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Visualizing Levels of Family Satisfaction and Quality of Life in Families with an Autistic Member(s)

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VISUALIZING LEVELS OF FAMILY SATISFACTION AND QUALITY OF LIFE IN
FAMILIES WITH AN AUTISTIC MEMBER(S)

By

Sarah Christolini and Camille Werstler

A research paper presented to the

FACULTY OF THE DEPARTMENT OF
MARITAL AND FAMILY THERAPY
LOYOLA MARYMOUNT UNIVERSITY

In partial fulfillment of the
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MASTER OF ARTS

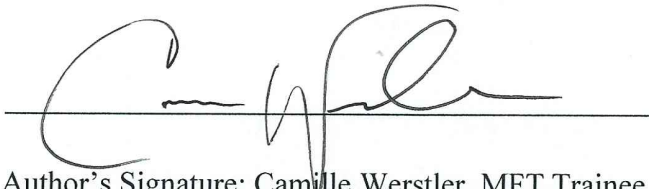
May 11, 2014

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

Signature Page

A handwritten signature in cursive script, reading "Sarah Christolini", written over a horizontal line.

Author's Signature: Sarah Christolini, MFT Trainee

A handwritten signature in cursive script, reading "Camille Werstler", written over a horizontal line.

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Research Project Mentor's Signature: Paige Asawa, PhD

Abstract

This research served to visualize levels of family satisfaction and quality of life in families with an Autistic member(s). Art-based qualitative survey was the primary method of gathering data. The vast majority of the literature on autism focused on the treatment of the child, yet some literature suggested a re-focusing on the family as the unit of treatment may improve family satisfaction and quality of life. Taking this into consideration this research explored how parents experience family satisfaction through written and visual responses. The theme of independence for the child with autism was present in all five visual responses which suggested a desire to see their child functioning autonomously. Due to the inherent bias of therapy's affect on relationships it was surprising that approximately half of the participants reported not experiencing a change in their relationship with their child after treatment. Both the data gathered and the literature reviewed lead to the research conclusion that the caregivers of a child with Autism experience a higher level of family satisfaction when they are flexible and gain support from mental health services and a community of family and friends.

Disclaimer

The information found in the research paper is based on the independent study derived from the researchers' review of the literature and data collected from the submitted qualitative questionnaire surveys. Loyola Marymount University cannot be held accountable for any of the information provided in this paper. The names and locations of the participants were not collected in this study to maintain confidentiality.

Dedication

This research is dedicated to all of the parents and families with a child or family member(s) on the Autistic Spectrum who struggle and strive on a daily basis to achieve some level of family life satisfaction. We thank the participants for their open and honest responses and the rich information they shared for this project.

Acknowledgments

We would like to thank Loyola Marymount University and specifically Dr. Paige Asawa, our research mentor, for their guidance, support, and encouragement throughout the research process. We would also like to thank our partners, families, and friends for their unconditional love and support. Last, but certainly not least, we would like to thank those who assisted in sharing with others about this research, those who visited the website, and the participants from which data was collected.

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Introduction

The Study Topic

The research served to explore and visualize levels of family satisfaction and quality of life in families with an Autistic member(s). The primary method of gathering data in this research was art-based qualitative survey. The literature on autism was mainly concerned with the diagnosis and treatment of the child. However, some literature suggested that a re-focusing on the family as the unit of treatment rather than the identified patient (IP) may assist in the reported improvement of family satisfaction and quality of life. This research explored how parents experience family satisfaction and assisted with visualizing these moments to capture the important qualities and meaning. The following research questions were informed by the literature and stemmed from personal curiosity and experience:

- 1) Can life satisfaction be achieved for families with an Autistic member(s)?
- 2) How can art therapy play a factor in the happiness of families with an Autistic member(s)?
- 3) How can art therapy make visible the possibility for families with an Autistic member(s) the opportunity to experience life satisfaction?

Significance of the Study Topic

Much of the current research on Autism focuses on the diagnosis and treatment of the individual; however, researchers believed that exploring the levels of family satisfaction and quality of life would support the recommendation of a re-focusing on the family as the primary unit of treatment. This study attempted to support the premise that family satisfaction can better support the family and individual with Autism rather than individual treatment. The current research available identified the impact of an autism spectrum diagnosis on a family and the

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grieving that occurs throughout the life of the family. The research also identified aspects of family functioning that are impacted by having a child on the autistic spectrum. However the research identified the necessity for further research on the treatment and support of the family as a unit.

Personal experiences of life satisfaction and mental disorders led the projects' researchers to explore creatively what happiness might look like for this specific population. Considering how other families might have also experienced the unconditional love and encouragement of life satisfaction, there was a desire to know more about what makes families happy, and if they are able to articulate their "happiness" through images, what similarities and differences might exist.

One of the researcher's has a younger brother with Down Syndrome, which provided a deeper and more personal understanding and passion for the research. This familial experience was what led her to peruse a career in mental health where she worked with children and their families on the autistic spectrum and with behavioral or emotional issues.

Due to the lack of art therapy literature concerning this topic, this research contributed to the understanding of family dynamics, family satisfaction, and strengths when challenged with the care of a member on the autistic spectrum. It is important to remember that "both normal children and children with autism thrive in an environment of patience, acceptance, and understanding" (Emery, 2004, p. 147). The future holds great potential for further research and understanding in this field and working with this population. The data gathered for this study offered an opportunity for further clarity on how to support children with Autism and their families.

Background of the Study Topic

According to the DSM-IV TR (2000), Autism is a disorder in which a person has abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity. The diagnostic criteria according to the DSM-IV TR includes: delays or abnormal functioning prior to three years old, in at least one of the following: social interaction, language as used in social communication, or symbolic or imaginative play. In addition, one must have ruled out that the behavior is not better accounted for by Rhetts's Disorder, or Childhood Disintegrative Disorder (DSM-IV TR, 2000).

The majority of articles on children with autism focused on the individual with the diagnosis. However the literature showed that the diagnosis has an impact on family functioning. Feetham (2007) explained that "family functioning includes a commitment to support the functions of the family that include: economic, safety, child rearing, care giving, and communication" (Johnson, Frenn, Feetham & Simpson, 2011, p. 233). Andrews, Bubolz, & Paolucci, (1980) stated that "family functioning includes generational relationships, unique sets of rules, priorities, and ethics. The family is also considered to be a mediator between the individual and the environment" as cited in (Johnson, Frenn, Feetham & Simpson, 2011, p 232).

Treatment specific to ASD (autism spectrum disorder) should also be sensitive to the unique diagnostic considerations of the population, for example children with "autism in general tend to express anxiety through changes in their behavior rather than verbally. Therapists may therefore note that depression and anxiety will not always be verbalized by the client, but may become apparent through behavioral changes," and Woods also suggested that "individuals with ASD may not have diminished emotionality, however it may be more accurate to say that individuals with ASD have greater difficulties in understanding and compartmentalizing their

own emotions or in conveying these to others” (Woods et al., 2013, p. 3). The literature's findings on treatment effectiveness are diverse, but what appeared congruent between documents is the consideration that each client’s individual needs and presenting problems must inform the treatment.

Some studies suggested that a considerable number of families with a member(s) of Autism display characteristics of resilience and report becoming stronger due to their specific familial disability. Evidence from similar studies suggested that family connectedness and closeness, positive meaning-making of the disability, and spiritual and personal growth have been factors in this process of recovery. Our research offered a visual display of what is referred to as life satisfaction, which for some, perhaps means resilience.

In recent years, the direction of disability research has shifted from a unitary focus on individual quality of life to a broadened examination of perspectives held by the entire family unit. The emergence of key theories, including Bowlby's (1969) attachment, Bronfenbrenner's (1979) ecological, and Turnbull, Summers, and Brotherson's (1984) family systems (as specifically related to families of a child with disability), have spurred a paradigmatic shift in the nature of family-related practice and policy. It is now understood that the family unit constitutes a dynamic, interconnected, and self-regulating system within which each individual is understood to be influenced by a set of shared, yet also unique, contextual factors. As such, disability theorists and practitioners have broadened their unitary, child-centered perspectives, and now seek to understand, from multiple levels of analysis, how child, family, and service characteristics, as well as surrounding socio-cultural contexts, interact and overlap in their contributions to family functioning. From this perspective, the significant ways in which having a child with a

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disability impacts all family members, including parents and siblings, can be addressed.

(Gardiner, E. & Iarocci, G., 2012, 2178)

This research served to demonstrate the impact the child with ASD has on the level of family life satisfaction and quality of life and how it might be experienced differently than what we describe as “normal” and yet still be achieved if supported by the various systems and treatment modalities.

Literature Review

Introduction

This research paper served to examine how Autism might affect the levels of family satisfaction and quality of life for families with a child on the Autistic spectrum. This section explored the literature on the definition of Autism, its surrounding myths, its affects on family functioning, and a brief overview of some of the modalities for individual and family treatment. Exploring the literature for a better understanding of Autism in children specifically, and the benefits and affects of art therapy for this population, was also examined.

The literature on autism is mainly concerned with the diagnosis and treatment of the child. However, some literature suggested that a re-focusing on the family as the unit of treatment rather than the identified patient (IP) may assist in the reported improvement of family satisfaction and quality of life. The research in this paper aimed to review the information available that might provide a clearer understanding of what families with an Autistic child need to improve their family satisfaction by looking at the available research on life satisfaction, autism in children, myths surrounding the diagnosis, and its effects on family functioning. Finally, research available on modalities of treatment for children with Autism and more specifically, art therapy's affect in treatment, was explored.

Life Satisfaction

Consensus has yet to be reached on how to best assess happiness. Diener (2009) pointed out that the specific measurements used in happiness research can lead to different conclusions, meaning it is important to consider the degree to which different studies assess the same construct. Much research in this area including the work by Bartels & Boomsma, (2009), DeNeve & Cooper (1998), and Diener, (2009) focused on subjective well-being; "a construct

composed of positive affect, negative affect, and life satisfaction”(Matteson, L. K., McGue, M. K., & Iacono, W., 2013, p. 90).

Research demonstrated the uniqueness and variance in formulating a working definition of family satisfaction. Gardiner and Iarocci for instance stated that family satisfaction “is now understood that the family unit constitutes a dynamic, interconnected, and self-regulating system within which each individual is understood to be influenced by a set of shared, yet also unique, contextual factors” (2012, p. 2178-9). This supported Sipos et al. definition that “the quality of life represents a dimension of the overall status and well-being that might be influenced by various factors” (2012, p.1).

Understanding Autism

Autism Spectrum Disorder (ASD), also known as pervasive developmental disorder (PDD), is a neuro-developmental set of disorders (Emery, 2004; Epp, 2008; Evans, 1998; Gazeas, 2012; Martin, 2008; Martin, 2009). To better understand Autism, one must consider the criteria required by the DSM-IV TR (2000) for a diagnosis of the disorder and its clinical definition. “The DSM-IV places autism in the broad, umbrella category of Pervasive Developmental Disorders (PDD). PDD in children are characterized most notably by severe delays in social and communication skills” (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 212). The research broadened this understanding by incorporating the first documented case and distinguishing characteristics.

As quoted in Neely, Amatea, Echevarria-Doan & Tannen,

Autism is a disorder that is social in nature. Three separate areas of need distinguish children with autism...these children usually have difficulty with social interactions (e.g., no interest in playing with others or understanding of reciprocity in interactions with

other children)...communication is often severely impaired, and in some cases, verbal skills are non-existent...[and] is stereotypic behaviors (e.g., hand flapping, or intense body rocking), along with restricted interests and activities. (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 212)

According to the DSM-IV TR (2000), Autism is a disorder in which a person has abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity. The diagnostic criteria according to the DSM-IV TR includes: delays or abnormal functioning prior to three years old, in at least one of the following: social interaction, language as used in social communication, or symbolic or imaginative play. In addition, one must have ruled out that the behavior is not better accounted for by Rhett's Disorder, or Childhood Disintegrative Disorder (DSM-IV TR, 2000).

Three categories are included in the criteria for a diagnosis of Autism: 1) Qualitative impairment in social interaction, such as impairment in the use of nonverbal behaviors such as eye-to-eye contact, body postures and gestures; failure to develop peer relationships appropriate to developmental level; a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people; or lack of social reciprocity; 2) Qualitative impairments in communication, such as: delay in or lack of the development of spoken language; impairment in the ability to initiate or sustain a conversation with other people; repetitive and stereotyped use of language; or lack of varied, spontaneous imaginative play or social imitative play; 3) Restricted repetitive and stereotyped patterns of behavior, interest, and activities, such as : encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal; inflexible adherence to specific, nonfunctional routines or rituals; stereotyped and repetitive motor mannerism; or persistent preoccupation with parts of objects (DSM-IV TR).

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With an onset before age three years old, some parents have reported suspicion of their child having the diagnosis soon after birth (DSM-IV TR, 2000). Most diagnoses are easier to recognize though after the age of two years old, when impaired social interactions and lack of interest in activities becomes more obvious to the caregiver. According to the DSM-IV TR (2000), there is an increased risk of Autism among siblings of a child with the disorder with an estimated 5% of siblings also having the diagnosis.

From a diagnostic viewpoint, autism is a pervasive developmental disorder involving delays in social interaction, social communication, and social imagination (Emery, 2004; Evans, 1998; Gazeas, 2012; Henley, 1989; Martin, 2008; Martin, 2009). This ‘triad of impairment’ present from birth, as noted above, is generally diagnosed in the first three years of childhood and impacts the individual throughout his or her life (American Psychiatric Association, 1994; Emery, 2004; Kornreich & Schimmel, 1991) and arguably the family’s.

Many forms of developmental delay and autism, as well as trauma and psychiatric problems with children, often prohibit or slow down normal development resulting in individuals who have not achieved the separation (from the primary caregiver necessary for individuation- the development of a more or less autonomous self) and live in a world of confusing objects in which they cannot find a place for themselves. (Dubowski & Evans, 2001, p. 12)

With this knowledge, it was apparent that family support and resources allowed families and opportunity to experience family life satisfaction. “Art therapy can be a valuable addition to the multidisciplinary treatment approach for [children with] ASD” (Gazeas, 2012, p. 15). With the increase in prevalence it was important for researchers and clinicians to find effective ways of treatment options to enhance the lives of individual’s with Autism so that they might live

more fully in the community (Emery, 2004; Epp, 2008; Evans, 1998; Gazeas, 2012; Martin, 2009).

“Humans are social beings for whom there is a strong, fundamental drive to form relationships of many kinds (Baumeister & Leary, 1995). Yet, children with autism lack the capacity to form relationships in a manner that is in accordance with a typically developing child” (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 215). Understanding Autism as a parent or caregiver, as a child or family member, and as a clinician was important for processing the disorder and the challenges one might face.

Myths surrounding the Diagnosis of Autism

The research surrounding Autism’s origins focused on clarifying myths surrounding the diagnosis of Autism. Research has found that some of the myths related to diagnosis have to do with blaming the parents and subsequent guilt they feel as a result. The literature suggested that many parents have heard that “autism is the result of some emotional distress experienced by the mother during pregnancy or as a result of bad parenting.” (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 213). This may cause additional stress to the mother and likely lead to a decrease in felt/experienced level of life satisfaction despite that a definitive cause for autism is truly unknown. What is known is that “there is a complex interplay between genetics and other environmental factors” (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 213) and that emotional distress or ‘bad parenting’ is not the cause for the mental illness.

Neely identified the myth that “A person with autism cannot be educated” and challenges this notion by suggesting that “one of the most effective interventions for autism is educational in nature.” (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 213). Neely explains that individuals with autism need highly “individualized educational environments in which they can

receive both life skills and occupational skills training” (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 213) increasing the possibility for greater autonomy of the child and family satisfaction of the caregiver.

Neely also contradicted the idea that all “people with autism do not make eye contact, smile, laugh, or show other signs of affection” and explained, “while autism is a disorder characterized by impairments in social interactions, people with autism are capable of affection and emotions” (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 213).

People with autism are not as responsive to typical social cues, so the person with whom they are interacting must show more understanding in the interaction. The lack of response to normal social cues does not mean there is an absence of typical human emotions and feelings (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 213)

This was key to remember when exploring this topic because just because the emotions and communication style is different in families with ASD member(s), they are still able to and imagine achieving some degree of high life satisfaction/quality of life.

Some parents disregard a diagnosis of Autism and or refuse treatment because they believe their child “will outgrow current problem behaviors” (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 213). However Neely asserted that, “Autism is a life-long disorder with no cure. A child with autism will become an adult with autism. It is harmful to suggest that a child will “grow out of” problem behaviors reported by a parent. While elimination of problem behaviors might be unattainable, there are effective interventions available to reduce problem behaviors, as well as teach daily living skills to help a child with autism lead a more normal life” (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 213) and the family achieve a higher degree of life satisfaction/quality of life.

The claim that there has been a substantial rise in Autism is controversial. The Center for Disease Control (2012) marked Autism as the fastest growing developmental disability in the United States and notes the uncertainty as to why this noticeable increase has occurred. Hollander (2003) suggested the increase in prevalence of Autism may be due to several factors including improvement in diagnostic tools and broader definition of the disorder as well as better efforts in diagnosis (Center for Disease Control, 2012).

Autism's Effects on Family Functioning

The majority of articles on children with autism focused on the individual with the diagnosis. However the literature showed that the impact of this diagnosis had a significant effect on the family functioning. Feetham (2007) explained that “family functioning includes a commitment to support the functions of the family that include: economic, safety, child rearing, care giving, and communication” (Johnson, Frenn, Feetham & Simpson, 2011, p. 233). Andrews, Bubolz, & Paolucci, (1980) stated that, “family functioning includes generational relationships, unique sets of rules, priorities, and ethics. The family is also considered to be a mediator between the individual and the environment” as cited in (Johnson, Frenn, Feetham & Simpson, 2011, p 232).

Johnson stated that, “the prevalence of Autism Spectrum Disorder (ASD) is 1 in 110 persons in the U.S. Both parents of children with ASD are under stress that may impact their health related quality of life (HRQL) (physical and mental health)” (Johnson, Frenn, Feetham & Simpson, 2011 p. 232). Johnson wrote that “parents of children with ASD are stressed with caring for their child and the decision making that accompanies the care” and identified the relationship between “the stress of personal and family life (finances, work responsibilities, balancing the needs of siblings) and the discrepancy in expectations related to family functioning

were negatively associated with parents' mental health" (Johnson, Frenn, Feetham & Simpson, 2011, p 234).

Neely's research noted that "the impact on the family of a child receiving an autism diagnosis can be devastating both socially and emotionally...Furthermore, the child's behavioral limitations can dominate family life and restrict the family's outside activities" (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 211). These feelings of disappointment are related to the process of grieving. Research suggested that not all families are able to work through this process on their own. "Moreover, these feelings of blame and guilt may remain unexpressed owing to family norms. Left unacknowledged these feelings can negatively impact the relationships that family members develop with each other and with the professionals that work with their child" (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 215) as well as their reported and felt level of life satisfaction/quality of life.

"The child with autism goes through many developmental stages, and there is grieving to be done at each stage. For example, parents might grieve for the toddler who does not play with others, the elementary school child who is not invited to parties or to spend the night out, or the teenager who is not working toward independence. Grief happens throughout the family's life and not necessarily in any particular order" (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 215) and might very well have a significant impact on their reported as well as felt level of life satisfaction/quality of life. In a hermeneutic phenomenological study by Cashin (2004), it was found that the parents' social connectedness was altered both in their communication and interactions outside the home. The parents had limited new experiences and communication relying on the repetition of old patterns so as not to elicit behavioral disturbances. These parents' social contact also appeared to decline, as taking their child to unfamiliar social situations often

led to reported behavioral disturbances. According to Gray (2002), the majority of the parent's who participated in his study reported a "loss of typical family socializing experiences as one of the worst effects of autism on their families"(Gray, 2002, p. 218). Families with an Autistic member seem to have less money, material objects, energy, and luxury when compared to families without a child with a developmental disability (Cashin, 2004).

The literature also suggested that families having a child with autism can limit families' social interactions. Baxter (1989) suggested that, "parents are most willing to take their child with a disability to gatherings involving family and friends and least willing to take them to places involving people with whom they are not close," as quoted in (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 215) often due to the accompanying distress the child with ASD might experience.

Families are impacted by the diagnostic process and seeking treatment, "Although some parents report positive experiences, most parents express frustration with the diagnostic process, (Hastings & Taunt, 2002; Osborne & Reed, 2008)" (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 214). Mothers and fathers of children with a disability, such as autism, acquire a new identity and experience changes including symptoms of psychological stress, a deep sense of loss, a prolonged crisis, and a decrease in self-esteem (Cashin, 2004; Waisbern, 1980) and likely a change in reported and felt level of life satisfaction/quality of life.

Modalities of Treatment for Individuals with Autism

"When considering interventions for autism, there is agreement on the importance of proof that a treatment is actually effective; that is, it actually produces positive gains in skills of the person with autism. Most behavior analysts and treatment providers adhere to a standard of "effectiveness" that incorporates objective measurement using an experimental design that is

implemented with adequate control over validity threats and other potential confounding variables” (Davis, Rosswurm, Zane, 2008 p.44). The research available focused on both cost and effectiveness of treatment, but also acknowledged parent's and health care provider's motivation to find the right treatment for each child.

According to Green et al, 2006 a survey suggested that the average parent of a child with autism has tried seven different therapies (as cited in Davis et al., 2008, p. 48); the child’s experience of the presenting problems though remained unaddressed. Research suggested that “individuals with ASD can learn specific social and emotional behaviors when the training interventions are highly structured, for example a social skills training group for children with high functioning Autism has resulted in improvement of social and emotional skills” (Ramadoss, Machalicek, Rispoli, Lang, O'Reilly, 20011, p.120).

Families for Effective Autism Treatment (FEAT), argued that “the importance of using effective treatment is underscored when considering the cost of caring for individuals with autism. It is likely that children who do not receive effective early intervention services will require long-term special and custodial care throughout their lives, which for 1996 was estimated to cost over \$13 billion a year” (as cited in Davis et al., 2008, p.45). Therefore, “given the enormous cost of caring for these individuals over their lifetime, efforts are being focused on effective early intervention strategies in the hopes of offsetting some of the long-term costs” (Davis et al., 2008, p.45) as well as the families level of family satisfaction/quality of life if possible.

Andersen et al. (1987) argued that Applied Behavior Analysis (ABA) has been shown to produce substantial benefits for many children with autism (as cited in Davis et al., 2008, p.45). Therapists may also consider using CBT in their treatment of individuals with ASD. Golan

argued that combining interactive media with CBT for managing one's own emotions can teach adults with ASD to effectively learn to recognize complex emotions in others (as cited in Woods et al., 2013).

Ayres (1979) and others (e.g., Huss, 1983) asserted sensory integration techniques could be used to reduce the results of sensory dysfunction (such as self-stimulation). Grandin (1992) noted that "deep pressure, part of SIT, can provide a "calming effect" for persons with ASD" (as cited in Woods et al., 2013, p.3). In addition to the sensory integration techniques therapists working with children on the Autistic spectrum can do small things in session to support their client diagnosed with ASD.

Woods suggested that "asking the client about interests may also serve as an initial means for developing an alliance and increasing the comfort of the client with the therapy setting" (Woods, Mahdavi, Ryan, 2013, p. 2). Bromfield (2010) suggested that it is also important to consider the physical needs of the client, "a therapist's office for example may be too bright, too loud, etc., for the individual with ASD." It may be valuable to ask someone with ASD whether there is something in the environment that is overwhelming for that person. This may also be appreciated by the client as an empathic gesture that shows the therapist is aware of difficulties specific to ASD" (as cited in Woods et al., 2013, p.3).

Relationship Development Intervention® (RDI®) was an intervention that was purportedly a parent-based treatment designed to remediate the "core deficits" of autism spectrum disorders (Gutstein, 2000; 2005). Research found that "specific child characteristics (i.e., sensory processing symptom severity) may be associated with earlier initiation of services and family characteristics (i.e., maternal and paternal education) which may be associated with greater utilization of specific alternative therapies" (Davis et. al, 2008, p.145).

Treatment specific to ASD should also be sensitive to the unique diagnostic considerations of the population, for example children with “autism in general tend to express anxiety through changes in their behavior rather than verbally. Therapists may therefore note that depression and anxiety will not always be verbalized by the client, but may become apparent through behavioral changes,” and Woods also suggested that “individuals with ASD may not have diminished emotionality, however it may be more accurate to say that individuals with ASD have greater difficulties in understanding and compartmentalizing their own emotions or in conveying these to others” (Woods et al., 2013, p. 3). The literature's findings on treatment effectiveness are diverse, but what appeared congruent between documents was the consideration that each client’s individual needs and presenting problems must inform the treatment to not only assist in the individual but to provide additional support to the family and/or caregiver(s).

Modalities of Treatment for the Family Unit of the Individual with Autism

The literature on family treatment with a child with autism was sparse. However the literature available identified that “it is crucial for practitioners to be informed on the key issues in autism. The more accurate the information a practitioner has, the better equipped he or she is to help a family get the appropriate services needed for their child” (Neely et al., 2012, p. 213). Neely also stated that “It is imperative that parents understand no one is to blame for their child having autism” (Neely et al., 2012, p. 213) and that support is available.

As noted in other literature, families go through periods of mourning at life stages (Cashin, 2004; Neely et al., 2012; Olsson, 2001; Waisbern, 1980), Neely asserted that during these stages of the child’s life “it is important that an MFT provide the space for a family to grieve or mourn the loss of hopes and dreams for their child” (Neely et al., 2012). Neely also included that: “One crucial point to remember is that the grieving process is ongoing. It is nearly

impossible to grieve all at once. The child with autism goes through many developmental stages, and there is grieving to be done at each stage...The MFT should always be mindful of the cyclic nature of grieving” (Neely et al., 2012, p.222).

Neely considered questions the family’s therapist might ask of them to assist with life stages such as: “How does the family see itself now? How well does the family evaluate itself on how they live with autism? What have they done well? What might the family like to do differently to move forward?” (Neely et al., 2012, p.219). These kinds of questions can assist not only in the treatment of the individual with ASD but in the support to the family in increasing their level of family satisfaction/quality of life.

Benefits and Effects of Using Art Therapy with Children with Autism

Art therapy can be particularly beneficial for children with autism (Emery, 2004; Evans & Dubowski, 2001; Gazeas, 2012; Kornreich & Schimmel, 1991; Martin, 2008; Martin, 2009) having major affects on social and communication improvement and self-growth. The artwork created in therapy with a child with autism allows for a concrete object to function as something to look back on, remember, and learn from (Emery, 2004; Martin, 2009). The modality as well offers the opportunity for families to visualize what happiness would look like for their family.

As an early intervention tool art therapy offers the possibility of developing a basic ‘vocabulary’ so to speak, of emotions through drawing/representing them, and then, as they get a little older, how to make those learned connections to everyday life (Bragge & Fenner, 2009; Martin, 2009). From the literature and research available, art therapy seems to be a highly useful and beneficial tool for a child with autism (Berstein, Broek, & Keulen-de Vos, 2011; Bragge & Fnnner, 2009; Emery, 2004; Martin, 2008, Martin, 2009). The following information addressed some of the specific characteristics of the disorder, how art therapy appeared to affect children

and their families with autism, how this form of treatment affects their social skills, communication skills, and self-growth, and what patterns and themes have been noted in their art.

Art Therapy with Children on the Autism Spectrum

Art therapy treatment approaches for children with autism included object relations (Dubowski & Evans, 2001), developmental approaches (Dubowski & Evans, 2001; Emery, 2004), developmental/behavioral approaches (Dubowski & Evans, 2001; Gazeas, 2012; Martin, 2009), psychotherapy (Henley, 2001), and eclectic approaches (Epp, 2008; Evans, 1998; Gabriels, 2003; Kornreich & Schimmel, 1991).

Due largely to the troubling economic times and budget cuts, the demand for evidence based practice (EBP) is on the rise. Using art therapy as the primary treatment for children with autism can prove difficult despite anecdotal evidence that it has a positive effect on the individuals (Dubowski & Evans, 2001; Epp, 2008; Martin 2009). Art therapists must creatively think of ways to use EBP within the art therapy context in order to make a difference with this population (Epp, 2008).

Art therapy offered a “quality activity that the child can both learn from and enjoy” (Martin, 2009, p. 188). The therapeutic relationship and meaning sharing of the artwork is difficult to achieve when working with children with autism (Bragge & Fenner, 2009; Emery, 2004; Evans, 1998; Gazeas, 2012; Martin, 2009). These children required “encouragement, direction and sensitivity to participate in the [art-making] activity” (Evans, 1998, p. 18) and it is up to the therapist to “fill the gaps” so to speak with parts of the process such as spontaneity, that they are unable to explore (Bragee & Fenner, 2009; Evans, 1998). One study found that “therapist involvement in the creative process contributed to broadening the client’s engagement

and...contributed to a less intimidating therapy interaction providing alternative communicative means within the shared and independent space of art activity” (Bragge & Fenner, 2009).

One must keep in mind that working with a child who has autism looks much different than working with a child who does not. The research suggested that children with autism do not develop imagery schema the way most individuals do (Emery, 2004; Martin 2008). It is the process that these children find valuable rather than the notions of closure, completion, or satisfaction with an art product (Emery, 2004) that affects children with autism.

“By helping autistic children progress from schematic (formulaic) drawing to the realm of representational drawing and symbolic thinking, art becomes a tool for them to make sense of their environment” (Martin, 2008, p. 16). “With its focus on helping with the psychological and emotional development of the child, art therapy can offer a much focused form of primary intervention” (Dubowski & Evans, 2001, p. 101). Used as an intervention tool to encourage developmental growth and social relatedness, this technique offered these children a way to solve and cope with their problems visually (Bradish, 2010; Epp, 2008; Gazeas, 2012). The nonverbal expression experienced through the making of art supports children with autism to represent their experiences and encourages their growth (Bragge & Fenner, 2009; Emery, 2004; Gazeas, 2012).

Art Therapy Effects on Social and Communication Skills

The current literature regarded the use of art therapy as a tool for treatment with children with autism suggested positive improvement on social and communication skill development (Berstein, Broek, & Keulen-de Vos, 2011; Bragge & Fenner, 2009; Emery, 2004; Gazeas, 2012; Martin, 2008; Martin, 2009). “The art making process assists in the development of communication skills and thereby the therapeutic relationship with children with autism” (Evans, 1998, p. 17). As an art therapist, one was able to assess a child’s relationship to important objects

in their lives through the drawings created in therapy (Berstein, Broek, & Keulen-de Vos, 2011; Emery, 2004). Providing art making for children with autism gave them an opportunity to communicate to someone how they see things (Bragge & Fenner, 2009; Gazeas, 2012).

Research suggested “by working developmentally, art therapy can help individuals to move from one stage of drawing development to the next; building art as an alternative form of communication” (Gazeas, 2012, p. 15). It also suggested that behavioral problems are able to be addressed more easily which alleviates both the client and their family (Dubowski & Evans, 2001; Gazeas, 2012; Martin, 2009) and can lead to an increase in felt and reported level of life satisfaction/quality of life.

Various case studies have reported by family members of emotional, intellectual, and social improvement in their child (Bragee & Fenner, 2009; Henley, 1989; Kornreich & Schimmel, 1991). “Integrating art into recreation and leisure activities can mitigate a client’s symptoms through developing socially appropriate skills; an art therapy environment can help a child with ASD make this transition much more successfully than an art education can” (Martin, 2009, p. 188). By working with these children the therapist helped them to build up an array of shared experiences playing a part in the development of forming representations and creating symbols for everyday life (Bragge & Fenner, 2009; Epp; 2008; Evans, 1998). “In this way scaffolding begins to form for the future development of communication skills (Evans, 1998, p. 21).

One case study exemplified the support and structure art therapy offered for the improvement of communication skills in children with autism is a case in which a young boy confided to the art therapist that although his Grandma didn’t really ride a skateboard, (which he had depicted in his family portrait) she was a lot of fun (Kornreich and Schimmel, 1991). Art

therapy allowed for a safe space to be created in which this kind of imaginative expression is welcomed. The art functioned as a portal in which the therapist can gain insight into what the child is experiencing and emerges as expressive and cognitive communication (Bragge & Fenner, 2009; Epp, 2008; Evans, 2008; Martin, 2008).

Art Therapy Ability to Facilitate Expression and Self-growth

Art therapy offered the opportunity for an increased awareness of the self, (Emery, 2004; Gazeas, 2012) typically, a difficult accomplishment for this particular population. One particular study found that drawing a portrait was “an effective way to connect and engage in a relationship with the participants with ASD...Drawing together satisfied a need to know that, despite sensory difficulties, individuals with autism can see us” (Martin, 2008, p. 22).

By helping these children develop their drawing skills towards the representational, such as portrait drawing, they are offered the opportunity to develop towards a sense of ‘self’ (Dubowski & Evans, 2001; Martin, 2008). “The process of making art should be seen not simply as an elaborate symptom but as an adaptive, positive means of self-expression that has value as a conduit toward both creative and mental growth” (Henley, 1989, p. 55). For instance, in one particular case when a child with autism was observed in therapy, “he was able to communicate in his drawings things that he was unable to say in words... he could tell the therapist in words and pictures when he was frightened and overwhelmed and learned to use her explanations and reassurance to build a stronger self” (Kornreich & Schimmel, 1991, p. 84). It would seem that in this instance the therapeutic relationship had developed to some extent disproving that achieving a therapeutic relationship was impossible.

Achieving a therapeutic relationship with the client is possible, when working with a child with autism, it is just more challenging and takes extra work on account of the therapist

(Bragee & Fenner, 2009; Emery, 2004; Evans, 1998; Gazeas, 2012; Martin, 2009). This same concept can be said of a family with a child with ASD desiring happiness; while it is very possible, it too is accompanied by its unique and individual challenges, difficulties and work.

Patterns and Themes in Art

Children with autism are as unique and individual as other children (Martin, 2009). There seemed to be a pattern though that the drawings produced by these children appear to have been made by children of a much younger age (Bragee & Fenner, 2009; Kornreich & Schimmel, 1991; Martin, 2009). Some studies found that using markers were “clean, precise, and quickly produced effective results” proving most successful and satisfying for the client (Kornreich & Schimmel, 1991 p. 78). The therapeutic relationship which is typically so important to successful treatment was harder to achieve when working with children with autism because they do not care to “please, follow a directive, or be engaged with the therapist” (Emery, 2004, p.145). It takes time, patience and consistency to create the needed relationship between the client and therapists so that the child feels safe and comfortable to explore and express himself (Bragee & Fenner, 2009; Emery, 2004; Gazeas, 2012). “A good therapist focuses and employs the child’s strengths” (Gazeas, 2012, p. 17).

Conclusion

The literature available on family treatment with and Autistic child, suggested that more research needs to be done. There is a lack of literature on the effectiveness of family treatment on family satisfaction and quality of life in a family with a child with Autism. Additional research is also needed concerning the modalities of treatment currently being used in family therapy to support parents with a child with autism and an assessment of their effectiveness.

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Ultimately the goal in using art therapy with this population is “to open channels for the transformation of the clients ideas, concerns and issues into forms that are comprehensible to others” (Henely, 1989, p. 56). Art therapy has shown to improve children with autisms’ social and communication skills, their ability to express themselves and individual growth, the literature does not offer much insight to the effect it has on family life satisfaction.

These children desire to express themselves and be an active part of their world. The best treatment goals and techniques need to be researched beyond case studies to best inform clinicians what would be best for their client and their families (Martin, 2009). Reviewing the available research, family involvement and family therapy with the child with autism seemed to be non-existent; research that likely could show further improvement in the child’s life.

It is important to remember that “both normal children and children with autism thrive in an environment of patience, acceptance, and understanding” (Emery, 2004, p. 147). “Finding a way to engage with the autistic child within this approach includes techniques of mirroring and reflecting the individual...and may assist the child in finding ways to interact and adapt to the dominant forms of social existence and communication in this culture” (Bragge & Fenner, 2009). The future holds great potential for further research and understanding in this field and working with this population.

Research Approach

A qualitative methodology approach was used for this research, focusing on the artwork and responses of caregivers of children with autism. As qualitative researchers we were interested in the “meaning-how people make sense of their lives, experiences, and their structures of the world” (Creswell, 1994, 145) and what meaning they give to the concept of life satisfaction (happiness).

The primary method of gathering data in this research was art-based qualitative survey. Questions were developed to explore the experience of the family in treatment and their life satisfaction. A visual response was included to provide a depth of meaning and visual representation of the families’ happiness. A website was created in order to provide information and access to potential participants. A detailed summary of the project and requirements for participation were outlined on the website. Those interested in participating sent an encrypted request through the website which then allowed for PI’s to mail a qualitative survey to the participants. The survey was filled out in hard copy and returned to PI's. PI's served as qualitative researchers and were the “primary instrument for data collection and analysis” (Creswell, 1994, 145). This method of gathering the data allowed for a visual representation of families’ life satisfaction to be collected, a wide range of demographics be used and the confidentiality of the child and family to remain anonymous.

The survey contained questions that were concerned with the parent's opinion on how their child's diagnosis had impacted their family's daily life functioning. Questions were broken down into multiple choices and additional space was provided for participants to explain specifically how the question applied to their family. This supported the qualitative approach in

that it was “inductive in that the researcher builds abstractions, concepts, hypotheses, and theories from details” gathered from the survey questionnaires (Creswell, 1994, 145).

“Researchers generally prefer closed-ended questions because they can choose response options that represent categories that interest them and because the options can be designed to be easily quantified. However, open-ended questions are more useful than closed-ended questions” (Kite &Whitley, 2012, p. 439, pg 439) which was part of the rationalizing by PI’s in creating the questions.

In understanding that “it is easy to write questions that include unwarranted assumptions about the respondents’ characteristics or knowledge base...it is generally a good idea to verify that a respondent is familiar with a topic when asking questions about it” (Kite &Whitley, 2012, p. 442). Therefore PI’s provided definitions and further clarifications on the questionnaire and website. The website created for this research outlined the project, its overall goal for the research, and provided an encrypted form for volunteering to participate in the research study. In doing so the website contextualized the questions being asked in the questionnaire to families’ experiences with a child with Autism, assuring that families who volunteer to participate were familiar with the topic around which the questions would be based.

Due to participant art work being included in the research, ethical principles such as obtaining written informed consent were made as well as explained to the participants (Kapitan, 2010). The research project further exemplified the qualitative research methodology in that it was exploratory, interpretive, consisted of unknown variables, a questionnaire and survey, the researchers recorded the process, and the aim was to explore and interpret variables that appeared to not be currently considered in the field (Kapitan, 2010, p. 17).

Methods

Introduction

This section provides detailed descriptions of the methods utilized in this research study. The first section establishes the terms that assist in baseline understandings of terms that may unfamiliar to the reader. The next section is the design of the study that includes three sub-sections that outline the ways in which subjects were recruited for the study and how the data were gathered. The final section explores how the data was analyzed.

Definition of the Terms

Autism- A disorder with the presence of markedly abnormal or impaired development in social interaction and communication, and restricted repertoire of interests and activity (DSM-IV, 2000).

Quality of Life -“the quality of life represents a dimension of the overall status and well-being that might be influenced by various factors” (Sippos et al., 2012, p.1)

FEATS- A validity study of the formal elements art therapy scale (FEATS) for diagnostic information in patients drawings. (Gantt, L. 1990).

Grieving-“The child with autism goes through many developmental stages, and there is grieving to be done at each stage. For example, parents might grieve for the toddler who does not play with others, the elementary school child who is not invited to parties or to spend the night out, or the teenager who is not working toward independence. Grief happens throughout the family’s life and not necessarily in any particular order” (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 215).

Happiness- a state of well being and contentment (Merriam Webster)

Functioning- Feetham (2007) explains that “family functioning includes a commitment to support the functions of the family that include: economic, safety, child rearing, caregiving, and communication” (Johnson, Frenn, Feetham & Simpson, 2011, p. 233).

Neely’s research notes that “the impact on the family of a child receiving an autism diagnosis be devastating both socially and emotionally...Furthermore, the child’s behavioral limitations can dominate family life and restrict the family’s outside activities” (Neely, Amatea, Echevarria-Doan & Tannen, 2012, p 211).

ABA Andersen et al. (1987) argues that Applied Behavior Analysis (ABA), a treatment that modifies behavior as it relates to the individuals environment, has been shown to produce substantial benefits for many children with autism (as cited in Davis et al., 2008, p.45).

CBT-Cognitive behavioral therapy (CBT) is a form of treatment that focuses on examining the relationships between thoughts, feelings and behaviors. (NAMI)

Design of the Study

PI’s created a website with information on the research study (AutismAndFamilySatisfaction.weebly.com). See Appendix 1 for example of the website. It was made active post IRB approval on December 1, 2013. Families searching the Internet who found the website and met criteria had the option to self-select for participation in study. Self-selection allowed PI’s to collect a list of email and mailing addresses for the distribution of the survey, consent, and bill of rights (See Appendix A and D). Participation packets contained a preaddressed and stamped envelope to return the survey at no cost to the subject. Packets were sent to LMU’s Marital and Family Therapy Department. PI’s inputted data collected by survey in Qualtrics. Following data entry, PI’s assessed the usefulness of a focus group led by Dr. Paige

Asawa, to gain further information from participants. In the case that a focus group was deemed beneficial, an addendum was submitted to IRB for approval.

Sampling

The subjects for this study were the parents of a child/children diagnosed on the autistic spectrum. Participants self-selected for participation in the research survey by providing their email and mailing address through the website AutismAndFamilySatisfaction.weebly.com. Principle investigators then sent the consent, bill of rights, and survey questionnaire to the self-selected participants by mail. A pre-stamped envelope with return mailing address was provided to participants. The website was active until February 15th; all surveys postmarked prior to February 15th were accepted for data collection. The research website link was available on several resources for families with an autistic member.

Gathering of Data

The subjects for this study were the parents/caregivers of a child/children diagnosed on the autistic spectrum. The research packets sent to participants who signed up through the website AutismAndFamilySatisfaction.weebly.com included their signed consent form as well as their filled out survey questions and art response to the office of Marital and Family Therapy and Loyola Marymount University. Data was collected until February 15th and in-putted into the Qualtrics data base throughout the time of gathering the research packets from participants.

Analysis of Data

The data consisted of a qualitative survey that included art made by the participants. The data was collected from the start of the website until the final date of gathering: February 15th, 2014. All research packets were assembled and distributed through by PI's Sarah Christolini and Camille Werstler. The images made in the final question on the survey were analyzed using the

FEATs. Themes that evolved, elements of the works, and materials used were also carefully considered during analysis of data.

Participants' surveys, completed in hard copy, were inputted into Qualtrics by the PI's. Using Qualtrics software data was compiled into charts for analysis. Families that identified that they did not seek treatment for their child were grouped, and noted when comparing questionnaires completed by families that did seek specific types of treatment for their child or family.

The art gathered from the final question of the survey questionnaire was analyzed using The Formal Art Elements (FEATS). Analysis and comparison of the art included similarities differences, themes, and patterns. In addition, the art was coded for content and meaning as it relates to the theme of life satisfaction.

The data collected aimed to provide a deeper understanding of how families visualize life satisfaction (happiness). Imagery created by participants provided insight into aspects/levels of families' functioning that may support their particular level of family satisfaction. Patterns or shared imagery used by participants indicated aspects of family daily functioning affected by having a child with autism. Identified patterns and shared imagery also pointed to how treatment can better serve the family.

Results

Presentation of the Data

The data began to be gathered as soon as the website became active. The website tracked the number of views per day as well as notified PI's when there were questions requiring clarification by those interested in participating in the survey. Changes were made to the website based on the questions and concerns posed by the public. The first research packet was requested on December, 2, 2013 and mailed out later that week.

According to the website tracker, approximately eighteen people viewed the website within the first twenty-four hours. By the following week approximately twenty-five people had viewed the website. Through the duration of the website being active, the tracker estimated approximately thirty-five people viewed the website in all. PI's received requests from eleven participants to be sent a research packet for inclusion in the study. Packets were prepared prior to the date of making the website live, which allowed for research packets to be mailed to participants soon after notification of their interest.

Due to the low return rate of the research packets as the deadline date approached, the deadline for submission was extended and the date on the website changed. Participants were sent a reminder of their participation and notified of the extension. A total of five of the eleven requested research packets were mailed back to Loyola Marymount University for inclusion in the data. After careful consideration and guidance from PI's research mentor, a final option of faxing survey questionnaires and visual responses for inclusion in data was offered to those still needing to send in their packets.

Each participant was asked to "draw what happiness looks like for your family" on a separate provided blank sheet of paper; four of the five returned research packets used the

provided paper, one chose to draw their visual response on the back of the questionnaire. Participants were then asked to briefly describe their drawing, which all five packets did; some even surprised that it was actually being requested of them. Four of the five returned research packets included the blank sheet of paper with the requested drawing. One of the research packets returned the provided paper back, blank and explained what he would have drawn. PI’s drew the description of this response. This allowed for PI’s to examine all five responses simultaneously.

Responses to the qualitative surveys were input into Qualtrics by PI’s allowing for analysis and comparison of the data. The following graphs and images are the visual responses taken from the qualitative surveys. Some demographic background and the written description of the visual response submitted are provided below for a clearer understanding of what was collected.

8. Briefly describe what resources you sought for your child or family.

Text Response

Early interventions services that included speech, gross and fine motor development, specialized preschool program that focused on communication skills, socialization skills and motor development as well as support from the Regional Center in ABA and medical interventions.

Tri Counties Regional Center (ABA) Speech PT OT

Speech therapy, occupational therapy

Inpatient treatment psychiatric apt. Speech Psychiatric practitioner for med management Psychological professional for counseling (Boundary issues, fitting with peers, family counseling)

Psychiatrist - ongoing Psychologist - ongoing IED at school - ongoing Neurobehaviorist - full evaluation Social skills therapy 8 week program Alexian Brothers, saint Alexius outpatient school refusal program August 2012- 3 weeks

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

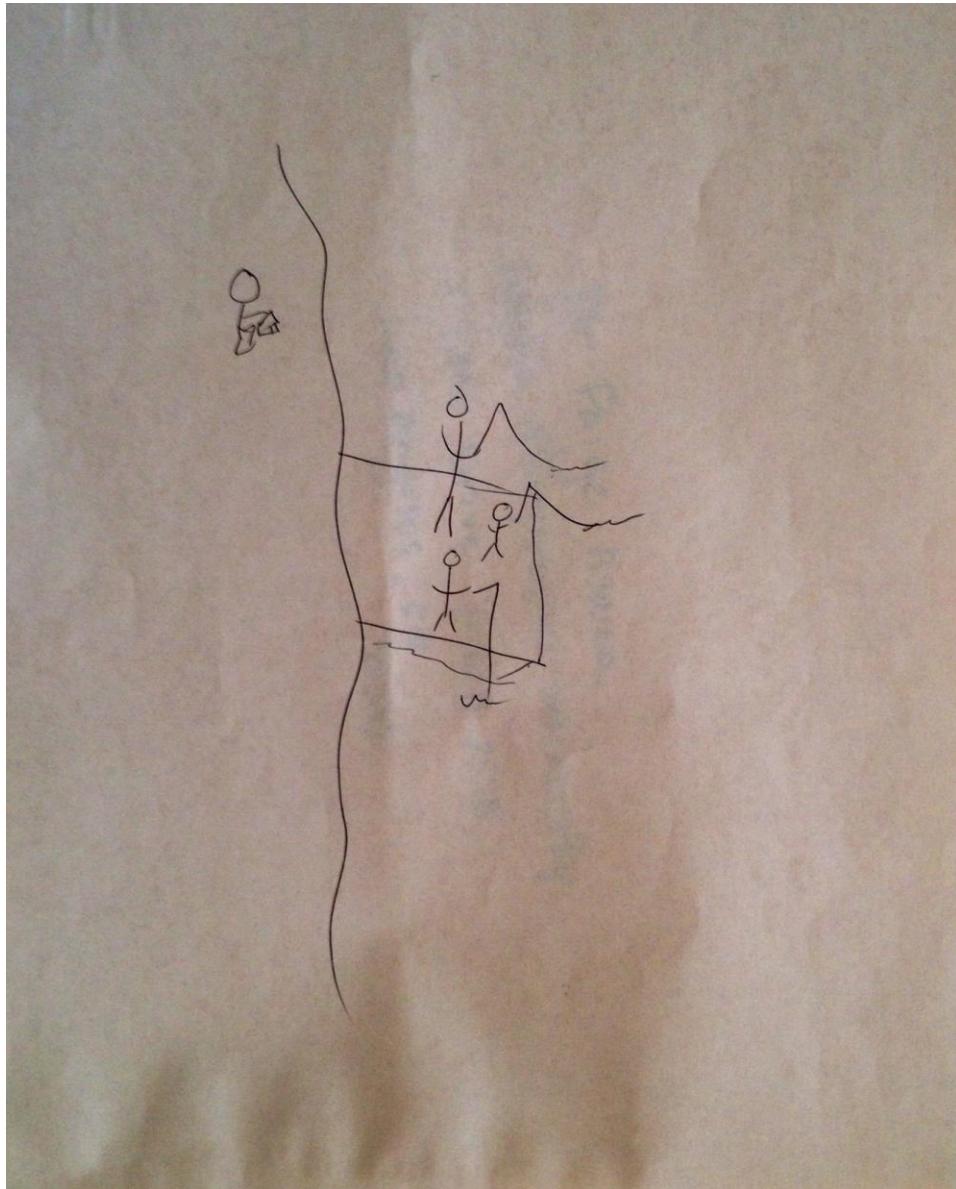
#	Answer	Response	%
1	IEP	5	100%
2	Occupational Therapy	4	80%
3	Speech Therapy	5	100%
4	Individual Therapy	3	60%
5	Family Therapy	1	20%
6	Other	2	40%
7	Other	2	40%
Other		Other	
ABA and PT		Treatment by neurologist	
PT		ABA	

#	Answer	Response	%
1	IEP	5	100%
2	Occupational Therapy	2	40%
3	Speech Therapy	4	80%
4	Individual Therapy	2	40%
5	Family Therapy	1	20%
6	Other	2	40%
7	Other	1	20%

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

Other	Other
PT	Treatment by neurologist
ABA	

Participant A:

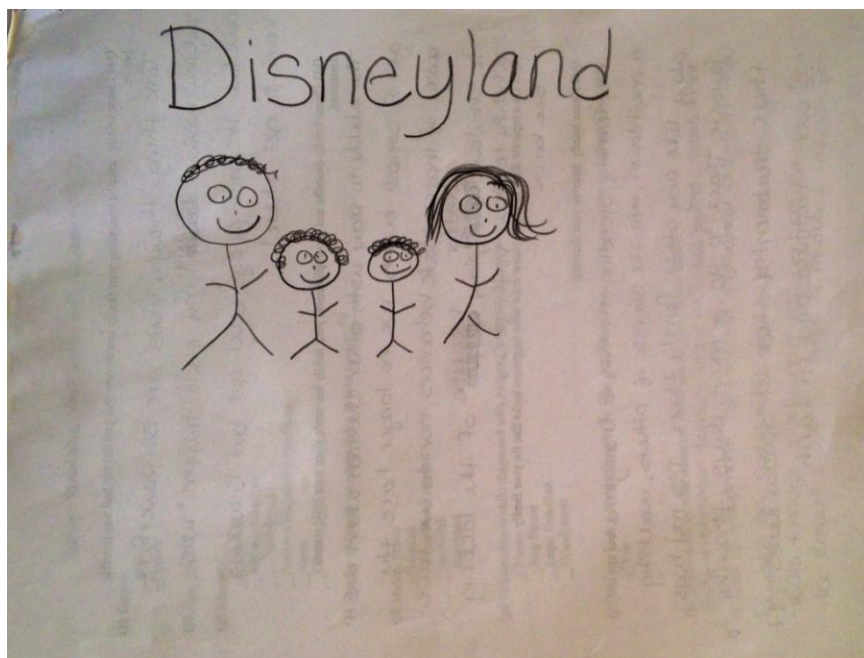


FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

Participant A was a 34 year old, married, Caucasian female, parent who sought treatment/support when her child was diagnosed on the autistic spectrum. Participant A sought speech and occupational therapy for her child who had received treatment for four years. She reported that her child has affected their family functioning in that “we eat different things due to his sensory issues with food. Our schedule is more regimented and inflexible.” Participant A reported feeling most satisfied with their family satisfaction before her child was diagnosed stating “we are happy, positive people.” Her reported level of satisfaction remained the same in response to level of satisfaction during and after the diagnosis and stated “we are still happy, positive people” and “we strive to always be happy, positive people. A diagnosis of autism is not the need of the world-in fact, it makes it easier to help our child.”

Participant A’s verbal description of her drawing was: “Forgive me but I have zero artistic skill. Husband and sons are fishing. I’m w/them but reading a book. All of us together is all we need to be happy.”

Participant B:



FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

Participant B was a 38 year old, married, Caucasian female, parent who sought treatment/support when her child was diagnosed on the autistic spectrum. Participant B sought early intervention services that included speech, gross and fine motor development, a specialized preschool program focusing on communication, socialization, and motor developmental skills as well as family support and medical interventions. Participant B reported receiving additional support from groups with other parents of autistic/special needs children. She reported that her child's behavior affects their family functioning in that they must plan "where and what time we go; need to be sure we bring things of comfort for new places, foods of preference and his iPad!" Participant B reported feeling most satisfied with their family satisfaction before her child was diagnosed writing "diagnosed early!" Her reported level of satisfaction remained the same in response to level of satisfaction during and after the diagnosis and stated "early diagnosis = better outcome!" and "It's a tough road and long battle, but we're committed to seeing it through."

Participant B's verbal description of her drawing was: "My family spending the day @ Disneyland w/o a meltdown, w/o the stares of others, walking along like any other family there. It's my boys favorite place to go, an most days, thanks to their treatment of those w/ 'specialized needs', it is our 'happiest place on earth.'"

Participant C:



Participant C was a 46 year old, divorced, Caucasian female, parent who sought treatment/support when her child was diagnosed on the autistic spectrum. Participant C sought resources that included a psychiatrist, psychologist, an IEP, a neurobehaviorist full evaluation, an eight week social skills program, and outpatient mental health services; her child has been receiving treatment for four years. Participant C reported receiving additional support for her and her husband through individual counseling and medication support. She reported that her child's behavior affects their family functioning socially and that her divorce had "occurred due to lack

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

of acceptance of issues.” Participant C reported feeling satisfied with their family satisfaction before her child was diagnosed writing “we were a strong family unit. We enjoyed each other and supported others interests and hobbies. We communicated as a family and went to gatherings and family events.” Her reported level of satisfaction decreased dramatically in response to level of satisfaction during the diagnosis and stated “child wanted to die. Would choke mom and hit and scream. Would pull knives to threaten. Every waking moment was potential for stress. Daughter felt neglected by parents because time spent on son/brother.” Participant C’s level of family satisfaction slightly increased after the diagnosis; she described she “felt better there was a reason for behavior. Can’t undo what was already done and felt. Family still falling apart as a unit.”

Participant C’s verbal description of her drawing was: “For son: being able to spend time with family completing goal of becoming eagle scout. For daughter: spending time with family outdoors somewhere (dinner, parties). For mom: spending time with family w/o emotional outbursts. Drawing: Family time-outside of home and all smiling.”

Participant D:



Participant D was a 47 year old, married, Caucasian male, parent who sought treatment/support when his child was diagnosed on the autistic spectrum. Participant D sought the Tri Counties Regional Center (ABA), speech, physical, and occupational therapy. He reported that his child has affected their family functioning in that “our entire functioning is centered on [child]. Most of the time he is home and awake one or the other has to be engaged with [child]. We do everything in shifts. Our home is modified to support/protect [child].” Participant D reported feeling somewhat satisfied with their family satisfaction before his child was diagnosed stating “we were not perfect but we were ok.” His reported level of satisfaction

decreased slightly during the diagnosis of his child, he stated “we knew something was wrong and did not know if we could handle it” and “we strive to always be happy, positive people. After the diagnosis of his child, his level of satisfaction increased once again to the same level before the diagnosis. He stated “it’s not perfect but I think we are working towards ‘good enough.’”

Participant D’s verbal description of his drawing was: “You are kidding right? Apparently not. [Child] on a carousel, [wife] and I safe knowing he will be OK for a minute or two.”

Participant E:

PI’s drew the description of Participant E’s written description when analyzing the responses. This allowed for PI’s to examine all five responses simultaneously to make comparisons and observations. The image drawn by PI’s was not from the participant but an interpretation by PI’s.

Participant E is a married, Caucasian male, parent who sought treatment/support when his child was diagnosed on the autistic spectrum. Participant E sought in patient treatment, psychiatric support for medication management, speech therapy, and a psychological professional for ongoing counseling pertaining to boundary issues, fitting in with peers, and family therapy. Participant E’s child has been receiving treatment for twelve years. He reported that his child has affected their family functioning in that it is disruptive because they are “unable to do things planned” and he is “self-absorbed-wants to do what he wants at his time.”

Participant E reported feeling least satisfied with their family satisfaction before his child was diagnosed stating “We had to deal with a lot of tantrums, outburst, money medication changes. His behavior was erratic. He was adopted at age eight. When he joined our family he had pre-

existing attachment issues and multiple foster placement disruptions prior to joining our family.” He reported an increase in level of satisfaction both during and after the diagnosis and stated “we better understood some of his behaviors and challenges” and “we began to get support, strategies for assisting him, and moved from behavior disruption school placement to autistic protocol school strategies.”

Participant E’s verbal description of his drawing was: “The picture would be of our son living independently outside our home, graduated from high school, and working in a job that would provide an ongoing existence. It would include a smiling; confident; and competent in the work he chooses to pursue. It would include him living by himself or with others who cooperate and manage their own environment.”

Analysis of the Data

The research questions originally posed by PI’s were the following:

- 1) Can life satisfaction be achieved for families with an Autistic member(s)?
- 2) How can art therapy play a factor in the happiness of families with an Autistic member(s)?
- 3) How can art therapy make visible the possibility for families with an Autistic member(s) the opportunity to experience life satisfaction?

Based on the data collected and the responses by participants, PI’s were able to conclude that life satisfaction can in fact be perceived to be achieved for families with an Autistic member(s). The survey provided an opportunity for families to identify specific factors that impact their daily life satisfaction. Data collected also demonstrated that art therapy can offer the possibility for families with an Autistic member(s) to experience life satisfaction. Due to the high percentage of participants whose experience of therapy had a positive effect in their family life satisfaction, PI’s extrapolated that art therapy could also play a factor in the happiness of families with an Autistic member(s).

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Examining the series of texts, responses, and drawings made by participants, PI's looked for themes, similarities, and differences some of which included independence, family unity, flexibility, and improved communication. A feeling of being judged/uncertain of others views or affected by them because of their parenting and/or child's diagnosis was present in all five surveys. This additional stressor seemed to play a factor in the overall tone of the responses submitted; some seeming defensive and others at times even apologetic.

The effect of parent's self image/self esteem, and relief in the diagnosis explaining their child's behavior varied from increased insight, strength, and determination, to doubt in oneself and no change at all. Other themes noted included an intentional avoidance of situations where the child may be triggered due to lack of control of environmental factors and an intentional need for preparation including extensive planning ahead. Social isolation, often times by choice, was a repeated theme in responses, allowing for increased control of the environment and interactions with others, and a decreased misunderstanding of child's behaviors when interacting with others.

While four of the five participants reported being married, only one participant reported no change in the relationship with their partner. The other four participants reported a loss in closeness and one even divorce; suggestive of a loss in life and family satisfaction. The effect on siblings and other family members, including difficulties with misunderstanding from extended family members, was another topic shared by participants in each survey pointing out the additional stressors coming from "traditional" support systems.

Participants overall reported a need to protect and advocate for their child and family as it is a "tough road and long battle" as described by one participant. A desired change in the relationship with their child was not a unanimous response by participants. Surprisingly about half of participants did not desire a change and believe that the change needed, is an increase in

understanding and empathy from others. The other half of respondents desire for change included things such as their child speaking, an increase in trust and respect in the relationship, and an increase in independence. “Small” victories/accomplishments such as an increase in understanding and honesty with self, social interactions with others such as play and restaurant dining, and even outings such as going to the movies held significant meaning for the families and appeared to be factors that families identified as impacting their level of life satisfaction.

Demographics of Participants

Of the five participants surveyed, two were male and three were female. All participants reported being Caucasian and between the ages of 34-47. Four of the five participants reported being married; only one reported being divorced. All participants identified as parents of a child with Autism. Participants reported having additional 2-4 other people living in the home. While the locations of the participants is unknown, based where PI’s mailed research packages to, the locations of participants came from either Arizona, California, Illinois, West Virginia, Alabama, Georgia, Texas, West Virginia, or Pennsylvania.

None of the participants reported using the same mental health treatment services. While all five participants reported using occupational and speech therapy for their child, other mental health services varied from individual and family therapy to support groups and psychiatric care. All five participants described “change” for their family and even more, for their child with autism, as something very difficult. Flexibility, understanding, and control of one’s environment were all described to some degree as aspects that assist the families with dealing with “change.”

Based on the demographics known and resources used by the families, it would appear that participants were determined and motivated to access and obtain services for their child and family.

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When looking for common themes within the art responses, the subject matter of being outside and a sense of independence were examined. While the home was referenced in two of the five drawings, the family members were all depicted in some sort of outside environment. PI's noted as well the lack of color in the works, the common material of pen or pencil used, and the overall inclusion of immediate family members. Using the criteria from the FEAT Scales, PI's examined the similarities and subtle differences using the rating scales #1 Prominence of Color, #3 Implied Energy, #4 Space, #7 Realism, #10 Details of Objects and Environment, and #11 Line Quality to extract a deeper meaning and analysis of the visual responses.

Examining the first scale, #1 Prominence of Color, all five drawings were absent of color. As a reminder, participants were not required to use a particular material; PI's intentionally did not supply materials such as crayons or markers, or encourage participants to use these materials in order to gather more information about the families choice in the response.

Overall the art responses had a low-mid rating for the third scale, #3 Implied Energy and #4 Space. A smaller portion of the paper was used in four of the five responses. According to the FEATS scale, when comparing the drawings used for rating to the art responses of participants the works would have scored on the lower to mid-range in almost all the scales looked at. Considering the time these families have and the length of the questionnaire prior to the request of the art response PI's were surprised by the apparent uniqueness and detail given to the varying activities described.

The following information and graphs are examples of the data gathered from the qualitative surveys using the data collection system, Qualtrics. Data gathered demonstrated a low variety in demographics of participants. All five participants were Caucasian, a parent, and in their mid-thirties, late forties. PI's deduced that participants are likely to be mid-high SES based

on their ethnicity, internet access, marital status and reported extensive mental health treatments used for their child or family in addition, all five participants reported seeking services/treatment for their child(s) after the diagnosis of ASD; the varying forms of support/treatment are shown.

Surprisingly only about half of the participants reported a desire to have a change in the relationship with their child despite each participant reporting that their child(s) behavior effects their family functioning. Even more surprising was that only half of participants noted a change in the relationship with their child after services/treatment was provided. This was surprising due to the inherent belief that “change” is an effect, or at least a goal to some degree, of receiving mental health services.

Those who did report a change in the relationship with their child due to services/treatment stated “we have become closer, I think I understand him better,” “he has bonded with us. He has adapted to school and home requirements and rule, to a limited effect,” and “years of learning and understanding so relationship is much better.” About half of participants reported desiring a change in their relationship with their child(s). The following desired changes were reported: “We have a good relationship, it’s his ability to relate to the world and the world’s ability to understand and empathize that I want to change,” “I would like him to speak,” “we would like to trust him. Have him respect us. We hope he can better interact with all family activity,” and “I would like to step back more with activities like scouting and see more independence.” These responses suggested a desired increase in their child’s autonomy as an individual.

Only half the participants reported other family members used mental health/support services. These services included groups with other parents of Autistic/special need children, family counseling, and individual counseling, including medication support. Based on the

responses it would appear that those who received services and interventions earlier on in diagnosis reported a higher felt and experienced level of life satisfaction. Four of the five participants reported a change with their partner and stated these changes included, “I think we are more stable. We are not as close though,” “we have gotten closer-better at the ‘unified front’ tactic,” “more arguments, stress has increased in our life,” and “divorced.” These responses suggested a decrease in life satisfaction due to conflict in personal relationships.

Exploring any changes in self image/confidence, four of the five participants reported a change. These changes were: “I have realized how strong and determined I am. I fight to ensure needs are met without concern of what the districts’, for example, opinion is of me. I know no one else will advocate for my child, nor will anyone else take the steps to ensure my child is prepared for the life ahead,” “Decreased, turns out I can't fix everything,” “At times, I struggle with other mothers, feeling judged by them. I feel like they don't think I'm a good enough mother,” and “I question my ways not sure of doing correct thing. I trust others less. Confidence decreased. These responses demonstrated a decrease in life satisfaction and demonstrated the benefit therapy for the caregiver could provide in increasing self-image and in turn affecting the level of felt and experienced level of family satisfaction.

Participants described their child’s behavior as effecting their family functioning in that the focus had to be on their child. “Planning where and what time we go; need to be sure we bring things of comfort for new places, foods of preference and his iPad!” was an example of one participant’s response. Two described how decisions and actions are made centered around the effect the choices will have on the child; “Our entire functioning is centered on [child]. Most of the time he is home and awake one or the other has to be engaged with [child]. We do everything in shifts. Our home is modified to support/protect [child],” “We eat different things due to his

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sensory issues with food. Our schedule is more regimented and inflexible.” Two participants described their child’s effect on their family functioning more negatively describing him/her as “disruptive - unable to do things planned Self absorbed - wants to do what he wants at his time,” and “socially - husband and wife would take turns going out with non ASD child - family parties, dinner, movies, restaurants, amusement parks. Divorce occurred due to lack of acceptance of issues. Stopped going out as a family due to social/ emotional issues and meltdowns.” The responses demonstrated the difficulty the families experienced in maintaining the desired level of life satisfaction.

All five participants reported a change in how their family copes with change and new routines; they described the difficulty and sacrifice made in this coping as stated in the following responses, “my family is learning to be flexible as well as sacrificing, learning to understand that no one can get what he/she wants all the time, and what's important is that one has what is needed,” “We talk about them more,” “It is much more difficult now - but we also have found ways to work with/around these difficulties. In our house, changes must be planned out/for,” “We avoid changes and avoid doing things when he may cause disruption or problems,” “We do not live like a family unit. Everyone needs to be self reliant because I spend a lot of time trying to control environment so son is less upset.” The responses revealed the effect change has on the felt and experienced level of life satisfaction within the family.

All five participants described the effort made to minimize changes and be in control due to the difficulty change causes for their child. These responses included “My family is learning to expect the unexpected. As much as we try to prepare, we can't always predict what will be. We can't control everything but our reactions to the situation and how to make the best of it,” “We try to minimize it and where necessary mitigate. We have to think about even small changes

a lot more,” “Again - it is more difficult but we are able to work with it,” “We have to forecast the changes so that he knows what is going to happen. We sometimes avoid change all together,” “Change always issue. I personally explain what could change for son so he is never surprised by it. Daughter sometimes thinks she can change her brother's way of thinking. Does not totally understand. We cope with change less because we are trying to prevent some.” The various effects change has on the families based on the responses, showed that life satisfaction is desired but not prioritized for these families.

A unanimous self-reporting that the social life of the family has been affected by their child was reported. Participants stated, “Ironically the more we come to "accept" the lack of control we have, the more others seem to want to socialize with us, or so it seems. It may be as our children get older, they and their peers mature and acceptance grows or people's comfort with the situation improves...,” “We don't go a lot of loud or crowded places and it is much more difficult to get a babysitter we trust so that my husband and I can go out,” “We do not meet other families or get involved with his school. Do not have people over. Our daughters avoided bringing friends to our house, “Do not attend party as family/celebrations/holidays. We do things as individuals. We go out less for dinner but try and challenge son into going.” One participant reported a change in their family’s social life but described it as decreasing but not significantly. The theme of isolation demonstrated a decrease in life satisfaction.

When asked to describe how interactions between family members have changed, the lack of support, understanding, and empathy was surprising. Three descriptions described this stating “my sister in law tends to avoid my youngest child and does not care for the way we parent which has strained that relationship. My mother in law doesn't like handling my youngest child on her own/without my husband or myself - it's hard for that not to change interactions and

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cause resentment as no one seems to take the same issue with our neurotypical child,” “our adult daughters get angry when his behavior ruins or disrupts family plans. They avoid visiting,” “no family time - individuals in family do things with other individuals - never a family that does things together.” One participant did describe interactions as somewhat improving. Their response was, “I think as expressive language improves interactions improve. When family can understand verbal communications, their comfort levels increase; it also helps that the tantrums decrease because the understanding has increased.”

Using various images differentiating emotions participants were asked to indicate their level of family satisfaction before his/her child was diagnosed and to describe this reported level of satisfaction. Participants described themselves as “not perfect but we were ok,” and “we are happy, positive people.” One participant described the difficulty they experienced prior to their child’s diagnosis: “We had to deal with a lot of tantrums, outbursts, many medication changes. His behavior was erratic. He was adopted at age 8. When he joined our family he had preexisting attachment issues and multiple foster placement disruptions prior to joining our family.” Others described their strengths: “We were a strong family unit. We enjoyed each other and supported other's interests and hobbies. We communicated as a family and went to gatherings and family events.” Depending on the severity of their child's behaviors and the strength of the family support system in place, families experience varying levels of stress prior to diagnosis, effecting the felt and experienced level of family satisfaction.

Reported level of family satisfaction changed for some participants during the process of diagnosis. Participants’ responded, “we knew something was wrong and did not know if we could handle it,” “we are still happy, positive people,” “we better understood some of his behaviors and challenges.” One participant explained the high stress during this period reporting

that his “child wanted to die. Would choke mom and hit and scream. Would pull knives to threaten. Every waking moment was potential for stress. Daughter felt neglected by parents because time spent on son/brother.” The responses supported the recommendation that these families seek family mental health services to increase felt and experienced level of family satisfaction.

After the child was diagnosed, levels of family satisfaction changed once again for respondents. The difficulty and effort was described, “it's a tough road and a long battle, but we're committed to seeing it through,” “it's not perfect but I think we are working toward "good enough," “We strive to always be happy, positive people. A diagnosis of Autism is not the end of the world - in fact, it makes it easier to help our child,” “we began to get support, strategies for assisting him, and moved from behavior disruption school placement to autistic protocol school strategies,” and we “felt better there was a reason for behavior. Can't undo what was already done and felt. Family still falling apart as a unit.” Through these reflections families expressed the grief experienced in the process of their child being diagnosed. Specifically surrounding the "tough road and long battle" ahead of them and its impact on family unity and life satisfaction. However, families also identified relief through understanding the source of their child's behaviors. Some participants identified increased motivation and empowerment to obtain resources and support the child and family in order to improve their quality of life and level of life satisfaction.

Participants were asked to describe something their family could do now that they had not felt was possible to do prior. Assuming this change in ability had a positive effect on the level of life satisfaction, responses were unique per respondent. Things such as “talk[ing] things through; words are so powerful- lacking words and seeing my child "trapped" was awful. He's

not at age level yet, but is working hard to get there,” being able to “discuss [child], treatment, medical issues, and future in a very honest manner,” the ability to “go to the movies as a family. With his sensory issues, I wasn't sure we'd be able to ever do that as a family again,” “go out and know that he will not constantly call us and disrupt our time away from him. We can allow him to participate in family activity without having him sabotage our plans,” and what might seem simple to a family without a child with disability but is an achievement for a family with a child with a disability, “go to a restaurant to dine out.” Participants made clear these seemingly “small feats,” for a family without a child with disability have great impact on the families with a child with disabilities and the families level of life satisfaction.

When asked about accomplishments the family has made since their child started treatment due to the inherent assumption that this would affect the family's level of family satisfaction participants described things such as “the ability to play with other children when we are at social events. We no longer have the worry of inappropriate behaviors nor do we have to shadow and/or play because of the lacking ability to play with peers,” the task of having the child “eat more than 6 foods. The first time he ate everything we were eating when we were eating was a huge accomplishment for us,” moving to another city including the difficulty of switching school with little disruptive behavior and the attending a “self contained classroom now when before he didn't last 45 min in school. We are still succeeding in scouting events.” Through these varied accomplishments shared by families, there are two themes that stand out: the child's increased autonomy as well as the child developing capacity for more cohesive interactions within family and social groups. These accomplishments allowed for increased family life satisfaction by improving how the family functioned, increased comfort at social events,

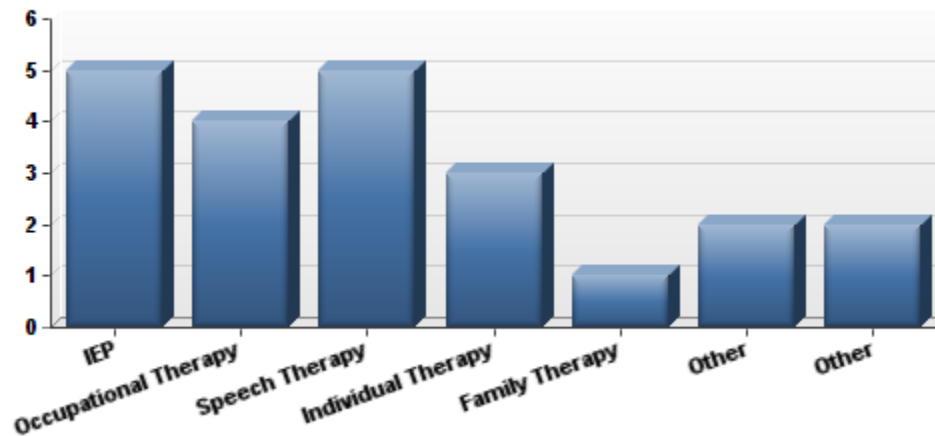
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decreased need for constant vigilance or management of child's behaviors, and decreased additional accommodations required in daily tasks, such as making dinner.

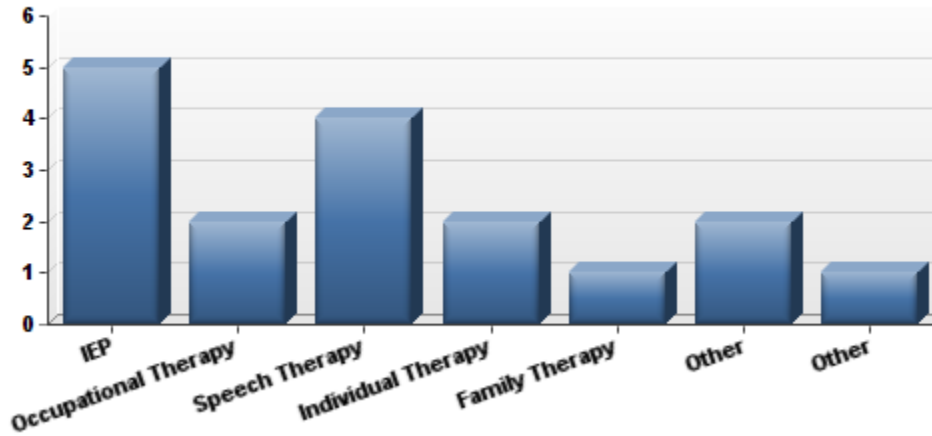
My Report

Last Modified: 03/24/2014

9. What resources has your child received in the past? Please select all that apply.



10. What resources does your child currently receive? Please select all that apply.



13. How long has your child been in treatment?

Text Response

since age of 3

4+

4

12

4

Meanings

Families in our study who received early diagnosis and early interventions presented their experience with a greater sense of hope for continued growth and family functioning. In addition to this sense of hope there was also a greater sense of self efficacy, families felt better prepared to cope with change or the unexpected and to seek out the support they needed as a family.

As identified previously in the literature, “The art making process assists in the development of communication skills and thereby the therapeutic relationship with children with autism” (Evans, 1998, p. 17). The research underscored the importance of communication development to family life satisfaction. Parents identified that as communication with their child improved, understanding improved between parent and child. And as a result families were better able to cope with change as a family and better understand the source of their child's discomfort. Families shared that as communication improved family's social lives also improved; allowing families to do activities outside the home that improved the family's quality of life like attend movies or go out to dinner. Art therapy as a modality for developing communication and relational skills can support this improvement of communication and in doing so the family's quality of life.

Important to remember though is that many studies show that the key elements of therapeutic techniques and approaches when working with children with Autism typically include set, regimented schedules, structure and routine (e.g., Cale, Carr, Blakeley-Smith, & Owen-DeSchryver, 2009; Kenny, 2002; Booth, Martin, Matthews, Taylor, 2011). Thus, art therapy's at times flexible, unstructured, non-traditional and perhaps even unusual approaches to therapy may prove unhelpful for some. For parents of children with ASD, the negative ramifications of non-traditional therapeutic work may prove more harmful than helpful.

The importance of functioning as a family outside the home to families was also reflected in the art created by parents. Parents identified situations they would like to experience outside the home “like other families do,” identifying the importance of not feeling observed or judged by others. Of the five parents participating in our research, all five expressed similar experiences of feeling exposed in public and under observation and judgment from others for their child's

behavior. Parents also identified that this feeling of judgment from strangers or their extended family has affected their self confidence in their ability to parent. Although some families noticed a distancing in their relationships with extended family, many parents also noticed a strengthened relationship with their partner. These parents identifying an increase in their ability to communicate about difficult topics together, being more unified on parenting approaches, and working as a team to plan for the needs of their child.

Tunali and Power (2002) found the highest levels of life satisfaction among mothers who had lessened their emphasis on career success and learned to disregard others' opinions of their child's behavior. Four out of five parents identified that their self image was negatively impacted by these experiences and they noticed a decrease in their confidence, specifically surrounding their capabilities as a parent. The existence or absence of a unified support system directly affects the parents' self-image or self-esteem and this should inform clinical practices of MFT's working supporting these families. MFT's should consider how they are supporting the family system as a whole in the treatment of the child with autism and how they can support the parents' confidence in their abilities as parents and caregivers.

Mothers and fathers of children with a disability, such as autism, acquire a new identity and experience changes including symptoms of psychological stress, a deep sense of loss, a prolonged crisis, and a decrease in self-esteem (Cashin, 2004; Waisbern, 1980) The parents answers were blunt and real. They vented, and they gave thanks. It was a rich – and often painful experience reading their answers to the simple question, “How has your child in the autism spectrum affected your life and your family’s life?” Their responses were coded into 15 negative themes and 9 positive themes that were subsumed into five clusters. With 24 themes – and each of the themes capturing dozens of personal stories – it is clear that there is no single or simple

answer to our question. One mother answered wryly, “How long have you got?”

According to Sipos et al. “the quality of life represents a dimension of the overall status and well-being that might be influenced by various factors” (2012, p.1). The research illuminated some of the factors referenced by Sipos et al. by which a family's quality of life may be influenced. Parents identified that the reaction of their extended families to their child's diagnosis and behavior impacted familial relationships, making it harder to find support like child care which impacts the family's life satisfaction.

Parents also identified the “unity” of the family as an important factor to family life satisfaction. Families who spoke to their family's ability to function as a family (flexibility, understanding, connectedness) were able to articulate a clearer idea of what happiness looks like to their family, some identifying specific situations they are currently able to experience as a family. Families who identified less connectedness in their immediate family and individuation of family members identified more general situations where their family could experience happiness in the future.

These same families also used this section to identify changes that would need to happen before these situations could be actualized, indicating an area for desired support that is not currently being addressed in their child's treatment. One Mother's responded to our question “How would you like your relationship with your child to change” even though she answered “no.” This mother shared her desire that the world’s perception and acceptance of her child is what she would like to change. Her response illuminates the work that still needs to be done in the mental health community to remove stigma surrounding Mental Health.

Conclusion:

The intention of the research was to inform our clinical practices and how we support families seeking treatment for their child diagnosed with Autism. The research process gave us the opportunity as clinicians to take a step back from clinical and DMH formulated goals for treatment to get a better understanding of the everyday goals families make for themselves that impact their quality of life. By better understanding the goals families may not vocalize in treatment, like wanting to be able to go out to dinner or watch from the sidelines as their child participate in activities on their own, we can better support these families in attaining these goals to improve their quality of life as mental health providers.

The five participants expressed similar experiences of feeling exposed in public and under observation and judgment from others for their child's behavior. The research indicates the need for support of the family system in the treatment of the child with autism. The existence or absence of a unified support system directly affects the parents' self-image or self-esteem and this should inform clinical practices of MFT's working for and supporting these families.

In future research we would want to collect a more diverse sample of participants to better represent all families receiving Mental Health services in the US. Some changes we could make to our research process to facilitate this might be to provide the survey in additional languages. In addition we could consider ways of presenting our proposed research to families who do not have Internet access at home. By using a website to request for participation, we were limited in our ability to reach out to families who did not have Internet access. The survey length may have also restricted participants. The amount of time required to complete the packet may have been too difficult for families lacking the needed support at home to have space to complete the

process. By reducing the number of questions more parents may find time to contribute their experiences to the research.

Through our own research process we also identified areas in need of further research. Families in our study who received early diagnosis and early interventions presented their experience with a greater sense of hope for continued growth and improvement family functioning and quality of life. In addition to this sense of hope there was also a greater sense of self efficacy, families felt better prepared to handle change or the unexpected and to seek out the support they needed as a family like attending family therapy or support groups. Additional research should be done to explore how the family support system impacts prognosis of child diagnosed with autism as well as how family buy in during treatment may help support resiliency in a child diagnosed with Autism.

Further empowerment of families with a child with Autism through group work, public activism, and social support groups could prove fruitful and beneficial in the future. The parents who participated in this research offered in-depth responses to how their child in the autism spectrum had affected their families' life satisfaction which allowed for PI's to get a small but significant insight into how to best serve this population in the future.

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Appendix A: Consent Form and Bill of Rights

LOYOLA MARYMOUNT UNIVERSITY
Informed Consent Form

Date of Preparation 9/24/2013

Loyola Marymount University

- 1) I hereby authorize Camille Werstler, MFT Candidate and Sarah Christollini, MFT Candidate to include me in this mixed methods research study: Visualizing Family Satisfaction: Families with a member on the Autistic Spectrum.
- 2) I have been asked to participate on a research project which is designed to explore the levels of life satisfaction and quality of life I experience as a member of a family with an individual on the Autistic Spectrum.
- 3) It has been explained to me that the reason for my inclusion in this project is that I identify as an individual with a family member who is on the Autistic Spectrum.
- 4) I understand that if I am a subject, I will complete a survey. All identifying information will be carefully removed. This process has been fully explained to me.

The investigator(s) will use the information gathered to assess families' level of satisfaction and quality of life who have a family member on the Ausitic Spectrum.

These procedures have been explained to me by Camille Werstler, MFT trainee and Sarah Christollini, MFT trainee.

- 5) It has also been explained to me that this information will be used for research purposes only and that my identity will not be disclosed. I understand that I have the right to review the research project before April 1, 2014.
- 6) I understand that the study described above may involve the following risks and/or discomforts: The research project may include material and artwork from my experience completing the survey that will be available in a scholarly way on the internet, considering my own quality of life and satisfaction may be triggering.
- 7) I also understand that the possible benefits of the study are to better understand what families with a member on the Autistic Spectrum feels and needs to have a high satisfaction of daily living and quality of life.
- 8) If the study design or the use of the information is to be changed, I will be so informed and my consent reobtained.
- 9) I understand that Camille Werstler or Sarah Christollini who can be reached at camillewerstler@gmail.com will answer any questions I may have at any time concerning details of the procedures performed as part of this study.

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

- 10) If the study design or the use of the information is to be changed, I will be so informed and my consent reobtained.
- 11) I understand that I have the right to refuse to participate in, or to withdraw from this research at any time without prejudice to.
- 12) I understand that circumstances may arise which might cause the investigator to terminate my participation before the completion of the study.
- 13) I understand that no information that identifies me will be released without my separate consent except as specifically required by law.
- 14) I understand that I have the right to refuse to answer any question that I may not wish to answer.
- 15) I understand that if I have any further questions, comments, or concerns about the study or the informed consent process, I may contact David Hardy, Ph.D. Chair, Institutional Review Board, 1 LMU Drive, Suite 3000, Loyola Marymount University, Los Angeles CA 90045-2659 (310) 258-5465, david.hardy@lmu.edu, OR The research mentor, Dr. Paige Asawa, at(310) 338-4562
- 16) In signing this consent form, I acknowledge receipt of a copy of the form, and a copy of the "Subject's Bill of Rights".

Research Participant's Signature _____ Date _____

OR

Subject is a minor (age _____), or is unable to sign because _____

Mother/Father/Guardian _____ Date _____

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

LOYOLA MARYMOUNT UNIVERSITY

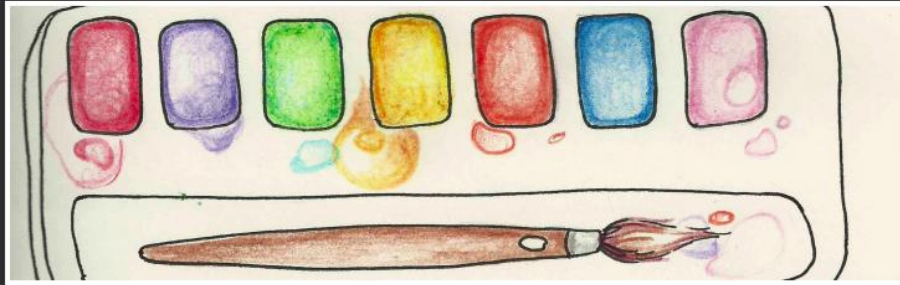
Experimental Subjects Bill of Rights

Pursuant to California Health and Safety Code §24172, I understand that I have the following rights as a participant in a research study:

1. I will be informed of the nature and purpose of the experiment.
2. I will be given an explanation of the procedures to be followed in the medical experiment, and any drug or device to be utilized.
3. I will be given a description of any attendant discomforts and risks to be reasonably expected from the study.
4. I will be given an explanation of any benefits to be expected from the study, if applicable.
5. I will be given a disclosure of any appropriate alternative procedures, drugs or devices that might be advantageous and their relative risks and benefits.
6. I will be informed of the avenues of medical treatment, if any, available after the study is completed if complications should arise.
7. I will be given an opportunity to ask any questions concerning the study or the procedures involved.
8. I will be instructed that consent to participate in the research study may be withdrawn at any time and that I may discontinue participation in the study without prejudice to me.
9. I will be given a copy of the signed and dated written consent form.
10. I will be given the opportunity to decide to consent or not to consent to the study without the intervention of any element of force, fraud, deceit, duress, coercion, or undue influence on my decision.

Appendix B: Website

Visualizing Family Satisfaction with a Child with Autism



[ABOUT THE PROJECT](#) [HOW TO PARTICIPATE](#) [FAQ](#) [MATERIALS MAILED IN RESEARCH PACKET](#)

Project Overview

Through this research we hope to gather unique family experiences and perspectives of life satisfaction to better understand and serve families with an Autistic member(s) that informs and enriches our services now and in the future. With our own personal connections to the research topic, we are dedicated to application of this research in our future work as art therapists and hope to better inform the practices of our peers also supporting families with an autistic member.

This research serves to examine levels of family satisfaction and quality of life in families with an Autistic member(s). The primary method of gathering data in this research is qualitative survey. The literature on autism is manly concerned with the diagnosis and treatment of the child. However, some literature suggests that a re-focusing on the family as the unit of treatment rather than the identified patient (IP) may assist in the reported improvement of family satisfaction and quality of life. This research explores how parents experience family satisfaction and assists with visualizing these moments to capture the important qualities and meaning. Due to the lack of art therapy literature this research can contribute to the understanding of family dynamics and strengths when challenged with the care of a member on the autistic spectrum.

Create a free website with [weebly](#)

Visualizing Family Satisfaction with a Child with Autism



[ABOUT THE PROJECT](#) [HOW TO PARTICIPATE](#) [FAQ](#) [MATERIALS MAILED IN RESEARCH PACKET](#)

Frequently Asked Questions:

Q1. Will my contact information be shared with anyone else?

A. No, your contact information is collected using a private encrypted account, and all contact information will be deleted following the completion of study.

Q2. Will I be asked to share any identifying information?

A. No, survey questions do not ask for any identifying information, but include some demographic questions to assist projects validity.

Q3. Am I obligated to complete the survey, if I submit my contact information.

A. No. At any point during the survey you have the right to decline participation.

Q4. Who are you?

A. We are two graduate students working towards our masters in Marital and Family Therapy, with a specialization in Art Therapy. Both with our own personal connections to the subject of our research, we are currently working with families and children with emotional and behavioral needs and hope to use this research to improve in our future work as MFTs.

If you have a question that is not included in the FAQ section, please feel free to submit it using this form. The answered question will appear in the FAQ section above.

Name (optional)

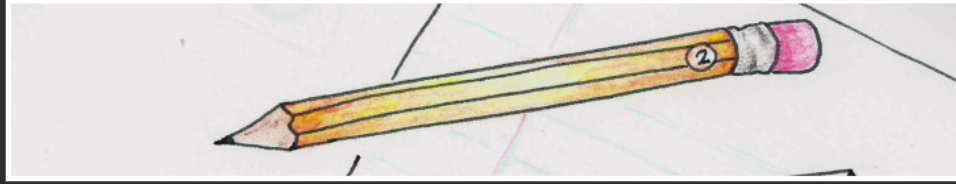
First

Last

Comment *

Submit

Visualizing Family Satisfaction with a Child with Autism



[ABOUT THE PROJECT](#) [HOW TO PARTICIPATE](#) [FAQ](#) [MATERIALS MAILED IN RESEARCH PACKET](#)

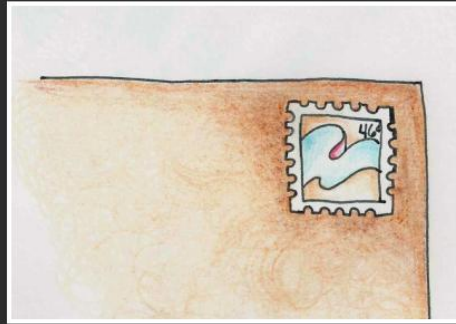
Materials Included in Research Packet

The research packet includes necessary materials for data collection. This includes: a consent form detailing parts of the project and concerns you may have, a copy of your bill of rights as a participant, the survey questions, and a pre-stamped and self-addressed envelope to return the survey.

See drop down menu for samples of materials that will be included in your research packet.

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Visualizing Family Satisfaction with a Child with Autism



Contact Us!

Contact information provided will be used only to contact you with information pertaining to this study. A research packet will be mailed to your address with a self addressed prepaid envelope.

[Documents](#)

[ABOUT THE PROJECT](#) [HOW TO PARTICIPATE](#) [FAQ](#) [MATERIALS MAILED IN RESEARCH PACKET](#)

Interested participants should provide their contact information below. We will be sending out hard copies of the survey to you and self addressed envelopes for easy return

email and mailing addresses for interested participants can be submitted using the form below
Dec 1st 2013 12pm to February 15th.

(Deadline for postmarked survey return has been changed from
February 15th to March 1st due to increased participation)

Contact Information

This information is stored confidentially and will not be retained following the end of the study.

Email Address

Mailing Address

Never submit passwords through Google Forms.

Powered by
 Google Drive

This content is neither created nor endorsed by Google.
[Report Abuse](#) - [Terms of Service](#) - [Additional Terms](#)

Create a free website with [weebly](#)

Appendix C: Instructional Letter to Participants

Dear Participants,

Thank you for volunteering to participate in our research study. Through this research we hope to gather unique family experiences and perspectives of life satisfaction to better understand and serve families with an Autistic member(s) that informs and enriches our services now and in the future.

In this envelope you will find:

- Informed Consent Form
- Bill of Rights
- Survey
- Blank Sheet of Paper
- Pre-stamped and addressed return envelope

Steps:

1. Please read through the Bill of Rights and Informed Consent documents
2. If you are willing to complete the survey, please sign the Informed Consent
3. Next complete the survey
4. Return completed documents (*signed consent form, answered survey questions, and drawing*) in the pre-stamped envelope
5. Mail envelope at your earliest convenience

In your return envelope please make sure you have included:

- Signed consent form
- Completed survey
- Art response

Please be aware that returned envelopes postmarked after February 15th will not be considered for data inclusion in the research.

If you have any questions please feel free to leave them on the FAQ section of the website. (AutismAndFamilySatisfaction.weebly.com) we will aim to respond within 48 hours.

Appendix D: Survey Questionnaire

Survey: Visualizing Family Satisfaction with a child with Autism

Q1 Gender

Male

Female

Q2 Age _____

Q3 Ethnicity

Caucasian

African American

Latino/Hispanic

Native American/Pacific Islander

Asian

Other: _____

Q4 Number of Family members living in your home: _____

Q5 Marital Status

Married

Single/Never married

Divorced

Separated

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

Q6 Relationship to child diagnosed with Autism (on the autistic spectrum)

- Parent
- Step Parent
- Legal Guardian
- Grandparent

Q7 Did you seek treatment/support for your child when he/she was diagnosed on the autistic spectrum?

- Yes
- No

Q8 Briefly describe what resources you sought for your child or family:

Q9 What resources has your child previously received? (Please select all that apply)

- IEP
- Occupational Therapy
- Speech Therapy
- Individual Therapy
- Family Therapy
- Other(s): _____

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

Q10 What resources does your child currently receive? (Please select all that apply)

- IEP
- Occupational Therapy
- Speech Therapy
- Individual Therapy
- Family Therapy
- Other(s): _____

Q11 Where has your child previously received treatment? (please select all that apply)

- In home
- At school
- Private Practice
- Outpatient Facility
- Other(s): _____

Q12 Where does your child currently receive treatment? (please select all that apply)

- In home
- At school
- Private Practice
- Outpatient Facility
- Other(s): _____

Q13 How long has your child been in treatment? _____

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

Q14 Have any other members of your family received Mental Health treatment, services, support?

Yes

No

Q15 Please describe the Mental Health treatment, services, support received by this family member(s)

Q16 Does your child's behavior affect your family's functioning?

Yes

No

Do not wish to answer

Q17 If you answered yes above, please describe how your child's behavior affects your family's functioning.

Q18 Has your relationship with your child changed since beginning treatment?

Yes

No

Do not wish to answer

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

Q19 If you answered yes above, please describe how your relationship with your child has changed.

Q20 Would you like your relationship with your child to change?

Yes

No

Do not wish to answer

Q21 If you answered yes above, please describe how you would like your relationship with your child to change.

Q22 Has your relationship with your partner changed since your child started treatment?

Yes

No

Do not wish to answer

Q23 If you answered yes above, please describe how your relationship with your partner has changed.

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

Q24 Have you noticed a change in your self-confidence/ self-image?

Yes

No

Do not wish to answered

Q25 If your answered yes above, please describe how your self-confidence/self-image has changed.

Q26 Have you noticed a change in how your family copes with new routines?

Yes

No

Do not wish to answer

Q27 If you answered yes above, please describe the change in how your family copes with new routines.

Q28 Have you noticed a change in how your family copes with change?

Yes

No

Do not wish to answer

Q29 If you answered yes above, please describe the change you noticed in how your family copes with change.

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

Q30 Have you noticed a change in your family's social life?

Yes

No

Do not wish to answered

Q31 If you answered yes above, please describe how your family's social life has changed.

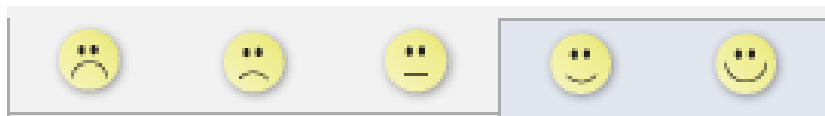
Q32 Have you noticed a change in interactions between family members?

Yes

No

Do not wish to answered

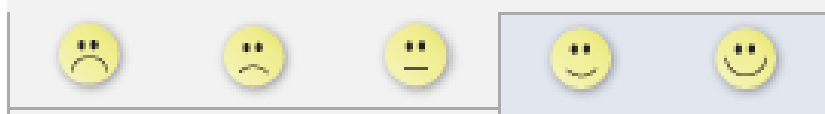
Q33 If you answered yes above, please describe how interactions between family members has changed.



Q34 Select one of the images to indicate your family satisfaction before your child was diagnosed

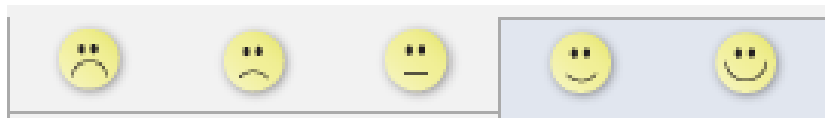
Q35 Please briefly describe why you selected the level of satisfaction above

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER



Q36 Select one of the images to indicate your family satisfaction when your child was diagnosed

Q37 Please briefly describe why you selected the level of satisfaction above



Q38 Select one of the images to indicate your family satisfaction after your child was diagnosed

Q39 Please briefly describe why you selected the level of satisfaction above

Q40 Please briefly describe something your family can do now that you did not feel was possible before.

FAMILY SATISFACTION WITH AN AUTISTIC MEMBER

Q41 Please briefly describe and accomplishment your family has made since your child started treatment.

Q42 On a separate sheet of paper, please draw what happiness looks like for your family.

Q43 Please briefly describe your drawing.