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EXPLORING THE NEEDS OF FAMILIES OF YOUNG CHILDREN WITH AUTISM

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Samantha M. Williams

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Capstone Approval Page

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Student Name (print or type): Samantha A1~m~s

Faculty Supervisor (print or type): MO~ES M" MLAjL{ KU

Faculty Approval Signature: !td~ Ad~ _~

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This thesis project sought to study the impact of autism upon, as well as the subsequent needs of, families of young children with autism for the purpose of examining how to best provide educational services to these families. In order to accomplish this aim, the student researcher analyzed current literature and research studies related to the topic and observed several support group meetings for parents of young children with autism. This study found that a number of essential concerns and factors commonly apply to the service of families of young children with autism and that a "family-centered" approach is most effective for educators to adopt. Such a project is warranted given the growing population of early childhood educators, families, and children affected by autism spectrum disorders.
TLEC 497 UNIVERSITY HONORS CAPSTONE:
EXPLORING THE NEEDS OF FAMILIES OF YOUNG CHILDREN WITH AUTISM

Samantha M. Williams
TLEC 497 Capstone Project
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INTRODUCTION

According to the National Institute of Child Health and Human Development, "the best conservative estimate...is that one child in every 1,000 children has an ASD" (NICHD, 2005, p. 4). However, this statistic hardly registers its full impact unless one understands the nature of autism. Autism, otherwise known as ASD or autism spectrum disorder, refers to a "complex neurobiological disorder of development that lasts throughout a person's life" (Ibid., p. 2). A triad of symptoms most often characterizes this condition: delays in or lack of communication and language, difficulties with social interaction, and perseverance in highly repetitive or ritualized behavior. Even these commonalties do not define all individuals on the spectrum; autism is known to present itself in as many unique ways as there are people with the disorder. With their steadily increasing prevalence among young children and lack of a universal cure or treatment, autism spectrum disorders are easily among the most challenging disabilities facing modern society.

The families of young children with autism deserve special consideration given that "increasing numbers of very young children are receiving a diagnosis of ASD...and children are being diagnosed at younger ages" (Davis, 2008, p. 1278). As the unspoken and regularly identified "experts when it comes to their children", the parents of these children with autism are placed in a unique and somewhat double-edged position (Harte, 2009, p. 24). While they can be said to understand their child and his or her needs more deeply than any other adult, they must also live and cope with the disability of autism on a persistent and daily basis. Ideally, and as promoted by the research literature, these parents should be recognized and supported. Following the common assumption that "a child at risk places a family at risk", it is especially important for early childhood and early childhood special educators to "play a critical role in
enhancing the quality of life not only for a child with a disability, but also for that child's entire family" (Van Haren & Fiedler, 2008, p. 231). However, how can professionals adopt this role successfully without extensive knowledge about families of young children with autism and the various dynamics at play in their lives?

In order to guide educators in answering this question and many others, this study strives to examine the impact of autism upon the families of young children with autism. Observing the demands and requirements of autism will bring forth a familiarity with the range of needs manifested by this population, as well as what manner of educational and support services work best in meeting those needs. To successfully develop a more complete knowledge of the families of young children with autism, it is at first necessary to explore the general and specific characteristics of these families. Next, education professionals must become familiar with the nature and effects of individual conceptions of, or perspectives about, autism and disability.

Finally, it is crucially important that educators use the information they have obtained to reflect upon their own educational practices and craft an ideal image of effective service provision that can actually and immediately be pursued.

Before one may proceed further, a small aside is warranted. In addition to the literature, the words and experiences of actual parents of young children with autism will supplement and fortify the bulk of this study. The student researcher attended parent support group meetings presented by the Easter Seals Autism Parent Group, the Ogle County Autism Parent Group, and The Autism Program (TAP) Service Center. It is her hope that the stories of these parents will provide professionals with a realistic and memorable vision of families of young children with autism and their possible trials and tribulations.
PART I: GENERAL CHARACTERISTICS AND NEEDS OF FAMILIES OF YOUNG CHILDREN WITH AUTISM

The various characteristics and needs that can generally be assumed to apply to the families of young children with autism are complex and supported by much research and exploration in the literature. Therefore, the most relevant and important areas of concern for educators warrant individual examination.

PARENTING STRESS

It is a commonly accepted assumption among the research literature that families of young children with disabilities often operate under more stress than families with typically developing children. However, it appears as though autism has a particularly significant impact on families. Osborne and Reed found that the literature demonstrated "more highly pronounced levels of parenting stress in parents of children with ASD than in parents of children with almost any other type of disability or health problem" (2009, p. 54). It is not difficult to imagine the various detrimental effects of such elevated tension; in a 2007 article focused on quality of life issues, Lee et al. reported that "parents of children with autism ... are at a greater risk of experiencing physical and psychological distress ... and emotional distress" (2007, p. 1148).

Because parenting stress often necessitates examination and relief in the process of working with families, a great deal of the research on families of young children with autism focuses on uncovering its dynamics. Generally, in the case of autism, researchers are concerned with the effects of two main factors: the symptoms and severity of the child's individual presentation of autism, and the level and number of the child's behavior problems (Osborne & Reed, 2009, p. 55). It is also important to attempt to provide evidence of the direction of causality between these factors and the parenting stress itself. Although many research studies to
date have been inconclusive or presented conflicting results, some long-term studies have yielded important information for consideration.

As per Osborne and Reed's twin studies, it appears that the dynamics of parental stress differ depending upon the respective age of the child with autism (2009, p. 69). Families of younger children with autism tended to deliver results indicating "that ... the severity of the ASD, rather than the severity of the child behavior problems, is associated more strongly with parental stress", while families of older children demonstrated the reverse relationship (Ibid.) These results make logical sense considering families' gradual process of adaptation to disability. For example, Davis and Carter found that parents of toddlers with autism are most significantly affected by their child's developmental delays in social interaction, indicating a focus on the symptoms of autism (2008, p. 1288). As young children with autism grow older and their families become more adjusted to the experience of parenting a child with a disability, the focus shifts to ever-salient behavior problems. Interestingly enough, Osborne and Reed also found "that initial parenting stress has an effect on subsequent child behavior problems" rather than just the behavior problems themselves leading to stress (2009, p. 70). Given this established relationship, the insistent strain on families of young children with autism certainly calls for understanding and remediation.

THE CHILD'S LIFE WITH AUTISM

As was mentioned beforehand, it is possible for the disability of autism to manifest itself in many different ways. For example, some children display the so-called "classic" autism (represented by the traditional triad of symptoms), while others are characterized by Asperger's Syndrome (a higher-functioning form of the disability) or other non-specified disorders (NICHD, 2005, p. 2). However, whatever the characteristics of their child's particular form of autism, it is
clear that many families of young children with autism are preoccupied with their child's everyday life.

This preoccupation is not unwarranted. Typically, young children with autism display a number of behaviors or issues which may include but are certainly not limited to "temper tantrums and aggressive behaviors ... fear and anxiety ... [and] screaming, difficulties with eating [and] toilet training, ... and self-injurious behavior" (Cassidy et al., 2008, p. 120). Some of these behaviors and concerns can directly and disruptively impact people outside of the family's inner circle, resulting in challenging situations in social arenas such as school or the neighborhood park. Other behaviors, such as the child with autism's general avoidance of social interaction, can simply result in unusual or atypical behaviors that nevertheless affect the child's daily life. For example, one mother stated that her seven-year-old son often entertained himself with video games while same-age peers were visiting for a play date.

When taking this information into account, it is not surprising that a number of research studies have documented families' specific concerns with regards to their child with autism's everyday life. In their study examining the quality of life (QOL) of children with autism, Lee et al. (2007) discovered that children ranging in age from 3 to 17 had a "diminished quality of life" and created for their parents "higher levels of concerns about ... well-being" in relation to issues such as academic achievement, self-esteem, and mistreatment by peers (p. 1155). However, it is also necessary to keep the actual perspective of the child in mind. As a young adult with autism revealed to one parent support group, many children with the disability are aware of the fact that they are distinctly "different" from their peers during their later childhood years (second to third grade), creating even more potential for misunderstandings and difficult social encounters. It seems as though a constant goal of families of children with autism is to ensure that their child
has a fighting chance at a somewhat fair and "normal" experience of life despite the very real challenges and societal limitations that exist.

**EFFECTS OF AUTISM ON FAMILY LIFE**

The presence of a child with autism clearly has a number of distinct and significant effects on a family's life. In addition to the actual process of adapting to and parenting a child with a disability, the parents of these children must also grapple with other demands and conditions that are exaggerated in scope and impact from those experienced by families raising typically developing children. Finances, school involvement, and general family functioning and well-being are all examples of areas in which the families of children with autism may encounter different or more challenging obstacles. A universal concern of the parents in one support group was that their eight-year-old children actively avoided talking over the phone.

Nevertheless, the effects that a child with autism causes to ripple throughout his or her family can hardly be said to be wholly negative. Bayat (2007) noted that many of these families evidence characteristics of resilience, or "the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful" (p. 702). This resilience could be said to be a direct and positive result of the child's autism, and family members noted a number of benefits received from living with a child with a disability. For example, some parents reported undergoing several "transformations" or life-changing experiences" in which they "gained new roles [and] acquired new traits" or positively altered "they ways [they] related to other people" (Ibid., p. 703). Other, more tangible effects included an increase in family connectedness as parents and children bonded together to provide the best life possible for the child with autism and a more optimistic and accepting life philosophy. As Bayat assures, "the grim generalizations of the negative and overwhelming experiences of families of children with disabilities" do not
provide a full or accurate picture of the experiences and characteristics of all families of young children with autism (2007, p. 703).

ADAPTATION TO THE DISABILITY

As soon as parents discover that their child has a disability or developmental delay of some sort, they must begin the process of adaptation. They now have a complex new identity as not simply parents but as parents of a child with special needs. However, much as with any other concept that applies to families, adaptation is a vague entity which takes on different appearances and pathways depending upon the unique nature of individual parents. Some researchers and professionals support the traditional notion that families adapting to life with a young child with special needs travel through Kubler-Ross's five stages of grieving (e.g., denial, bargaining, anger, depression, and acceptance), and many parents certainly do experience this cycle (Krauz & Meszaros, 2005, p. 8). However, a number of families may find it easy to accept or tolerate their child and his or her disability immediately, and still others do not progress through a sequence of stages in any predictable sort of manner.

As Krauz and Meszaros demonstrate in their case study of a mother of a child with autism, the process of adapting to being the parent of a young child with a disability is complex and dynamic (2005). Their topic parent Linda encountered a number of hardships and breakthroughs in her nineteen years of caring for her son Philip. For instance, while he failed to show evidence of recognition or attachment as a young child, he also allowed Linda to enjoy a kind of "effortless" company and peace (Ibid., p. 5). Fortunately, and despite the wide variety in their individual trajectories through parenthood, parents usually do have experiences centered around common themes such as "diagnosis", "getting adequate treatment", and "hopes and fears" (Krauz & Meszaros, 2005, p. 4). A great deal of how parents successfully and functionally...
contend with these themes depends upon their own psychological well-being and enduring life perspectives. As an example of this, consider the moment of diagnosis. Diagnosis usually occurs near the beginning of families' journeys towards adaptation because it is at this point that the child's disorder is officially recognized. Charlotte Moore, the mother of two young children with autism, speaks of the fact that "[h]aving my boys 'labelled' has many practical advantages" such as being guaranteed the educational and financial supports they require in order to be successful (Moore, 2008, p. 495). Nevertheless, she can also see why some parents may harbor different perspectives with respect to diagnosis given that labels may "confine [children] to a pigeon-hole where they will be viewed as a collection of symptoms, not as an individual" (Ibid., p. 493). The process of adaptation to disability is full of such different opinions and many-sided situations.

**TREATMENT OF THE DISABILITY**

Given its uncertain nature and the fact that modern research still has much to learn about its specifics, autism is a disability that tends to generate medical and social controversy. Inevitably, this interest leads to the production and availability of numerous treatments for autism that many parents, eager to provide their child with the best chances possible, do not hesitate to explore and implement.

Jenny McCarthy's memoir of her early years of parenting her young son with autism, Evan, highlights several of the more controversial treatments. For example, McCarthy consulted with a "Defeat Autism Now! (DAN)" doctor who explores "medical issues unique to the autistic child such as... food and environmental allergens [and] mineral depletion and absorption issues" (2007, p. 198.) As part of Evan's treatment, he consumed medication that forced his body to expel "yeast or candida overgrowth" which was supposedly the cause of his atypical behavior
and a result of his autism and weakened immune system (McCarthy, 2007, p. 165). However, the methods of DAN! doctors are far from being the only treatments available. One of the parent support group meetings was held solely to discuss the topic of adopting a gluten-free casein-free (GFCF) diet for children with autism. According to the group leader, some children with autism may naturally have difficulties in processing certain proteins found in common grain and dairy products, resulting in some of the neurological symptoms and complications of autism.

In the vast majority of parent support group meetings observed, DAN! doctors, GFCF diets, and other so-called "fad" treatments were mentioned at least once. It was not uncommon for parents to share their findings about certain vitamins or drug therapies with the other attendees and bring in their own evidence of treatment effects. The research is often critical of these treatments, claiming that they "have no substantial body of research showing that they are effective in treating any aspect of autism" (Zane et al., 2008, p. 46). Nevertheless, parents often try multiple approaches ... in a shotgun blast approach, hoping that one of them or a combination will cure their child" (Ibid, p. 48). It is difficult to completely ignore controversial fad treatments simply due to the fact that so many families of young children with autism are actively involved with them. Fortunately, a number of parents and their young children with autism also take part in more credible behaviorally-based interventions, such as Applied Behavior Analysis (ABA), which "[work] to reinforce wanted behaviors and reduce unwanted behaviors" (NICHD, 2005, p. 8). Given the nature of autism itself, it is nearly inevitable that families will be following at least one method of treatment (whether it be "fad" or research-based) before and during their interactions with educators.
PART II: CONCEPTIONS OF DISABILITY AND AUTISM

Apart from developing their awareness of and exploring the general characteristics and needs of families of young children with autism, it is also essential for educators to understand the significance of conceptions of disability. Simply put, one's conception of disability is his or her individual ideas and opinions about what it means to be disabled or to have a disability such as autism. Because families differ widely with respect to so many different characteristics, it is no wonder that they also vary greatly in their conceptions of disability.

What parents believe about disability heavily influences their interactions both with their child with autism and with the external world. For example, McCarthy describes the separation of a group of mothers of children with autism into two sides: the "'woe is me' moms" and the "'I'll do anything if it will help my kid recover' moms" (2007, p. 138). These two groups of parents undergoing roughly the same hardships harbored two distinctly different ideas, or conceptions, of autism; the first group saw disability (and autism in particular) as something that was fated to occur and difficult to change through any kind of intervention, while the second group certainly seemed to believe that intervention and treatment can severely combat any deficiencies. Parents' conceptions of disability likely affect their entire life outlook and perspective. While some mothers and fathers become burdened by negative perceptions of what their child with autism cannot or may not be able to do in the future, other parents, like Charlotte Moore, nurture conceptions of disability that view autism as a cluster of symptoms which act much like the traits that discriminate between any two individuals (2008, p. 497).

Obviously, the variety of conceptions of disability held by parents will hold numerous and different implications for effective care and service delivery. However, it is also necessary for professionals to gain a deeper understanding of the sources of these perceptions in the hopes
of shaping a more positive and equitable perspective that is most conducive to beneficial progress. To identify one important source of families' conceptions, one needs to look no further than Charlotte Moore's 2008 article entitled "Thoughts About the Autism Label: A Parental View". In her diatribe about labeling, Charlotte Moore proclaims that "[t]he way a culture defines or classifies a disability reveals a lot about the prevailing values of that culture" (2008, p. 498). For example, in "South Africa", she imagines that she may be likely to "be called upon to ask a witch doctor to expel the evil from [her] children" (Ibid.). Cultural heritage and country or place of origin have a great deal to do with how families incur values and expectations regarding disability.

The countries of China and Japan serve as particularly poignant examples of how perspectives on autism can differ widely across the world. According to McCabe's 2008 article exploring "Autism and Families in the People's Republic of China", many people of Chinese heritage still nurture profoundly negative perspectives in relation to disability, so much so that "persons with disabilities are [often labeled as] 'useless burdens on society'" (p. 40). In stark comparison to the United States, it is a rare occasion for a Chinese child with autism to gain entry into any sort of formal school (Ibid., p. 45). Keiko Tobe's insightful graphic novel series With the Light highlights similar, although not quite as extreme, differences in Japan. For example, the "person-first" language and perspectives expected in countries such as the United States are not as rigorously followed, and it is still a difficult process to acquaint young children with autism with the most free and appropriate educational environment possible throughout their early years (Tobe, 2008, Volume One; Tobe, 2008, Volume Two). Families with origins in these countries, several others across the world, or even in particular regions of the United States may thus come into early childhood education with vastly unique ideas and perspectives on
autism simply as a result of their cultural background and upbringing. However, despite the particular nature or degree of realism and optimism of their perspectives, it is essential that educators become aware of and work to effectively and positively influence conceptions of disability.

PART III: ACTUAL PRACTICE AND EFFECTIVE CARE IN EARLY CHILDHOOD EDUCATION FOR THE FAMILIES OF YOUNG CHILDREN WITH AUTISM

How is it possible for educators and other early childhood professionals to translate their knowledge of the characteristics, needs, and conceptions of disability of families of young children with autism into effective education and care? Van Haren and Fiedler's article entitled "Support and Empower Families of Children With Disabilities" suggests that it is all related to one's perspective towards service delivery. They advise that education professionals provide support services that are "family-centered" in that they accomplish the following:

"(a) include families in decision-making, planning, assessment, and service delivery ..., (b) develop services for the whole family and not just the child, (c) are guided by families' priorities for goals and services, and (d) offer and respect families' choices regarding their level of participation" (Van Haren & Fiedler, 2008, p. 231).

Nurturing this type of services is valuable in that it ensures that the focus of professionals is always upon what is best for each particular family and young child with autism, given their unique and individual needs and circumstances.

However, there is no denying the fact that the body of information related to young children with autism and their families is dynamic and ever-changing. As a result, it may be helpful for educators working with these individuals to find a relatively simple way of remembering and recording the needs and characteristics of these families and young children.
The visual conceptual model featured in this paper represents one such method of keeping families of young children with autism in mind. Much like a puzzle, families are crafted out of essential factors that undoubtedly affect their lives on a daily basis. The puzzle pieces of the "Essential Factors Concerning Families of Young Children with Autism" puzzle clearly delineate areas that educators should seek to become aware of, if not also knowledgeable about, during their work with these individuals in the service of more effective care. Many of the "puzzle pieces" originate from characteristics and concerns that have been previously addressed, while others simply reflect good teaching and professional practice. Each puzzle piece in the conceptual model can serve to provide foundations for further exploration or spark questions that educators might peruse in order to further extend their thinking. If even one piece is left unexplored and unexamined, the family unit as a whole may suffer from a lack of complete care.

Keeping a family-centered mentality is certainly called-for in working with families of young children with autism especially due to the fact that services provided under such a philosophy naturally address all of the puzzle pieces in the visual conceptual model. Fortunately, a few easily understandable and clear principles guide the implementation of a family-centered approach. As Van Haren and Fiedler suggest, the goal is on supporting and empowering families, giving them the necessary attention and provisions that they require to be successful while nurturing the success of their child. For example, professionals must "[r]ecognize families as experts and build on family strengths" instead of following processes that work to the contrary (2008, p. 232). Van Haren and Fiedler's article provides further in-depth suggestions for educators; many of their prescriptions follow those of general good teaching practice.

Nevertheless, when considering actual education and service provision in working with young children with autism and their families, a number of additional recommendations are in
order. For example, Harte found that assessment is most functional and beneficial in the cases of young children with autism when the evidence utilized is creative, insightful, and nurturing of a common ground between parents and educators. Parents and teachers in Harte’s study used the "photovoice" method, in which "photographs [are] paired with interviews", and found that this strategy allowed them to easily discuss and evaluate children's behaviors in relation to a common theme (2009, p. 24). It is also essential to keep the popular requests of parents of young children with autism in mind in the process of planning, delivering, and evaluating service delivery. Cassidy and colleagues, for instance, noted that many parents of preschoolers with ASD overwhelmingly desired a number of improvements to current service provision, such as increased availability of speech and language therapy and "improved knowledge, communication and co-ordination among professionals" (2008, p. 123). Given that fad treatments, other medical inquiries, and particularly controversial social topics are often an apparent focus among many families of young children with autism, professionals must furthermore be prepared to address issues related to those areas and many others which have little or no precedent for generally appropriate protocol. Overall, however, truly effective care provision depends upon both the educator’s accumulation and use of information and his or her ability to apply and individualize this body of knowledge to the families and children under his or her care. No one set of recommendations can be said to work proficiently for all families, and much is up to professional judgment in the interests of a family-centered approach.

CONCLUSION

Despite the numerous unanswered questions addressed to them, autism spectrum disorders are only continuing to increase exponentially among today's population of young
children. Due to this fact and given the age and ability of these youngsters, it is crucially important for educators providing services to young children with autism to also be aware of the needs and functioning of these children’s family units. When considering how to best provide effective services to families in the hopes that both they and their young children with autism will experience beneficial and successful outcomes, it is necessary to examine the impact of autism and the family’s subsequent needs. As discussed in this paper, educators could best guide themselves through this process of examination and towards their ultimate goal by exploring the general characteristics and needs of families of young children with autism as delineated by the literature, become familiar with the idea and effects of conceptions of disability, and, finally, reflect upon and modify their actual educational practice (in the services of a family-centered approach) in order to make it more effective. This paper fully explored and addressed all three of these steps on the journey towards providing families of young children with autism with what they need to be successful. However, it is also necessary for educators to remind themselves of the fact that their learning will never be done. As the author discovered in her observations of parent support group meetings, both parents and other professionals treasure the experience of teaching others more about their lives and experiences with young children diagnosed with ASD. If beneficial outcomes for children with disabilities and their families can continue to be a possibility in the future, educators must seek to meet these individuals halfway.
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Ogle County Autism Parent Group.


The Autism Program (TAP) of Illinois in Rockford Service Center Social Skills Group Meetings for young children with autism.


ESSENTIAL FACTORS CONCEIVING FAMILIES OF YOUNG CHILDREN WITH AUTISM
HONORS THESIS ABSTRACT

THESIS SUBMISSION FORM

AUTHOR: Sarwln* M. Wi(fiqrns

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