

CALIFORNIA STATE UNIVERSITY, NORTHRIDGE

SUPPORT GROUPS FOR FAMILIES OF CHILDREN WITH AUTISM

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by

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ABSTRACT

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The purpose of this project is to create a PowerPoint explaining the importance of support groups for families of children with autism to teachers and school administration. Once they are educated on the meaning of the support groups they can begin to make referrals to their proper students and parents. In addition, they would not only have a better understanding of why some behaviors are displayed in their schools or classrooms by these students but they could learn how to address them in a more empathetic manner. If the teachers and school administration staff are prepared in recognizing typical behaviors that may be displayed by family members of children with autism then, they can become that child's advocate in seeking the proper help and support which may result in not only improving their home life but their behaviors at school. The main focus of the support groups is to reassure family members that they are not alone and that feelings of guilt, shame, and resentment are normal. The support groups provide people with an area where they feel safe to communicate with others who are going through similar situations.

Chapter 1

Introduction

“We may not choose where we come from, but we can choose where we go”

Unknown

There has been a noticeable increase in the number cases of children diagnosed with autism each year in the United States (Rotatori, Deisinger, Wahlberg, Burkhardt, & Obiaker, 2012). To give a better understanding of the prevalence of autism, the Autism Speaks website noted that there are more children each year being diagnosed with Autism than diabetes, cancer and AIDS combined. According to the current statistics on this website, Autism affects 1 in every 88 children and when broken down by gender it is diagnosed 1 in every 54 boys. Males are four times more likely than females to have autism however, females who have autism are more likely to exhibit severe Mental Retardation (American Psychiatric Association [APA], 2000). Since the current statistics suggest autism affects 1 in every 88 children, it makes autism one of the most common and devastating developmental disorders (Burras, 2012).

Statement of Need/Problem

There is evidence that Autism doesn't only affect the one who is diagnosed but that it affects the entire family; parents, siblings and grandparents. Verte, Roeyers and Buysee (2003), found that siblings of children with high functioning autism (HFA) between the ages of 6 and 11 years old internalized and externalized more behavioral

problems. Having a child with autism can not only be stressful but can be very tiring for the parents and if they have other children they may be too exhausted to pay attention to them, which may lead the “typical” children to feel alone. This then leads to problems because the typical children may then find alternative ways of getting their parents attention, which is typically done in a negative manner such as hitting others. Miller-Wilson (2012), stated that parents who have children diagnosed with autism not only have higher stress levels but also experience the following emotions; anger, frustration, resentment, despair, guilt, overwhelmed, lonely and embarrassment. Miller-Wilson (2012), also mentioned that depression and anxiety tend to impact the families of children with autism. With the statistics in children with autism rising, there is a need for public awareness in understanding the developmental disability.

Purpose

The initial step is to create a power point for teachers and school administrators on the importance of the need for a support group for the siblings and parents of children with autism. Many teachers and school administration staff are unaware of the stressors that families who have children with autism face. However, the ultimate goal and purpose of this project is to create a support group for parents and siblings of children with autism to have the opportunity to discuss and understand common difficulties that other parents and siblings in similar situations go through and for the families to have the chance to get nonjudgmental input. Families who have children with autism face many challenges and need the opportunity to discuss possible frustrations or concerns and be able to get feedback from other parents and siblings that are or have gone through similar struggles. This project would allow parents and siblings of children with autism to recognize that

they are not alone and to give them the opportunity to openly express difficulties they may be experiencing while not feeling afraid or ashamed. It is important for the siblings of children with autism to understand the importance of all the services their sibling may be receiving at home and at school in order to not feel a sense of resentment or jealousy due to all the attention. Therefore, there is a need for families of children with autism to have an understanding of the disorder in order to help not only those diagnosed but those who care for them.

Significance

As a result in this project, family members of children with autism will be able to gain a better understanding of the autism disorder, of possible behavioral strategies to help lessen possible stressors, along with building a greater support network with people who have or are faced with the same difficult circumstances. If the family is knowledgeable and trained in different treatment interventions they may be the ones to notice the greatest benefits.

Terminology

The following is a list of terminology:

Autism Disorder- “Autism is a severe developmental disorder that brings difficult changes into the family unit” (Kaminsky and Dewey 2002, p. 225) Common typical characteristics are as followed: delay in speech, resistance in change or changes in routine, insistence on similarity or repetition, lack of eye contact, sensitivity to sensory sensations such as light, sound, touch or certain textures, repetitive behaviors, known as “self-stimulatory behaviors,” such as rocking, hand flapping, or spinning objects, lack of

pretend play, inability to initiate or sustain conversation, lack of imitation, aloofness, preference for being alone, echolalic speech (repeating what has been said), and seeming not to hear others. (Boutot and Tincani, 2009, p.22).

Asperger's Disorder- According to the DSM-IV-TR some "essential features of Asperger's disorder are severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interests, and activities. In contrast to Autistic disorder, there are no clinically significant delays or deviance in language acquisition." (American Psychiatric Association [APA], 2000, P. 80).

In chapter II, which is the next chapter covers a variety of different areas in depth that relates to children with autism.

Chapter II

Review of Literature

The purpose of this chapter is to first introduce the reader to the concept of Autism and how it is diagnosed. The second is to explain and clarify the possible causes and treatments. The third is to describe examples of common characteristics. The fourth is to discuss the prevalence of the diagnosis. Lastly, is to explain the importance and benefits of group counseling.

Autism

The word “autism” comes from the Greek word “autos” which means “self”. The word autism is used to describe a person who is removed from social interactions; an isolated self (WebMD, 2012). Autism is an impaired or abnormal development in social interactions and communication (American Psychiatric Association, 2000). Autism is a disorder in which a person has problems with language, social skills, and may display repetitive, restricted behaviors (Clinical Reference Systems, 2010).

A person with autism can range from high functioning to very severe (Clinical Reference Symptoms, 2010). Autism is the most common disorder in a group of conditions called Autistic Spectrum Disorders (ASD), which could also be called Pervasive Developmental Disorders (PDD) (Clinical Reference Systems, 2010). There are five ASD disorders; Autism; the child exhibits problems with social skills, language, repetitive and restricted behaviors, Asperger syndrome; is a form of high-functioning autism in which they may display good language skills but have trouble being around others and may display behavioral problems, PPD-NOS (pervasive development disorder

not otherwise specified); this is a general diagnosis given to children when they do not meet all specific criteria of autism or Asperger syndrome but have some similar symptoms, Rett syndrome; is a very rare disorder that only affects girls in which autistic-like symptoms begin 6 to 18 months after birth, Childhood disintegrative disorder; is a rare disorder in which a child develops normally but then around the age of 3 or 4 begin to show autistic-like symptoms (Clinical Reference Systems, 2010).

Children with autism may have and display a variety of symptoms in the following areas; Social skills- they may resist being held or cuddled, may be withdrawn or fail to form relationships, may avoid eye-to-eye contact, and may prefer to play alone (Clinical Reference Systems, 2010).

Language and imitation- usually exhibits delays in speaking compared to children of the same age, cannot understand or copy speech or gestures, displays abnormal speech by pitch, rate, tone or rhythm, speech will be immature and unimaginative, propensity to make up words or echo what someone else says, and an inability to engage in fantasy or imaginative play such as storytelling or role playing (Clinical Reference Systems, 2010).

Behavior, activities, and interests- develop strong habits and compulsive behaviors, lining up cars or stacking blocks, difficulty to changes in routine, obsessed with one topic or idea, attachment to unusual objects like a car door, walk on tiptoes or flicks or twiddle fingers for long periods, head banging, rocking, staring, sudden screaming spells, and possible seizures (Clinical Reference Systems, 2010).

Sensory problems- problem with senses, sensitive to sounds, textures, tastes, smells, feeling of clothes on skin unbearable, will cover ears to loud sounds (Clinical Reference Systems, 2010).

Causes of Autism

Clinical Reference Systems (2010) mentioned that people who have autism have a problem in the brain which has been shown by brain scans. The brain scans showed that the structure or shape was different in children with autism, the cause is however unknown (Clinical Reference Systems, 2010). Autism like many other disorders sometimes runs in families and therefore there may be certain genes connected to autism (Clinical Reference Systems, 2010).

Barrus (2012), suggests that there is a biochemical etiology for a certain spectrum of autism based on a reaction between propionic acid and ammonia released by *Candida albicans* in the gastrointestinal tract. Ammonia and propionic acid create a reaction between one another that results in the production of beta-alanine, which is a chemical similar in composition to gamma-aminobutyric acid (GABA), which is an inhibitory neurotransmitter that has been presented to have higher quantities in autistic patients (Barrus, 2012). Having an excess amount of GABA has been proposed to be a possible contributor to autism (Barrus, 2012). Landrign (2010), stated that autism is a biologically based disorder of the brain development that implies that the cause is clearly due to genetic factors such as mutations, deletions and copy number variants. Other indirect evidence suggests that autism also comes from environmental contributions demonstrating the sensitivity of the brain such as lead, ethyl alcohol, methyl and mercury

(Landrign, 2010). However, evidence from studies done in early pregnancy found that the most powerful proof of concept evidence was detected by exposure in early pregnancy to misoprostol, thalidomide, valproic acid; maternal rubella infection; and the organophosphate insecticide, chlorpyrifos (Landrign, 2010).

The big question in looking for the cause of autism seems to be are vaccines the cause of autism? According to Rodriguez (2010) no, vaccines are not the cause of autism and Rodriguez went into detail to explain that the vaccine controversy began in 1998 when a physician in England did a small study based on reports from parents of 12 children with autism who claimed to have evidence showing that there was a relationship between autism and a combination of childhood vaccines such as the MMR also known as measles, mumps and rubella, the claim has since been widely refuted.

How Autism is diagnosed

Children with autism may appear to be normal during the first couple of months of life and then seem to become more unresponsive to you (Clinical Reference Systems, 2010). Diagnosis of autism occurs later than children who are born with obvious disabilities such as Down syndrome or cerebral palsy but earlier than dyslexia or attention deficit disorder (ADD) (Hornstein, 2011). Many parents notice that there might be a possible problem in their child's development when they compare them to other children their same age. Most parents notice this before their child's first birthday (Clinical Reference Systems, 2010). Autism can be diagnosed by general practitioners who have specialized training in autism but typically autism diagnoses are made by psychologist, psychiatrist, speech therapist, or neurologist (Clinical Reference Systems,

2010). According to the autism speaks website physicians use the Diagnostic and Statistical Manual (DSM) for mental disorders as a tool in determining the diagnosis of autism spectrum disorder.

According to the Diagnostic and Statistical Manual IV-TR by the American Psychiatric Association [APA], (2000), the diagnostic criteria for Autistic Disorder include the following:

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

- (1) qualitative impairment in social interaction, as manifested by at least two of the following:
 - (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (b) failure to develop peer relationships appropriate to developmental level
 - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
 - (d) lack of social or emotional reciprocity
- (2) qualitative impairments in communication as manifested by at least one of the following:
 - (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - (c) stereotyped and repetitive use of language or idiosyncratic language
 - (d) lack of varied, spontaneous make believe play or social imitative play appropriate to developmental level
- (3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

- (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
- (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)
- (d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder. (APA, 2000 P. 75).

Prevalence of Autism

Ahearn and Tiger (2013) believe that many see that autism has been seen as an epidemic with the belief that the increase of cases has been due to underlying environmental causes however, they believe the rise in autism prevalence is likely the result of improved surveillance, recognition, and the expansion of diagnostic criteria. Autism has had a 600% increase in the last 10 years (Van de Water, 2012). Autism diagnosis rates have been climbing steadily since the 1970's, in 1975 autism diagnosis rates were 1 in 5,000, in 1995 rates were 1 in 500, in 2001 autism rates were 1 in 250, in 2009 rates were 1 in 110, and now in 2012 autism diagnosis rates are 1 in every 88 (Van de Water, 2012). The number of people being diagnosed with autism has surpassed other major chronic conditions such as Multiple sclerosis, Crohn's disease, Type 1 diabetes, and Asthma (Van de Water, 2012).

Autism Treatments

According to the Centers for Disease Control and Prevention (CDC, 2012) there are currently no medications that can cure or treat the core symptoms of autism, however there are medications that can help people with autism manage symptoms of high energy levels, inability to focus, depression, and seizures. The U.S. Food and Drug Administration (FDA) approved risperidone and aripiprazole which are both antipsychotic drugs to treat people with autism who may experience severe tantrums, aggression, and self-injurious behaviors (CDC, 2012). Parents must monitor their children's progress and reactions while he or she is taking medications to make sure that the negative side effects do not outweigh the benefits (CDC, 2012). WebMD mentioned that between the 1960's-1970's treatments for autism focused pain and punishment by using medications such as LSD, electric shock therapy, and behavioral therapy.

Research has shown that early treatment services from birth to 3 years old help assist those children with autism on how to walk, talk and interact with others which means it is crucial for parents to contact their child's doctor if they believe that their child has autism or other possible developmental problems (CDC, 2012). Although early interventions has had the most positive effects on children with autism, interventions at any age can really be helpful (CDC, 2012).

There are several treatments available for people who have autism and some are broken down in the following categories:

-Behavioral and Communication Approaches -Applied Behavioral Analysis

(ABA) is widely accepted among schools and health care providers and treatment clinics.

ABA improves a variety of skills by discouraging negative behaviors while encouraging positive behaviors (CDC, 2012). The ABA approach has the greatest amount of empirical support for its effectiveness of behavioral and intervention techniques used with individuals with autism (Ahearn & Tiger, 2013).

-Occupational Therapy helps children with autism by teaching them life skills such as; getting dressed, eating, bathing and relating to others (CDC, 2012).

-Sensory Integration Therapy helps a person deal with certain sights, textures, sounds and smells (CDC, 2012).

-Picture Exchange Communication System (PECS) helps teach communication skills by using picture symbols to ask, answer questions and have conversations for those who cannot speak (CDC, 2012).

Some dietary treatments have been developed such as the gluten free casein free (GFCF) diets but unfortunately they do not have the scientific support needed in order to make it a widespread recommendation, dietary treatments are individualistic (CDC, 2012).

Some controversial types of treatment according to the CDC (2012) include but are not limited to:

1. Special diets that include eating duck fat.
2. Chelation, which is a treatment to remove heavy metals like lead from the body.
3. Biologicals such as secretin's.

4. Body Based systems such as deep pressure

Common Issues Faced by Family Members

There are many emotions that go through parents when they hear that their child has been diagnosed with autism such as feelings of anger, fear, guilt and other difficult emotions (Clinical Reference Systems, 2010). Having children with autism causes stress on the entire family by putting tension not only on sibling relationships, marriage, but on finances as well (Clinical Reference Systems, 2010). According to a study done by Rivers & Stoneman (2003) they found that when marital stress was high, typically developing siblings reported more negative behaviors and less satisfaction directed towards their sibling with autism. Rivers & Stoneman (2003) reported that family stress originates in the marital relationship and that whether the typically developed children sense or witness any difficulties between their parents' relationship will cause problems to arise by negative behaviors. A study performed by Kaminsky & Dewey (2001) found that there were low levels of intimacy and social behaviors between siblings of families who had children with autism. Beyer (2009) stated that it is very difficult for typically developed siblings to have a "normal" sibling relationship when their brother or sister has autism because of the cognitive limitations, as well as the social and behavioral challenges involved with autism. Sibling relationships play a key role in learning how to understand others emotions and thoughts, when a sibling is unable to cognitively recognize them it puts the other typically developed siblings in jeopardy of their developmental growth (Beyer, 2009). Siblings of individuals with autism had high levels of internalizing and externalizing behavioral problems (Ross & Cuskelly, 2006). Aggression and anger was identified to be the most common types of behaviors displayed

within sibling interactions of children with autism (Ross & Cuskelly, 2006). Siblings of children with autism whether they are older or younger tend to become their siblings second parent by taking care and disciplining them (Beyer, 2009). Parents tend to put added stress and pressure on the typically developed children to assist them with their child who has autism, which then can lead to negative relationships between the siblings (Beyer, 2009). Beyer (2009) mentioned that typically developed siblings tend to report having feelings of resentment due to their sibling with autism getting all the family's special attention and being allowed to display what would be considered inappropriate behaviors by other family members.

Findings from Benson & Karlof (2009) study indicated that parents face a significant amount of psychological distress when raising a child with an autism spectrum disorder and have a higher level of anger which affects their well-being in both direct and indirect ways. Parents face several struggles when they are dealing with their child with autism and a lot of parents face isolation from society and even family members due to their child's tantrums and uncontrollable/ unpredictable behaviors (Hillman, 2007). Hillman (2007) stated that the presence of autism changes the structure of the family, as well as increasing the family's risk for stress and depression. Hillman (2007) stated that previous studies reported parents of children with autism had higher stress levels than parents of children with mental retardation, cerebral palsy, and Down syndrome. When examining marital rates among parents of children with disabilities compared to those with typical developing children the marital rates are lower and the divorce rates are higher (Hillman, 2007). Gray (1993) results found that mothers tend to feel more stigmatized by their child's autism disorder than fathers. There are more single mothers

who undertake the care of their child with disabilities and findings suggest that two thirds of mothers who have children with autism suffer from depression (Hillman, 2007).

Studies found that the mothers stress level was related to the child of autism's behavior whereas, the fathers stress level wasn't associated with the challenging behaviors but associated with their partners depression (Meadan, Halle, & Ebata, 2010).

Meadan, Halle, & Ebata (2010) listed 7 of the most common concerns of parents of children with autism which are as followed: (a) the permanency of the condition, (b) lack of acceptance of behavior associated with ASD by family members and society (c) low levels of support (d) economic burden, including negative impact on parents' career/ income (e) parents' concern about the future for their children in adulthood (f) challenging behaviors with ASD (g) psychological factors of the parents such as locus of control, coping style, and perceived self efficacy.

Traditionally, the grandparents' role with their grandchildren has been to share and provide past experiences in a way to reconnect with the past in order to continue the family's legacy (Hillman, 2007). Hillman noted that previous research found that grandparents of autistic children hurt twice: once being for their child and another for their grandchild, and go through a period of mourning. Grandparents express grief over their grandchild's disability which has caused a sense of conflict with the parents (Hillman, 2007). Unfortunately, it is very common for parents and grandparents to experience difficulties in communication which result in feelings of sadness, frustration, and disappointment (Hillman, 2007). Grandparents provide both emotional and instrumental support to the parents of children with autism through various activities (Hillman, 2007). When examining African- American and Latino cultural norms they

both tend to put an emphasis upon family unity and past researchers found that grandparents of children with developmental disabilities were at a greater risk for depressive symptoms (Hillman, 2007).

Benefits of Support Groups

Families who have children with autism can benefit from attending support groups by sharing common concerns and possible solutions to problems with other families who are in similar situations (Clinical Reference Systems, 2010) When families were experiencing high marital stress Rivers and Stoneman, (2003) found that when the family actively participated in social support groups they benefitted by the siblings displaying and increase in positive behaviors and higher sibling satisfaction. Social support groups were found to help decrease depressed moods of family members of children with autism regardless of their stress level (Benson & Karlof, 2009).

Yalom & Leszcz (2005) believe therapeutic change occurs through “intricate interplay of human experiences” which they have listed into eleven primary therapeutic factors as followed:

1. Instillation of hope- Not only is hope required to keep the client in therapy so that other therapeutic factors may take effect, the power of expectations extends beyond imagination alone. Seeing others getting better is inspiring, seeing that others have solved problems similar to our own.

2. Universality- Many individuals enter therapy with the disquieting thought that they are unique in their wretchedness, that they alone have certain frightening or

unacceptable problems, thoughts, impulses, and fantasies. Learning I'm not the only one with my type of problem; "We are all in the same boat", Misery loves company".

3. Imparting information- Under the general rubric of imparting information, I include didactic instruction about mental health, mental illness, and general psychodynamics given by the therapists as well as advice, suggestions, or direct guidance from either the therapist or other group members.

4. Altruism- In therapy groups, as well as in the story's imagined Heaven and Hell, members gain through giving, not only in receiving help as a part of the reciprocal giving-receiving sequence, but also in profiting from something intrinsic to the act of giving. Putting others' needs ahead of mine, giving part of myself to others.

5. The corrective recapitulation of the primary family group- The therapy group resembles a family in many aspects: there are authority/parental figures, peer/sibling figures, deep personal revelations, strong emotions, and deep intimacy as well as hostile, competitive feelings.

6. Developmental of socializing techniques- Social learning- the development of basic social skills- is a therapeutic factor that operates in all therapy groups, although the nature of the skills taught and the explications of the process vary greatly, depending on the type of group therapy. Many lament their inexplicable loneliness: group therapy provides a rich opportunity for members to learn how they contribute to their own isolation and loneliness.

7. Imitative behavior- Clients during individual psychotherapy may, in time, sit, walk, talk, and even think like their therapists. There is considerable evidence that group

therapists influence the communicational patterns in their groups by modeling certain behaviors, for example, self-disclosure or support.

8. Interpersonal learning- It is the group therapy analogue of important therapeutic factors in individual therapy such as insight, working through transference, and the corrective emotional experience.

9. Group cohesiveness- Cohesiveness is the group therapy analogue to relationship in individual therapy. Feeling of belonging to and being accepted by a group, feeling alone no longer.

10. Catharsis- Getting things off my chest, learning how to express my feelings, being able to say what was bothering me instead of holding it in.

11. Existential factors- Recognizing that life is at times unfair and unjust, learning that I must take ultimate responsibility for the way I live my life no matter how much guidance and support I get from others.

The distinctions between these factors are subjective and are interdependent and neither occurs nor function separately (Yalom & Leszcz, 2005).

There are thousands of support groups worldwide online or in person that focus in autism related subjects. According to an article in the New York Times by Jane Gross (2004), stated that in 1990 the first sibling support group had children who had siblings with either Down syndrome or cerebral palsy and that now since the increase in diagnosis of autism the focus has shifted. A testimonial by a 16 year old girl who has a younger brother with autism was conducted in a study that interviewed siblings of children with

autism, she stated that being the “normal” child meant often being left with feelings of guilt, frustration and neglect (Fujimori, 2011). Fujimori (2011) went on to discuss this young women’s determination to change the feelings that not only she has been feeling but of her peers as well. This young women not only raised money for a charity called Post-21 Club of Bergen County which provides programs for those with autism after they are too old for school programs but she also developed her own support groups for people in similar situations to hers (Fujimori, 2011). This is just one of several similar articles from children who have siblings with autism and all have ended by stating that by participating in support groups whether they were online or in person gave them the sense of feeling that they were not alone and that the feelings of guilt, anger and neglect were common and should not feel ashamed. Autism Speaks Social Network has several support groups specifically geared to better assist those depending on their needs such as “Autism moms”, “Autism dads”, “Autism Single parents”, and “My Life as a Parent With Autism Group” just to name a few (Carpenter, 2009). These groups have anywhere from 200-700 members involved (Carpenter, 2009).

Chapter III

Project Audience and Implementation Factors

As presented in the previous chapters, research has shown an increase of the number of children diagnosed with autism over the last 10 years. As the number of children diagnosed with autism continues to rise, the number of families affected also increases. Research has shown that sibling relationships play a vital role in the social and behavioral environment of children. It is crucial for the siblings and parents of children with autism to seek and participate in support groups so that they can openly discuss with others, who have similar situations, their difficulties and/or help and give others feedback or resources. Based on the literature review I will be providing a PowerPoint for teachers and school administrators which will sensitize them to the issues siblings and other family member's face when they have a brother or sister diagnosed with autism.

Support group guidelines/ structure

- Teachers who have children or siblings with autism will be able to refer their students and families to local support groups run by Regional Center employees, MFT trainees and or MFT interns who specialize in autism.
- Every meeting will have three designated areas (parents, siblings, and "daycare" rooms for the children with autism)
- Support group meetings will last for sixty minutes once a week.
- Every meeting will be an open meeting, meaning anyone can come.
- Every meeting will be an open speaker meeting meaning anyone can volunteer to speak and or share.

- Every meeting will have a group leader/facilitator to assist the group and to make sure that group members are following the group rules of respect and confidentiality.
- The group leader/facilitator will be in charge of deciding on the nightly topic and then open it up to the group members to voluntarily participate.
- Meetings for Spanish, Hebrew, Chinese, Korean, Japanese, Italian etc. speaking families will be held at designated areas, which will be labeled.
- Meetings will be free of charge but will accept donations for “daycare” supplies.

Meetings will not have a specific agenda that they need to follow during their sessions except for the facilitator to go over group norms at the beginning of every session since meetings are open and people come and go from week to week and for the group facilitator to ask if anybody has anything they wanted to share or discuss with the group after they go over group norms. After the group leader goes over the group norms and the layout of the meeting he/she will then ask the group about a specific topic or question. Group members are the ones who control what they want to discuss or share, the facilitators job is to make sure that everyone is having equal time to share and that everyone is respectful of one another.

Environment and Equipment

The support groups will be held on school campuses, local churches or recreational centers. Each meeting will have three rooms; parents room, sibling room, and baby sitting room. The sibling and parent room will be provided with detached chairs

in order to make a group circle to make sure everyone can see who is speaking and have a better setting for building relationships. The babysitting room will be provided with toys such as play dough, cars, blocks, balls, etc. for the children with autism to play with while their parents are in their support group.

Chapter IV

Conclusion

The purpose of this chapter is to summarize the previous chapters and to provide the author's thoughts and concerns regarding the project. In addition, this chapter will also provide some suggestions for future research in order to get a more in-depth understanding of clients who have siblings with autism.

Summary

The purpose of this project is to create a PowerPoint for teachers and school administration to educate them on the issues siblings and other family member's face when they have a brother or sister diagnosed with autism and to communicate the importance for them to attend support groups. Once the siblings and/or other family members attend a support group they will have a better sense of a community and belonging. In addition, the teachers and administration staff will be able to recognize some common behaviors expressed by the siblings and/or other family members of children with autism in order to make the support group referral. If the teachers and administration staff are knowledgeable concerning the behaviors expressed by their students they can take steps to provide them with a support group where they are allowed to express their feelings in an area that is free of judgment and learn possible coping skills or strategies from others in similar situations as themselves.

Discussion

Children who are diagnosed with autism typically receive many services through the state such as speech therapy, occupational therapy, physical therapy and behavioral therapy to name a few, but the family members of those children do not usually receive any services for themselves such as individual or group counseling. I am sure that as the autism rates continue to rise there will be an increase in resources for the family members of children with autism as well.

In my opinion as being a special education assistant, special education teachers and autism specialists and their teams do an outstanding job in providing the child with autism with many necessary services. My main focus however is the well-being of the surrounding family members of those children. Feelings of depression, resentment, anger, isolation and an increased risk of divorce are only a few symptoms felt by siblings and family members of children with autism. I believe these symptoms will improve with the ability to attend a support group.

Future Work/ Research

It is important to point out that the information provided focused heavily on the negative side effects siblings and family members of children with autism may experience and that not all experiences may be negative. It would be of interest to study different cultures and religions in the diagnosis of autism and treatment for surrounding family members.

In addition, more in depth research can be offered on the longterm financial concern that comes along with the diagnosis of autism for not only the patient and family members but also the society

References

- Ahearn, W., & Tiger, J. (2013). Behavioral approaches to the treatment of autism. APA Handbook of Behavioral Analysis, Vol. 2: Translating Principles into Practice, 301-327.
- American Psychiatric Association. (2000). Diagnostic and statistical manual of mental disorders (4th ed., text rev.). Washington, DC: Author.
- Autism. (2010). Clinical Reference Systems, 2012 (1), NA. Retrieved on October 24, 2012 from <http://go.galegroup.com/ps/i.dp?id=GALE%7CA218206180&v=2.1&u=csunorthridge&it=r&p=HRCA&sw=w>
- Autism spectrum disorders. (2010). Clinical Reference Systems, 2010 (1), NA. Retrieved on October 24, 2012 from <http://go.galegroup.com/ps/i.dp?id=GALE%7CA218206180&v=2.1&u=csunorthridge&it=r&p=HRCA&sw=w>
- Autism Speaks. (2012). What is autism?. Retrieved on October 25, 2012 from <http://www.autismspeaks.org/what-autism>
- Autism spectrum disorders health center (2009). Retrieved on October 20, 2012 from <http://www.webmd.com/brain/autism/mental-health-autism>
- Benson, P., & Karlof, K. (2009). Anger, stress proliferation, and depressed mood among parents of children with asd: A longitudinal replication. Journal of Autism and Developmental Disorders, 39(2), 350-362.

- Burrell, T., & Borreg, J. (2012). Parents' involvement in asd treatment: what is their role?. *Cognitive and Behavioral Practice*, 19(3), 423-432.
- Burrus, C. (2012). A biochemical rationale for the interaction between gastrointestinal yeast and autism. *Med Hypothesis*.
- Centers for disease control and prevention. (2012). Retrieved on October 24, 2012 from <http://www.cdc.gov/ncbddd/autism/treatment.html>
- Eyler, L.T., Pierce, K., & Courchesne, E. (2011). A failure of left temporal cortex to specialize for language is an early emerging and fundamental property of autism. *A Journal of Neurology*, 949-960.
- Hillman, J. (2007). Grandparents of children with autism: A review with recommendations for education, practice, and policy. *Educational Gerontology*, 33(6), 513- 527.
- Hornstein, S. (2011). Changes in mothers' experiences of receiving an autism diagnosis: A contextualized case study. ProQuest LLC.
- Johnson, N., Frenn, M., Feetham, S., & Simpson, P. (2011). Autism spectrum disorder: Parenting stress, family functioning and health-related quality of life. *Families, Systems, & Health*, 29(3), 232-252.
- Langrigan, P. (2010). What causes autism? Exploring the environmental contribution. *Current Opinion in Pediatrics*, 22(2), 219-225.
- Luther, E., Canham, D., & Cureton, V. (2005). Coping and social support for parents of children with autism. *Journal of School Nursing*, 21(1) 40-47.

- Matson, J., Hattier, M., & Williams, L. (2012). How does relaxing the algorithm for autism for autism affect dsm-v prevalence rates?. *Journal of Autism and Developmental Disorders*, 42(8), 1549-1556.
- Mazumdar, S., Liu, K., Susser, E., & Bearman, P. (2012). The disappearing seasonality of autism conceptions in california. *PLoS One*, 7(7), e41265.
- Meadan, H., Halle, J., & Ebata, A. (2010). Families with children who have autism spectrum disorders: Stress and support. *Exceptional Children*, 71(1), 7-36.
- Miller-Wilson, K. (2012) Impact on families of autistic children. Retrieved on September 11, 2012 from http://autism.lovetonknow.com/Impact_on_Families_of_Autistic_Children
- Rivers, J.W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders*, 33(4), 383-394.
- Rodriguez, D. (2012). Do vaccines cause autism? Retrieved on October 24, 2012 from <http://www.everydayhealth.com/autism/vaccines-autism.aspx>
- Ross P., & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual and Developmental Disability*, 31(2), 77-86.
- Rotatori, A., Deisinger, J., Wahlberg, T., Burkhardt, S., & Obiakor, F. (2012). An innovative community-based clinic that serves individuals with autism spectrum

disorders. *Autism Spectrum Disorders: Inclusive Community for the Twenty-first Century*, 139-161.

Rivers, J.W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: marital stress and support coping. *Journal of Autism and Development Disorders*, 33(4) 383-394.

Tomeny, T.S., Barry, T.D., & Bader, S.H. (2011). Are typically- developing siblings of children with autism spectrum disorder at risk for behavioral, emotional, and social maladjustment? *Research in Autism Spectrum Disorders* (6), 508-518.

Van de Water, J. (2012) Immunologic factors in the etiology of autism. PowerPoint presented at the Help Group Summit, Los Angeles, California.

Verte, S., Roeyers H., & Buysse, A. (2003). Behavioral problems, social competence and self-concept in siblings of children with autism. *Child, Health & Development*, 29(3), 193-205.

Yalom, I.D., & Leszcz, M. (2005). *The theory and practice of group therapy*. Fifth edition. (pp. 1-111). New York, NY: Basic Books.