so participants can form some expectations for learning and discussion during the session.

Slide 5

Therapy

- Additional therapies to benefit a child with ASD:
 - Occupational therapy
 - Speech therapy
 - Music therapy
 - Social skills therapy
 - Play therapy
 - Art therapy
 - Animal therapy
 - Physical therapy
- Does anyone care to share their experiences with different therapy options?

There are many different types of additional therapies that children with autism may benefit from. The list displayed here represents just a few of the available therapeutic options.

To learn much more about the several different types of therapies, check out the "Living with ASD" web link:
<http://livingwithasd.com/Treatments.html>

Slide 6

Early Intervention

- Treatment must be extensive to be effective.
- The sooner treatment occurs the better.
- You are your child's first and best teacher.
- Choose interventions that will address all ranges of your child's challenges.
- Explore your intervention options
 - School-based
 - Center-based

The National Research Council (NRC) recommends that a treatment plan include “a minimum of 25 hours per week, 12 months a year in which the child is engaged in systematically planned, and developmentally appropriate educational activity.”

The sooner you are able to begin intervention, the better the results will likely be for your child. A child's brain is most receptive to learning while he/she is very young.

Make sure the intervention that you choose encourages parental involvement. Treatment providers should be willing to teach you how you and your family can support your child.

Intervention can address many different skills, such as: speech, social, etc. Make sure to begin an intervention which addresses all skills.

There are special school and center- based programs available. Visit these places and see if there are other children like your child, and decide if you could see your child there.

<http://www.rethinkautism.com/about/autism/Schools/YourRights.aspx>

Slide 7

Education

- Be aware of what your child's school must offer (several different laws).
 - Individuals with Disabilities Education (IDEA)
 - Free Appropriate Public Education (FAPE)
 - Individualized Education Program (IEP)
 - Individualized Family Service Plan (IFSP)
 - Extended School Year (ESY)
- It is important to keep up with the law.

This list highlights just a few of the different laws that schools must abide by while educating your child. Learn more about these laws and other related laws at:

<http://www2.ed.gov/about/offices/list/osers/osep/index.html>

- IDEA is the nation's special education law. It serves approximately 6.8 million children and youth with disabilities in the US.
- FAPE are public services for those with special needs starting at age 3.
- IEP is for children in the public school system. An evaluation for eligibility is needed.
- IFSP is for preschoolers (ages 3-5) who are at risk for developmental disabilities.
- ESY is for children who need extended help in the summer to prevent them from regressing.

Laws are frequently changing, so it is important to keep current with changing laws and advocate for your child.

Slide 8

The IEP

- Individualized Education Program (IEP)
 - This is a written document that outlines the child's educational plan.
 - Once the IEP is developed, don't forget that it can change.
 - IEP meetings are important.
 - The IEP should include both academic and non-academic goals.
 - Social skills
 - Functional skills
 - Other related skills

An IEP is for a child who may need special services within the public school system.

An IEP needs to be flexible enough to change with the changing needs and skills of the child. IEP meetings are important to discuss changes or additions to the child's programs at any time. These can occur at any time when either parents or professionals feel necessary.

Slide 9

Supporting your child at home

- Work with the school.
- Share what you are working on at home with the school.
- Communicate well with the teachers.
- Set reasonable expectations.

Find out what your child is working at learning or accomplishing while at school, and spend time at home working with them and reinforcing them for these tasks. Also, share what you are working on at home, so the school can work on this as well.

Develop a trusting relationship with your child's teachers. Share what is happening with your child and discuss what is going on while he or she is in the classroom.

Setting high (but reasonable) expectations and sticking to those while at home is essential, however, you must be willing to adjust expectations when working with a child with ASD.

Slide 10

Financial Stress

- Having a child on the autism spectrum can drain a family's resources due to expenses such as evaluations, home programs, and various therapies.
- These costs may cause one parent to give up his or her job, yet financial strains may be exacerbated by only having one income to support all of the family's needs.

Slide 11

Paying for it all

- Is it worth it?
 - Different intervention approaches could cost from 30,000 to 100,000 dollars a year.
 - Figure out long-term costs before beginning treatment.
 - Time commitments can be very extensive
- Extra Expenses
 - Expense of therapy
 - Expense of medication
 - Expense of childcare

How much will this cost?

Treatment expenses can easily add up. Find out which treatments will have the greatest impact on your child and focus on those that are supported by research. Some alternative treatments will be very costly with little research supporting their effectiveness. Find out if the treatment is covered by your health insurance, and what services can be provided at no cost by your state or local school district. If you have to pay for treatment out-of-pocket, figure out your long-term costs before you begin the treatment.

Under the IDEA Act, a child is guaranteed free education. This education may be appropriate but is it the most ideal or what may be best for your child? Consider all your options.

Additional Resources - Week 3

For Adults

- *Hopes and Dreams: An IEP Guide for Parents of Children with Autism Spectrum Disorders.* By Kirby Lentz
- *Helping Children with Autism Learn: Treatment Approaches for Parents and Professionals.* By Bryna Siegel
- *Autism & Diet: What You Need to Know.* By Rosemary Kessick
- *The Complete IEP Guide: How to Advocate for You Special Ed Child.* By Lawrence M. Siegel

For Children

- *Cool Bananas: Favorite Kids' Rhythms for Calming, Cool Downs and Bedtime Routines.* By Genevieve Jereb
- *Ethan and Phoebe: A Child's Book About Autism.* By Deborah Ann Moore
- *The Kid-Friendly ADHD & Autism Cookbook, Updated and Revised: The Ultimate Guide to the Gluten-Free, Casein-Free Diet.* By Pamela J. Compart

Websites

- http://www.kidneeds.com/diagnostic_categories/articles/autism_spectrum_disorder.htm
 - Autism and Autism Spectrum Disorder (ASD)
- <http://www.usnews.com/health/blogs/on-parenting/2009/12/02/how-to-get-early-intervention-autism-therapy-for-your-child.html>
 - How to get early intervention autism therapy for your child
- <http://video.healthination.com/usnews/autism.html>
 - Movie clips regarding ABA therapy, what autism is, signs of autism, autism therapy options

Parent Handout - Week 3

Finding a Good Educational Fit for Your Child

Is Early Intervention Really Effective?

- Learning and development is most rapid in the first five years of life. Early intervention is critical for children with autism to have the best chance at normal development. 50 years of research by the Department of Education reports that early intervention services increase the developmental and educational gains for a child. A child who participates in early interventions will need less services later on in life, report less failing grades, and offer more long-term benefits for the community. Source: U.S. Department of Education. (2009). *What is early intervention?*

Paying for It All

- Treatment, medicine, childcare, therapy - costs all add up quickly for a family of a child diagnosed with ASD. It is important to find treatment in your area and explore the options that the state will pay for (this varies by state).
- See if your state requires insurers to pay for autism therapy. Fifteen states have passed laws that require insurers to pay for early intervention. Check out autismvotes.org for more information on insurance coverage.
- If time and your lifestyle allows, do therapy yourself. If you are unable to find a trained therapist or afford one, this is always an option.

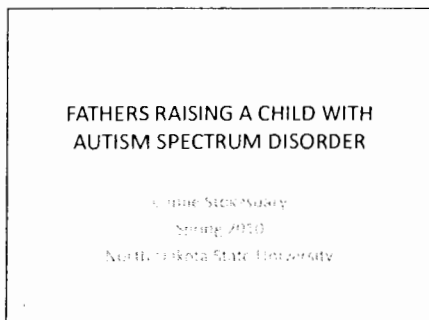
HOMEWORK REMINDER

- Reflect: Discuss with your spouse or significant other if therapy is an option or additional therapies is an option. Is your school doing the best it can be doing for your child?
- Father-Child Activity: Have a day, or a couple of hours, where you and your child do an activity together. Suggestions:
 - Instrument making
 - Homemade playdough
 - Scavenger Hunt
 - Make a fort
 - Arts and crafts
 - Color
 - Do a puzzle

APPENDIX 4

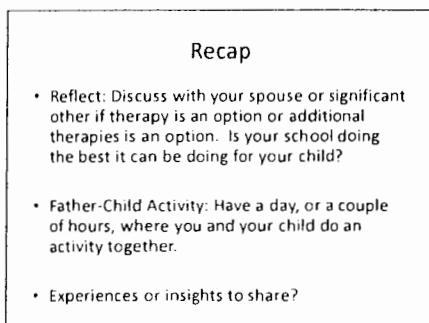
TRAINING COURSE SESSION FOUR

Slide 1



Introduce yourself and welcome the participants.

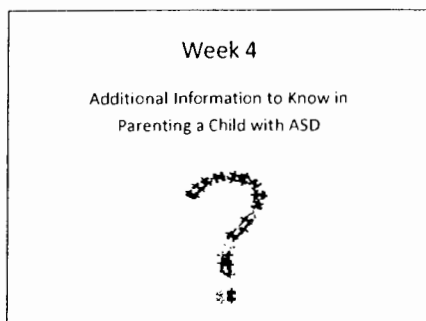
Slide 2



What did you and your partner discuss? What did you do with your child this week as a special activity? How did it go?

Does anyone care to share how your week went and experiences with your child?

Slide 3



Tonight's session will include a question-and-answer with professionals and others who will be available to address concerns, answer questions, and discuss issues you may be having with raising your child with ASD. Please feel free to ask questions.

Slide 4

Lesson Objectives

- Opportunity to ask questions to professionals, teachers, doctors, and other fathers

Explain objectives so that participants can form some expectations for learning and discussion during the session.

Slide 5

Tonight's Panel

- Panel may include:
 - Teachers
 - Special education
 - Counselors
 - Family
 - Individual
 - Subling
 - Nutrition
 - Other fathers of children with ASD
 - Doctors
 - Pediatrician
 - Otolaryngologist
 - Therapist
 - Applied Behavioral Analysis
 - Occupational
 - Physical
 - Speech
 - Music
 - Art

Panel members may include any suggested individuals on the list, including participants or community professionals.

Contact the panel members ahead of time for their participation. Assist the flow of discussion by asking panel members to introduce themselves. Ask participants to write initial questions or topics for discussion on a 3x5 card and act as the moderator for sharing those questions with the panelists.

Slide 6

What's In Your Own Community

Select resources for the panel according to what is available in your community:

- Autism Centers
- Autism Specialist
- Support Groups
- Resource Centers
- Pediatricians
- Therapists
- Additional Help

Please feel free to take advantage of useful people in your own community in order for fathers to get the most out of the question-and-answer night. Provide addresses, phone numbers, and websites for helpful people and places in your community.

Slide 7

Take Home Activity

- **Reflect:** Read just one article or book concerning a topic of your interest regarding your child's ASD.
 - Feel free to use past resource lists for books and websites
- **Father-Child Activity:** Check out the library and read a book, or two, with your child.
 - Suggestions
 - Dr. Seuss
 - Fluffy Bunny
 - Put me in the Zoo

Hand out the take-home sheet.

Children with autism tend to like rhyming sequences, poetry, and sing-song tunes. *Fluffy Bunny* by Piers Harper is a soft touch book. *Put Me in the Zoo* by Robert Lopshire is colorful and involves rhyming. *Dr. Seuss* books often have a rhyming tone to them with humor included. These examples might interest your child.

Slide 8

Resources

For Adults

- Ten Things Every Child with Autism Wishes You Knew. By Ellen Notbohm
- Toilet Training for Individuals with Autism or Other Developmental Issues, 2nd Edition. By Maria Wheeler
- Taking Autism to School. By Andieanna Edwards
- Taking Autism to School. Coloring Book by Ellen Weiner

For Children

- I Am Literally Unique: Celebrating the Strengths of Children with Asperger Syndrome and High-Functioning Autism. By Rene Marie Carson

Websites

- <http://ydeq.healthnation.com/news/autism.html>
 - More info regarding PBA therapy, what autism is, signs of autism, and autism therapy options
- <http://livingwithautism.com/>
 - Living with Autism Spectrum Disorder

Additional books and websites for participants to use are listed. Please keep in mind previous resource lists along with those listed on your take-home sheets from the past couple of weeks.

Additional Resources - Week 4

For Adults

- *Ten Things Every Child with Autism Wishes You Knew*. By Ellen Notbohm
- *Toilet Training for Individuals with Autism or Other Developmental Issues, 2nd Edition*. By Maria Wheeler
- *Taking Autism to School*. By Andreanna Edwards
- *Taking Autism to School: Coloring Book*. By Ellen Weiner

For Children

- *I Am Utterly Unique: Celebrating the Strengths of Children with Asperger Syndrome and High-Functioning Autism*. By Elaine Marie Larson
- *What Would You Do?: A Kid's Guide to Tricky and Sticky Situations*. By Linda Schwartz, Beverly Armstrong, and Sherri M. Butterfield
- *Little Rainman*. By Karen L. Simmons.

Websites

- <http://video.healthination.com/usnews/autism.html>
 - Movie clips regarding ABA therapy, what autism is, signs of autism, and autism therapy options
- <http://livingwithasd.com/>
 - Living with Autism Spectrum Disorder

Get Involved

- Find local resources, services, and support through the Autism Society of America website
 - http://209.200.89.252/search_site/chapter_map.cfm

Parent Handout - Week 4

Additional Information to Know in Parenting a Child with ASD

Websites

The Internet is a great place to find resources, gain information, and get support; however it is important to verify what you read on the Web, as some material written for the Web may not undergo review for accuracy. Take a look!

Advocacy Organizations - These organizations are devoted to supporting the autism community and related causes.

- Autism One - www.autismone.org
- Autism Society of America - <http://www.autism-society.org>
- Autism Speaks - <http://www.autismspeaks.org/>
- Defeat Autism Now (DAN) - www.danconference.com
- Families for Early Autism Treatment - www.feat.com
- Organization for Autism Research (OAR) - www.researchautism.org
- Unlocking Autism (UA) - www.unlockingautism.org

General Information Sites – These sites provide articles and links that can keep you up to date with the latest news concerning the Autism Community.

- Autism Resources - www.autism-resources.com
- Autism Today - www.autismtoday.com
- Center for the Study of Autism - www.autism.org

Research Journals and Magazines

- *The Advocate* (www.autism-society.org): Published by the Autism Society of America. This publishes research and articles concerning the entire autism spectrum disorder.
- *The Autism Perspective* (www.theautismperspective.org): Provides clear and unbiased information from people with autism, parents, researchers, and others who support those on the autism spectrum.
- *Autism Spectrum Quarterly* (www.asquarterly.com): A blend of a journal and a magazine; provides research-based information about autism.

National Support Groups

- Autism Society of America - <http://www.autism-society.org>
- Asperger Syndrome Coalition of the US - <http://www.asperger.org>

In addition to these national organizations which provide support groups, many states have their own local support groups which may be beneficial to you.

APPENDIX 5

LEADER'S GUIDE

FATHERS RAISING A CHILD WITH AUTISM SPECTRUM DISORDER

LEADER'S GUIDE

Camie Stokesbary, M.S.

North Dakota State University

Target Audience

- Fathers of children diagnosed with Autism Spectrum Disorder (ASD) and their families

Time

- One to two hours for each series, depending on activities chosen

Goal

- To emphasize the importance of father involvement with children who have been diagnosed with ASD and encourage father participation with their child. It will focus on key aspects of raising a child with ASD which should familiarize fathers with essential information, provide social support, and highlight important resources.

Preparation and Supplies

- Pen/pencil and paper
- Power Point presentations
- Take-home handouts
- Evaluations

Objectives

As a result of participating in this training course, learners will:

- Learn tips for moving forward regarding their child's diagnosis of ASD.
- Increase their knowledge of ways to promote positive parent, sibling, and peer relationships with their child.

- Learn about additional therapy options, as well as the importance of early intervention, and how to financially afford interventions.
- Gain additional information and support from professionals and fathers of children with ASD.

Power Point Presentation

- Refer to the take-home handouts throughout the presentation
- Provide opportunities for discussion throughout the presentation. Allow time for participants to ask and answer questions and talk as a group.

APPENDIX 6

EXTENDED LEADER'S GUIDE

FATHERS RAISING A CHILD WITH AUTISM SPECTRUM DISORDER

LEADER'S GUIDE

Instructional Guide for Usage

Outline of the Training Course

The Fathers Raising a Child with Autism Spectrum Disorder (ASD) training course is a parent education training series focused on fathering a child diagnosed with ASD. It is focused on fathers who are parenting a child from the age of diagnosis to age 6. The curriculum includes 4 training sessions and is intended for use particularly with fathers of children diagnosed with ASD, as well as others who work with children diagnosed with ASD. The 4 series in the training course include:

- Defining Autism and Moving Beyond the Diagnosis
- The Key to Family, Sibling and Peer Relationships
- Finding a Good Educational Fit for Your Child
- Additional Information to Know in Parenting a Child with ASD

Format of the Training Course

Each of the 4 sessions in the training course is designed to facilitate an educational approach that is in-depth, interactive, and flexible to the needs of the educational setting. Educators using the training course should become familiar with the material thoroughly prior to its use. Each session contains the following key components:

- Lesson Objective page
- Additional Resources Page
 - Includes listing of additional books, articles, videos, websites, and organizations to access further information.
- Participant Handouts
- Lesson Overheads

Using the Training Course

How might the training course for fathers raising a child with ASD be used or adapted?

The training course may be used in a variety of formats such as:

- A father education course through a local community education program.
- As an educational booth at a parents' fair.
- Individual lessons offered to fathers through local programs such as Head Start.
- Web based, self learning course.
- Professional development for community professionals working with children and families with ASD.

These examples demonstrate the wide range of possibilities that exist for use of this training course.

This training course is intended particularly for use in a father education program or with a father support group. The information presented makes this training course helpful for use as an in-depth parenting course for fathers raising a young child diagnosed with ASD. The course will be most effective if all of the series are offered as a part of a parenting course over a number of weeks. However, each series of the training course can be an independent unit that is taught singly or in combination with other series. Thus, each individual using the training course should adapt it to the needs of the particular group.

The training course series and accompanying materials may be adapted to a variety of educational settings. The length of each series may range from 45 minutes to 90 minutes. The handout in each series is intended to be copied and handed out to the participants at the appropriate time in the series.

Teaching the Training Course

In facilitating the training course, individuals will be most successful if they have familiarized themselves with the material and come prepared. Here are some tips to prepare for a quality educational experience:

Prior to offering a course:

- Distribute information advertising the training course in appropriate places (newspaper, radio, hospitals, psychologists, etc.).
- Set specific time and location
- Arrange for equipment and other materials that are needed.
- Review the leader's guide.
- Copy participant take-home handouts and any evaluations that will be used. Make sure copies have been made.

- Organize refreshments, child care arrangements, or any other needs.

At the time of the course:

- Arrive early to arrange training course materials and equipment.
- Arrange the class setting so it is comfortable and participants can engage in discussions.
- Greet participants (and families) as they arrive and use name tags if possible.
- Start on time, stick to the schedule, and end on time.
- Encourage participants to introduce themselves.
- Conduct the opening discussion.
- Explain any group rules for the course. These may include opportunity for each person to talk (or not), need for respect, and avoidance of criticism or judgment of others.
- Encourage participants to ask questions and share comments.
- Take short breaks if needed
- Hand out participant take-home handouts.
- Conduct the training course evaluation at the conclusion of the course.

Evaluation

Individuals who use this training course are encouraged to evaluate the effectiveness of the training course for fathers who are raising a child diagnosed with ASD. A set of evaluation tools for use in such evaluation efforts has been developed and is included. The evaluation includes a pre-test and post-test.

Conclusion

Why is a training course for fathers who are raising a child diagnosed with ASD so important? Because, fathers are a critical part of a child's life and have a major impact on a child's development. It is the hope of the training course to educate and make fathers aware of the resources, activities, ideas, and support that is available to them and their families to help promote a positive environment for themselves, their child, and their family.

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APPENDIX 7

PERSONAL GOAL SHEET

APPENDIX 8

PROGRAM EVALUATION FORMS

Fathering a Child with ASD

Program Evaluation -- Pre-Program Form

This brief form is designed to gather feedback from fathers who participate in the parent training and support program. It should be completed at the beginning of participation in the program. Please take a moment to share your thoughts with us. Circle or check the answer that applies to you. When you have completed this form, please return it to the person who provided it to you.

Demographic Information

1. Age _____
2. Number of children _____
Ages of children _____
3. Family status
 - a. Married
 - b. Single (never married)
 - c. Remarried
 - d. Separated/Divorced
 - e. Cohabiting
 - f. Widowed
4. Education
 - a. Some high school
 - b. High school/GED
 - c. Some college
 - d. 2-year college degree
 - e. 4-year college degree
 - f. Master's degree or higher
5. Racial or ethnic background
 - a. Caucasian
 - b. Native American or Alaskan native
 - c. African-American
 - d. Hispanic
 - e. Other _____
6. Employment status
 - a. Employed full time (40+ hours a week)
 - b. Employed 26 to 39 hours a week
 - c. Employed less than 25 hours a week
 - d. Seeking employment
 - e. Not seeking outside employment (includes retired, student, etc.)
 - f. Other _____
7. My child diagnosed with ASD is:
 - a. Male
 - b. Female
8. Age of my child diagnosed with ASD _____
9. My relationship to this child is:
 - a. Biological father (or adoptive)
 - b. Stepfather
 - c. Grandfather
 - d. Other father figure (uncle, etc.)
 - e. Other caregiver (foster parent, etc.)

Please respond to the following statements using the scale below. Circle the appropriate response.

	1	2	3	4	5	6	7
	Very low	Low	Moderately Low	Moderate	Moderately High	High	Very High
10. My understanding of autism spectrum disorder and how it affects my child.	1	2	3	4	5	6	7
11. My feeling of support from within my family in raising a child with ASD.	1	2	3	4	5	6	7
12. My feeling of support from outside my family in raising a child with ASD.	1	2	3	4	5	6	7
13. My awareness of support resources in the community to assist my child and my family.	1	2	3	4	5	6	7
14. My level of confidence as a parent in raising a child with ASD.	1	2	3	4	5	6	7
15. My skills as a parent in assisting and guiding my child with ASD.	1	2	3	4	5	6	7
16. My links to other parents and families raising a child with ASD.	1	2	3	4	5	6	7
17. My efforts to proactively connect with my child with ASD.	1	2	3	4	5	6	7
18. My quality of relationship with my child with ASD.	1	2	3	4	5	6	7

Fathering a Child with ASD

Program Evaluation – Post-Program Form

This brief form is designed to gather feedback from fathers who participate in the parent training and support program. It should be completed at the end of participation in the program. Please take a moment to share your thoughts with us. Circle or check the answer that applies to you. When you have completed this form, please return it to the person who provided it to you.

Please rate how useful each of the following sources of information has been to you on raising a child with ASD. Circle the appropriate response.

	1	2	3	4	5	6	7
	Not at all useful		Some what useful		Moderately useful		Very useful
1. Your parents	1	2	3	4	5	6	7
2. Your spouse or partner	1	2	3	4	5	6	7
3. Other relatives or in-laws	1	2	3	4	5	6	7
4. Education system (school, special education, etc.)	1	2	3	4	5	6	7
5. Medical professionals (doctor, pediatrician, etc.)	1	2	3	4	5	6	7
6. Therapists or counselors	1	2	3	4	5	6	7
7. Parents with children with ASD or similar conditions	1	2	3	4	5	6	7
8. Support or advocacy groups	1	2	3	4	5	6	7
9. Books, magazines or articles	1	2	3	4	5	6	7
10. The Internet	1	2	3	4	5	6	7
11. Fathering a Child with ASD class and materials	1	2	3	4	5	6	7

Please respond to the following statements using the scale below. Circle the appropriate response.

	1	2	3	4	5	6	7
	Very low	Low	Moderately Low	Moderate	Moderately High	High	Very High
12. My understanding of autism spectrum disorder and how it affects my child.	1	2	3	4	5	6	7
13. My feeling of support from within my family in raising a child with ASD.	1	2	3	4	5	6	7
14. My feeling of support from outside my family in raising a child with ASD.	1	2	3	4	5	6	7
15. My awareness of support resources in the community to assist my child and my family.	1	2	3	4	5	6	7
16. My level of confidence as a parent in raising a child with ASD.	1	2	3	4	5	6	7
17. My skills as a parent in assisting and guiding my child with ASD.	1	2	3	4	5	6	7
18. My links to other parents and families raising a child with ASD.	1	2	3	4	5	6	7
19. My efforts to proactively connect with my child with ASD.	1	2	3	4	5	6	7
20. My quality of relationship with my child with ASD.	1	2	3	4	5	6	7

