Late diagnosis of autism among African American children

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LATE DIAGNOSIS OF AUTISM AMONG AFRICAN AMERICAN CHILDREN

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Lysette Nana Etti
Kathleen Patrice Holsey
June 2008
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ABSTRACT

The purposes of this study were to raise awareness and to analyze the process of diagnosing African American children with autism and identify variables that correlate with late diagnosis. There are no medical diagnostic tests for autism, thus health providers must rely on experience and professional judgment to recognize specific features that are associated with autism spectrum disorder. It is therefore imperative to understand why these features seem easily recognizable in Caucasian children and not as easily in African American children. This study provided a basis for understanding the perception of health providers, by utilizing the DSM-IV criteria for diagnosing a child with Autism, and the behavior of families in situations involving late diagnoses. The study found that although race is not the primary reason why African American children are often diagnosed late it can be a significant factor. Therefore to overcome the race component in regards to accessing needed services, African American mothers must be highly knowledgeable, very assertive, and consistent in their advocacy for their child. In addition to educating themselves, African American mothers can also become good advocates for their child by networking with other mothers.
ACKNOWLEDGMENTS

The researches of this study would like to acknowledge all of the participants that took part in this study. We feel the participants' willingness to share their information was vital to the success of this study. We would also like to acknowledge and express our gratitude to Cecilia Johnson and the West End Family Counseling Center staff for their support towards completing this study. Last, our sincere appreciation goes to the Social Work Department, particularly Dr. Rosemary McCaslin, at Cal State San Bernardino University, for giving us the opportunity to conduct a study that could potentially be beneficial to mothers of autistic children.
DEDICATION

Lysette’s dedication:

I would like to dedicate this thesis to my husband of 12 years. You are the best thing that ever happened to me. I don’t know what I did to deserve you but I know I will love you for ever.

Kathleen’s dedication:

This thesis is dedicated to Will, my support and the love of my life, and Keith and Midori Ward, who made it possible for me to be where I am today.
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CHAPTER ONE
INTRODUCTION

This chapter includes the problem statement and the purpose of the study. It gives a brief overview of the history and increasing awareness of developmental disabilities in the United States, the establishment of services for persons with developmental disabilities, and disparities seen in the mental health sphere. The chapter also outlines the purpose for the study. Mental health disparities among African American children were examined and justification was given for why this study was conducted. Last, a research question was proposed, and implications for social work practice were discussed.

Problem Statement

Over the past sixty years, public awareness of developmental disabilities has increased dramatically. Historically, persons with developmental disabilities were considered immoral deviants and forced to isolate from society. Often, developmentally disabled persons were put in workhouses or asylums. Most were mistreated, neglected, and abused. During the 1940s and 1950s,
parents of disabled persons organized themselves to advocate for better services for their loved ones. During the 1960s and 1970s, the parents’ movement worked to improve conditions in state institutions, create community services, create educational and employment opportunities, initiating legislation, and challenging the conventional wisdom that persons with disabilities could not be helped. (Minnesota Governor’s Council on Developmental Disabilities, 2007, pp. 1-3)

Eventually, policies and laws were enacted to ensure the humane treatment, safety, and protection of individuals with developmental disabilities.

Increasing knowledge and awareness of individuals with disabilities led to increasing knowledge of the various types of developmental disabilities that exist. Today, individuals that are diagnosed with Mental Retardation, Cerebral Palsy, Autism Spectrum Disorder, Visual and Auditory Deficits, various Genetic and Chromosomal Disorders, such as Down Syndrome and Fragile X syndrome, and Fetal Alcohol Spectrum Disorder, are described as having developmental disabilities (Minnesota Governor’s Council on Developmental Disabilities, 2007).
As new knowledge of the nature of developmental disabilities emerges, so then should a proliferation of mental health services. Unfortunately, even with increasing awareness of developmental disabilities, there is still a lack of adequate mental health services. Presently the agency responsible for servicing persons with developmental disabilities is California’s Regional Centers (RC). Regional Centers are designed to provide advocacy and assistance to developmentally disabled populations. In order to qualify for services, a person must be diagnosed with a developmental disability before the age of 18. The disability must be continual or must be expected to continue throughout the person’s live-span, and the disability must be a substantially handicapping condition. (Inland Regional Center [IRC], 2005)

The United States Department of Health and Human Services created the Office on Disability (OD) in October, 2002, to work on programs, policies, and initiatives to assist the 54 million Americans with disabilities. The National Institute for Occupational Safety and Health (NIOSH) reports that there are approximately 4.5 million individuals in the United
States who have a developmental disabilities such as mental retardation, autism, down syndrome, cerebral palsy, traumatic brain injury, and epilepsy (NIOSH, 2007).

Havercamp, Roth, and Scandlin study, (2004), concluded that:

Health promotion, disease prevention, early detection, and universal access to care are the cornerstones of a balanced community health system. Individuals with developmental disabilities face barriers in each of these areas. The medical and dental care of individuals residing in the community must be obtained from community-based providers, yet many health professionals have little exposure to individuals with developmental disabilities and, as a result, are sometimes uncomfortable treating them. In order to ensure access to quality services, there is a need for specialized training for health professionals. This need was recognized in the Developmental Disability Act, first authorized in 1962. (p. 425)

Individuals diagnosed with developmental disabilities need mental health support in order to cope
with their disability; however, most have a hard time finding effective treatment and services. Publicly, developmentally disabled individuals' must contend with issues such as social segregation, stigmatization, and opportunity restrictions. Another issue surfacing in relation to the lack of mental health and other services available to individuals with developmental disabilities is racial and socioeconomic inequality, particularly for other Blacks and African Americans. According to Lowe (2006):

Over the past 20 years, there have been numerous reports and government initiatives which have called for/required mental health services to take action to reduce inequality in access, experience and outcome for black and minority ethnic (BME) communities. The focus of these initiatives however has largely been on adult psychiatric services and this appears to have unwittingly contributed to the view that racial inequality is not a significant issue in Child and Adolescent Mental Health Services (CAMHS). Consequently there is an unjustified complacence in many CAMHS about the need to take action to make its services more accessible and
It is extremely important to address the mental health concerns of and lack of services for black children as soon as possible. Many studies have clearly shown that early intervention is the key to countering some of the effects developmental disabilities. One of the more recent developmental disabilities receiving massive public attention is Autism Spectrum Disorder (ASD). "It is estimated that in the United States, 1 in 166 children is diagnosed with ASD" (Brown, Brown, & Brown, 2007). Autism is a developmental disorder that affects communication, social interaction and creative play. According to Brown et al.,

ASD can be diagnosed in children as young as 18 months. However, recent studies have found a glaring racial disparity in age at diagnosis. The average age at diagnosis was 5.5 years for white children and 7.5 years for black children. They had many more visits than white children yet still were not diagnosed. (Brown, 2007, ¶ 4-5)

In spite of these disturbing facts, there have been no significant measures to prevent or remedy the issue.
Worse, because the issue is largely ignored, African American children with Autism may be at higher risk for child abuse and neglect.

Children with disabilities are, on average, 3.4 times more likely to be maltreated. Broken down by form of maltreatment, children with disabilities are 3.88 times more likely to experience emotional abuse, 3.79 times more likely to be physically abused, 3.76 times more likely to be victims of neglect, and 3.14 times more likely to be sexually assaulted than children without disabilities.

(Consortium for Citizens with Disabilities [CCD], 2001, ¶ 5)

Families raising children with disability face comparatively high levels of stress. It is, therefore, important to recognize the effects associated with high stress levels on the functioning of these families.

General neglect, the most common form of child abuse, can be associated with a high level of stress within the family system. Studies have shown that neglectful parents report more stress than non-neglectful parents, which is a source of concern in the child welfare system, where African American children continue to maintain a
disproportionately high representation. Without raising awareness of this problem, autistic children who do not receive early intervention are likely to encounter more challenges as adults, resulting in additional financial cost to the community. Furthermore, African American youth represent the majority of all juveniles in detention and of young offenders serving time in adult prisons. This situation is further exacerbated by the fact that the criminal justice system cannot effectively respond to the needs of the developmentally disabled.

The risk is magnified if a disability goes unnoticed for several years. Thus, this increases the likelihood that African American families with an Autistic child component are more likely to require intervention from a Child Welfare and Mental Health Agencies. It is imperative that individuals working in the social services sphere (i.e., social workers and mental health workers) understand that there may be a significant correlation between late detection of Autism in African American children and familial child abuse and neglect. This is not to say to that child abuse and neglect should go unpunished; but rather, when social workers encounter African American cases of child abuse and neglect with an
evident Autistic child component, intervention should be the desired course of action over removal of the child from the home. Intervention(s) and assistance from social workers, mental health and medical professionals will equip parents of autistic children with the resources and skills to respond appropriately to the stress associated with raising an autistic child.

Purpose of the Study

Considering the problems associated with delayed diagnosis and its implications, it is extremely crucial to implement immediate changes in the diagnostic process in order to provide every child the opportunity of timely autism diagnosis, thereby, offering them a chance towards achieving their fullest potential. Furthermore, early identification and intervention are critical to minimize the symptoms associated with autism. The purpose of this study, therefore, is to raise awareness, analyze the process of diagnosing African American children with autism and identify the variables that correlate with the late diagnosis.

This was accomplished by utilizing two focus groups discussions and two face-to-face interviews, with African
American and Caucasian mothers of children with autism, to identify common themes in relations to participants' experiences in the diagnostic process. Also the autism diagnostic criterion, established by the medical community, was utilized to increase participants' level of awareness of the diagnostic criteria. The combination helped to identify possible pattern of bias that may exist in the medical community, in relation to diagnosing African American children with autism.

An unbiased response to the question above requires the perception of the families as well as that of the health care providers. A qualitative participatory research approach was utilized to conduct this study. The study consisted of two focus groups and two face-to-face interviews. The participants in the first focus group consisted Caucasian mothers of children with autism. The second focus group consisted of African American mothers of children who have been diagnosed, with autism. The face-to-face interviews consisted of two African American mothers. Data collected from both the focus groups and the face-to-face interviews were analyzed for common themes.
Significance of the Project for Social Work

For future social workers committed to serving clients, this is an area of significant concern. Typically, social workers work with the entire family system. In certain cases, families would be referred to other professionals. It is therefore the ethical responsibility of the social worker to make certain that clients are receiving adequate services and there are no service gaps. If there are any factors compromising services, it is also the ethical responsibility of the social worker to not only uncover those factors but also work towards eliminating them. The findings from this study will increase social workers competency in working with this population as well as assist social workers in educating families on how to become effective advocates.

Problem identification and assessment are the first two components social workers rely on to complete the generalist model. Therefore, assessing the nature of the problem, to determine variables that most correlate with late diagnosis would be of great benefit to social workers towards improving the well-being of the most economically and socially disadvantaged groups. Furthermore, social workers rely on collaborative efforts
with other care providers to accomplish a systematic approach to treatment. Social work intervention would be ineffective if African American children, a focused segment of the population served, are not receiving appropriate care from other providers. To bridge the gap in the manner in which services are provided, and allow every child equal opportunity to achieve their fullest potential, it is imperative to determine why African American children with autism tend to be diagnosed later than Caucasian children.
CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter reviewed articles that relate to the subject of disparities in providing mental services to minorities, including mental health diagnoses and interventions. It examined the autism diagnostic process, outcomes of providing early interventions, and the relationship between children with developmental disabilities and child abuse. Each article included a summary and a critical analysis. The articles were critiqued for their strengths and limitations, and a broad overview of the research methods was presented. Last, theories guiding the study were discussed.

Health Disparities among Minorities

Mental health has remained an area of significant concern, especially for minorities, in the United States. Mental health issues also have been the focus of attention for both federal and state administrations. However, despite all the attention, evidence suggests that very few quantifiable positive outcomes have been achieved. On the contrary, the problems encountered by
minorities regarding access to mental health services seem to be getting worse (Lowe, 2006).

Several studies have been conducted to determine the factors that are most associated with mental health disparities. Hatton and Kendall (2002) stated that despite socioeconomic advancement made by minorities, race, especially among blacks, remains a more significant barrier to improved health than socioeconomic class. The article further suggested that race continues to be a factor in health disparities because race is "a pervasive issue that affects every area of life" (p. 29). This article raises awareness regarding the lack of available health services for minorities. However, the article did not provide any data to support this conclusion.

Fortunately, there are many other reports where research data do indicate the existence of significant race-based disparities in health services in the United States.

In their 2004 report, the Council on Minority Mental Health and Health Disparities suggested that minorities, who represent an underserved population in mental health, should be included in the discussions of mental health disparities. Further, the 2001 Surgeon General’s Report reviewed disparities in mental health and concluded that,
“culture, race, and ethnicity are vital considerations when assessing the prevalence of mental disorder, the burden of mental illness, psychiatric services use, and the unmet mental health needs of racial and ethnic minorities” (as cited in American Journal of Psychiatry, 2004, p. 389). Mental health disparities, as evident from these reports, continue to be a significant problem for minorities.

Unfortunately, no segment of the population is immune to mental illness. Mental illness can affect any individual, regardless of their demographic group. Children represent a significant number of those affected by mental illness. Mental illness in children includes developmental and intellectual disabilities. Autism Spectrum Disorder (ASD) constitutes the second most common serious developmental disability after mental retardation and intellectual impairment. In the United States alone, 560,000 persons are diagnosed with ASD each year from birth to age 21 (Nadel & Poss, 2006). Autism has become the fastest growing developmental disability affecting children and continues to increase at disheartening rates.
The earliest known recorded case for diagnosing ASD was by a psychiatrist named Leo Kanner in 1943. The term initially used by Kanner to refer to children who exhibited this disorder was "Air of Aloneness" indicating that they behaved as though they were absolutely alone even when they were not. Presently, ASD is known as a complex neurological developmental disorder that is present throughout a person's life. Diagnosing ASD can be very challenging because there is no medical diagnostic test for autism. ASD has no pathognomonic sign or laboratory test to detect it (Nadel & Poss, 2006). Thus, persons have to rely solely on the competence of clinicians to adequately assess and recognize the behavioral characteristics that define ASD.

Late Diagnosis of Autism

More recently, increasing evidence has revealed that autism can be accurately diagnosed in very young children. Despite these advances in early detection, research has also shown that children are frequently not diagnosed until school age (Ittenbach, Levy, Mandell, & Pinto-Martin, 2006). Thus far, no significant studies
have been conducted to determine why some children tend to be diagnosed late.

In a 2006 research study conducted by Levy, Listerud, Mandell, & Pinto-Martin, 406 Medicaid-eligible children, residents of Philadelphia County, were tracked to determine the probability of receiving a diagnosis based on ethnicity rather than presenting dysfunctions. From the total sample, 242 were blacks, 118 were white, and 33 were Latinos. The male to female ration was 4:1, consistent with the demographics of autistic children. Autism tends to affect males at a higher ratio than females. The study found that, on average, white children were diagnosed at 6.3 years of age, while black children were diagnosed at 7.9 years (Levy et al., 2006). On average black children were diagnosed a year and a half later, compared to white children. This study also found that, once the children were in the mental health system, black children required about three times the number of visits, and a period three times longer than those for typical white children, to receive a diagnosis of autism (Levy et al., 2002). A significant limitation of this study is that it only focused on Medicaid-eligible
children, and may not be representative of the larger ASD population.

Another study by Novak, Mandell, and Zubritski, (2005), the researchers examined the diagnostic patterns after children enter specialty care. The study looked at the same sample as the previous study. The findings from this study reported that black children who eventually received an autism diagnosis were three times more likely than white children to have been misdiagnosed initially. The study further revealed that black children were more likely to receive an initial diagnosis of conduct or adjustment disorder.

Few studies have succeeded, so far, in raising awareness of the disparity in diagnosing autism in African American versus Caucasian children. There is evidence to show that awareness has brought some improvement in the age at which children with autism are diagnosed. The findings of a study conducted by the American Academy of Pediatrics (as cited in Novak et al., 2005, p. 1482) showed that, contrary to other research, ethnic minority children with autism did not receive a diagnosis at an older age as compared to Caucasian children. However, the ethnic minority families that
participated in this study may have been from a higher income and socioeconomic bracket. Therefore, ethnicity may be co-linear with other variables, such as income, which the study found to have a stronger association with the age of diagnosis (Novak et al., 2005, p. 1483).

However, the above result suggests that exposing these disparities could potentially generate the efforts needed to eliminate them, thereby improving health services for at risk and vulnerable population. Despite the glimpse of hope, studies thus far have not been able to identify the reasons for the delay in the diagnosis of black children with autism compared to Caucasian children.

Identifying reasons for this delay is crucial because early identification of autism provides an opportunity for early treatment, which can have a profound effect on a child’s overall development. Early treatment optimizes the opportunity for autistic children to live up to their fullest potential and may also result in considerable cost saving to both the families and the system (Novak et al., 2005, p. 1484). Early intervention is necessary in order to provide every child the opportunity to achieve their fullest potential. Early
intervention will further reduce parental stressors and provision of effective services may enhance the safety and well-being of families of children with developmental disabilities. It may help decrease child abuse and neglect within this particular population.

Developmental Disabilities and Child Abuse

There is a significant amount of research that suggests that the tasks associated with parenting a child with a developmental disability are sources of stress on the family system; thus, children with developmental disabilities are at high risk for child abuse. In reviewing the literature on the risks of child abuse and neglect in relation to children with developmental disabilities, a single theme consistently emerged: childhood disparities. Many studies show that disparities in health and well-being are rooted in early childhood. These disparities reflect gaps in access to services, unequal treatment, adverse congenital health conditions, and exposures in the early years linked to elevated community and family risks (Johnson & Theberge, 2007, ¶ 1). Disparities in health and well-being are elevated risks for Black children with developmental disabilities
because of the racial inequality and institutional racism that currently exist in America. Racial inequality creates greater calamities for African American children.

Another paramount issue connecting the risk factors for child abuse and neglect in children with developmental disabilities is familial stressors. The Ohio Family Support Council (OFSC) argues that when parents discover their child has a developmental disability, family relation become strained (2007). There are numerous difficulties associated with parenting a child who is developmentally disabled. Children with developmental disabilities can face several challenges that may, or may not, include life threatening health impairments, difficulties with learning adaptive skills, difficulties with undertaking various activities of daily living, a need for specialized support, and difficulties with behavior problems (National Center for Family Support 1999, p. 2-3). "Parents of special needs children often experience anger toward their child and [the entire family system]; they feel guilty, confused, frustrated, helpless, fearful and remorseful" (Darr-Wright & Wright, 2003, p. 5). These challenges can lead to parental stress which creates risk of child abuse and neglect.
Familial stressors can elevate the risk of child abuse. In a report conducted by the United Nations International Children’s Fund (UNICEF), many theories were posed holding that a disabled child faces increased risk as the result of child-produced stress on the family. It is theorized that the cycle of increasing tension begins long before the child is diagnosed as having a disability (p. 7). To an unknowing parent, a developmental disability may present as a form of disobedience and defiance. Children with developmental disabilities and behavioral problems may be at an even greater risk for child abuse and neglect than children with developmental disabilities without behavioral problems. Studies show links between parental stress, coercive parenting practices, and maladaptive behaviors in children with developmental disabilities (Curtis et al., 2007, p. 751). This suggests that parents parenting a child with an undiagnosed disability may assume their child is misbehaving, acting out, or being defiant.

In looking at literature and research on familial stressors, researchers have identified three key components that lead to high stress for parents/families caring for a child with a developmental disability. These
include the child’s disability in relation to behavioral problems financial strains due to the child’s physical, emotional, and medical needs the overall emotional strain on family relations and the strain on sibling relations (Oelofsen & Richardson, 2006, p. 1).

Levels of familial stress can vary depending on a child’s specific behavioral byproducts of the disability. Behavior problems are common in young children with developmental disabilities (Emerson, 2003, p. 53). Each developmental disability and disorder manifests a specific expression of behavioral problems; the degree of impairment may differ from one individual to another (Emerson, 2003, p. 59). Children with developmental disabilities also have behavior problems that interfere with development or functioning. According to research conducted by the Vanderbilt Kennedy Center for Research on Human Development (2008), children with developmental disabilities are likely to exhibit the following behaviors as a result of their disability: self-injurious behaviors, aggression toward others, and property destruction. An untreated or inadequately treated disability/disorder increases the probability of more
restrictive living, restrictive school placements, and increased family or caregiver stress (¶ 1-3).

Another familial stress associated with raising a child with a developmental disability is financial strain on family resources. "The majority of persons with developmental disabilities require long-term supportive care or services" (Chen et al., 2004, p. 58). Children with developmental disabilities may have multidimensional health ailments. Finances become a source of stress when there is not enough money for the needs of the family (Devenny, 1998, ¶ 1-30). Families featuring a child with developmental disabilities are likely to have increased demands on their financial resources to pay for medical care, additional therapies, babysitters, and participation in special programs. "Direct medical and non-medical costs can include physician visits, inpatient hospital stays, [and] assistive devices" (Chen et al., 2004, p. 59).

Often, families must choose between paying for their disabled child's specialized needs and paying for basic necessities for the family, such as food or rent. If a family cannot pay for both, a child may go without needed care. The family may not be able to pay their bills, buy
food, or buy medicine for other family members (OFSC, p. 3, 2007). There is a need for cost effective health services for families with children with developmental disabilities. Stress in relation to the financial costs of caring for a child with a developmental disability can also lead to child neglect, medical neglect, and child abuse.

The most significant issue relating to risk factors for child abuse and neglect in relation to children with developmental disabilities is the overall effect the child’s disability has on the entire family. In families where there is a child with a development disability stress is high. The family must always be alert; there is always a probability of crisis. The stress associated with a child with developmental disabilities may also transfer to other familial relations. The diagnosis of developmental disability in a child can trigger a range of emotional responses in parents and across family systems (Hiebert-Murphy & Trute, 2002, p. 271).

Challenges for children with disabilities pose significant day-to-day obstacles for the entire family. Obstacles [encountered] include natural reactions to the disability (i.e., sense of shock or numbness,
denial, grief, shame, guilt or depression), chronic stress and dramatic changes in lifestyle, difficulty undertaking family routines, enormous financial costs and lost opportunities for employment or education, continuous added out-of-pocket expenses, extraordinary time demands and difficulty with management of certain developmental disabilities. Parents may lack skills needed to cope with their child’s particular disability. (National Center for Family Support [NCFS], 1999, p. 3)

There is clearly a need for more specialized services for families experiencing these difficulties.

Literature on sibling relationships in relation to children with developmental disabilities indicates that there are four common concerns and anxieties for these siblings. These include concerns for the child (i.e., cause of the disability, the availability of appropriate care provision, the longer term future). There are also concerns related to parents (i.e., perceived differential expectations for their behavior and that of the sibling, communication with the parents, anxiety about the pressure on parents’ time), their own feelings in relation to their relationship with their disabled
sibling, and their own health, and worries about peer attitudes (Gallagher & Powell, 1993). An earlier study also concluded that “parental time and attention towards the child with the disability may arouse feelings of jealousy or resentment among other children of the family or increase existing feelings... thus exacerbating general familial stress” (Simeonsson & McHale, 1981, p. 169-171).

Research conducted on parent-child relations of normally-developed siblings of disabled children shows there are different stressors associated with being a sibling of a child with special needs. Miller (2001) found that parents put very high expectations on their normally-developing child. This creates high sources of stress for the child, particularly for boys. Girls experienced heightened pressure because they were often expected to be in the role of a parent-surrogate. As a result, conflict arose between the siblings and the child with special needs, which eventually lead to anger, resentment, and guilt.
Early Intervention for Autism

Throughout the years, a significant number of treatments have evolved from different philosophies. Due to the fact that each program has a different philosophical base and uses a different treatment approach, there are considerable overlaps in the components of each program. However, two elements that are common to the success of most intervention programs designed for ASD are the intensity of program delivery, and age of the child (Corsello, 2005). This further suggests that early diagnosis is the key to successful treatment.

An article on early intervention re-examined the first empirical study conducted on an autism intervention. This was a study conducted by Lovaas, in 1987. The study compared two groups of children receiving behavioral intervention for autism. The mean age for the experimental group was 35 months, and the control group was 41 months. Both groups received a significant number of intensive one-on-one interventions for an extended period of time. A follow up study was conducted when the children were between the ages of nine and nineteen. The
experimental group continued to have significantly higher IQs than the control group (Corsello, 2005).

A second study that examined the relationship between pre-intervention variables and the outcome of intervention also found that pretreatment mental age is the only variable that correlates with the outcome of behavioral intervention (Ben-Itzchak & Zachor, 2006). In this study, the progress of children with ASD was examined before behavioral intervention, and reassessed a year after intervention. The findings from this study supported the first study by Lovass (1987). Pretreatment mental age of the child is the only significant variable that correlates with the most desirable outcomes (Ben-Itzchak & Zachor, 2006, p. 297).

Theories Guiding Conceptualization

Systems theory was utilized as a guide for conceptualization of this study. Systems theory offered a way of conceptualizing the relationship between people and environments. It also encouraged a balanced approach by emphasizing a “goodness of fit” between people and their environment. Systems theory assumes that a problem arises because of a misfit between individuals and the
systems of which they are part. The goal of this theory is to increase the goodness of fit between individuals and the systems affecting them. In relation to autism diagnosis, it is essential that each client is viewed in the context of their environment, and health professionals should utilize that system as an asset towards recovery. Systems theory would provide for a more cohesive relationship and aid in the diagnostic process.

Empowerment and strengths perspectives were also utilized to assist participants in recognizing their ability to influence an accurate diagnosis and acquire appropriate resources. The strengths perspective assumes that every individual has knowledge, skills, and resources that can be utilize to transform their lives. The purpose of the strengths perspectives was to emphasize mutuality. The participants' contributions in this study were utilized as an asset towards increasing the researchers' level of awareness of the participants' subjective interpretation in relation to the diagnostic process. Presumably, the participants in this study were empowered, by being partners in a participatory research study. Participants felt empowered by the knowledge gained through shared experiences. Through this
collective group experience the participants developed a sense of community.

Summary

This chapter reviewed articles on disparities in mental services for minorities, including mental health diagnoses and interventions. The chapter examined the diagnostic process in diagnosing autism, outcomes of providing early interventions, and the relationship between children with developmental disabilities and child abuse. Each review included a summary and a critical analysis. The articles were critiqued for strengths and limitations, and a broad overview of the research methods were presented. Last, theories guiding the study were discussed.
CHAPTER THREE

METHODS

Introduction

This chapter includes the methodology for this study. It provides a detailed description of the study. The sampling procedure and data collection process discussed. The processes for soliciting participants were outlined. Measures taken to protect human subjects were discussed and an outline on how data were analyzed discussed.

Study Design

This study attempted to identify the variables that account for late diagnosis of autism among African Americans children by utilizing a qualitative participatory research approach. Furthermore, after identifying the variables that correlate with the late diagnosis, the study provided better alternatives to mitigate shortcomings inherent in the assessment procedures. Consideration of both cultural and psychosocial backgrounds of the families of children that are diagnosed, as well as possible biases in the clinical system, were explored throughout the study.
A qualitative participatory approach was selected as the research method because it provided the right atmosphere where participants would most likely feel empowered. Historically, communities of color have been the subjects of research where their problems and needs are defined and remedies imposed, with negligible community participation or representation in the process. A participatory research design provided participants with the opportunity to share their individual perspectives. Individual perspectives were analyzed to identify common themes. A focus group consisting of selected responders was formed by joint efforts of both members of the research team. Two researchers analyzed the responses this increased and enhanced the validity of the study.

One member of the research team shared the same ethnic and racial background as the subjects in the study. This important aspect increased assurance that rich conceptualized data was collected, because there is no stronger identification with a community than actually being a part of it. Therefore, having a member of the research team from the same ethnic and racial group was definitely an advantage. The other member of the research
team shared the same racial group, but was of a different ethnic group. This further provided a broader perspective in understanding the phenomena that may be more inclusive, because this provided a more in-depth and un-biased perspective.

In order to bring the perception of health care providers into the diagnosis process, The Diagnostic and Statistical Manuel of Mental Disorders (DSM-IV-TR) was utilized. DSM IV diagnostic criteria for Autism Spectrum Disorder was utilized as a reference tool to compare with the participant’s awareness of what health professionals look for when making a diagnosis.

The findings from this study empowered families by providing education on how to effectively advocate for their children. With parents becoming better educated in recognizing the early symptoms of autism and professionals acquiring greater proficiency, children are generally being diagnosed at much younger age now than previously. However, despite this progress, studies have shown that African American children with autism continue to be diagnosed at a later age than their Caucasian counterparts. The purpose of this study was to determine
why African American children with autism tend to be diagnosed at a later age than Caucasian children.

Sampling

The study focused on mothers, rather than fathers, because both facilitator/researchers conducting the study were female. Female participants are more likely to be comfortable and forthcoming with female facilitator/researchers. Therefore, mothers of autistic children were more accessible for this study than were fathers. Another reason mothers were chosen for this study, is because they are typically the primary caretaker of the child(ren). Mothers are usually aware of any issues or concerns relating to the child’s diagnoses and, presumably, they regularly attend to the child’s medical and special needs, e.g., doctor visits, communicating with service providers.

Initial participants were recruited from autism support groups in the Inland Empire and other neighboring regions. Flyers were also posted at three Regional Centers in the Inland Empire (See Appendix A). In addition, the researchers conducted a short presentation explaining the thesis topic to local autism support
groups in order to generate participants. A location that is familiar and accessible to the participant was utilized to conduct the focus group. The researchers in this study were responsible for providing the equipments, tools, and recourses to conduct the session and collect the necessary data. A snowball sampling method was also utilized to obtain participants for this study. Individuals from the support group who were interested in taking part in the study recommended other participants for this study.

The focus groups were both held on a Monday; both groups were by facilitated by Cecilia Johnson LCSW. Ms. Johnson is a License Clinical Social Worker at the West End Family Counseling Center in Ontario, California. The group was also co-facilitated by the researches of this study. The Caucasian focus group was conducted on Monday February 18, 2008 and the African American focus group was conducted on Monday March 03, 2008. Both focus groups were held in the evening from 6:00p.m.-8:00p.m. Before the discussions began each participant filled out an intake form (See Appendix B). Each group lasted approximately two hours. The focus group discussions followed the group discussion guidelines (See Appendix
C). Refreshments were provided by the researches and gifts baskets were raffled off at the end of the discussions. The researchers also traveled out to Barstow, California to conduct face-to-face interviews with two African American participants who were unable to participate in the focus group.

This sampling method had some limitations. While the snowball technique is very effective in getting participants, it also creates possible subject bias. Snowball sampling relies on referrals from initial subjects to generate additional subjects. Thus, it is very likely that the subjects that are referred to be studied are influenced by the network of referral subjects. For example, individuals could have been coached on what to say. This limitation, however, was minimized because the researchers provided guidelines for the participants.

A second limitation was the factor of the mental and emotional state of the participant with regards to their perception of the problem. For example, one participant’s child had just recently been diagnosed. Thus, the participant may have exaggerated her experiences because she was still very upset over what she had recently gone
through. On the other hand, the participants who had the same experience years ago did not remember important details and was unable to speak on certain topics because they no longer viewed particular topics/issues as significant now as they did initially. The limitations were taken into consideration when the researchers’ analyzed the result of the study.

Qualitative data were obtained from sampling units. Families with an autistic component were the elements. African American mothers and Caucasian mothers of children who are autistic were the sampling units. Individual participants were recruited from autism support groups and through snowball sampling. Ten participants were recruited for two focus groups. Five Caucasian mothers were assigned to the first focus group, three African American mothers were assigned to the second focus group, and two African American mothers participated in a face to face audiotape interview.

Data Collection and Instruments

Data were collected during an informal interviewing process within the dynamics of the focus group and personal interview session(s). During the initial phase,
participants completed an initial intake form, which collected information regarding certain independent and dependent variables (See Appendix I). Independent variables for this study included:

- gender of the child, measured as nominal
- other children with autism, measured as ratio,
- medical insurance status, measured as nominal,
- access to a primary care physician, measured as nominal,
- maternal education level, measured as ordinal,
- marital status, measured as nominal, and
- income, measured as ordinal.

The questionnaire also included some dependent variables:

- age when the child was first seen by a health professional, in relation to development delays, measured as ratio,
- age when the child received an autism diagnosis, measured as ratio
- number of visits before the child received an autism diagnosis, measured as ratio, and
- prior behavioral diagnoses before arriving at the diagnosis of ASD, measured as nominal.
The second phase focused on gathering qualitative data from each group regarding perceptions, attitudes, underlying issues and concerns later analyzed for common themes. The data from the focus group(s) and personal interview discussions were tied to the above variables to get a clearer analysis of what variables most correlate with a late diagnosis of autism.

Focus groups are particularly effective for gathering detailed and in-depth information in order to achieve a holistic understanding of the participants' perspectives. A major strength of this approach is the yielding of detailed information with useful individual perspectives and direct quotations. Videoing and audio-taping the focus groups and the face-to-face interviews provided an opportunity to observe and assess the body language, tone of voice, and reaction of the participants towards one another in a comfortable milieu. Information gathered from the observation was extremely useful to determine valuable qualitative data. Focus groups are also an effective means of recognizing common themes among participants. In utilizing focus groups the researcher were able to determine perceived biases of the two focus groups in relations to their interactions with
the medical community. Although focus groups are effective for gathering detailed information, they also provide significant challenges.

Typically, focus groups require considerable amounts of time to arrange and coordinate. There is little or no anonymity for participants, and very limited confidentiality, if that is possible. These limitations may inhibit participants' willingness to share valuable information. Therefore, the facilitators of the focus group(s) had to be very skilled in order to encourage participants to provide valuable information. The facilitator prepared a set of open-ended questions that were carefully worded and arranged for the purpose of generating motivation among the participants to contribute valuable information. Questions were short, easy to understand, and devoid of jargon. This enhanced their comprehensibility to the interviewees. The facilitator also discussed issues of confidentiality, and provided participants the opportunity to ask relevant questions and express any of their concerns. Questions focused on participants' perception of the diagnostic process (See Appendix D). Topics discussed included:
• participants prior knowledge of ASD,
• what happened during the initial visit with a health professionals,
• feelings experienced during visits with health professional,
• individual opinion of the diagnostic process, and question such as,
• studies have reported that black children with ASD tend to be diagnosed later than average; what do think about this?
• how can mothers advocate for their children in order to receive a timely and accurate diagnosis?

Procedures

Data for this study were gathered utilizing a qualitative research approach. In addition, the DSM-IV diagnostic criteria for autism was also utilized as a tool during the discussions to increase parents’ level of awareness, thus assisting them in becoming more knowledgeable of the diagnostic process. Due to the fact that there is no laboratory test to detect autism, parents have to rely on the professional judgment of
health care professionals. Therefore, it is extremely important that parents are made aware of the diagnostic criteria(s) (See Appendix E).

Qualitative data were obtained from an in-depth interview utilizing a focus group(s) and personal interview(s). The facilitator used open-ended questions to obtain useful and valuable data. The study utilized video and audio media to gather data, which was analyzed. Approval to document the session in video and audio media was obtained from the participants.

Protection of Human Subjects

The focus groups and personal interviews consisted of human subjects. Direct questions were asked of the participants, notes were taken during the interviewing process, and video and audio recording was utilized with the participants consent (See Appendix F). Each participant was given an informed consent form (See Appendix G). In order to ensure protection of confidentiality for all subjects participating in the study, the information obtained during the interviewing phase was viewed by the facilitator and the researchers conducting the study. At the start of the (before the
participants attend) participants completed an initial intake form. Each participant was identified by first name only.

The participants were also given a video-audio use consent form and notes were taken. Individual direct responses from the interview were only included in direct quotes. At the end of the study each participant received a debriefing form (Appendix H), detailing the major aims of the study.

Data Analysis

Data for qualitative analysis were predominately obtained through video and audio recording and written transcripts. The participants were asked several questions. Each response was hand written, video-taped, and audio-tape during the interviewing phase of the study. Individual comments from all participants were included, and nonverbal interaction (e.g., laughing, crying, and smiling) were also noted. The researchers refined the participants' responses by highlighting major themes such as universal complaints and areas of concern.

The study’s questions were designed to find out when participants first had concerns for their child’s
developmental well-being and individual perceptions of the diagnostic process. Participants were also asked to share their opinions on how to empower and educate mothers to be good advocates for their children. Common themes and experience were highlighted in each group; both were compared and analyzed. The study detailed disparities found in experiences and services for African American mothers of children with autism.

Analysis utilized variables with three levels of measurements: nominal, ordinal, and ratio. Nominal measurement was utilized to obtain information from focus group participants regarding their individual perception of the diagnostic process. Ethnicity, gender of children, medical insurance status and access to a physician, maternal education level, marital status, and income was considered in analyzing the data. Utilization of the above variables identified patterns and, or, unconscious bias' of children diagnosed with autism, in relation to rates of occurrence which exist in the medical community.

Identifiable themes were put into categories to determine which variable(s) most correlated with the dependant variables. Common themes were identified to determine which variables correlates most with the age of
diagnosis. This included possible correlations with disparities seen in services for African American children with autism.

Summary

This chapter outlined the methods utilized to conduct this study. It detailed the study design and the rational for the approaches used in the study. The chapter also described the samples used in the study and provided justification for why the samples were chosen. In addition, the chapter also detailed specific data being collected. The procedures used to gather data were discussed. The issue of human protection was discussed and adequate protection for participants were defined. Last, the chapter covered how data analysis was conducted for the qualitative and quantitative studies.
CHAPTER FOUR

RESULTS

Introduction

This chapter discusses the results of the study. Participant’s demographics and commons themes discovered from the focus groups are highlighted. Demographic information that was analyzed was obtained from the participant’s initial intake forms which each participant filled out before the focus group. Participants were identified by first name only. Items included on the intake form were participants’ race, educational level, marital status, available healthcare, socioeconomic status, and child demographics.

Presentation of the Findings

The study consisted of ten participants; five participants were assigned to the Caucasian focus group and five African American group. The results of the study confirmed the studies' initial hypothesis. The initial hypothesis suggested that African American children tend to have a two year delay in diagnosis for autism in comparison to their Caucasian counterparts. The results
confirmed that African American children are more likely to receive a late diagnosis for autism.

Results from Initial Intake Form

The data from the initial intake form indicated that race does correlate with a late autism diagnosis. However, the results further suggested that although African American children are more likely to be diagnosed late, race is not the factor that most correlates with a late diagnosis. The data indicates that socioeconomic status most correlates with a late diagnosis for autism despite participants’ race. According to the data, two African American mothers and one Caucasian mother that were of a higher socioeconomic status possessed a more competent approach towards accessing needed information leading up to an early and accurate autism diagnosis. Mothers of higher socioeconomic status were also more efficient in navigating through the healthcare system, educational system, and Inland Regional Center system despite health professionals’ lack of expertise and reluctance to provide appropriate resources and support in relation to meeting their child and family’s needs.

The data showed that education and occupation do correlate with an early and accurate diagnosis of autism.
Participants that had a high education level seemed to be competent in their ability to advocate and access, services, and resources for their child. Participants that had a lower education level felt less competent to advocate and access adequate services. The participants with a lower education level also seemed to be less knowledgeable in relation to accessing the right information and resources. Another significant finding of this study was that race was not a factor if the child had autistic siblings.

The data indicated that participants with one or more children already diagnosed with autism were most likely to receive an early and accurate diagnosis. According to the data, four participants from both studies who had children previously diagnosed with autism reported very early diagnosis. This indicates that, due to the fact that there is no laboratory testing to confirm an autism diagnosis, health professionals may rely on family history and parent's level of awareness to confirm a diagnosis for autism.

The data also showed that African American children with autism are more likely to be misdiagnosed as having behavioral problems or cognitive disabilities, such as
mental retardation and conduct disorder. Out of all ten participants two African American children were initially misdiagnosed with mental retardation; only one Caucasian child was initially misdiagnosed. This finding was very interesting because the Caucasian child was initially misdiagnosed with Attention Deficient Disorder, which is a diagnosis that can potentially be viewed by society as less dysfunctional and possibly less stigmatized. This suggests that African American children are more likely to receive a late diagnosis for Autism because of an initial misdiagnosis.

Another interesting finding from the initial intake forms was that two female children, one African American and one Caucasian, received an early diagnosis; each received a diagnosis at three years of age, which was earlier than to their male counterparts which tended to be diagnosed between the ages of six to ten. This suggests that female children of any ethnic background are more likely to receive an early diagnosis for autism, suggesting that gender may play a role in the diagnostic process.

It is possible that there may be a gender bias among health professionals in diagnosing children with autism,
because the male children in this study were more likely to be viewed by the health professional as having behavioral challenges. The female children were able to receive a timely and accurate diagnosis. This also suggests that health professionals may take disruptions in female children more seriously than in male children. This can also be related to society’s view of the notion that males are expected to develop slowly and sometimes misbehave. In relation to autism and an early diagnosis this notion may result in a delay in diagnosing male children of any ethnic background.

The number of doctor visits before the child received an autism diagnosis was also significant in this study. The study revealed that children who saw the doctor more tended to have an earlier diagnosis. Furthermore, the Caucasian mothers in this study reported more doctors’ visits than the African American mothers. This raises the issue of possible reasons for a difference in doctor’s visit despite the fact that all participants’ had access to a health care provider. It is possible that Caucasian mothers may have been able to access referrals for other healthcare specialists while African American mother may have not been given the
opportunity to see other specialists in relation to concerns about their child’s development. Another possibility is that African American mothers may not seek assistance when they are encountering difficulties with their child; rather, they may prefer to address the problem within the family unit.

Marital status and access to health care did not have any significant correlation with the diagnostic process. Seven participants were married, but did not report that their marriage was a contributing or hindering factor. One participant was divorced and another was widowed. They too did not report marital status as being significant. However, the participants that were married appeared better equipped in their ability to manage the stressors associated with raising an autistic child.

Focus Group Results

The focus group discussion questions were designed to uncover the participants’ perceptions in relation to late diagnosis of children with autism. Common themes were utilized to identify any unconscious biases in the medical community, inequalities in the diagnostic process, access to the health care system, mother’s level
of awareness of their child's disability, and knowledge of late diagnosis among African American children. In addition, the discussion questions focused on identifying strategies to help mothers become better advocates for their children.

In the Caucasian focus group there were five participants. In the African American focus group there were three participants. Two additional African American mothers were included in the study through face-to-face interviews. Each focus group lasted approximately two hours; both groups were facilitated by a licensed clinical social worker. The individual face-to-face interviews lasted approximately an hour and a half and took place at a public library.

In general, most of the Caucasian participants, with the exception of two who already had a child previously diagnosed with autism, did not have prior of knowledge of autism spectrum disorder. The Caucasian mothers reported that very little information was provided to them during the initially doctor visit. The mothers reported they felt discouraged and upset by the lack of knowledge their doctor had in relation to identifying the reasons for their child's emotional and developmental deficits. For
example, one mother reported that even though she expressed frustration and concerns to her physician that her child was not verbal or potty trained at four years old, her physician had no knowledge of what her child’s problems were, nor did the physician provide any additional resources to assist her. The mothers took it upon themselves to conduct research on developmental disabilities.

All the mothers reported that after their child was diagnosed they found that the health professionals had limited knowledge of autism spectrum disorder and had no knowledge of available resources. As a result the participants had to educate themselves about the disorder through the internet and other forms of media. One of the mothers was a teacher. She reported she had to document her child’s daily behavior and present it to her physician to facilitate the diagnostic process.

In this study only one Caucasian mother stated that she had prior knowledge that African American children tend to be diagnosed later than Caucasian children. She also stated that Hispanic children also tend to receive a late diagnosis for autism. Her knowledge was partly due to the fact that she is a school teacher and has direct
contact with children. The participant also has a child with autism, thus she may be able to easily recognize the disorder. The remaining four participants had no knowledge of possible late diagnosis for African American children.

In the African American focus group the participants did not have prior knowledge of autism spectrum disorder. During their initial doctor visit the mothers reported that the heath professionals had little knowledge and their concerns for their child’s disorder were not taken seriously. One mother was told she should be happy that her child was not active because he would be able to stay out of trouble. Another was told her son’s behavioral challenges were the result of mental retardation.

When the African American mothers finally received an accurate diagnosis, the physicians became critical about their lifestyle and no additional resources or services were offered to help assist them. Unethical assumptions were made regarding the lifestyle of two participants. For example, one mother was asked by her physician what type of illegal substance did she use while she was pregnant. The mothers expressed hurt and
frustration for the lack of knowledge and empathy from her physician. The other participants expressed similar sentiments with regard to their physicians' response to their child's diagnosis and reluctance to believe them.

The mothers were also frustrated with the physicians' lack of empathy and lack of knowledge of available resources regarding their child's disorder. In order to get adequate resources for their children the African American mothers had to research other strategies to meet their child's needs. One mother had to relocate to a new geographic area to access more appropriate services for her son. All of the mothers had to educate themselves on their child's disorder and its byproducts. The participants reported they had to research the internet, books, and other media sources to increase their level of awareness. In relation to their knowledge of possible late diagnosis of autism among African American children, the mothers were more aware than the Caucasians of this phenomenon and other health disparities among minorities, specifically African Americans.

Despite the difference between the focus groups several common themes were present. One of the major complaints in both focus groups was the lack of knowledge
and experience physicians possess in working with autistic children and their families. According to Sarah, one of the participants from the Caucasian focus group, the doctor didn’t have any information for me regarding my child’s disability. I was told to go buy book on autism from the book store. When I got the book I was horrified. I did not want my husband to read it. There was no hope offered in the book. It basically said my child would remain this way for the rest of her life.

Florence, a participant from the African American focus group shared similar concerns; “the doctor’s just didn’t know what was wrong with my child. It took ten years for my child to be diagnosed. I was shock by the level of ignorance these people have.”

Another common theme shared by both focus groups was reported gaps in services. Both groups complained that health care professionals are unaware of what services are available. For example, Shannon, a participant from the Caucasian focus group stated that, “during my first visit my doctor referred me to a neurologist, and then the neurologist referred my back to the doctor. It just seemed like everyone was very confused. This was very
frustrating to me.” Florence, the African American participant whose son was diagnosed at ten years old stated,

before my son was diagnosed with autism he was diagnosed with conduct disorder then mental retardation. This just didn’t make sense to me. I couldn’t believe all the tests my son was made to undergo. My entire family was affected by this long drawn out process. It also became financially difficult because I had to take time off work to keep all the appointments.

The most significant common theme between the focus groups was the consensus that mothers of autistic children must educate themselves on their child’s disability. Penny, a participant from the African American focus group, stated, “in order for health care professionals to listen to your concerns you must educate yourself and know what you are talking about, because no one cares about your feelings.” She further stated that, you must also know your child’s strengths, weaknesses, and what will benefit your child.

Cheryl, a participant from the Caucasian focus group, stated, what was most helpful to me in
getting my child diagnosed was keeping a journal of my child’s behavior, because you shouldn’t expect the physicians to know. The only thing they care about is how much money you can spend. You must know your child for yourself.

The two African American mothers that were interviewed face-to-face reported having a very different experience in the diagnostic process than the African American mothers in the focus group. Both mother reported they did not have any prior knowledge of disorder. However, other professionals were able to quickly and accurately identify the disorder. Also, additional resources were made available to them. During the initial visit with the health professionals, Pamela reported the experience as supportive and encouraging. The other participant, Cheryl, felt she and her family were interrogated. According to her, she and her children were questioned in separate rooms and were discourage from sharing any information with each other.” At the time Cheryl felt this was procedural and had no objections to the process. In relation to their knowledge of possible late diagnosis of autism among African American children,
both Pamela and Cheryl said they had no knowledge of the phenomenon.

The difference between the interview participants and those in the focus groups was that Pamela and Cheryl live in Barstow, California, a small military town where services appear to be more accessible despite racial or ethnic background. This suggests that services may be more available and easily accessible in certain geographical areas. This may also be due to do such variables as, low population, quality health care, services designed for military employees, and specialized governmental programs and services designed to target populations in rural areas. The lack of universal specialized programs may be the reason why other participants in this study had difficulties accessing and receiving the appropriate diagnosis and accessing available resources. Furthermore, the lack of available services may have contributed to health professionals' reluctance to give an autism diagnosis.

To assist the mothers in increasing their level of understanding of this disorder, the study utilized the DSM-IV criteria as an educational tool for both focus and individual face-to-face interviews. The mothers were
provided with copies of the DSM-TR IV criteria for autism spectrum disorder. All but one mother had no prior knowledge of the physical manifestations physicians assess for to make a diagnosis of autism. The mothers were asked to read the diagnostics criteria in order to determine how accurately they understood them. Most mothers confirmed that the majority of the symptoms stated in the criteria were noticeable in their children; however they were unaware of the fact that health professionals utilize these criteria to make a diagnosis. All the mothers agreed that a complete understanding of the diagnostic process is crucial to an early and accurate diagnosis.

Summary

In this chapter the findings from the study were discussed. Variables related to participants' demographic information were analyzed. The chapter also included detailed interpretations of the discussion from each focus group and the face-to-face interviews. The issues surrounding health professionals lack of knowledge and reluctance to give a diagnosis of autism was discussed. The issue of late diagnosis among African American
children was explored and analyzed and mothers’ ability to become better advocates was explored. In addition, possible factors that relate to the findings, such as geographic location and available services were explored. Last, the diagnostic criteria were examined in relation to participants’ level of understanding.
CHAPTER FIVE

DISCUSSION

Introduction

This chapter highlights the major findings of the study and briefly discusses the findings in relation to late diagnosis of autism for African American children. Theoretical approaches will be identified for working with families with an autistic child. Suggestions for more effective social work interventions will be examined and discussed. Recommendations for social work practice, policy, and research will be explored. Recommendations for additional research will also be explored and discussed. Last, the limitations of this study will be analyzed and discussed.

Discussion

As discussed in the results section of this study, the participants' primary concerns were lack of physicians' knowledge and resources in relation to their child's symptoms of autism spectrum disorder, service gaps, and the need for parental and health professionals to increase their level of education. In relation to the study's hypothesis that African American children tend to
receive a late diagnosis of autism in comparison to their Caucasian counterparts, the study found that although race is not the primary reason why African American children can be diagnosed late it can be a significant factor. Therefore, to overcome the race component in regards to accessing needed services, African American mothers must be highly knowledgeable, very assertive, and consistent in their advocacy for their child. In addition to educating themselves, African American mothers can also become good advocates by networking with other mothers.

As previously stated, race was not the primary variable that correlated with a late diagnosis of autism in this study. Overwhelmingly the data revealed that socioeconomic status was the most significant variable associated with a late diagnosis of autism. It is possible that any child, despite racial background, can be diagnosed late if they are of lower socioeconomic status. However, African American families of lower socioeconomic status are even more likely to receive a late and inaccurate diagnosis.

Also, the study found that, in certain geographic areas where participants reported available resources,
neither race nor socioeconomic status was a hindrance to receiving a timely and accurate diagnosis. Two African American participants from Barstow, California reported no problem in receiving an accurate diagnosis and accessing adequate resources to meet their child’s needs. Although one of these participants was of low socioeconomic status, services were made available to her and her child was able to receive behavioral interventions at home. The child was initially assessed by a psychiatrist as soon as she was identified at school as having developmental challenges. This suggests that geographic location may be a significant variable in obtaining an early diagnosis for autism.

Recommendation for Social Practice, Policy, and Research

Social workers are mandated by the social work code of ethics to be competent in the services they provide. Therefore, it is important for social workers to receive appropriate education and trainings on how to recognize autism while assessing families’ needs. It is also important that social workers are aware of available resources and treatments for autism. In terms of child welfare, it is imperative for social workers to be able
to distinguish the need for appropriate medical attention versus what could be considered child abuse and neglect. Thus, adequate training is needed to effectively serve this population.

Theoretical approaches can be used to enhance social workers’ ability to serve families with an autistic component. Systems theory would be the most effective because it recognizes each family in the context of their unique environment. Therefore, all family dynamics are taken into consideration in assessing their unique needs, resulting in a higher quality of care.

Another theory that can be utilized to enhance social workers’ ability to serve families with an autistic child is client-centered theory. This approach to care focuses on creating services designed to meet the families’ specific needs. It also allows for social workers’ objectivity in creating a more holistic approach to treatment. It also creates an opportunity for social workers to think out side the box, stretching their practice repertoire, to create a better fit between the client and the services provided. Last, this approach is empowering because it recognizes families as equal partners in deciding services.
With adequate education and utilization of an appropriate theoretical framework it is possible to minimize health disparities among minority children in the child welfare system. Appropriate intervention and resources can also reduce family stressors associated with having a child with special needs.

In particular, social workers must be adequately trained to close any existing gaps in services. This means that for the process to be successful the social workers must take on the role of a broker, linking families with quality health care professionals that are knowledgeable about developmental disorders and specifically, autism spectrum disorder. Social workers must be able to link families with appropriate services and adequate resources. Social workers must also act as change agents in pioneering appropriate assessment and intervention for children with disabilities.

Limitation

Throughout this research project valuable information was uncovered; however, there were some limitations to this study. The primary limitation was that this study focused solely on one minority group,
African Americans. Health disparities do exist among other ethnic minority groups, such as Hispanic Americans. Therefore, one can assume that Hispanic children with autism may also tend to be diagnosed late. It would be extremely beneficially to the medical community as well as the Hispanic population if further research is conducted on possible late diagnosis of autism for Hispanic children.

Another limitation to this study was that the perspective of the medical community was absent. Although the study attempted to recognize the perspective of the medical community by utilizing the diagnostic criteria in the DSW IV for autism spectrum disorder, it was not sufficient. Actual data from the medical community, either in the form of face-to-face interviews or surveys with psychologists and psychiatrists, who typically diagnosis autism, would have been more effective in revealing the medical community’s true perspective. The medical community’s perspective would have also been beneficially to the participants in this study who expressed that frustration with the medical community was one of their primary issues in attempting to access appropriate services for their children. Furthermore,
since individuals have to rely solely on the professional judgment of the health professionals it was extremely important that the participants get a clear understanding of what health professionals look for in diagnosing autism.

The final limitation in this study was the fact that two participants from the African American focus group were unable to attend. As a result the participants had to be interviewed individually. This was a limitation because the cohesiveness within a focus group discussion may have generated more valuable information from them. Also, the interviews were conducted by the researchers; this may have influenced the information given by the participant. It is possible that the participants may have felt pressured to provide information that they thought was needed in this study.

Based on the above limitations it would be beneficial for further research to be conducted on late diagnosis of autism for minority children. This study provided significant information that would assist mothers in their efforts to obtain accurate and timely autism diagnosis. Thus far studies continue to reveal that early intervention is the only way that autistic
Therefore it is imperative that every child, regardless of race and socioeconomic status, is given that opportunity. For this to occur, further research is needed to incorporate what would benefit mothers of all ethnic groups. More research on late diagnosis of autism for minority children would also contribute towards efforts to overcome all health disparities that exist within the health care system.

Summary

This chapter highlighted the major findings of the study and briefly discussed the findings in relation to late diagnosis of autism for African American children. Theoretical approaches were identified in relation to working with families with an autistic component. Suggestions for more effective social work interventions were examined and discussed. Recommendations for social work practice, policy, and research were explored. Recommendations for additional research were also explored and discussed. Last, the limitations of this study were analyzed and discussed.
APPENDIX A

PARTICIPANT RECRUITMENT FLYER
Autism Study

California State San Bernardino University graduate students are seeking African American mothers of Autistic Children to take part in a 60 minute discussion group addressing such topics as: diagnosis, treatment, and support.

Refreshments will be provided.

Beautiful gift baskets will be raffled off at the end of the discussion.

If you are interested in participating, please call Lyzette (909) 702-6729, or e-mail Kathleen Holsey92507@yahoo.com for details.

Your participation will be very valuable and very appreciated.
APPENDIX B

PARTICIPANT RECRUITMENT FLYER
Autism Study

Cal State San Bernardino University graduate students seeking mothers of Autistic Children to take part in a 60 minute discussion group addressing topics such as diagnosis, treatment, and support.

Refreshments will be provided.

Beautiful gift baskets will be raffled off at the end of the discussion

If you are interested in participating, please call Lyzette (909) 702-6729, or e-mail Kathleen Holsey92507@yahoo.com for details.

Your participated will be very valuable and very appreciated.
APPENDIX C

INITIAL INTAKE FORM
INITIAL INTAKE FORM

First name only __________________

1) What is the gender of your child diagnosed with Autism?
   Male ____ Female ____

2) Number of other children diagnosed with autism? _______.

3) Do you have health insurance?
   Yes ____ No ____

4) Do you have access to a primary health physician?
   Yes ___ No ___

5) What is your educational level?
   a) Grade completed ____.
   b) Associate Degree
   c) Bachelors Degree
   d) Post Graduate Degree

6) What is your marital status?
   a) Single
   b) Married
   c) Divorced
   d) Widowed

7) What is your income bracket?
   a) less than $25,000 per year
   b) 25,000 to 35,000 per year
   c) 35,000 to 45,000 per year
   d) more than 45,000 per year

8) Was your child first misdiagnosed with any of the following: Attention Deficit Disorder, Mental Retardation, Oppositional Defiance Several Emotionally Disturbed, or Other Disorder?
   a) Yes
   b) No

9) Number of doctor visits before your child received an autism diagnosis? _______.

10) What age was your child first seen by a health professional, in relation to development delays? _______.

11) At what age was your child diagnosed as autistic? _______.

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APPENDIX D

FOCUS GROUP DISCUSSION GUIDE
FOCUS GROUP DISCUSSION GUIDE

Topics that will be discussed:

- Participants prior knowledge of ASD,
- What happened during the initial visit with a health professionals,
- Feelings experienced during visits with health professional,
- Individual opinion of the diagnostic process, and question such as,
- Studies have reported that black children with ASD tend to be diagnosed later than average; what do think about this?
- How can mothers advocate for their children in order to receive a timely and accurate diagnosis?
APPENDIX E

DIAGNOSTIC CRITERIA FOR AUTISTIC DISORDER
DIAGNOSTIC CRITERIA FOR AUTISTIC DISORDER

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

(1) qualitative impairment in social interaction, as manifested by at least two of the following:
   (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
   (b) failure to develop peer relationships appropriate to developmental level
   (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
   (d) lack of social or emotional reciprocity

(2) qualitative impairments in communication as manifested by at least one of the following:
   (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
   (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
   (c) stereotyped and repetitive use of language or idiosyncratic language
   (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

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

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

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.
APPENDIX F

VIDEO-AUDIO USE CONSENT FORM
SAMPLE PHOTOGRAPH/VIDEO/AUDIO USE
INFORMED CONSENT FORM
FOR NON-MEDICAL HUMAN SUBJECTS

As part of this research project, we will be making a photograph/videotape/audiotape recording of you during your participation in the experiment. Please indicate what uses of this photograph/videotape/audiotape you are willing to consent to by initialing below. You are free to initial any number of spaces from zero to all of the spaces, and your response will in no way affect your credit for participating. We will only use the photograph/videotape/audiotape in ways that you agree to. In any use of this photograph/videotape/audiotape, your name would not be identified. If you do not initial any of the spaces below, the photograph/videotape/audiotape will be destroyed.

Please indicate the type of informed consent
☐ Photograph  ☐ Videotape  ☐ Audiotape

(AS APPLICABLE)

• The photograph/videotape/audiotape can be studied by the research team for use in the research project.
  Please initial: ______

• The photograph/videotape/audiotape can be shown/played to subjects in other experiments.
  Please initial: ______

• The photograph/videotape/audiotape can be used for scientific publications.
  Please initial: ______

• The photograph/videotape/audiotape can be shown/played at meetings of scientists.
  Please initial: ______

• The photograph/videotape/audiotape can be shown/played in classrooms to students.
  Please initial: ______

• The photograph/videotape/audiotape can be shown/played in public presentations to nonscientific groups.
  Please initial: ______

• The photograph/videotape/audiotape can be used on television and radio.
  Please initial: ______

I have read the above description and give my consent for the use of the photograph/videotape/audiotape as indicated above.

The extra copy of this consent form is for your records.

SIGNATURE __________________________ DATE ___________
APPENDIX G

INFORMED CONSENT FORM
INFORMED CONSENT

The study which you are being asked to participate is designed to explore how parents experience the process of arriving at a diagnosis of autism for their child. It is likely that there will be no, or minimal, risk involved in this study. However, if the diagnostic process was stressful for you, it may be stressful to remember those events. The researchers will provide additional support by having a licensed clinical social worker facilitate both focus groups. The clinical social worker will be able to recognize any emotional distress and provide the necessary support.

This study is being conducted by Lysette Etti & Kathleen Holsey under the supervision of Professor Rosemary McCaslin, Department of Social Work, and California State University, San Bernardino. This study has been approved by the Department of Social Work Sub-Committee of the CSUSB Institutional Review Board.

In this study, you will be asked to share your experiences in relation to the diagnostic process. The discussion should take about 45 to 60 minutes to complete. All of your responses will be held in the strictest of confidence by the researchers. Respondents will be identified by first names only. You may receive the group results of this study upon completion after September 2008. The study will be available at San Bernardino’s John M. Library 5500 University Parkway, San Bernardino CA 92407 California State University, and at West End Family Counseling Services, located at 855 North Euclid Avenue Ontario, Ca 91762, (909) 983-6847.

Your participation in this study is voluntary. You are free not to answer any questions you are uncomfortable answering, and, should you choose, you may withdraw from this study at any time. When you have completed the focus group discussion, you will receive a debriefing statement describing the study in more detail. If you have any questions or concerns about this study, please feel free to contact Professor Rosemary McCaslin at (909)-537-5507.

By placing a check mark in the box below, I acknowledge that I have been informed of, and that I understand, the nature and purpose of this study, and I freely consent to participate. I also acknowledge that I am at least 18 years of Age. Place a check mark here ☑️ Today’s date: __________
DEBRIEFING STATEMENT

The study you have just completed was designed to evaluate the diagnostic process in relation to Autism in Black children in comparison to Caucasian children. The study explored why some children are receiving late diagnosis for autism, despite advancements in the diagnostic process. There is still no official testing to confirm an autism diagnosis. Parents have to rely on the professional judgment of the health professionals. Therefore, it is imperative that every parent is made aware of the diagnostic criteria for autism.

The researchers hope that raising awareness on this issue and clarifying the DSM-IV criteria health professionals use to make a diagnosis will be useful to parents as they advocate for their children. Early diagnosis leads to early treatment. Early treatment optimizes the opportunity for autistic children to live up to their fullest potential.

In this study, two focus groups were conducted in order to obtain individual views of the mental health process surrounding possible late diagnosis among Black children with Autism. The study also sought to identify similarities and differences between interactions and language levels of the sample with the medical community. The Diagnostic Statistical Manual-Four (DSM-IV) was used as a tool to assist researchers in generating discussion about the diagnostic criteria needed to qualify for an Autism diagnosis. This criteria was utilized to increase participants level of awareness of the psychological, behavioral, and emotional manifestations health professionals look for in children to make a diagnosis of autism. Being aware of the DSM-IV diagnostic criteria can assist mothers in becoming better advocates for their children.

Thank you for your participation and your confidentiality. If you have any questions about the study, please feel free to contact Professor Rosemary MaCaslin, at (909) 537-5507. If you would like to obtain a copy of the group results of this study, please contact John M. Library or the Pomona Regional Center.
APPENDIX I

INITIAL INTAKE FORM RESULTS TABLE
<table>
<thead>
<tr>
<th>Race of Participant</th>
<th>Marital Status</th>
<th>Educational Level</th>
<th>Income Bracket</th>
<th>Sex of Child</th>
<th>Age at First Doctor's Visit</th>
<th>Age at Initial Diagnosis</th>
<th>Number of Visits Before Diagnosis</th>
<th>Prior Misdiagnosis</th>
<th>Health Insurance</th>
<th>Primary Physician</th>
<th>Autistic Siblings</th>
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**Race**

0=African American  
1=Caucasion

**Marital Status**

1=Single  
2=Married  
3=Divorced  
4=Widowed

**Educational Level**

0=Less Than Grade 12  
1=High School Diploma  
2=Associate's Degree  
3=Bachelor's Degree  
4=Post Graduate

**Income Bracket**

1=Less than $25,000 per year  
2=$25,000 to $35,00 per year  
3=$35,00 to $45,00 per year  
4=Greater than $45,000 per year

**Sex**

1=Male  
2=Female

**Prior Misdiagnosis**

0=No  
1=Yes

**Health Insurance**

0=No  
1=Yes

**Primary Physician**

0=No  
1=Yes

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REFERENCES


ASSIGNED RESPONSIBILITIES PAGE

This was a two-person project where authors collaborated throughout. However, for each phase of the project, certain authors took primary responsibility. These responsibilities were assigned in the manner listed below.

1. Data Collection:
   Team Effort: Lysette Etti & Kathleen Holsey

2. Data Entry and Analysis:
   Team Effort: Lysette Etti & Kathleen Holsey

3. Writing Report and Presentation of Findings:
   a. Introduction and Literature
      Team Effort: Lysette Etti & Kathleen Holsey
   b. Methods
      Team Effort: Lysette Etti & Kathleen Holsey
   c. Results
      Team Effort: Lysette Etti & Kathleen Holsey
   d. Discussion
      Team Effort: Lysette Etti & Kathleen Holsey

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