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## A Phenomenological Consideration of Conflicts and Crisis Impacts of Autism on Single Parenthood: A Hermeneutical Transformative Approach

by

Andrew Ahimiejiese Ovienloba

A Dissertation Presented to the

Graduate School of Humanities and Social Sciences of Nova Southeastern University

in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

Nova Southeastern University 2014

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## Graduate School of Humanities and Social Sciences

**Nova Southeastern University** 

This dissertation was submitted by Andrew Ahimiejiese Ovienloba under the direction of the chair of the dissertation committee listed below. It was submitted to the Graduate School of Humanities and Social Sciences and approved in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Department of Conflict Analysis and Resolution at Nova Southeastern University.

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September 30, 2014

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**Date of Final Approval** 

### Dedication

This dissertation is dedicated to the loving memory of my late mother Madam Cecilia, father, Pa. Ihondare, and sister, Juliet

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### ABSTRACT

The field of autism in epidemiology has received much attention in recent times especially as scientific information evolves on the causes and impact of autism spectrum disorder. Just as medical research is conducting to arrest the growing pace of autism with current research indicating one out of every 68 children in the United States diagnosed autistic, the field of the social science has equally produced some literature on the subject. Much of the social science and epidemiological information in the field has bothered on framing the concept (Murray, 2008), historical dimension and causation of the disease, and its associative influence on family (Grinker, 2007). However, not much has been done to assess the phenomenon from the point of view of conflict analysis and resolution (Sabatelli & Waldron, 1995) to fully understand their sense of conflict ambiguity and ambiguous loss of a child with autism (Cridland et al. 2014; O'Brien, 2007). This research therefore attempted to bridge that gap through reflexive analysis of transcripts from phenomenological interviewing of 19 participants comprised of 14 single parents and 5 married couples with autistic children. While the primary focus of the research was Single parents, married couples served comparative analytical purpose of data validation. Theories of phenomenology, Resilience, human needs, stereotypes & identity, relative deprivation, attribution, critical theory, ambiguous loss, etc. operationalize to frame the research language for hermeneutical transformative interpretation and social action about the phenomenon. Results from the study indicate conflict behavioral experience, a burden curve and resilient risk factors associated with caring for an autistic child leading to possible crisis borderline.

Keywords: Autism, Single Parenthood, Caring burden, Conflict, Crisis, Resilience, Caring burden, Ambiguous loss

### CHAPTER ONE: INTRODUCTION

The early part of the 20<sup>th</sup> century witness a whole lot of scientific breakthrough in epidemiological science just at it witness disease that defied scientific explanation and cure. One of such pariah named in the early 1940s was autistic spectrum disorder. It was categorized a spectrum because of the myriad of associated behavioral disorders that seemingly worked in tandem to create a maladjusted life of not only the victim of the disorder but that of the family and friends as well. Recently, Janet (Pseudonym), a 39 year -old single mother of an autistic child took her life and the life of her autistic child. In the events that preceded her death, close friends and fellow associate testified to her growing concern about her autistic child and the difficulties she was undergoing dealing with the autistic child. Knowledge about the relationship between the 39-year-old mother and the pains of being able to deal with being alone with a child struggling with autism is sparse. At the memorial service held, several mothers with similar situation mourn effortlessly and narrated their untold ordeal in raising autistic children as a single mother. This singular experience may not be a sufficient reason to generalize about the crisis association between autism and parenthood. It however, thus presents a thinking thesis for philosophical research possibilities.

My intention in this research therefore is to design a phenomenological study that will assess the level of conflict and crisis in raising an autistic child as a single parent and deduce a relational conflict management solution through my studies. This study will equally attempt to comparatively study implication of autism for full parenthood (mother and father living together) as way of validating the level of association between single parenthood crisis and autism.

### **1.1 Aims/Research Problem**

Hall, Neely-Barnes, Graff, Krcek, Roberts, & Hankins, (2012), in their research "Parental Stress in Families of Children with a Genetic Disorder/Disability and The Resiliency Model of Family Stress, Adjustment, And Adaptation" indicated the levels and layers of stress often created by the presence of a family member with some form of disability. Additionally, they observed, "two-thirds of mothers of children diagnosed with a developmental disability may experience elevated stress levels" (p.25). Konstantareas and Homatidis, (1992) equally corroborated this findings when they indicated families with children having disabilities or autistic conditions often create some levels of relationship modification in conjunction with the attendant stress and low self-concept that comes with having an autistic or disabled child. In "Single Mothers with Handicapped Children: Different from their Married Counterparts?" Schilling, Kirkham, Snow & Schinke (1986) analyzed from their research that parents of handicapped children experienced extraordinary stress in attempting to cope with the demands of social and cognitive demands of such children.

Quoting Holroyd and Lazarus (1982) Schilling, Kirkham, Snow, & Schinke (1986) defined stress as occurring "when environmental and/or internal demands tax or exceed the individual's resources for managing them" (p.70). Coping on the other hand is the "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p.70). Different opinions could analyze as factors exacerbating and influencing stress and coping mechanisms in the existential framework of the relationship between family needs and raising an autistic child. Some of those possible realities could be the concept of unmet needs not excluding economic constraints further tasked by the levels of financial and emotional capital needed to respond to the constantly evolving needs of an autistic child (Brown, Ouellette-Kuntz, Hunter, Kelley, & Cobigo, 2012). Additionally stress and coping capacity could equally affect the resilience of parenting of an autistic child arising from social alienation. Neely-Barnes, et al (2011) indicated in their research on "Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualization" that parent often experience blame from community members and extended family for their children's autistic condition, thus creating an enduring feelings of guilt, self-blaming game, and parental metal health (Pp.208-209).

These available researched analysis presents window for descriptive analysis with regard to the dilemma that often confronts families that are struggling with managing their stress related issues in living with a condition of a handicapped child. Despite these researched resources that are available, in the field of the psychology not much is available to explain the role or place of conflicts and crisis that could significantly affect the phenomenon of social and cognitive dissonant state of both the parents of an autistic children. Schilling, Kirkham, Snow & Schinke (1986) analyzed that a parent's stress and failing coping disposition arises from a growing frustration in the belief that her skills at helping a handicapped child is grossly inadequate. Additionally a referential comparison on the slow level of the child's development compared to peers often exacerbates a feeling of stress and cognitive dissonance of some sort. Weiss & Lunsky (2011) also indicated in their research stressors from caring for children with autism disorder could

lead to full blown crisis if left unattended (p.521). This research therefore aims to assess data through structured and unstructured interviews (Moustakas 1994, Pp.114 -115). These data from such interviews will provide information to describe how experiences of single parents of autistic children stimulate or influence conflict and crisis in their lives. Intense appreciation of generated data will guide thematic discussions on best practice management to avoid possible emotional breakdown resulting from inadequate conflict management skills through phenomenological qualitative analysis.

#### 1.2 Purpose Statement/ Objectives

Available resource on the phenomenon of autism and single parenthood focus more on parent's effort at helping autistic children to meet up with their developmental process and the stress that emanates thereof. Not much said about the unique experience of single parents regards to conflict and crisis that could arise from the stress of inadequate coping mechanisms thereof (Lesack, Bearss, Celano, & Sharp, 2014; Bekhet, Johnson, & Zauszniewski, 2012; Konstantareas and Homatidis, 1992). This gap existing in the field of research about conflicts in the relationship construct between autistic children and their single parents call for attention. Conflict here frames as the relationship problem patterns constructed between a parent and a child and a child with the parent. Specifically, in this research it is seeks to assess groups of conflict behavioral experience for example in the process of living with cognitive challenges of an autistic child.

The purpose of this phenomenological study will be first to bridge existing gap in research on the phenomenon. Secondly, it is a research aimed at attempting to describe the conflict and crisis experience of single parents living with autistic children. The phenomenon of autism and single parenthood understood as follows: (i.) Single parenthood referred to as an unmarried male or female with no consistent presence of a significant other in his or her life. (ii.) An autistic child categorized as children having problems with "ability to communicate, form relationships with others, and respond appropriately to the environment. It is a behavioral pattern that often manifest itself in restricted and repetitive patterns of behavior, interest, and activities" (The New York Times Guide to Essential Knowledge 2<sup>nd</sup> edition, 2007; Lesack, Bearss, Celano, & Sharp, 2014).

Creswell indicates, "The basic purpose of phenomenological research is to reduce individual experience with a phenomenon to a description of the universal essence..." in a way that unifies and vivifies the significance of such experience with the phenomenon for social action. A critical study of the phenomenon of autism and single parenthood presents that opportunity for individuals that fit into that paradigm to share their experience in order that their pains and crisis can become creatively available for textual and structural interpretation and social relevance. The objective of this research therefore is to contribute to the body of knowledge by opening new frontiers of knowledge discussion about single parenthood association with autism with possibility of policy reorientation.

### **1.3 Justification of Study**

The purpose for this study is to contribute to the body of knowledge on autism and single parenthood. For the most part, the field of autism studies has focused through an analysis of the theory of mind blindness of the autistic child. It expands through clinical response to the needs of the autistic child. Suffice to note that not much done from the point of view of conflict resolution dilemma of the caregiver. This study therefore intends to explore that inner life conflicts, social, relational, emotional struggles, and challenges that confronts the daily life of the caregiver. Caregiver in this research primarily zeroed on the case of single parenthood. As indicated in the preceding pages, the foundation and inspiration for this research comes from the suicide and homicide case experienced in a family with an autistic child. It has become important because there abounds untold struggles of single parents in the field with no outlets to tell share their experience. This phenomenological study therefore provides that pedagogical outlet.

The question about understanding the indices of the process of conflict and crisis internalization by caregivers in the process of caring for their autistic child or children is central. This level of studies has equally received little or no attention. The focus therefore will be to use this study to bring the discussion to the limelight in order to attract social and emotional support for persons in the categories of single parents often overwhelmed by their experience. The study provided suggestions generated from the knowledge acquired from the research on how best to create a support system within the society that will reinforce the resilient abilities of single parents through conflict management strategies as way of responding to their conflict generating stressors in the context of routine of life with an autistic child.

One of the single most important questions that may plaque this study in the field of conflict analysis and resolution is that question of relational value of autism and single parenthood to the field of conflict resolution. Nonetheless, engrained in the veins of those questions, as sound as it may be is the pointer to the definition of conflict, or conflict situation, and what we conceptualize as conflict experience. Mitchell (1981) opined that the definition of conflict and conflict situation could often time be minimized to be invested in physical violent situation of armament or physically injurious relationships. That is hardly the sum total of a true definition of conflict. "Any situation in which two or more social entities or 'parties' (however defined or structured) perceive that they possess mutually incompatible goals" (P. 17) is a conflict situation. Mutually incompatible goals could resonated as unmet economic, social, and political needs (Berrera, 1997) whereby at least one of the parties perceive the futility of that unmet dream as attributable to an association with the other party which results in conflict behavior or resentment, psychological, and emotional war of multiple kind not excluding homicide or simply emotional blackmail. Within that understanding, this research therefore is a conflict research that builds on the psychological dimension of conflict behavior. It is aimed at assessing the sources of conflict goals, such as "(i) existing values systems, (ii) perception of scarcity, (iii) physical limitations of the amount of material goals at any one point in time with view to understanding how these variables of possible incompatibility factor into conflict relationship behavior between autistic children and their single parents. These conflict variables is assessed through various theories of human needs, identity, feminism, stereotypes, relative deprivation, attribution, resilience theory, social constructivism, phenomenology, and critical theory to explicate how autism and single parenthood may lead to emotional distress as a result of inadequate conflict management skills. These theories among functions to clarify the social, political, economic, and emotional aspects touched by the conflict relationship construct between the concept of autism and the lived experience of those caring for autistic children.

#### **1.4 Research Questions**

Creswell (2007) opined research questions provide an opportunity to encode and foreshadow an approach to inquiry" (p.107). For Creswell there are two categories of adopting a research question namely, the central question that explores the central phenomenon of the research and the sub-questions that attempts to tease out "major concerns and perplexities to be resolved (Pp. 107-109). The Central question further delineates into four categories of i.) Exploratory: this seeks to expand knowledge of the phenomenon. ii) Explanatory: asking questions that explains experiential patterns related to the phenomenon under study. iii.) Descriptive: Asking questions that give a descriptive account of experience of the phenomenon. iv.) Emancipatory: Creswell saw this as engaging in social action about the phenomenon. In the case of autism and single parenthood, I will like to see social action as the intended transformational solution that further contributes to better understanding of the phenomenon from the point of view of the research participant. This social action advocacy plight will lead to the design of transformational package providing an in-depth assistance to single parents of autistic children. Such social actions will forestall conflict and crisis leading to emotional tantrum or breakdown with unimaginable consequence. These research realities become a possibility as the wider society begins to understand the untold challenges of single parents living with autistic children and push for productive support. Thus, a solid case is made for better support system for single parents living autistic children.

Sub-questions in the research design address the context or background to participants' experience of the phenomenon of autism and single parenthood. Conceptualizing this research, I will like to see the central question as akin to the textual question of what is autism. What is single parenthood? The sub-questions as structural questions that helps the participants to respond to how they experience autism, how they experience single parenthood, how they feel autism impact single parenthood and verse versa. The structural or sub-question could be seen as that which "calls for information needed for a description of ... (p.109)" autism and single parenthood. Creswell indicated that a good research question should be able to reduce the "entire study into a single overarching question and several sub-questions" (p.108). Therefore, my study of the phenomenon of autism and single parenthood reduced to central question of:

"What is the impact of autism on single parenthood?"

This prototype question served as a guiding principle informing my research questions that provided data for description of experience of the phenomenon by the participants. Some of my data collection question included: A.) Tell me something about being a parent? B.) Describe for me your concept of an autistic child. C.) What is your experience of having an autistic child at home? D.) Tell me how you see the community impact your life as a single parent of an autistic child. D.) How will you describe for me your life with or without autism? E.) Please, describe for me what have been your sources of strength or skill single parent of an autistic child. It suffices to note that these questions prefaced with familiar discussion about life in general in order to create a more conducive environment for the specific phenomenological research questions.

### Conclusion

Research in the field of autism is a growing field that is yet to see its final step of application of different philosophical and theoretic areas of specialized analysis. This research is yet one more step intended to contribute to this populating field of study with the intention of philosophically framing the phenomenon of autism and single parenthood for the universal appreciation of its social, economic, political and psychological challenges for policy change. The strength of this phenomenological research is anchored on the framing and descriptive analysis of the data collected from the structured interviewing with research participants. Through the creative strategies of phenomenological analysis the concept of stress, resilience, conflict and crisis management will be used to unify and evaluate isolated individual experience of the phenomenon in order to establish a commonality for better understanding of the issue.

### CHAPTER TWO: LITERATURE REVIEW

Literary analysis on the subject of autism and family interactions have been studied under different sub-headings since 1943 when the psychiatrist Leo Kanner first coined the term to conceptualize the behavioral pattern of those diagnosed to fall in the categorized of self-absorbed personality or pervasive disorder. A great deal of research has been invested in understanding the personality trait of the concept of the autistic child (Grinker, 2007). Different theories and textual analysis have proffered different reasons on the increased prevalence of the disorder in recent times. While some scholars analyzed the social influence models as contributing to the prevalence (Liu, King, & Bearman, 2010), other available analysis focus on the public health challenge increase that the disease pose for the society as its conundrum seem to defy every available scientific understanding of effective management and cure (Newschaffer & Curran, 2003). Some recent research has equally attracted interest on the dynamics of autism and disabled child in the family, its pros and cons (Shonkoff, Hauser-Cram, Krausee, Upshur, & Sameroff, 1992, Konstantareas and Homatides 1992, Schilling, Kirkham, Snow & Schinke 1986, Gottlieb 1997, Harris 1984, Bendixen, Elder, Donaldson, Kairalla, Valcante, & Ferdig, 2011, etc.).

Researched data on the concept of single parenthood and autism are quite limited, even when they do exist, they are quite insignificant in the depth of related issues addressed from a phenomenological perspective nay, conflict resolution theory or distinctive conflict attribution theory caveat. However, available resources stress the association between having an autistic child and increased stress related experience (Freedman, Kalb, Zablotsky, and Stuart 2012). Solomon and Chung (2012) in their research "Understanding Autism: How Family Therapists Can Support Parents of Children with Autism Spectrum Disorders," indicated "parents of children with autism experience a variety of chronic and acute stressors that can erode marital satisfaction and family functioning" (p.250). The full implication of this research finding definitely presents opportunities for further research on the salient conflict and crisis import of this embodied significant experience.

Different analysts from different field of study especially clinical psychology, Genetic psychology, medicine, social work, and family theorists have indicated the pervasive impact of autism on their caregiver but each from its articulate professional perspective (Slifirczyk, Krajewska-Kulak, Brayer, & Maciorkowska, 2013; Lopez-Wagner, Hoffman, Sweeney, Hodge, & Gilliam, 2008; Neely-Barnes, Hall, Roberts, Graff, 2011; Hall, Neely-Barnes, Graff, Krcek, & Roberts, 2012). Freedman, Kalb, Zablotsky & Stuart (2012) in their study "Relationship Status Among Parents of Children with Autism Spectrum Disorders: A Population-Based Study," contested the most commonly cited statistics indicating 80% + of family with autistic children often end up in divorce but nevertheless affirmed on the emotional and financial plight that often confront family in this existential condition (p.539ff). To understand the phenomenon of autism and parenthood as currently studied and analyzed by scholars, it may serve a useful purpose to review and analyze the phenomenon under classified subheadings.

### 2.1: Understanding the Concept of Autistic Disorder

This research project begins on the premise of a complex dynamic relationship that exists between autistic child or children and single parenthood leading to the possibility of a dynamic scenario of conflict and crisis. The complexity of this phenomenon has yet to receive the synergistic and extensive attention needed to understand the variables that may possibly engineer conflict and crisis behavior in single parents of autistic children. Available researches however focus more on the psychoclinical and medical dimension of the impact of the disease on the child. A number of scholars and researchers have attempted to assess the concept and larger issue of autism. One common denominator that runs across these available literatures is the concept of understanding of the core meaning of autism as neurological disorder that is fronted with stereotyped, self-absorbed, and antisocial monolithic behavioral pattern (Liu, King, & Bearman, 2010; Newschaffer, & Curran 2003; Schleve, Blumberg, Rice, Visser & Boyle, 2007). Assessable definitions of the concept content agree with the descriptive definition provided by the United States' Center for Disease Control and Prevention (CDC). CDC defines autism spectrum disorders (ASDs) as

...a group of developmental disabilities that often are diagnosed during early childhood and can cause significant social, communication, and behavioral challenges over a lifetime. People with ASDs have a different way of understanding and reacting to people and events in their world. These differences are caused by the way their brain processes information "a group of developmental disabilities that can cause significant social communication and behavioral challenges (CDC ADDM network Community Report 2008, p.2). The CDC's definition has often provided a basis for researching and analyzing the behavioral patterns of individuals that falls within this diagnostic preference. The operational concepts in this definition are the significance of language communications and social interactive ability in autistic children. The definition is more of a reductionism theory that limits and restricts the totality of the dignity of the human personhood to visible and elemental constructs of socially constructed psychoanalysis of unilateral relationship. This is a social construct that reduces the philosophical theory of mind versus body to linguistic abilities and relationship building within preset parameters. Some of the key aspects left unattended to however, is the role of the environment and the impact autistic disabilities could and often have on the environment of the caregivers and verse versa.

The term, autism was coined by psychiatrist Leo Kanner in 1940's from the Greek word for self to enunciate the behavioral pattern of an affected child's sense of selfabsorption and lack of interest in other people (Rodier 2012, in 2011 World Book). Generally, scientists believe that autistic disorder is the result of an abnormal brain development that could also be a genetically inherited abnormality not excluding the age of parent factor (Shelton, Tancredi & Picciotto, 2010). Autism equally referred to as pervasive development disorder in the Diagnostic and Statistical Manual of Medical Disorder, Fourth Edition (DSM-IV-TR). While there are no current known cure for autistic disorder, Rodier (2012) outlined "(1) abnormal social interaction, (2) abnormal communication, and (3) restricted and repetitive interests and behaviors" as the symptoms through which autistic disorder is diagnosed. As at 2012 collection by CDC had estimated the current prevalence of autism in the United States, to be 1 in every 88 children (11.3 per 1,000) having symptoms of autism. However, as at March 2014, the data has significantly progressed to 1 in every 68 reported by CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. See data below in figure 1.

Identified Prevalence of Autism Spectrum Disorder ADDM Network 2000-2010 Combining Data from All Sites							
Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children.			
2000	1992	6	6.7 (4.5 - 9.9)	1 in 150			
2002	1994	14	6.6 (3.3 - 10.6)	1 in 150			
2004	1996	8	8.0 (4.6 - 9.8)	1 in 125			
2006	1998	11	9.0 (4.2 - 12.1)	1 in 110			
2008	2000	14	11.3 (4.8 - 21.2)	1 in 88			
2010	2002	11	14.7 (14.3 - 15.1)	1 in 68			

Figure 1: Statistical data diagram from the CDC, reviewed in March 2014

While ASD prevalence estimates in the overall population increased 23% for the 2-year period 2006–2008, and 78% during the 6-year period 2002–2008, the largest increases over time were noted among Hispanic children and non-Hispanic black children and among children without co-occurring intellectual disability. Better identification in these specific groups explains only part of the overall increase, however, as estimated ASD

prevalence increased in all groups when data were stratified by sex, race/ethnicity, and intellectual ability. Previous reports from the ADDM Network have discussed under ascertainment in racial and ethnic minority groups, and ADDM data have revealed ASD as one of the few developmental disabilities for which a positive correlation exists between socioeconomic status (SES) and identified prevalence of the condition (*18*). Further investigation is need for better understanding of potential ascertainment bias and disparities by race/ethnicity and SES in access to diagnostic and treatment services for children with ASDs. If these gaps are decreasing, continued ASD prevalence increases might be expected overall and among specific groups (Baio 2012).

Different factors could have been responsible for the increases in the growing number of children diagnosed with autistic disorder in the United States. Some of such reasons could the growing pace of awareness of the disease (Grinker, 2007), the action by the CDC in data collection process through the formation of National Database for Autism Research (NDAR) in 1990. There is equally the increased and robust expansion of research finding on the inferential causes of autism. For example, Scientists from available research data now estimates the role environmental factors play in autism and other related disorders. More has equally be known that "women exposed to *rubella*, also called *German measles*, or certain drugs during early pregnancy have an increased risk of having a child with autism" (Rodier 2012, In 2011 World Book). Furthermore, the prevalence of autistic disorder is not evenly distributed among genders and cultural groups. For 2008, the overall estimated prevalence of ASDs among the 14 ADDM sites was 11.3 per 1,000 (one in 88) children aged 8 years who were living in these communities during 2008. Overall ASD prevalence estimates varied widely across all sites (range: 4.8–21.2 per 1,000 children aged 8 years). ASD prevalence estimates also varied widely by sex and by racial/ethnic group. Approximately one in 54 boys and one in 252 girls living in the ADDM Network communities were identified as having ASDs. Comparison of 2008 findings with those for earlier surveillance years indicated an increase in estimated ASD prevalence of 23% when the 2008 data were compared with the data for 2006 (from 9.0 per 1,000 children aged 8 years in 2006 to 11.0 in 2008 for the 11 sites that provided data for both surveillance years). Moreover, an estimated increase of 78% when the 2008 data were compared with the data for 2002 (from 6.4 per 1,000 children aged 8 years in 2002 to 11.4 in 2008 for the 13 sites that provided data for both surveillance years). Because the ADDM Network sites do not make up a nationally representative sample, these combined prevalence estimates should not be generalized to the United States as a whole (Baio 2012).

On a cross-cultural assessment, it does appear that the significant increase is not unique to communities in the United States, rather a growing problem in the world. For example, Research with about "55,000 children 'in South Korea indicated that about 1 in 38 children were autistic." England equally with a" national sample of (n = 7,461 adults) from 2007 conducted by Brugha and colleagues got a consistent diagnosis of 1 percent across board" (Insel, 2012). It is equally randomly estimated in South Africa that 1 in 166 children have autism (Grinker 2007, p.7). "The Autism Society of America, ... estimates that 1.5 million Americans suffer from some kind of autism and predicts a figure as high as 4 million for the year 2014" (ibid, p.9). One significant area of flaw that these studies and some other similar ones have is that they give minimal attention on the ratio per single parents. Additionally, they do not tell us how the perception of this diagnosis affects the mental wellbeing of caregivers specific to their cultural and social groupings. Specifically how can we estimate autism as deconstructing and reconstructing family from a conflict resolution theoretical framework?

#### 2.2 Deconstructing and Reconstructing Autism and Family

One theoretical lens that scholars have advanced towards the understanding of the substance of autism is the theory of mind and social cognition. The Theory of mind and social cognition focuses on the expected social and cognitive development projected to be evident in a child at certain age (possibly 3-4 years) and the actual evident development visible in the language skills and communicative ability of the child (Cutting & Dunn 1999). The absence of this language and communicative ability often spells autistic behavior based on the provisions of psychological analysis (DSM-5, 2013). This diagnosis naturally engenders a change in relational and family dynamics. Some of those behavioral pattern often ascribed to children with autism include aggressiveness, tantrums, impaired social communications/repetitive, non-compliant, and pervasive behaviors (Lesaack, Bearss, Celano, & Sharp, 2014; Strid, Heimann, & Tjus, 2013). Karst, Vaughan, & Hecke (2012) indicated multiple layers of problems that often confront parents of autistic children leading to multiple levels of family distress not excluding parenting stress and increase in mental and physical health problem leading to high rates of ineffective family social functioning and disruptions (p.247).

Konstantareas and Homatides (1992) pointed to early research that outlined low self-concept and stress related behavior on the part of mothers of disabled child or children. Some researchers have indicated fathers tend to be more affected by the social interaction challenges of a disabled child (Shonkoff, Hauser-Cram, Krausee, Upshur, & Sameroff, 1992). The presence of psychological problem of low self-esteem and selfdoubt in the parenting challenges of mothers may be evidence of a challenge of coming to terms with the normative circumstances facing the autistic child or the conflict of not being able to engage in meaningful communication with the child. These frustrations definitely have enormous implications for both the primary parent caregiver and the child. Olsson and Hwang (2001) in "Depression in mothers and fathers of children with intellectual disability," observed in their studies mothers with children with autism were at higher risk of depression compared to mothers with other forms of disabilities. Different factors may be contributing to the elevated stress level of parents of autistic children. Olsson and Hwang observed, "High stress caused by the difficult behavior of a child in combination with restrictions in personal life may be some of the factors that contribute to a higher risk of depression in mothers of children with autism." (see Olsson et al. 2000, p.540; also see, Solomon, et al. 2012; Brown et al. 2012; Hall et al.; Ślifirczyk, et al. 2013; Weiss et al. 2011). In "the relationship between autism and parenting stress," Schieve et al (2007) concluded from their quantitative analysis that parenting a child with autism comes with a unique kind of stress away from that experienced by other parents. Schieve and colleagues observed:

Parents of children with autism were more likely to score in the high aggravation range (55%) than parents of children with developmental problems other than

autism (44%), parents of children with special health care needs without developmental problems (12%), and parents of children without special health care needs (11%). However, within the autism group, the proportion of parents with high aggravation was 66% for those whose child recently needed special services and 28% for those whose child did not. The parents of children with autism and recent special service needs were substantially more likely to have high aggravation than parents of children with recent special service needs in each of the 3 comparison groups. Conversely, parents of children with autism but without recent special service needs were not more likely to have high aggravation than parents of children with other developmental problems (Schieve et al., 2007, p.5114).

Furthermore, in a research conducted by Gottlieb (1997) on "single mothers of children with developmental disabilities: the impact of multiple roles," it was observed that caregivers that fall on this category are often fraught with some psychological challenges resulting from the stress of filling in for multiple roles as a single parent. Fulfilling multiple roles may include providing the extra financial needs for the treatment of the autistic child and playing the role of an extra-care needed by the demands of the autistic condition of a child. Working to be able to meet the level of needs of the situation by putting in enough hours at work to meet financial demands and providing that safe and meaningful or constructive environment for the child could be estimated to generate a conflict of determining efficient time allocation for the different role. The process of determining more effective and efficient time allocation or making a scale of preference choice could play significant role of stress for a single parent in the absence of an

alternative helping hand. Gottlieb's research indicated a primary caregiver mother could be fraught with long term "financial and care giving burden, restrictions on family life style and career goals" (p.5). These identified burdens from an a priori knowledge could definitely locate the single parent in a very vulnerable position of enduring stress and crisis if not efficiently given attention. Gottlieb's findings thus provide many opportunities for asking the salient questions about the impact analysis of consequences of enduring stress for the single parents whose dream and ambitions affected by the burden of a road less traveled with an autistic child. Looking at the various layers of stress for single parents becomes even more relevant given the fact that the quantitative study conducted by Gottlieb only controlled for employment purposes in a field that has fewer researches on the subject.

From the point of view of family system theory, the family is a complex organizational unit whereby what affects one implies some measure of implications for the health of the rest of the members of the unit. The presence of an autistic child could be analyzed to presents a possible disequilibrium for the entire family relational structural health (Shonkoff et al. 1992). Some of the possible attainable consequences of having to deal with autism in the family system is the invariability of resource and time allocation that may result in family organizational stress of unequal attention given to every member. In addition, we could estimate adjustment problem needs of such family that may likely tilt itself towards the needs of a more depended disabled member. We could also analyze under family system and family life cycle theory, "families have a fairly predictable life cycle governing their growth, development, and functioning" (ibid) such that anything out of the expected normal, changes the process theory of the entire unit in

terms of its input and output. Again, there could be other factors contributing to the stress levels and management process. These may include conflict mediation between "stressors and outcomes" that may include the variables of coping styles, psychological acceptance of the diagnosis and self-efficacy (Weiss et al., 2011, p.522). Philosophically, when there is tension between personal conflict stressors and outcomes, there is the possibility of the phenomenon of emotional and relational or perceptive crisis. This is where the opportunity arises in the field of autism and family studies.

On the question, how does the presence of an autistic child impacts the life of a family and especially a single parent family? The answer perhaps lie not so much as in the variable of what it means to be autistic but in the science of what it means to be single parent and caring for an autistic child in the holistic sense of the term. It is much easier to recognize the variation of autism today given the enormous researches done in the field. Nevertheless, it important to note:

Autism is a lifelong developmental disability, affecting both verbal and nonverbal communication as well as social comprehension and social interaction. It is not a mental illness, per se, nor is it simply mental retardation. Other characteristics of autism may include repetitive activities; stereotyped movements; lack of empathy and reciprocity; and difficulty with interpersonal relationships, understanding group dynamics, and with participation in give-and-take negotiation. Autistic individuals may also be unable to recognize the facial expressions of others. Baron-Cohen (1995) has described autism as "mind blindness" (the inability to make inferences about what others know, think or feel). This, in part, accounts for

impaired empathy being a core feature of autistic spectrum disorders (ASDs) (Morton, 2001) (Jennings, 2005, p.587).

The central piece of autism in family stressors and outcome therefore is in the realization of a lifelong process requiring a new skill to handle. Dealing with this order or an adjustment process may analyze as the psychological impact of autism on the family. Crisis arises from the process of reconstructing and realigning the family system theory to fit into the reality of making meaning out of the life of a child or sibling whose wellbeing will for the foreseeable future, depend on the emotional and social capital of the rest of the family. What is needed here therefore, is a pragmatic theory that reinforces the resilience abilities of a parent for effective and efficient conflict management that fully understands the conflict and crisis implication of the unfolding experience of a lifelong commitment to care for the autistic child. One major gap that remains unfilled in the identified researches on the impact of autism on the family is the ability to note the conflict implications of the problem from a human factor model perspective. This model enables patties involved in one form of relationship or the other to evolve skills and relational models that improves and minimizes conflict-generating behavior. For ultimately, one key pointer in the foregoing analysis is the behavioral tensions that could exist between a caregiver and the recipient resulting from autism.

### 2.3. Autism and Family Disorder, Conflict and Crisis Implications

Harris (1984) analyzed and indicated that the presence of a disabled child could complicate family dynamics in a way that impacts heavily on the primary caregiver that in most cases is the social role of a mother. Such dynamics may include emotional insecurity with the marriage, fear of the unknown about the future of the child and the social indifference that may follow especially etiological behaviors of autistic children. Despite the depth of analytical resources put into the study very little or nothing in depth about the substance of the conflict and crisis impact challenging emotional, psychological, and psychosocial dynamics of caring for an autistic child could engrain on the single parent caregiver. The hypothesis therefore becomes, if the presence of an autistic child changes the dynamics of a normal couple how much more said about a case study of a single parent with no subordinate caregiver in the presence of an autistic child. Research has equally corroborated the idea that the presence of an autistic child or children in home has the high risk of engendering high level of stress for maternal and paternal stress (Reed & Osborne, 2013; Jennings, 2005). It is estimated that a good number of cases of families with an autistic child lead to possibilities of divorce (Bendixen, Elder, Donaldson, Kairalla, Valcante, & Ferdig, 2011). If the presence of autism weakens the survival chances of a regular family because of attendant demands on both family financial resources and time, how much more could such task a single parent? It definitely suggests some measure of elevated family stress experience.

Family stress theory holds that "stress (manifested as depression, social isolation, role restriction, marital discord, etc.) is a signal of disequilibrium in personal or family functioning that may result in coping with either normative or non-normative events" (Shonkoff et al. 1992). The implication of this theory for a single parent with an autistic child is quite significant in terms of the enormity of the restrictions and social isolation with familiar relationships as consequence of having to limit association to environments only acceptable to the autistic child. Additionally, career choices have to accommodate

the needs of tending for the disabled child. This adjustment factor impedes already limited social and financial resources thus increasing stress experience for the single parent.

In the research findings of Freedman, Kalb, Zablotsky, and Stuart (2012), it indicated from their multivariate analysis that there was no evidence that Autism Spectrum Disorder suffered any form of increased risk due to living with single parents. The flipped side of the equation is the likelihood that the increased caring skills adopted by the single parent may have bridge the gap. The question then arises as to what the impact or consequence of the additional emotional, physiological and psychological resource extension could take on a single parent in the absence of spousal support? Another possible lens for understanding this caveat is to look at the outcome economic health of a single parent resulting from this make up extended caring needs for the autistic child. As analyzed above, the choice of job or career will naturally revolve around the needs of an autistic child. Thus, a single parent may end up working minimally for financial needs as against working to achieve a career dream. This hard choice may likely generate resentment and absence of fulfillment of self-actualization needs (See Schultz, & Schultz, 2013, p.249).

Moreover, economic strength of a parent will naturally affect the level of care and additional resources that made available for especially a disabled child. For example what happens when the provisions of Medicaid and Medicare is not enough to keep up with the needs of an autistic child. In the research findings of Lukemeyer, Meyers and Smeeding (2005) "Expensive Children in poor families: out of pocket expenditures for the care of the disabled and chronically ill children in welfare families," it was observed that roughly '20% of families incurred a total cost exceeding \$100 in their out of pocket spending on a disabled child's medical expenses'. The extra cost of supplementing for the non-government provided expenses is deductively a financial stressor for parents. This is heightening for a single parent with limited source of additional financial resources. Besides, the possibility of low employment rate as a result of the level of attention and care required for attending to the needs of a child with special needs further complicates the economic health of the single parent. Furthermore, if as Currie (2009) analyzed in her research that the impact of the socioeconomic status could play a very significant role in the level of care a child gets and the quality of life that the providers experience, how much more will such a variable present for a single parent? According to the most recent statistical data provided by the Center for Disease Control and Prevention (CDC, March 2014) caring for an autistic child remains a financial caring burden.

It is estimated to cost at least \$17,000 more per year to care for a child with ASD compared to a child without ASD. Costs include health care, education, ASD-related therapy, family-coordinated services, and caregiver time. For a child with more severe ASD, costs per year increase to over \$21,000. Taken together, it is estimated that total societal costs of caring for children with ASD were over \$9 billion in 2011 (http://www.ncbi.nlm.nih.gov/pubmed/24515505)

Children and adolescents with ASD had average medical expenditures that exceeded those without ASD by \$4,110–\$6,200 per year. On average, medical expenditures for children and adolescents with ASD were 4.1–6.2 times greater than for those without ASD. Differences in median expenditures ranged from

\$2,240 to \$3,360 per year with median expenditures 8.4–9.5 times greater. (http://www.ncbi.nlm.nih.gov/pubmed/17690969)

In 2005, the average annual medical costs for Medicaid-enrolled children with ASD were \$10,709 per child, which was about six times higher than costs for children without ASD (\$1,812) (http://www.cdc.gov/ncbddd/autism/features/autism-keyfindings2012.html) In addition to medical costs, intensive behavioral interventions for Children with ASD cost \$40,000 to \$60,000 per child per year.[11]

(CDC, http://www.cdc.gov/ncbddd/autism/data.html)

The above data for the most part indicates the role of the government in providing for the needs of these children for those enrolled in the various government programs. Nonetheless, government provision may not necessarily shield the parent from economic challenges in terms of likely lost paid time from job and the challenge of trying to access information that may cost time and money. Additionally, government figures may not have fully captured out-of-pocket expenditures. Hence, the level of financial burden eludes current statistics.

Furthermore, the burden of uncertainty not only about the immediate needs of the disabled child but the fear of the unknown when the primary caregiver dies may necessarily create an emotional conflict and crisis for the single parent who realizes that the life of this child revolves around him or her both financially and emotionally. The question then arises as to how we could estimate the level of conflict and crisis or the significant variables that could throw the subject over the cliff of being overwhelmed. Raising a child is in itself is a significant burden that often requires learning experience

of behavioral and needs modification. Having an autistic child adds to that burden significantly that may lead to burnout, physical, and mental exhaustion (Manor-Binyamini, 2011). Another question that arises here therefore is what does this additional stress and crisis in the absence of spousal support do to the psychological wellbeing of the single parent? Attending to this central question provides a phenomenological focus for this research, to fill that gap that is seemingly absent from available literature that often identifies the enigma with less emphasis on the consequence on the single parent caregiver.

#### 2.4. Autism and Single Parenthood as a Relational Conflict

Literature on studies specific to the impact of autism on single parenthood as a relational conflict leading to a possible personal crisis remain quite limited since not enough significant studies have been carried out to address the phenomenon. As demonstrated above, a whole lot of information on the subject is derivable either through clinical inference of research generalizations that are in some cases applicable to some aspect of the plights of single parents' experience with an autistic child. This point of knowledge through clinical generalizations makes this study more appealing for a phenomenological study of the phenomenon from the point of view of conflict analysis and resolution away from typical clinical caveat. Conflict and crisis are for the most part a personal journey that is best described and absorbed by the individual that undergoes that aspect of life challenges. Folger, et al (2005) defined conflict as "the interaction of interdependent people who perceive incompatibility and the possibility of interference from others as result of this incompatibility" (p.4). The family environment is a relationship-building circle of interdependence where shared interests and dreams often

affect the experience of each or one another as the case may be. These relationships are most often not conflict free. The question therefore is not so much about the absence of conflict but the type of conflict behaviors that are present. In the case for single parents and autistic children, it is a relationship of lifelong dependence where interests and dreams call to question on the level of attributive cost and benefits of association that may define the conflict behavioral experience.

The sum total of the Folger et al.'s definition may not speak specifically for the kind of conflict that may exist in the like of a relationship of single parent versus autistic child. However, if conflict behaviors are expansively inclusive and resulting from incompatible goals then the possibility of competing goals in the process of attempting to achieve a goal between a single parent and an autistic child becomes conflict variable for analysis. For example, non-compliant behaviors from an autistic child is a normative conflict variable of incompatibility with the needs of a single parent whose interest may be to get the child to behave in a certain desired way. As Lederach (1995) indicated, "conflict emerges through interactive process based on the search for and creation of meaning" (p.9). This process of a search for mutual but coextensive meaning in the peculiar relationship between single parents and autistic child could possibly engender relational conflict and crisis (Bendixen, Elder, Donaldson, Kairalla, Valcante, & Ferdig, 2011). "A crisis is any situation in which a person's ability to cope is exceeded" (Lanceley 2003, p.15). It is this possible experience when autistic parent caregiver exceeds her or his ability to cope with the stress related experience of providing the peculiar kind of relational and emotional care for an autistic child that requires conflict behavioral studies. It is important when we consider how the relational crisis stressor

behavioral pattern between an autistic child and a single parent may likely tasks not only their parental ability but also a mental health possibility of self-doubt that requires a hermeneutical transformative study approach appropriate to this group of people.

Bush and Folger (2005) indicated that transformative theory responds to those kinesthetic questions that bother on the substance of what is involved in the conflict situation that individuals endure (p.45).

According to transformative theory, what people find most significant about conflict is not that it frustrates their satisfaction of some rights, interests, or pursuit, no matter how important, but that it leads and even forces them to behave toward themselves and others in ways that they find uncomfortable and even repellant. More specifically, it alienates them from their sense of their own strength and their sense of connection to others, thereby disrupting and undermining the interaction between them as human beings (Bush and Folger 2005, Pp. 45-46).

Thus, the psychosocial influx of an incremental forced change of social relations and selfidentity re-construction in relations to peers by single parent of autistic parents presents a unique opportunity for a transformative and hermeneutical study. If we assume crisis to be a product of an incremental experience of conflict over time, then resolving that crisis bearing conflict using the tools of conflict analysis and resolution becomes inevitably sound. It fills that literature gap that has approach the subject of autism from a clinical perspective for the most part. Birenbaum and Cohen (1993, in Gottlied, 1997) noted that two thirds of the children residing in residential care are from single parents compared to one fourth of children living at home. If this is true, then looking at the experience that contributed to this observation is a significant interest area for further investigation. This variable possibly reflects the level of burden and stress related to playing multiple role of providing for disabled children coupled with meeting other domestic and financial responsibilities. Some of the added stress that could further compound the challenges of singles parents in relation to caring for autistic children may be poverty, role strain, social isolation, and social stigma (Mclanahan and Sandefur, 1994; Mulroy & Pitt-Catsouphes, 1994 in Gottlieb, 1994). These social and psychological burden consequently heightens the stress and crisis level of single parents whose effect may lead to unforeseen reality like it happen in that of the a single parent that served as a backdrop for this research.

#### Conclusion

One of the great dangers of analyzing the case between single parent and disabled child nay: autism is the danger of problematizing autism and single parenthood as an evil that inflicts each other. Alternatively, if not well tended it has the potentials of becoming a case of generating variables that further stereotype autism and single parenthood as a misnomer. With the social pre-scripted template of social definition of a matrimonial home of husband and wife as best suited place for caring for children either able or disabled research coded, the relationship between autism and single parenthood becomes an interest. This makes the phenomenological, transformative and hermeneutical method more appealing for conducting the research based on the opportunity the methods provides for originality in data collection and analysis.

## CHAPTER THREE: THEORETICAL FRAMEWORK OF THE PHENOMENON OF AUTISM AND SINGLE PARENTHOOD

Theories represent the lens that serves to clarify the various ways issues and phenomenon interacts. It serves a clarifying bridge between perceptions of actions and in actions regarding how actors in the society vivify and embody a particular phenomenon like autism and single parenthood to create reality for themselves. Theoretical and pragmatic analysis of the concept of single parenthood and autism is relatively a new phenomenon in the academic community. Theoretical resources on the phenomenon of autism are evolving in the empirical science as more information generates on the science of autism. Perception theory on the phenomenon of single parenthood has equally received some theoretical and pragmatic evolution as will be evident in this research finding.

One aspect of theory that has yet to receive significant attention is the social scientific dimension of the conflict and crisis association between autism and single parenthood. For example, theoretical analysis on how the relationship between autism and single parenthood may likely lead to increased socio-cultural stress relationship with the autistic child, the wider society, and life crisis outcome is yet to be exhaustively tested except on the level of quality of life and economics. This research therefore is set to bridge that gap by looking at the various possible theories that underpins the conflict association between autism and single parenthood through a phenomenological analysis. I engage this caveat by looking at what scholars have theorized about the two phenomenological variables of autism and single parenthood. To better understand the

conflict dimension of autism and single parenthood it may serve a useful purpose to explore some key theoretical concepts as they apply to the subject under study. Understanding the connective dimension of these theories to the phenomenon of autism and single parenthood will provide the frame of this research as it bothers on conflict and crisis.

#### 3.1: Human Needs Theory in Autism and Single Parenthood

Human needs theory is facilitated around the belief that all human beings have basic biological and social needs that are driven by emotions and values that must be satisfied" (Spangle & Isenhart, 2003, p.45). These human needs are equally context and social driven. They color the various perspective of reality evaluation by all human beings. According to Maslow, these needs functions on priorities. However, prioritization of these needs may be subject to offset by social events or other unforeseen circumstance like dealing with a lifelong dilemma of caring for an autistic child. Such an unforeseen life process as in autism could reorder levels of prioritizations (Schultz & Schultz, 2013, PP246-247). Maslow (1954) argued that all human beings possess some hierarchy of need that shapes their worldview and when these needs are unmet, it adds up to some form of social and psychological crisis of some sort.

Hierarchies of needs include, psychological, safety and security, love and belonging, esteem (self and social approval), social-actualization, knowing and understanding, aesthetic needs (order and balance) (Maslow 1954, In Spangle et al 2003, p.45). Tomer (2002) contends human wellbeing builds on individual investment in both personal and social capital and disequilibrium in this reality changes the equations of a rated sense of self and ability to function at the apex level of attaining a dream. Levels of attainment of this incremental dream could affect the wellbeing of the individual depending on how events play themselves out. In order words, an unprepared for event in life process might create a deep sense of vulnerability leading to identity challenges and threat. Identity construction is a permeable event that is ongoing in human existential reality. However, "psychological state of challenges and threat can be faced through changes in physiological responses that are concomitant with [circumstantial] experiences" (Inzlicht & Schmader, 2012, p.56).

Silverman (2006) argued that raising an autistic child could be one of such event that alters a caregiver's preplanned life process. For Silverman, caring for an autistic child often alters the mother's life and presents new challenges that weak social institutions and poor community services makes even worse. In this caveat, level of the feelings of challenges and threat to self-actualization and life satisfaction is elevated. "Challenges and threat theory maintains that responses to stressful situations are a combination of individuals' assessment of available resources relative to task demands: when resources are higher than demands, individuals are more likely to experience challenge, whereas when demands exceed resources, individuals experience threat" (Ibidem). However, provisional support system of friends and family could lift the burden. Silverman (2006) raised a critical point of autism as blamed on the mother from the Freudian and "chauvinist" and this is Drs. Kanner and Bethelheim perspective. However, the research failed to build on how that ideological construct persists in the experience of women or how acquiescing such a mentality could hurt the wellbeing of a female caregiver. This unexplored notion leaves room for further research and

questioning about the tenacity of what role the notion of "refrigerator mother still play today and how especially single mothers see their world and cognition of autism.

From the perspectives of Maslow (1954), Tomer, (2002), Silverman (2006), Staub (2003), Catton, Jr. (1959), Bubolz, Eicher, Evers, & Sontag (1980) on the impact of human needs on the wellbeing and quality of life of individuals it could be argued that the crisis and conflict behavior in autism and single parenthood could be predicated on the forced theory of value realignments inconsistent with existential dreams and set goals. Sirgy (1986) equally noted whereas society structures to meet human needs, the quality of life of individual structures in a sense around the political and social design of that society. Therefore, failure in the social structure to meet the need of individuals in their circumstance greatly factors into the level of quality of life and wellbeing of persons. In relation to autism, the conflict of negotiating safety, security, and self-actualization in the face of limited access because of additional burden of raising an autistic child constraints the opportunity for effectively and efficiently competing for scarce resources that could perhaps lead to some form of crisis. As succinct as these predicates and predication might be, it is difficult to isolate and predicate motivation of individuals on any isolated variables of need on any specific action. For Chung (1969), "the dynamic structure of human needs and its relationship to motivation is a multidimensional phenomenon" (p.223). Therefore, the full implications of the Maslow's hierarchy of human needs' variables remain to be tested (Dawes, 1995) as it relates to conflict and crisis behavior in autism and single parenthood. A critical analysis of this correlation may help to ascertain which of the needs' variable deficiency creates inclination towards either resilience or crisis mode response in response to the shifting experience of caring for an autistic child.

#### 3.2: Stereotypes and Identity Theory

The concept of stereotypes and identity theory is a pervasive concept that social scientists and more specifically the field of social psychology have adopted as a lens through which individual and groups conceptualized as they deal with in-group and intergroup relations. In the growing field of conflict analysis and resolution, the concept takes a new nuance as conflict scholars attempt to excavate the role stereotypes play within ingroup and inter-group conflict relations to either sustain or escalate conflict behavioral relations. In this wise, pertinent question about how and why stereotypes play fecundity role in conflicts, its origin, and mutational factors becomes relevant to understand its tenacity in shaping perceptions and social identity construct. Bar-Tal & Teichman (2005) indicated

the concept "stereotype" pertains to the cognitive repertoire (i.e., beliefs) that people have about the characteristics of other groups, and "prejudice" refers to the attitude that people hold toward another group (e.g., Leyens, Yzerbyt, & Schadron, 1994 ; Stroebe & Insko, 1989 ). The journalist and commentator Walter Lippmann (1922 ) coined the term "stereotype" in his book Public opinion to describe the uniform pictures (i.e., preconceptions) that group members hold in their minds to simplify their view of the world and for reaching common agreement regarding events in their environment (P.3).

Analyzing on the concept of stereotype from a social constructivist perspective we may argue that it creates a framework for identity construction because of its ability to reinforce prejudices and perception about the image of the other. In order words, stereotypes define the relational values of association both in the in-group and out-group conflict relationship. In the context of autism and single parenthood, stereotypes and identity presents itself as a social construction aimed at either reinforcing perceptive values for defining a sociological caste for sociological effects. It may serve a role as an out-group conflict relation. Smedley (1998) in "Race" and the construction of human identity," argued that race for the most part was used as a social stratification project in the societies where they prevail. Essentially then, race as a social construct is a value-laden stereotype used to both isolate and frame a reference point for relating with social groups of people. Such social group identification comes with liability values that history has proved to be odious and burdensome for the most part. The question therefore is what is the valued-burden of a social construction of autism in one hand and single parenthood on the other?

Murray (2008) contend the social dilemma that confronts autistic persons comes from the cultural narratives and social fictions that have come to shape the identity of autistic persons through the use of social stereotype vocabularies from both the print and news media. These social phraseologies of stereotypes create a burden of the concept of self and relationship constraints as autistic persons are constantly define with stereotypes of self-absorbed, indifferent, anti-social, and mentally retarded. The undercurrent implications of these stereotypes and identity construct are that they frame a circle of social dominance of discrimination of various kinds, reinforces social hierarchical and group behavioral expectations that could serve to limit opportunities but accelerating social burden and crisis for caregivers (Sidanius & Pratto, 2001; Bernstein, 2005; Cerulo, 1997, Brekhus, 1996; McGart, Spears, & Yzerbyt, 2002, Bar-Tal & Teichman, 2005). The associative burden of these class stereotypes become even more elevated in the scenario managed by a single parent that has its own sociological stereotypes and sociological identity crisis in the American society. For example, Weinraub, Horvath, & Gringlas (2002) analyzed that single parents are blame as the primed factor for the gross decline in the American cultural values leading to most vexing social problems. McGarty, C., Spears, R., & Yzerbyt, V. Y. (2002) argued that such initialization of single parent stereotypes feeds into social identity and social categorization theory that victimizes and defines inter-group relation of ascribing social power and instrumental functions. Bar-Tal & Teichman, (2005) reasoned that group and individual stereotypes legitimizes ambivalent behaviors of hatred, disgust, exclusion, negative evaluations, and moral unconcern towards those stereotyped.

Stereotype behaviors could be express in either overt and subtle avoidance or social exclusion from access towards meeting human needs, like employment and participation in social services of borderline acceptability (Contrada, Ashmore, Gary, Coups, Egeth, Sewell, Ewell, Goyal, & Chasse (2000). Staub (2003) indicated in his research that limiting access to meeting human needs often leads to inclination towards aggression and hostility towards the agents perceived to be a variable for limitation. For Tomer (2002), the sum total of what leads to total well-being of individuals goes beyond economic capital to include sufficient investment in social capital and when these are inadequately provided for by various circumstances, conflict and crisis could not be ruled out. Contrada, Ashmore, Gary, Coups, Egeth, Sewell, Ewell, Goyal, & Chasse (2000) contended that individuals respond to their discriminatory stereotyped and social identity categorizations differently. In some cases it could lead to the stereotyped taking positive actions towards psychological group identification, personal achievements, self-hate, major stressor or depressive symptoms and in extreme cases assertive reactions as a selffulfilling prophesy of resolving the spiral of cognitive dissonant experience.

Furthermore, Ralph (2009) presented some salient points from a cross sectional study of reports from magazines about attitudinal shift in the perception theory of single parents in the American mainstream culture in the 20<sup>th</sup> century. For Raph (2009) even though the perceptions of what appear to be acceptable enjoyed a shift due to the growing rate of divorces and unmarried child bearing, it does however minimize the burden of being single parents by giving a unilateral verdict of a norm that finds celebrity in the super structure of the American society. One point that remains to be tested nonetheless is the variable of how this seemingly acceptability has translated into the experience of single parents of disabled children. How does their experience of raising an autistic child for instance differ from those of married couples within the caveat of a shift in perception? It is significant to have a reevaluation of negative stereotypes of a group. When there is a combination of in-group and inter-group stereotypes within the same family ecological structure, then the complexity of the unwholesome marriage will need to be studied extensively in order to fully understand how a combination of double stereotypes of autism and single parenthood affects the lives of those affected. This is particularly important especially from the point of view of the research conducted by Grotevant, Dunber, Kohler, & Esau (2000) on "Adoptive Identity." These researchers examined the struggles of adopted children and parents as they attempt to negotiate their socially constructed identity of being an 'adopted child with adopting parents.'

Grotevant and colleagues indicate the role of perceived appearance, adaptability to the environment, and crave for that envisioned identity mentally considered complete, acceptable, and cohesive. Furthermore, societal attitudes and perceptions feed into how adopted children negotiate and underscore the child's sense of self with other significant domains of identity and the nominal or perceived acquiesced stigma of adoption (p.385). Milstein et al (2010) noted that parents of autistic children equally struggle with coming to term with the diagnosis of their child as autistic. This is possibly because of the social identity burden associated with being parents of an autistic child. "Identities exist only in societies, which define and organize them. Thus the search for identity includes the question of what is the proper relationship of the individual to society as a whole (Baumeister, 1986, p. 7)." (See Grotevant, Dunber, Kohler, & Esau, 2000, p.379). This in-group and inter-group struggle may be analyze as a dilemma emanating from the enigma of social stereotypes energizing both social and psychological conflict and crisis of some sort arising from exclusion and deprivations from the social order. Exclusion from the social order pings on an experience that could eviscerate the sense of being fully human and fulfilled.

#### 3.3: Relative Deprivation Theory in Autism and Single Parenthood

The theory of relative deprivation is a theoretical resource that social scientist use to analyze various psychological and social factors involved in conflict situations. These social psychological factors are most commonly associated with issues of social identity, perceptions and responses to feelings of privileges and disadvantages as they relate to existential experiences. Often times the feelings of a relative deprivation lead to zero sum thinking. Zero sum thinking taps on the social structure of a thinking of group and individual comparative conflict processing of feeling of subjectivity of relative deprivation of certain social or circumstantial essentials of life in relation to other persons (Walker & Smith, 2002). Social and psychological wellbeing therefore is often times framed from the reference point of a cognitive alternative to the present situation adjudged unacceptable. "In social psychology, the study of human happiness and wellbeing finds that they are the results of having an integrated, relational sense of autonomy and social connection, more than any other factor" (Bush & Folger, 2005). The absence of these perceived integration therefore especially when compared to other groups exacerbates that feelings of alienation and a conclusion of relative deprivation. Wright & Tropp (2002) analyzed that "inequality in the distribution of resources and status, and the resulting stratification of groups into relatively advantaged and disadvantaged positions, is a basic feature of most social contexts" (p.227). The disadvantaged therefore cognitively feels deprived and unintentionally left out of the social or economic share of available resources.

The factors in the theoretical framing of relative deprivation are the concept of justice and social behavior as these impact that referent cognition of social comparison, perception of social identity, and self-esteem and social justification for a particular experience (Ellemers, 2002, p.240). Ellemers (2002) indicated a nexus between the theory of social identification and relative deprivation in the context of their predicates. Social identity construction begins from the cognitive construct of "personal versus social identification," and relative deprivation builds on a framing of "behavioral consequences of individual versus group deprivation" (p.242). Relative deprivation theory essentially creates the synergy for predicting behavioral consequence of social identity construct of

comparative perception of self and therefore a pull towards a redress of the perceived injustice in the social stratification pendulum.

In referencing the building theory of autism and single parenthood from the perspective reality of relative deprivation, it is imperative to look at the various indices that enable a feeling of sociological and psychological sense of deprivation in order to comprehend a possible consequent or expected behavior. Some of the variables that are often evident in the circumstances of relative deprivation include, social distribution of economic resources (employment and income), access to social infrastructures of education, housing, and medical benefits. Others are social and occupational mobility, stereotypes and social alienation, discriminations, perception of injustice and fairness in the allocation of social, political and economic resources (Wegener, 1991, Delhausse, Luttgens, & Perelman, 1993, Pedan, 1992, Sweeney, McFarlin, & Inderrieden, 1990). Relative deprivation in autism and single parenthood may assess from multiple angles of analysis. We could appreciate this from the point of view of theory of unmet needs of families with autistic children through limitation in employment opportunities that accommodates the needs of those within the framework of single parents of autistic children.

Brown et al (2001) argued from their findings about the functional capability of children with autism and their parents' unmet needs. For Brown and colleagues, the unmet needs of families with autistic children possibly correlate to the severity of the autistic disorder. Rather, the concept of unmet needs depends on the assessment of the parents on how the parents adjust and deal with the daily care and cost of managing the

disability of the child. These unmet needs could either be on the level of social support services, financial and emotional constraints not otherwise provided for by the available government support services could translate into a crisis burden for the family. What is needed therefore is a pervasive support structure that assists family with the needs of their autistic child at all levels of development. Current practice in Canada where the research was conducted indicated less available services for school aged autistic children. The question then is what is the predictable impact of this stressful experience on a single parent navigating the socially constructed identity of being single versus parent of an autistic child? Lukemeyer et al (2000), Plant (2011), Freedman et al (2012), and Murray, S. (2008) indicated the social liability that both parents of autistic children and autistic children themselves often face as a result of the social and medical condition they are saddled with. Social liability may include inability to respond fully to the incremental needs of a lifelong need of an autistic child that could limit social and occupational choices for the caregiver. We could also look at the perception of the notion of a normal child versus an autistic child. Additionally, the liability of attributive factor of genetic curve of parent with regards to history of autism in the family, age of parents factor and community judgments burden on the parents that goes to shape perception of identity (see Shelton, Tancredi & Hertz-Piciotto, 2010).

These social conditions, often carries the baggage of social stigma, the consequence of inadequate social support system, socioeconomic exclusion, and limited social and occupational mobility resulting from the liabilities of having to care for a child or young adult whose condition of life requires undivided presence and support from a parent. Berkman (1971) in his study of "Life stress and psychological well-being: a

replication of Langner's analysis in the Midtown Manhattan study," indicated that a combination of two stress factors could sufficiently create a mental health risk and the greater the number the higher the risk factors of possible mental health risk for individuals (p.39). The consequent implications of stress factors involving relative deprivation could therefore be in the association between autism and single parenthood where factors of social identity stereotypes threats, social economic deprivation, occupational mobility deprivation, inadequate social support system, and financial liability burden could significantly threaten the mental health and well-being of single parents.

Thus relative deprivation threat burden in autism and single parenthood refers to those variables of limitations associated with the time and financial burden of a lifelong care for the autistic child that creates comparative social inequality between single parents of autistic children and parents of normal children. These social injustice of inequality attributable to time required to meet the needs of an autistic child, could limit occupational mobility investment in personal capital of social evolution of opportunities for economic growth, educational opportunities and social interactions with peers. The threat of stereotypes of having an autistic child either passively or actively in the social arena equally creates a referendum for feeling of relatively deprived (Inzlicht & Schmarder, 2012). Essentially, relative deprivation theory in autism and single parenthood resonates as a comparative analysis of opportunity gained versus opportunity lost in life expectations. This comparative analysis tasks social structural identity crisis and internalized conflict acquiescing risk factors.

#### 3.4: Attribution Theory in Autism and Single Parenthood

The Greek philosopher Aristotle claimed to understand an event fully or a subject, it is imperative to understand "its constituents and functions," more especially given that different appraisal evokes different emotions (Power & Delgleish, 2008). Attribution theory is the philosophical "study of the causal interpretations that persons give to events in their environment" (Crittenden, 1983) as a meaning making process for either conflict resolution or escalation response. Attribution theory is closely associated with perception theory and the theory of mind because of the epistemological basis under which attribution operates. Attribution is a psychological response to conflicting events in one's environment in a process that often times ascribe blame to the other party as being responsible for the escalation of conflict events. Attribution operates through a circle of selective inattention of identifying those attributes that reinforces stereotyped perception about other parties in a way that serves to create cognitive consistency about present experience for attributing individuals. In this wise, attribution becomes "the linking of events with their underlying conditions" through the utility of perceptive information in "making causal explanation" about the prevailing condition of a specific event or events (Guiot, 1977). Thus, attribution could form a basis for justifying and excusing oneself from taking responsibility for the causality of a conflict or socially anomalous behavior.

Guiot (1977) analyzed that "identity construction invokes attribution" (p.693) through the social process of information management of labeling of social behavioral attributes that a perceiver uses to distance him or herself from others while inputting or acquiescing those qualities that reinforces intended social image. Crittendenn (1983) opine, "attribution theory is not one but a collection of theories addressed to complementary but distinct problems.... Attribution is a process that begins with social perception. It progresses through causal judgment and social inference, and ends with behavioral consequences" (426). In assessing conflict and crisis implications of autism in single parenthood, the theory of attribution provides valuable lens for exploring the central research question of how autism exacerbates and transform conflict and crisis for a single parent. Put in another words, how does single parents perceive their life with an autistic child? And how much of an association with raising an autistic child correlates with personal emotional experience of crisis, social identity construction, meeting personal occupational/ career goals and investment in personal social capital? Critical analysis of the association between autism and single parenthood through attribution theory zero on looking at the social perception of functional theory of autism's impact on the life of a single parent, and the causal judgment of how the single parent perceives his or her existential journey in the context of a life with or without an autistic child. Again, we could raise the question of to what extent could one attribute or create a social inference of present mental or emotional stress behavior to the consequence to caring for an autistic child as a single parent.

Clifford, Kim, & McDonald (1988) in analyzing "Response to failure as influenced by task attribution, outcome attribution and failure tolerance," observed that "...failure tolerance can be viewed as two-factor trait comprised of an affective and a behavioral dimension" (p.19). Applying the concepts of effort and ability attributions to explicate individuals' resolves to overcome challenges, Clifford, Kim, & McDonald (1988) contends an effort attribution (associated with low stability) implies that future success can be obtained simply by resolving to try harder, whereas an ability attribution (associated with high stability) implies that future success is unlikely no matter how diligently the individual works. A third observation regarding responses to failure is that effort attributions produce evaluations that are more negative by others than ability attributions (Eswara, 1972; Rest, Nierenberg, Weiner, & Heckhausen, 1973; Weiner & Kukla, 1970). This finding has been explained by the culpability associated with each of the two attributions: Lack of effort implies personal culpability, whereas lack of ability carries little or no implication of culpability and often elicits pity and assistance from others. Finally, failure is attributed to inappropriate strategy (p.20)

A closer application of the effort and ability attribution to the theory of autism and single parenthood from the above analysis may reveal effort attribution to the various conflict mediation processes. It may resonate within a possibly failed relationship and communication dilemma between autistic children and their single parents. This association may produce negative evaluations of both self-critique and societal pressure of some sort (Shonkoff et al. 1992; Konstantareas & Homatides, 1992)). Ability attribution may be akin to the perceived inability of a single parent to find or foresee a possible way out of the conflict circle of dealing with the disease and thereby leading to a crisis of helplessness and hopelessness. In this wise, culpability attributes medical or social system not being able to provide for the incremental needs of both the suffering child and mother. A third type of attribution that has received little attention is the liability attribution in autism and single parenthood. Bendixen, Elder, Donaldson,

Kairalla, Valcante, & Ferdig, (2011) noted a good percentage of families with a child diagnosed with autistic spectrum disorder often end up in divorce that invariably creates the scenario of a single parent caring primarily for the autistic child. So many factors may project into the reason for the divorce rate. Besides, it might serve a useful purpose for further research to look at the liability effects of even research records on the blame game of a child's root of autism. For instance, in a research conducted by Shelton et al (2010) the following were discovered:

In multivariate logistic regression models, advancing maternal age increased risk for autism monotonically regardless of the paternal age. Compared with mothers 25–29 years of age, the adjusted odds ratio (aOR) for mothers 401 years was 1.51 (95% CI: 1.35–1.70), or compared with mothers o25 years of age, aOR51.77 (95% CI, 1.56–2.00). In contrast, autism risk was associated with advancing paternal age primarily among mothers o30: aOR51.59 (95% CI, 1.37–1.85) comparing fathers 401 vs. 25–29 years of age. However, among mothers 430, the aOR was 1.13 (95% CI, 1.01–1.27) for fathers 401 vs. 25–29 years of age, almost identical to the aOR for fatherso25 years. Based on the first examination of heterogeneity in parental age effects, it appears that women's risk for delivering a child who develops autism increases throughout their reproductive years whereas father's age confers increased risk for autism when mothers are o30, but has little effect when mothers are past age 30. We also calculated that the recent trend towards delayed childbearing contributed approximately a 4.6% increase in autism diagnoses in California over the decade (Shelton et al, 2010, p.29).

Under liability attribution theory, the implication of this study may be obvious for parent who falls within the age categories analyzed by the researchers. Any parent who falls within the age bracket will definitely carry the burden of feeling responsible for the autistic challenges of the child. Moreover, if this further reinforced by the other parent in a conflict situation of a zero sum liability attributive thinking for a selective inattention point, it may feed into a personal distressed and dissonant feeling about self and possibly resentment for the child. Thus a liability attribution have the possibility of producing multiple and indeterminate results for parents of autistic children.

Furthermore, modern epidemiological research has equally indicated that at least one of the parents of autistic child carries the genes of autistic spectrum disorder and consequently transmits to the child (Rodier 2012, In 2011 World Book). Mclanahan and Sandefur, (1994), Mulroy & Pitt-Catsouphes, (in Gottlieb, 1994) argued on the liability factor of psychological, and emotional stress of social isolation that often trail autistic children and their families. Corrigan, Markowitz, Watson, Rowan & Kubiak (2003) in "An Attribution model of public discrimination towards persons with disability," observed how the propensity of causal attributions affect beliefs about persons with mental illness leading to affective reactions of avoidance, coercion, segregation, stigmatization, operational stereotypes, increased prejudice and withholding of help. These added liability variables may lead to a prepositional theory of what could have been in a life without the burden of autism and a zero sum thinking of perception of a life ruined because of the liability value of an autistic child. This research therefore provides an opportunity for understanding the impact of the liability attribution of autism on single parents. This will be assessed from the point of view of stress theory that assesses the

social organizational (family ecology) origin of the consequences of stress resulting from characteristics of unmet needs as a single parent of an autistic child (Aneshensel, 1992). If the research findings of Schieve et al. (2007) and Olsson & Hwang (2001) that associated higher depression and stress related problem with parents of autistic children compared to parents of normal functioning children, then attribution is rife and the impact becomes even more significant for zero sum thinking.

# 3.5: Phenomenological Theoretical Perspectives in Autism and Single Parenthood

Research about the various dimensions in which autism and single parents studied have often reclined to the evaluative and psychologized clinical and socio-economic experience of deprivation and needs. Very little research is available that fully explores the unique experience of single parents dealing with autistic children. A phenomenological exploration on this isolated experience provides that unique descriptive and hermeneutical opportunity to understand the experience. Phenomenology is position in the theory of knowledge about what is knowable and how phenomena are known in their natural state independent of the subjective influence of the knower on the known (Skuza, 2007). In other words, the philosophical objective of phenomenology is to investigate description of a phenomenon as consciously experienced by the subject knower devoid of theoretical causal explanations but through the lens of unexamined preconceptions and presuppositions (Phenomenology, 2012, Encyclopedia Britannica, Nasu, 2005, Silverman, 1980). Johann Heinrich Lambert, a Swiss-German mathematician and Philosopher was one of the foremost philosophers who applied phenomenological

methods in an attempt to "distinguish truth from illusion and error" (Phenomenology, 2012, Ibid).

Edmund Husserl (c.1930) gave the phenomenological theory of knowledge in depth approach when the philosopher indicated that phenomena is better known when it is investigated from its intentional consciousness. That is, the way the phenomena exist devoid of the presumptions of the investigator. This knowledge is attainable through a process of phenomenological *epoche*. Phenomenological *epoche* is the suspension of investigator's bias or suspension of presumptive beliefs. This methodological approach differentiates phenomenological methods from positivism and empiricism. Phenomenology treats positive data of experience as an invaluable asset, defying a rationalist's negation of experience, but insisting on verifications of concepts, resisting transforming reinterpretations of the substance of experience but examining such experiential data for what they are at the natural habitat. For Husserl:

what a philosopher must examine is the relationship between consciousness and Being; and in doing so, he must realize that from the standpoint of epistemology, Being is accessible to him only as a correlate of conscious acts. He must thus pay careful attention to what occurs in these acts. This can be done only by a science that tries to understand the very essence of consciousness; and this is the task that phenomenology has set for itself. Because clarification of the various types of objects must follow from the basic modes of consciousness, Husserl's thought remained close to psychology. In contradistinction to what is the case in psychology, however, in phenomenology consciousness is thematized in a very special and definite way—viz., just insofar as consciousness is the locus in which every manner of constituting and founding meaning must take place (Phenomenology, 2012, Encyclopedia Britannica.)

Phenomenological theory of knowledge is a descriptive presentation of the experience of the phenomena in a way that makes the phenomena more readily available for proper understanding and appreciation. Other philosophers of phenomenology who shares similar philosophical opinion like Husserl's include Wilhelm Dilthey, Martin Heidegger, Karl Jasper and Jean-Paul Sartre (Silverman, 1980). What the phenomenological theory of knowledge as an investigational tool presents for autism and single parenthood is an epistemological science that seeks to excavate the social geography of the unique experience of the phenomena through the epoche application. In "Self representationalism and phenomenology," Kriegel, Uriah (2009) argued that phenomenological investigation presents an essential tool for a comprehensive understanding of external and internal conscious experience of a phenomena. In this process, the tools of phenomenology makes the descriptive analysis of phenomena possible because it provides a basis for responding to questions about motivations and exogenous influence on the object. Svenaus (2009) in analyzing "The Phenomenology of falling ill: an explication, critique and improvement of Sartre's theory of embodiment and alienation," contends

...the alienation of the body in illness is not only the experience of a psychic object, but also an experience of the independent life of one's own body. This facticity of the body is the result neither of the gaze of the other person, nor of a reflection adopting the outer perspective of the other in an indirect way, but is a result of the very otherness of one's own body, which addresses and plagues us when we fall ill. (Svenaeus, 2009, p. 53)

In the context of autism and single parenthood, it could be philosophize that knowledge about the experience is still evolving. In order words, the limited knowledge about the phenomena is not so much as to whether a priori distress and stress or crisis exists in the context of the relationship but how this intricate relationship between autism and single parents mutually affects each other. Thus the pertinent question about what is autism? What is single parenthood? Becomes a research interest from the point of view of what is known through a priori knowledge (phenomenological epoche) versus what the real narrative experience is from the point of view of single parents account.

#### 3.6: The Phenomenon of Autism

Various theories abound about the origin and functionality of the concept of autism. Some of such accessible theories include the theory of the mind, behavioral theories, and emotions development. This theoretical framework states that a child's linguistic inability or ability to interpret emotional states of others or false-beliefs at an early developmental ages of 1-3 years may inferentially indicate growth and development or autistic manifestations (Cutting and Dunn, 1999). Some of the questions left unanswered by this theory of mind and emotional development are the variability of the different types of information at the development process of a child. For example, what role does poverty and wealth or education of family play in articulating a child's level of passing the false-belief test? Hypothetically, it is not possible for an educated and middle class family child to test same as a child from a less affluent environment where the resources of cognitive development may not easily be assessable on the same level as a more affluent peer. Additionally, Howard Gardner (1999) indicated in his theory of multiple intelligences that individual intelligence does not efficiently and accurately underscored on the same parameters given the fact that individuals may have evolved it but different intelligence at different levels and varied ways. However, Grinker (2007) a well-educated anthropologist's presentation of his daughter's experience with autism may be considered a testament to the substance of the theory of mind and emotional development as independent of variability in unearthing the presence of autism using the theoretical tool. Consequently, one point that remains a constant about autism is the fact that autism is a brain disorder that affects the life of individual over a lifetime in different ways. It is a spectrum because of the multiple factors and variables operating under the broad title of autism spectrum disorder. "The spectrum is broad enough to encompass both severely mentally retarded autistic person without speech and super-intelligent but socially awkward mathematician or physicist" (Grinker, 2007, p.10).

Another theoretical hypothesis advanced to explain the origin of autism is in the science of genetics and environment of a child's growth and development. The role of environment on the evolution of autism in children has often ended inconclusively complex. Rodier (2000) in "Embryology of Autism in her research "The Early Origins of Autism, New Research into the Causes of this baffling disorder is focusing on genes that control the development of the brain," indicated certain medication taken during pregnancy and some infectious diseases during pregnancy have been identified to serve as environmental causes of autism in children. Some of those environmental risk factors include, "utero exposure to rubella (German measles) ethanol, valproic acid and certain

vaccines containing thalidomide." The efficiency of these environmental factors acting independent of other collaborating genetic factors is inconclusive (Rodier, 2000). However, scientists have established the fact that genetic defects and age of parents in family have the likelihood of predisposing their genealogical offspring to inherit traits of autism (also Shelton, 2010).

The various forms of autistic disorder is therefore acquired during gestation period with the possible defects in the family tree of chromosomes that may either be brain or various part of emotional composition of all that have come to be understood as a pervasive disorder (Rodier 2000). Even in the best case of science that is available on the causes of autism, the fact of tracing autism to gestation and family genetic history may lead to attribution theory of casting blame on parents of the autistic child that may likely strain the cohesiveness of family structure and system theory. The high prevalence of conflicts among parents of autistic children could be pointer to this reality. In this sequence therefore, when a divorcee identity acquired through this process, identity question and crisis may likely follow.

#### 3.7: The Phenomenon of Single Parenthood

A single parent either male or female could be the father or mother of either a biological or an adopted child living in a household without the presence of a significant other to whom a legally defined setting of marriage established. Several theories have been advanced by different scholars to describe the phenomenon of single parenthood and the conflict impact such family arrangement could pose for either the single parent or the children if they are involved. Weinraub, Horvath, and Gringlas (2002) in their research indicated the changing dimension of the concept of family in the late 20<sup>th</sup> to 21<sup>st</sup>

century with "increase of children living in single parents household around the world with the United States having the highest proportion" (p.109). Between 1960 and 1997, the percentage of children living in single-parent family increased from 9.1% to 28% (U.S. Bureau of Census, 1998. In Weinraub, Horvrath, and Gringlas, 2002) using research finding from Ahlburg and DeVita (1992) and Bianichi (1995), Weinraub et al contends more than half of all Americans will likely experience living with a single parent in their lifetime. The U.S. Census Bureau 2010 reflected a decline in the proportion of children living with two married parents, 66% compared to 77% in 1980. 23% of surveyed American children lived in household of single parents. While 3% lived with only their fathers, 4% lived with only their mothers (U. S. Census Bureau 2010). National Center for Health Statistics (2007) opined that 39.7% of all birth is to unmarried women. In 2006, the statistics of single parents living with their children doubled the statistics of 1970 with about "13 million single parents lived with their children in America according to the U.S. Census Bureau, America's Family and Living Arrangements 2007." The interesting construct about the report is the fact that the increase of the number of children living with single parents works across racial divide.

There are various reasons theorized why the concept of single parenthood seem to have increased overtime. Single-parent family could be the result of different factors like divorce, teenage pregnancy, and a matter of premeditated choice given the social and biological circumstance of the likelihood of never getting a suitable male partner (Weinraub et al., 2002). In relation to the kinesthetic of this study on the conflict and crisis relationship between autism and single-parenthood different hypothesis have been tested on the impact of the different theories of single-single parenthood. One of such theories hypothesized is the impact of single-parenthood arrived at through divorce. Mauldon (1990) indicated that divorce have significant negative impact on the life of children with disabilities on different fronts. Primarily, the amount of resources both financial and emotional support depletes thus making life more challenging for both the single parent and the disabled child (Also refer Biblarz & Gottainer, 2000). This experience from an a priori analysis necessarily brings enormous strain on the psychological wellbeing of the single parent. However, the level of specific stress and crisis related experience that this experience could engender in the life of the single parent that could possibly lead to suicidal thoughts and homicide is yet to be efficiently tested.

Most available research on the subject of family composition or structure theories and socialization theories tend to be more focus on the impact of single parenthood on children normal or disable with a gap on what happens when the equation reversed. For example socialization theory hold that whereas two parent family presents optimal positive reality for children both able and disabled, single parenthood has negative impacts on children but more especially on disabled children (Lansford, Ceballo, Abbey, & Stewart, 2001). The Family structure model presented by Biblarz & Gottainer, (2000) equally supports the analysis of a negative impact of single parenthood on the outcome of a child's life developments performance with social skills and self-concept evolution. In these theoretical models, there seem to be not much analysis about the impact of disable or able children on single parenthood. There is not logical analysis as to how a possible negative variable experience could stimulate elevated stress and crisis experience for the single parents. The questions left on answered bothered on how the presence of double stereotypes of having an autistic child and living as a single parent could undermine the resilient skill abilities of single parents.

Simons, Beaman, Conger and Chao (1993) argued that the concept of single parenthood is not a homogenous concept given the variations in the dynamics of their life structure. According to these researchers, educational background plays a greater role in the methods and style of style management. This research critiqued that a great deal of studies focus more on the transitional and adjustment experience of divorced parents with little emphasis on those variables that stimulate stress related experiences. Simons and colleagues' research revealed a strong positive association between single parenthood, antisocial traits, psychological distress and poor economic resources. This finding suggests that there are multiple factors involved in the stress and distress experience of single parents requiring extensive study. The analytical finding of this research brings us to the concept of the human needs theory in the context of the psychosocial needs of single parents vexed with the circumstances of dealing with disabled child. The human needs theory has often address issues of interest-based negotiation in international political conflicts (Burton, 1979). Nonetheless, the human needs theoretical framework of basic human needs as constituting identity participations, autonomy, security and recognitions summarizes some of the life challenges that confront a single parent. The crisis of being in the single parenthood as most researches have indicated has to do with social alienation. This optimizes in dealing with an autistic child for example. Under this circumstance there is the economic insecurity and the seemingly loss of autonomous pursuit of dreams in favor of nurturing an autistic child. Such a circumvented circumstance presents phenomena outlets for re-examining the role the presence or

absence of specific variables may be having on the life traits of single parents of an autistic child or children as the case may be.

Davis, Avison, and McAlpine (1997), conducted a research study that examine comparatively the levels of depressive and stress experience of single mothers compared to married mothers testing various variables of childhood experience, economic resources and other outlaying variables of relevance to the experience of this population segment. One significant distinction about this research is that it focused precisely on the evolutionary environments of mothers, married or single. Whereas the environment of the personality development of mothers were observed to factor into their later life experience, certain factors were judged to exacerbate those latent potentials that only require a trigger for depressions and stress experience. Such examined triggers could be divorce, limited economic resources, level of education, and the absence of a protective presence of a spouse especially in the case of a single parent. The pathways for further is the fact that if after controlling for income as most research have done and findings shows that single parents are less likely to report psychological problem compared to childhood episodes of traumatic experience, then what happens if research is controlled for raising a disabled child in addition to having or not having a childhood difficulty?

Even though various statistics have indicated changes in the attitudes towards single parents, in the American society, there is no sufficient evidence to prove that such stereotypes have completely been eliminated (LaRossa, 2009). Theoretical research available at this time focus more on the variables of single parenthood and less association about intervening variables of disabilities as a causal factor of mental health status of single parents. This gap then leaves this research to attend to the question of how does autism affects the psychological wellbeing of single parents.

### 3.8: Resilience Theory and the Phenomenon of Autism and Single Parenthood

Resilience theory examines the competence and innate or environmental strength that individuals embody enabling them to overcome predictable consequence of an adverse situation or condition of living (Pillatt, 2012; Seery, 2011; Curtis & Ciccheti, 2003). The theory equally undertakes an analysis of the context in which enabling competences evolves, developed, or exercises in the context of confronting debilitating life conditions. Anne Edwards (2007) in *"Working Collaboratively to Build Resilience: A CHAT Approach*," indicated "however, resilience theory operate with an interactionist and arguably normative, framework of individual development which retains a separation of individual and context, rather than the more iterative account of cultural historical activity theory (CHAT) understanding of development" (Anne Edwards, 2007, p.256). Anne Edwards further contends 'resilience could be perceived as responsible engagement with one's world as well as a capacity to withstand difficulties.' For Walsh (2002)

A family resilience approach attends to adaptational processes over time, from ongoing interactions to family life cycle passage and multigenerational influences. Life crises and persistent stresses can derail the functioning of a family system, with ripple effects to all members and their relationships. In turn, family processes in dealing with adversity are crucial for coping and adaptation (McCubbin, McCubbin, McCubbin, & Futrell, 1998; McCubbin, McCubbin, Thompson, & Fromer, 1998); one family may be disabled, whereas another family rallies in response to similar life challenges. How a family confronts and manages a threatening or disruptive experience, buffers stress, effectively reorganizes, and reinvests in life pursuits will influence adaptation for all members and their relationships (Walsh, 2002, p.131).

Additionally, Walsh contends family belief system, organizational structure, and communication system all work to aid families in transforming experience of adversity into a shared purposeful journey that could be overcome. From this perspective then, resilience theory presents that unique opportunity to examine persistent outliers that either enhances the emotional strength of single parents in managing the challenges of caring for an autistic child or gaps that undercuts their strengths. It also categorized as a theoretical framework for conceptualizing under-utilized capacities for overcoming or managing predictable social, psychological, or medical existential crisis. Thus from this perspective, it could be argued that resilience theory examine those social, environmental, and psychological resources that aids in reversing risky crisis laden situations in an individual's life story. It is a positive adjustment experience from a crisis laden life experience to a fully integrated living.

The pivotal case for approaching the impact of conflict and crisis of autism on single parenthood from the point of view of resilience theory comes from a sociological analysis that stereotypes and alienation pages single parenthood as an unfamiliar ground for defining the concept of a family structured theory (see Thornton, 2009). March (2008) in "Motherhood, personal agency and breaching family norms," and Wolf (2009) the book review on "Single by chance, mothers by choice: how women are choosing parenthood without marriage and creating new American family by Rosanna Hertz," analyzed on the struggles of single parents who defies the conventional nuclear conceptualization of family structure. A conceptualization that objectify the values of nuclear family context of having children in the context of married couple living together as against single parent having a child out of wedlock. This is a social definition that not only limits access to social resources but equally creates a psychological sense of inadequacy that may further complicates the ability to meet existential goals of social, and emotional cohesiveness. When this socially defined alienation and identity stereotypes combines with the daunting task of caring for an autistic child, the need for personal resources that will assist in creative personal cohesion may become relatively limited. Such social evaluation may be resulting from either religious belief that passively informs policy provisions that may not necessarily advocate for the needs of single parents.

In the face of unfavorable environment where a double circumstance of unexpected life events of being single parent and caring for an autistic child, a phenomenological search for a framework that aids the resilient ability of individuals in this spectrum to manage their existential journey becomes a relevant phenomenon for research. Teasing out the wheels of hope that makes the difference under a misnomer circumstance is what the theory of resilience builds upon. The theory of resilience becomes of great relevance to either explicate either the role of latent energy aiding positive outcomes or under-managed risked factors left to blossom into crisis. Such latent resilient variable resources could be resources for managing unprepared for medical crisis of caring for a medically challenged child as a single parent. It could also be economic hardship, social exclusion, behavioral management hardship, and emotional strains not well managed leading to pervasive crisis experience. Finally, the resilience theory dynamic presents a valuable asset for understanding the coping mechanism of the dyad between single parents and autistic children (Seery, 2011). When we assess resilience theory beyond concepts of heroism and self-determination, to understand the operational phenomenon of the theory "in terms of an ability to cope with adversity, stress, and deprivation," (Begun, 1993, Pp. 28-29) then the role of a resilience theory in autism and single parenthood becomes a valuable conflict analysis tool for the subject.

#### **3.9: Critical Theory Frame of Autism and Single Parenthood**

Critical theory is a theory that arose from the Frankfurt School in Germany pioneered by a group of thinkers that included Max Horkheimer, Theordor Adorni, Herbert Marcuse, and Jürgen Herbermas (Hobden & Jones, 2005, In Baylis and Smith, 2005, p.242). The central thesis of critical theory is the invaluable role of the "human capacities and capabilities appeal in engineering emancipation" (Ibid) Fundamentally, critical theorist appeal primarily for political revolution, thus the focus on emancipation building on the class struggle in classical Marxist theory. Critical theory was a response to the social and political problems that bedeviled early part of the 20<sup>th</sup> century namely Nazism, fascism, and authoritarianism. However as Kellner (1990) argued, critical theory as a doctrine that energized and provided hermeneutical basis for engaging the social problem of the 1940-1960s equally possesses some robust methodical potentials for a critical analysis of the emerging social problem of our time from the point of view of culture, political economy, sociology, and social psychology. As a social movement, critical theory could be viewed from the point of view of seeking emancipation from all form of oppressive experience that impinge on human freedom, social, psychological and political isolationism, happiness and rational ordering of society (Kellner 1990, p.12).

The framing of autism and single parenthood in critical theory eloquently visualize in the context of Marx Horkheimer's analysis of the theory from a materialist perspective and Jürgen Habermas' reasoning that emancipation is essentially possible through communication and radical democracy (Hobden, & Jones 2005, Pratt, 1978, & Kellner 2005). Critical theoretical analysis of Horkheimer on materialism zeroes on "human needs and suffering. For him, the ways economic conditions produce suffering, in like manner it could engender changes necessary to eliminate human suffering and increase human well-being. Such a project requires a critical social theory, which confronts the social problems... (Horkheimer 1972:34ff)" (Kellner 1990, p.19). Thus engaging a phenomenon like autism and single parenthood that combines human needs and suffering, social isolation, stereotypes and identity crisis, in a critical analytical theory will bring the undervalued challenges of the sufferer to the forefront of social dialogue. Such analytical framework will be a drive towards emancipation of some sort from a critical theoretical perspective that encourages social advocacy, information sharing and social mobilization in favor of those suffering (Hobson 2010, p.11). The concept of autism and single parenthood is not only a social pathological or a mere medical misnomer it is equally a political and sociological phenomenon from a conflict mapping perspective. It hinges on the social and political condition that persons in this group live and share in the social strata of the society. It bears a stigma on isolation and inadequate participation in the social, economic, and political capital of the society that forms the bane of the crisis in autism and single parenthood.

Additionally, what has been lacking in the field is an adequate exploration of the social advocacy needs for the emotional challenges of single parents with autistic children. This is where tools of critical theory for social advocacy and needs communication become inevitable. Marcuse, Adorno, and Horkheimer, thought Marxism need to reconstruct to be more serviceable to the twentieth century capitalism (Agger, 1991, p.107). In that vein, a 'phenomenological consideration of the conflict and crisis impact of autism and single parenthood' is an attempt to re-engineer the field of autism in way that is more inclusive of all that is conglomerated in the field. Such critical theoretical framing of the subject thus creates an opportunity for single parents to relate their experience in a communicative model for self-emancipation. What is begging for emancipation in autism and single parenthood from the lens of critical theory is the theory of social isolation, hopelessness in the social and political design that ignores the struggles of a double stigma, and helplessness in the face of a social structure that denies and minimizes access to sustainable means of livelihood. Theories of hopelessness and helplessness hold that individual's perception or attributions of experience to either external or internal uncontrollable circumstance often negatively affects their emotion leading to depression (Power & Dalgleish, 2008, Pp. 104-106). The seemingly conundrum of overwhelming experience of ever growing sense of inadequacy of skills and insecurity with the management and care for autistic children by single parents could a priori be estimated to confirm the theory of helplessness and hopelessness. What is called for therefore is a critical theoretical framework that is comprehensive enough to assess the exogenous and internal variables that possibly creates risk of conflict of emotional distress in the relationship between autism and single parenthood.

## 3.10: Feminist Theory View of Autism and Single Parenthood

Kudlick (2003) argued that the concept of disability has a historical context that various scholars have struggled with in creating a specific definition that is far from being negativizing and stereotyping. The philosophical inadequacies in arriving at a consensus definition of what the concept of disabilities means has created a new dilemma that is in itself disabling more so for those who are saddled with the responsibilities of caring for this class of people. It is within this framework of conceptual struggle for meaning and ideological construct for autism and single parenthood that the theory of feminism as an epistemological theory offers a model for conceptualizing the various challenges that single parents of autistic children embody in their struggle. Chafetz (1997) offers feminist theory as that theory of knowledge that "...seeks to understand how gender is related to social inequities, strains, and contradictions" (p.98). Nowhere has this feminist debate about social inequities, strains, and contradiction found more meaning than in the challenges of dealing with a child's disability as a single mother. As Blum (2007) argued, "fewer mothers are blamed for causing their child's troubles in an era of "brain-blame." But more are blamed as proximate causes if they do not make unrelenting efforts, paralleling "concerted cultivation," to resolve them. (2) Such mothers often exceed concerted cultivation, as they seize authority, as vigilantes, within educational and medical systems in the midst of turf wars, cost containment, and a resulting proliferation of medication treatments; and (3) this maternal speedup holds mothers accountable for feminizing ties to sons, for policing gender boundaries while policing their own feminine care. In sum, mothers raising invisibly disabled kids may represent the model of maternal valor for an era of public stinginess and extensive medicalization (Blum, 2007, p.202).

These emanating pressures on regular mothers to meet society expectations of raising socially defined able and capable children no doubt may leave scare of emotional and cognitive burden on mothers. Hypothetically, when the bars of cognitive dissonance in the face of racing to meet societal expectations for women raising children are elevated, exceptional burden accelerates for single mothers of autistic children. Blum's research observed that mothers of disabled children experience shared stigma and ostracism assigned to their disabled children as the number of friends gradually depletes based on attributed stereotypes for being mothers of disabled children (P.207). Cook (1988) analyzed that a feminist theoretical perspective to the burden of caring for disabled children is particularly important given the unique role women play in the life of every child. For Cook, cultural expectations have come to define and structure unequal sexual delineation of management role of fathers and mothers in caring for especially ill children. Mothers provide strength and emotional stamina where fathers give in to hopelessness.

Feminist theoretical perspective shields light on the embodiment roles mothers play as they try to make sense of the life challenges of their ill children in attempt to reassess the scapegoating of mothers for the outcome of their children's fate. For Cook, "Some clinicians feel that they have already accomplished this revision once they come to reject mother-blaming as a cause of severe mental illness, without understanding that scapegoating of women still persists in their explanations of current functioning" (p.48). This attribution and stereotype theoretical gap therefore presents yet another veritable opportunity to explore the unique challenges of conflict and crisis single parents deal with in raising and caring for autistic children. Exploring the challenges of conflict and crisis single parents deal with in raising and caring for autistic children from a phenomenological perspective provides an avenue for these theories to be assessed in raw data. The need for this studies is evident in the analysis of Bummiller (2008) when she argued that the project of feminist disability studies was to improve the services made available to families and individuals impoverished through discriminatory policies that defines autistic people for instance as the other.

## 3.11: Autism and Single Parenthood in Family System Theory

Daly (2003) in "Family theory versus the theories families live by," argued there is a vault between scholarly theories about families and the actual experience that shapes the daily experience that often define the life of most families. This invisible experience that often escape the razor of theorist could be hypothesized to include often-unrecognized stressors that renegotiates family economic, political, and career goals due to unforeseen circumstance like dealing with a child's disability. Referencing clinical research conducted by Van Der Veen, Huebner, Jorgens, and Neja (1964), Bowen (1988) noted, discrepancies between the ideal expectations of parents and the actual, leads to dissatisfaction and maladjustment of parents to the reality of their family life satisfaction. In order words, crisis and conflict in family hypothetically comes when there are conflicting values leading to conflicts of incongruent behavioral patterns. Furthermore, Bowen observed, family valued based behavioral indices are often influenced by: (a) the level of congruity of values among family members. (B) The relative presence or absence of personal resources (e.g., self-esteem) and relational skills (e.g., communication) necessary to act in accordance with stated values. (C) the nature and magnitude of system-level constraints that serve as obstacles to realizing family-related values,

including family-related demands and stressors (Bowen, 1988, p.459) all reflective of the association between the ideal vs. reality.

Family system theory holds that family is a complex organizational unit where experiences are either equitably shared or unequivocally distributed. According to Shonkoff et al (1992), "families have a fairly predictable life cycle governing their growth, development, and functioning." The family circle represents a consistent ecological environment that embodies resilience of some sort in it that bears the problems, strengths and weaknesses, assets, and liabilities of all those involved (Ullmann-Margalit (2006). Weiss (2001) indicated in his research that raising children could present some level of stress for families but caring for autistic children raises the bar. Some of the stressors are behavioral problems from the child, financial constraints, health, and education (p.521). These attendant problems are notably present in most families with an autistic child. That stressors are present in families with autistic children especially single parents is to state the obvious. The core question for a family system theoretical analysis within this context therefore is not if stressors are present but what make certain families adjust congruently and some do not. For example,

Common outcomes of stressors can include increased parent stress (Saloviita et al. 2003), depression (Hastings and Brown 2002), marital discord and poor sibling adjustment (Prince 2007) and quality of life (Lee 2009), reflecting an impact on the entire family. There are known processes that mediate the relation between stressor and outcome, which include coping styles (Hastings et al. 2005), psychological acceptance (MacDonald et al. 2010), and self-efficacy (Hastings and Brown 2002) (Weiss, 2011, p. 522).

Patterson (2002) in "Integrating family resilience and family stress theory," indicated the operating factor in family systems is the balancing strategy. For Patterson, when family demands far exceed existing capabilities to achieve a level of family adjustment, imbalance ensues and this creates crisis. A family crisis is moment of significant disequilibrium and disorganization (p.351). Some of those factors that can aid and abet this crisis process could be community stigma, poor conflict communication and management process, financial resource control model, and perception of the conflict and crisis triggers (Patterson, 2002; Ślifirczyk, et al. 2013, Hall, et al. 2012; Schieve, et al. 2007).

The case for single parents of autistic children presents a different nuance to the case for parental stress theory in family system adaptive model. Schilling (1986) focused his argument on the fact that single parents experience more stress compared to married couple in caring for handicapped children. Patterson and Garwick (2004, 1994) in "Levels of meaning in the family stress theory" noted meaning making within the family plays a major role in shaping how members in the family ecosystem perceive their stressors. Family often time ascribes meaning to their stressors: "1) situational meanings, (2) family identity, and (3) family world view" (p.287). Taking this theoretical framework into focus philosophically granted that the environment and the social construct of the identity of being single with its social assets and liability of caring for an autistic child adds a nuance to identity construct. The social construct of the roles and meaning that society ascribes to being single is both transformational and constructive. The constructive meaning that forms the central piece of the sense of self creates a reality through which the world viewed as either fair or stifling. At this point one could note the

need for social and psychological conflict negotiation as apt make sense of the lifechanging situation of being single and caring for an autistic child. What the family stress theory portends for autism and single parenthood is a lens for re-evaluating and phenomenologically asking the question as to what exactly makes a difference between a thriving family with an autistic child and one that does not?

#### Conclusion

Reconciling the impact of autism on single parents through the lens of theories as presented above serves a framework role of clarifying indented issues link with the subject. It provided a layer for connecting with the subject both idealistically and practically. Perceptualizing the phenomenon of autism and single parenthood through the script of the various theories analyzed above situates the analytical basis for engaging on this project. The theoretical background analysis therefore provides the basis for interpretational insights towards analyzing research finding that will link ongoing discussions on the subject with cognitive reality of what participants might provide for understanding. It provides a window of expectation and a key to unlock the intentionality of unexpressed emotions in the research process. The above theories therefore provide the linguistic register for hearing the unspoken and verbalized experience of single parents and autism.

The entire theoretical framework could be summarized as encompassed in three theoretical frame of reference that include the hierarchy of human needs theories, relative deprivation, and critical theory. While the human hierarchy of needs theory vivifies the layers of incidents of safety and security, physiological, and esteem (love and social approval) that coordinates the feelings of relative deprivation arising from poor social resources needed to maintain a cohesive well-being critical theory provides and outlet for advocacy. This is even more visible when we consider these theoretical language of experience of autism and single parenthood from the point of view of challenges and threat theories that comes to play when needs far out-way available resources. In the face of this the drive or crave for changes becomes inevitable. Enduring conflict and crisis experience comes when changes are deemed either unattainable or unsustainable. Thus the resource of critical theory that emphasizes pedagogy and communication remains the invaluable tool for self-emancipation and social change. In this wise it will be important to articulate the core political and policy elements whose changes will positively invigorate existential changes to be aggressively pursued through the social medial.

# CHAPTER FOUR: RESEARCH DESIGN AND METHODOLOGY

This research combined the descriptive and hermeneutic phenomenological approach to data collection and analysis. Generally, the phenomenological approach attempts to generate a data of 5 - 25 participants in a research study for interpretative analysis. This research used a total ample size of enrolled 22 individual subjects (hereafter referred as 19 family participants) for both the main focused groups as well as the comparative verification group. The sampling comprised married and single parents of autistic children made up of 14 single parents and 5 married couples.

**Sample 1:** This sample population was single parents currently caring for at least one autistic child. This population of subjects was accessed from Montefiore Medical Center (MMC) records of all those currently caring for autistic children. These research participants were accessed from their record of receiving outpatient treatment for their autistic child in the MMC facilities through authorized medical personnel offering medical care. Participants equally enrolled through referrals from their pediatricians at the MMC facilities.

**Sample 2:** This sample group consists of married couples caring for at least one autistic child. This group of individual subjects served as a qualitative verification group for the hypothesis of the impact of autism on single parenthood. Once more, the group was accessed from the MMC outpatient record of visits to the facility for medical care for an autistic child through the assistance of authorized medical personnel. Additionally, some of the subjects came through referrals from their pediatricians or other participants.

Summarily, **Sample 1** consists of single parents between ages 27-52 years with at least one autistic child. **Sample 2** consists of married couples of the same age range above caring for at least one autistic child used as a comparative analytical group.

The participants enrolled based on the following criteria:

- Interested participant must be 18 and above and able to either receive or refuse consent.
- An interested Single parent must have at least an autistic child.
- Married couples with at least an autistic child.
- I considered demographics and educational background only for perspective variation analysis but not for enrollment qualification.
- Single parents may either be female or male individuals caring for at least an autistic child. Please note the condition of being single either by choice or through divorce was relevant but not a prerequisite. The reason for divorce will however be an important variable for consideration in data analysis.

## **4.1: Participant Recruitment Process**

We adopted two strategies for recruiting participants in this study. The first process was using direct contact with families through gatekeepers at MMC outpatient administration (Pediatricians). The second process was through printed flyers posted and distributed in public places within and outside of the MMC premises. The preference for this study was the utility of direct contact with individual families for interviewing through physician referral. Group interviewing was not entertained in order to enable sincere and honest responses as much as possible. Given the unavoidable utility of gatekeepers to secure volunteer subjects, efforts were made to minimize their influence on the participants. Participants had the opportunity to own their voice and unique identity both in their consents to participate and in responses given at interviews. Additionally, individual participants had the objectives and focus full explained to them prior to obtaining their signature for the consent form. There was room for questioning and detail clarifications of concepts not understood by the participants both prior to signing the consent and during the interviewing process. Participants were duly informed that they are at liberty to discontinue or withdraw their consent at any point if they so desire. Finally, participation in the research was only open to adults of 18 years and above who are psychologically able to give and reject consent. It suffices to note that participants were free to opt out of the research at any time without any liability. This information reflected in the informed consent document signed by each participant before the commencement of the interviewing sessions.

Through phenomenological interviews and direct observation of participants' experiences of autism in their life, I evolved an interpretation that compared the experience of participants' shared experience in union with my personal observation. In order to have a more comprehensive knowledge of the phenomenon of autism and single parenthood, it was my research plan to interview and observe families of married couples living together with an autistic child as a comparative reference point of assessment or validation of my analysis pack. My objective was to correlate the experience of participants with the view to understand how autism affects the experience of single parenthood and how single parenthood inversely affects the life of autistic children. From this angle, therefore, we could then assess the unique arena of conflict and crisis possibilities in the experience of single parent participants. The data collected will

describe and inform interpretation of the experience of the participants as a meaning making process.

# 4.2: Phenomenological Research Methodology and Procedures for Investigating Autism and Single Parenthood

Phenomenology and phenomenological research method evolved from the work of Edmund Husserl in the twilight of the 20<sup>th</sup> century. Husserl's method categorized as a transcendental philosophical method vested in understanding the qualities of consciousness (Giorgi, 2012; Mohr, 2012; Kumar, 2012; Stone, 2009; Wertz, 2005; Lopez & Willis, 2004; LeVasseur, 2003; Geanellos, 1998). In other words, phenomenology is the science of understanding the condition of being and the art of human experience of a given phenomenon. It is an understanding of the phenomenon from the subject's perspective of experience (Papadimitriou, 2012; Willig, 2007; Kumar, 2012, & Kvale 1996, p.52). Husserl (1970) in "Logical Investigation" defined phenomenology as "the science of essence of consciousness" aimed at excavating the core meaning of human experience. We could summarize that

... Phenomenology is interested in the activities of consciousness and the objects that present themselves to consciousness. Husserl realized the essential rationality of consciousness, that is, consciousness is a medium between a person and the world. Husserl, based upon the teachings of his professor, Brentano, elaborated the notion of intentionality, which is a characteristic of many acts of consciousness, and it means that certain acts of consciousness are intrinsically directed towards objects and the objects may be transcendent to the acts or immanent to them. In either case, an object is correlated with an act of

consciousness and it can be examined in relation to the act with which it is correlated (Giorgi, 2012, p.9).

The central phenomena demanding understanding of its quality of consciousness in this particular study are autism and single parenthood. Autism defined as a shared phenomenon whose impact cuts across cultural boundaries and social economic status. Just as autism is a shared experience by people of all races, cultures, and religion, the phenomenon of single parenthood is also universal. Individuals may have experienced the presence of an autistic child or children in their families, but there is no gainsaying that certain conditions in life like being a single parent may necessarily presents a unique level of experience of life and its possibilities. It is in the light of this that this research explored the phenomenon of autism in relation to single parenthood in order to understand how single parenthood is impacted by the presence of an autistic child and how inversely autism is impacted by the presence of single parent. The underlying focus is to investigate what role autism plays in a single parent's experience of elevated stress that could lead to possible distress or acquired resilient conflict management skills. The data collected created a posteriori knowledge needed for interpretation and description of experience of participants about the phenomenon. The steps for collecting data and analysis were as follows:

(i) Design research instruments – interviewing questions: The research adopted the various steps in phenomenological research. The interviewing questions, therefore, tailored to tease out the emotional and resilient challenges that single parents embody in caring for autistic children. (ii) Identify suitable participants for the study: Participants recruited with flyers that provided synopsis and qualification criteria for voluntary participation in the research. Moreover, participants for the most part, recruited through direct contact from the Montefiore Medical Center records of families requesting treatments for autistic children. A mailing containing a research flyer and information went out to families on outpatient record from the Montefiore Medical Center. Those that called for a follow up enlisted for participation.

(iii) Pre-interviewing session: Upon successful recruitment of volunteer participants for the research, a pre-interviewing session for individual volunteering participants held to provide an in-depth explanation of the objectives of the research. Participants had the opportunity to ask questions and seek clarification and details about the research. This process was important in order to secure well informed consent from participants.

(iv) Data Collection: Data collection was conducted through administration of interview questions to individual participants. Upon the signing of the informed consent, volunteering participants often opted for interview session(s) concurrently. The minimum estimated time allocated for the interviews was 45 minutes. The least time spent with families was 30 minutes. Some of the interviewing sessions lasted 2 hours.

(v) Collation, transcription, and analysis of collected data for phenomenological interpretation: Participants were given the choice to see the transcripts and analysis before final submission to the Department of Conflict Analysis and Resolution at Nova Southeastern University. The goal of sharing the transcript with the participant is to ensure accurate representation of the information shared by each participant. Additionally, coded audiotape utilized throughout the interviewing process with the consent of the participants. Majority of the participants consented except for one participant who opted not to be audio taped and respected.

Creswell (2007) observed that one of the major steps that a researcher needed to undertake in conducting a phenomenological research is to determine whether the research interest fits the phenomenological system of inquiry. For Creswell such phenomenon that cuts across the experience of several individual is suitable for phenomenological research approach (p.60). The phenomenon of autism and single parenthood is pervasive and fits into the category of the experience of several individuals. Thus the phenomenon is adjudged to be worthy of phenomenological study. Willis (2007) contends, "Phenomenology focused on the subjectivity and relativity of reality, continually pointing out the need to understand how humans view themselves and the world around them" (Creswell, 2007, p.53; Also, Kumar, 2012, p.791; Giorgi, 2012, p.10; & Stone, 2009). The subjective but generalizable experience of reality in autism and single parenthood experience creates the curiosity for better understanding. Undertaking this perspective of analytical research exploration firmly agrees with what Kvale (1996) describes as the core philosophy of phenomenology. For this author,

Phenomenology is interested in elucidating both that which appears and the manner in which it appears. It studies the subjects' perspectives of their world attempts to describe in detail the content and structure of the subjects' consciousness, to grasp the qualitative diversity of their experiences and to

explicate their essential meanings (p.53).

The Encyclopedia of Phenomenology (Embree, 1997) identified seven different perspectives of phenomenology. This includes: (a) the descriptive (Transcendental constitutive) phenomenology. This branch of phenomenology is concerned with the constitution of object in their pure transcendental consciousness, setting aside questions of any relationship of the phenomenon to the world in which one lives. (b) Naturalistic constitutive phenomenology: This branch of phenomenology focuses on entities of the investigative qualities of the how of consciousness. In order words, it probes for how consciousness constitutes things in the world of nature, assuming that consciousness is part of nature. (c) Existential phenomenology: This frame has to do with understanding concrete human existence with its associative issues of free choice or action in life situations forms the core interest of this branch of phenomenology. (d) Generative historicist phenomenology is concern with how meaning as found in human experience is generated from a collective human experience over a period. (e) Genetic phenomenology focuses on the genesis of meaning of things within individual experience. (f) Hermeneutic (interpretive) phenomenology is broadly concerned with the interpretations of the structures of experiences and interpretations. It strategically focuses on how things acquire understanding and interpretation by people who live through these experiences. The understanding and the interpretation of those who study these lived experiences remain equally central to hermeneutic phenomenology. (g) Realistic phenomenology: This phenomenological reasoning bothers itself with the structures of consciousness and intentionality, assuming they occur in a world that is largely external to consciousness

rather than brought into consciousness (Encyclopedia of Phenomenology, Embree, 1997. In Kuma, 2012, Pp. 791-792; Wojnar & Swanson, 2007, Pp. 172-173).

The Descriptive and hermeneutic phenomenology will for the most part shape and guide this research analysis. These types of phenomenology remain suitable for this investigation of the conception of autism and single parenthood because they zeroed on understanding and interpretation of meanings of phenomena. Secondly, the focus of this research is to describe and present a transformational interpretation of the phenomena of autism and single parenthood. The transformational dimension represents the social action about the phenomena from a conflict analysis and resolution modicum of theory research different from a psycho-clinical perspective.

#### 4.3: The Descriptive Phenomenology

The Encyclopedia Britannica (EB, 2012) explained that, "the objects of phenomenology are 'absolute data grasped in pure, immanent intuition,' and its goal is to discover the essential structures of acts (*noesis*) and the objective entities that correspond to them (*noema*)." Edmund Husserl's central project in phenomenology was to represent the human consciousness as pure as possible. His "central insight was that consciousness was the condition of all human experience. He sought to explain how to overcome personal biases, which stand in the way of achieving the state of pure consciousness. His insights launched a new philosophy and a new approach to scientific inquiry" (Moran, 2000, In Wojnar & Swanson, 2007, p.173). For Husserl, the 'theme of phenomenology is not much as the phenomena as it is "the manner in which knowledge of the world comes about" (EB, 2012).' Thus, a priori knowledge of the phenomena must be in bracket in

favor of the *aposteriori* knowledge of the subject of investigation. This process constitutes reductionism or the bracketing method. Husserl noted that the bracketing process makes it possible to "gain insight into common features of any lived experience. [Husserl] referred to these features as universal essences or eidetic structures and considered them to represent the true nature of the phenomenon under investigation (Deutscher, 2001; Giorgi, 2000a; Lopez & Willis, 2004; Luft, 2003)" (Kumar, 2012, p.174). Descriptive phenomenology therefore employs the bracketing method to suspend the bias of the researcher in order to present the raw data of experience from research participants (Giorgi, 2012; Wertz, 2005). This method emphasizes the importance of direct interaction between the researcher and the object of study while setting aside preconceptions, but attempting to promote neutrality and openness to the reality of others (Wojnar & Swanson, 2007, p.174).

The endpoint of descriptive phenomenological investigation is to present a theoretical model representing the essential structures of phenomenon under study (Colaizzi, 1978). Swanson- Kauffman and Schonwald (1988) referred to such model as a "universal skeleton that can be filled in with the rich story of each informant" (p. 104). Consistent with the Husserlian tradition, if the true structure of the phenomenon is identified, then anyone who has experienced the phenomenon should be able to identify his or her own experience in the proposed description (Kumar, 2012, p.798).

The tapestry of the descriptive phenomenological model presents that unique method for making available the experience of single parents and married couples' experience of the phenomena of autism devoid of personal bias and preconceptions. My personal bias for this research is that autism negatively impacts single parenthood. My a priori supposition is that the crisis of aloneness of hopelessness and helplessness in dealing with autistic children by single parents creates mutual crisis level environment for both the autistic child and the mother. However, with the tools of bracketing in descriptive phenomenology, this bias is kept in abeyance in order to present the lived experience as described by participants that may represent the universal structure of description of the phenomenon. The descriptive method therefore will shape the presentation of the findings while analytical discussions shaped by hermeneutical phenomenology. This process creatively engaged while ensuring the validity of the data collected through structured interviewing (Chan, Fung, & Chien, 2013).

#### 4.4: Hermeneutical Phenomenology

Martin Heidegger (1889-1976), a student of Edmund Husserl evolved hermeneutical phenomenology in an attempt to respond to pervasive questions of the meaning of being. Heidegger summarized his analysis by providing some ontological analysis to the "Greek concepts of *phainomenon* and logos. *Phainomenon* is "that which shows itself from itself," but together with the concept of logos it means "to let that which shows itself be seen from itself in the very way in which it shows itself from itself" (EB, 2012). Heidegger believed that human beings are meaning making beings, a product of their free choice, interpretative in the engagement with the world, and ultimately finds significance and meanings in the lived experience. The difference between the Husserlian descriptive phenomenology and Heideggerian hermeneutical phenomenology lies in their perception of the role of context for the knower as well as the role of the researcher's opinion and prior knowledge of the phenomenon (Simspson, 2007). In Husserl's descriptive phenomenology context is insignificant to the subject while in the Heideggerian hermeneutical phenomenology context is pivotal because for Heidegger human experience cannot be isolated from their cultural and broader socio-political environment in which they live (Wojnar & Swanson, 2007; Simpson, 2007). "The goal of hermeneutic inquiry is to identify the participants' meanings from the blend of the researcher's understandings of the phenomenon, participant-generated information, and data obtained from other relevant sources" (Kumar, 2012, p.799).

Through the theoretical resources of hermeneutical phenomenology, shared commonalities and meanings generated from the lived experience of parents of autistic children will analytically thematized in the research analysis. The lens of hermeneutics provides opportunity for looking at the participants' meaning from the point of view of various theories of knowledge that will further illuminate the understanding of the interpretations participant accord to their experience of caring for an autistic child. While the presentation of the findings will follow the descriptive phenomenological method, the hermeneutical phenomenological perspective will apply to the data discussion process. This choice is apt to the method especially when we consider Heidegger's categorization of the "interpretative process as circular, moving back-and-forth between the whole and its parts, and between the investigator's fore structure of the understanding and what was learned through the investigation" (Wojnar & Swanson, 2007, p.175).

#### **4.5: Data Collection Process and Methods**

Data collection in phenomenological research is a process of interviewing to collect information from individuals that have experienced or is experiencing the phenomenon under study (Haahr, et al. 2012; Kvale & Brinkmann 2009; Stone, 2009, Kvale, 1996). In this case, I developed open-ended interviewing questions that will stimulate participants' discussion of their viewed experience of autism and how they are experiencing the phenomenon of autism as either a single parent or married couple. Creswell recommends multiple interviews of participants and documented through journal, arts, music, and other crafted method that the researcher is comfortable. An average of 5-25 individuals is recommended for a sustainable and credible phenomenological research (p.61). According to Saunders (1982), a phenomenological researcher needs to have the rule of thumb that "more subjects do not yield more information. Quantity should not be confused with quality. The phenomenologist must learn to engage in in-depth probing of a limited number of individuals" (Saunders, 1982, p.356; Wertz, 2007) to yield the utmost result that explores and unearth the fact of the experience of the phenomenon under study. In this caveat therefore, my data collection for autism tailored to capture the experience and emotive connections that parents of autistic children have with the phenomenon of autism in their natural habitat. 99% of the interviews were conducted in the home of parents with the autistic children actually present. A total number of 19 families enlisted and interviewed between September 2013 and June 2014. The following table shows the constitution of the research participants.

<u>Participant #</u>	<u>Marital</u> <u>Status</u>	Race	Age	<u>Age of</u> <u>child</u>	<u>Economic</u> <u>status</u>	<u>Education</u>
BRIANA	Married	Hispanic	34	13	Dad employed	Dad/Mom High school
JUDITH	Married	Hispanic	35	3	Unemployed	High School
SADITH	Married	Hispanic	45	15		
DORA	Married	Caucasian	47	15	Employed	Bachelor's Degree
SHAKIRA	Married	Hispanic	34	19	Mom- unemployed	Some High School
JOSEPHINE	Never married	African American	41	10	Unemployed	High School
SARAH	Never married	African American	49	18	Employed	Higher Education
SOPHIA	Never married	Hispanic	37	9	Unemployed	GED
SERAFINA	Divorced	Hispanic	?	15	Employed	High School
DOROTHY	Remarried	Caucasian	46	13		
RUTH	Never married	Caucasian	32	5	Employed	High School
DEBORA	Never married	Caucasian	36	5	Employed	Bachelor's Degree
ZERA	Never married	African American	51	9		
ESTHER	Never married	African American	38	8	Unemployed	Graduate Degree
PERETA	Wants divorce	Hispanic	46	7	Unemployed	Bachelor's Degree
EILEEN	Never married	Hispanic	45	6		
REBECCA	Never married	African American	?	9	Employed	Bachelor's Degree
RHODA	Caregiver	African American	?	5	Unemployed	Some High School
ELIZABETH	Never Married	Hispanic	27	4	Unemployed	Junior High Sch.

Figure 2: Participant Demographics

An important feature that began to surface in the data collection process was the special percentage dynamics of how participants were describing their status that is quite relevant to how the data shaped itself. The chat below therefore demonstrates the percentage of improbable way participants chose to define their sense of identity or marital status and how this may factor into data coding and analysis.

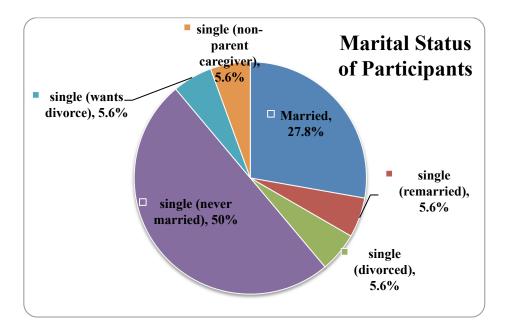


Figure 3: Breakdown of participants by marital status

It suffices to note that the selection of participants primarily based on two main criteria namely: (1) Participants must be 18years and above. (2) A Volunteering Participant must be caring for at least one or more autistic children at home. The racial dynamics that came into play was pure accidental and not predetermined in recruiting process. The chart below shows the percentage breakdown of participants by race:

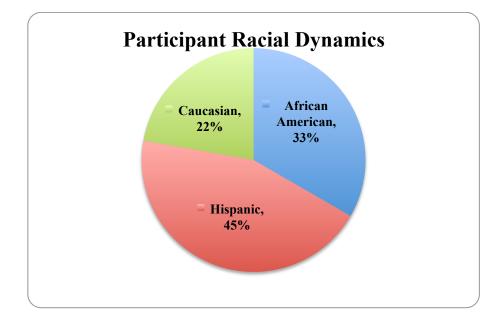


Figure 4: Breakdown of participants by race

Another variable dynamic that became visible was the economic and educational levels of the participants but these were not predetermined as criteria for enrolling participants for the study. These features all however add up to shape the quality of the research data collected. The key source of data for analysis in this phenomenological research is from structured audiotaped interviews (Bevan, 2014).

Campbell (2011)indicated there essential questions that two are phenomenological question builds upon in the process of collecting data from participants through interviewing. In the context of conflict and crisis in autism and single parenthood, we could frame the questions as follows: i.) What have you experience in term of autism as a single parent or as family? The framing of this question is dependent on the state of the individual interviewed. ii.) what context or situation have typically influenced or affected your experience of autism? (Campbell 2011, p.5) The operating phenomenon in this research is autism. Questions design tailored around understanding the participants' frame of reference regarding this phenomenon. Examples of such questions will be i.) Describe how Autism has impacted your life. ii.) What meanings or lessons will you classify with your experience of autism? What will you say have significantly influenced meanings that you are ascribing to your experience of autism? The essence of these questions is to enable a thorough understanding of the phenomenon of autism in the context of the participant has lived experience either as a single parent or married couple (see Bevan, 2014).

One great point to bear in mind in conducting this research is textual and structural framework. The textual questions will build on what the experience under investigation is. The structural will focus on how that significant experience was actually experience by the participants. Such tailored question into these categories of questioning will enable a framework of organization of interest for data that will ground the description of the concept of conflict and crisis in autism and single parenthood. For this research intent of eliciting structured meanings and coherence in the validity of the data, structured questions were generated and subsequently approved; by the Institutional review boards of Montefiore Medical Center (research Site) and the Nova Southeastern University by the beginning of the interviewing process. See below in figures 5.1 and 5.2, the graphical description of how the various analyzed model of investigative questions reflects in the question design (figure 5.1) and operationalize in the actual interviewing process.

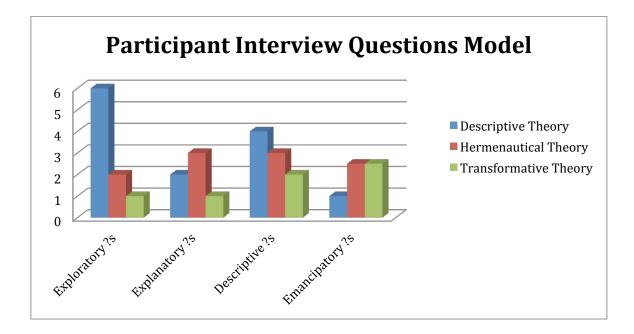


Figure 5.1: A graphical model of participant interviewing questions design.



Focus / Central question: What is the impact of autism on single parenthood?

# 1. Exploratory questions (Expanding knowledge of phenomenon)

- i. Describe for me what it is like to be a single parent.
- ii. How will you describe autism and a child with autism
- iii. How does the presence of an autistic child define your life as a single parent?

# 2. Explanatory questions (Experiential patterns)

- i. Could you please share your personal experience of raising/caring for an autistic child as a single parent with me?
- ii. What will you categorize as your greatest challenge and point of unresolved pain as a single parent of autistic child?
  - **3.** Descriptive questions (Account of experience)

i.	Describe for me the various ways you think the community (family, church, social services, and friends) have been of help to you in caring for an autistic child		
ii.	What do you perceive as some of the lapses in those support systems if any?		
iii.	Describe for me some of your career shift and economic challenges as a result of having an autistic child		
	4. Emancipatory questions (Social action about phenomenon)		
i.	Please describe for me what have been the source(s) of your strength and skill in living with and raising an autistic child.		
ii	What will you see change for single parents of autistic children?		

Figure 5 above attempts to demonstrate efficient method adopted that allows the descriptive, hermeneutical phenomenology, and conflict transformative theory to shape the data collection process (King, Keohane, & Verba, 1994, Pp.28-29; Willig, 2007; Paul Ricoeur, In Bevan 2014). This creative typology will not only bring out the description of the phenomenon of autism and single parenthood but also it will vivify how single parents and married couples interpret the impacts autism have on their lived experience (Brady & Collier, 2004). The four models of question design (Exploratory, Explanatory, descriptive, and emancipatory) is an imperative break down of the textual and structural method of a phenomenological investigative design that teases out the depth of knowledge of the phenomena under study (Murdoch, & Franck, 2012; Campbell, 2011). The exploratory questions allow the participants to give their first person account of the knowledge of the phenomena of autism and single parenthood the explanatory explores the experiential patterns. The descriptive questions give an opportunity for the participants to provide a hermeneutics of their experience of how autism actually impacts

their lived experience within the wider spectrum of the society. Meltzoff (2006) indicated for a descriptive research to enjoy some measures of validity, the researcher has the onerous task of analytically presenting what a subclass of the phenomenon being described have in common and what makes them distinctive from the rest of the group (p.84). This perspective therefore provides a justification for a hermeneutical nuance to both the mode of raising questions and presentations. The emancipatory provides an opportunity to know about the transformative and resilient conflict management of living with and caring for an autistic child. This adopted phenomenological method provides an opportunity for understanding the wider spectrum of knowledge about the association of the phenomena of autism and single parenthood (Chan, Fun, & Chien, 2013; Rapport & Wainwright, 2006).

# 4.6: Phenomenological Data Analysis

Phenomenological data analysis involves some sets of methodological framework vested in the utility of resources from interviewing exercise. It does this by comparing the common thematic threads between participants (Bolling, 2012). Campbell (2011) indicates two substantive elements utilized as a guiding post for data analysis in phenomenological research. These guideposts are "horizonalization, which is an attempt to understand participant's experience and Clusters of meaning that includes unification of interpretations into themes" (Campbell 2011, p.6 & Creswell 2007, p.61). Horizonalization crystallizes the notion of taking certain lead-on and pointed statements from the participants that could possibly afford a window of understanding of the participant's experience of the phenomenon like autism. Such statements may include expression of anxiety, fears, depressive situation, happy moments, and other similar

statements that depicts the participant's deep level of a personal meaning-making journey with the phenomenon of autism. Clusters of meaning utilizes in the context of a phenomenological research as that system through which the researcher sectionalizes certain interpretative words on the participant's experience that he or she conceptualized as pain, anxiety laden, frustration or happy moments. It is my opinion that such similar interpretative words from chosen 19 participants for this research will group into themes that either gives credence to a common experience by the group or differentiates one or two members of the research participants from the rest of the group's interpretative experience (Meltzoff, 2006, p.84).

Dale (1996) in Bolling (2012) outlined the significance of qualitative research compared to experimental research. For Dale whereas qualitative research is able to tap on issues of emotions and other experiential issues to provide a rich tapestry of knowledge about a phenomenon, experimental research is bugged with issues of cause and effect that will not look into the deeper meaning of the phenomenon (p.1969). The object and focus of phenomenological research is to understand the conscious experience of a subject about phenomena (Cohen, Manion, & Morrison, 2007) and these include the emotional connection with the phenomenon. Data analysis in phenomenological research therefore is a unifying descriptive account of the total experience of the research participants about the phenomena under study. In this case, we analyze on all associative variables linking the experience of autism and single parenthood. This unification of the descriptive account is in two perspectives. For example, account on what the participants experienced about autism either as a single parent or as married couple. This account description will be the comparative analysis of the phenomenon of autism in single parenthood situation and married couple context. This information deduces from the audiotaped data of structured and open-ended interview transcribed and coded for textual and structural analysis (see Hosseini & Abdi, 2012).

Furthermore, Moustakas (1994) identified two methods of phenomenological analysis namely the Van Kaam and Stevick-Colaizzi-Keen process. The Van Kaam method consists of seven stages of analysis, (a) listing and preliminary grouping: This involves listing every expression relevant to the experience (Horizonalization). (b) Reduction and Elimination to determine the Invariant Constitution: This process will including testing each expression for two requirements. In doing this, two questions are paramount: (i) Does it contain a moment of experience that is a necessary and sufficient constituent for understanding the phenomena. (ii) Is it possible to abstract and label it? If so, it is a horizon of the experience. Expressions not meeting the above requirements are eliminated. While preserving exact descriptive terms, overlapping, repetitive and vague expressions are deleted. The horizons that remain are the invariant constituents of the experience. (c) Clustering and thermatizing the invariant constituents. (D) Final identification of the invariant constituents and themes by application and validation. (e) Using the relevant, validated invariant constituents and theme, we construct for each coresearcher an individual textual description of the experience. (f) Construct for each coresearcher an individual structural description of the experience. (g) Construct for each research participant a textural-structural description of the meanings and essences of the essence of the experience, incorporating the invariant constituents and themes (Moustakas, 1994, Pp.40-41).

This method concludes with a unification of descriptive analysis of the entire textural-structural texts. The second method is the Stevick-Colaizzi-Keen process. The difference that this method presents resonates from the account of the researcher's knowledge about the phenomena through the textural and structural descriptive analysis of the participant's account using the various phenomenological core normative processes (see Bevan, 2014, p.137; Moustakas, 1994, p. 42; Hosseini & Abdi, 2012). One point to bear in mind in selection of these methods is the styled that the researcher so chose to adopt bearing in mind that phenomenological analysis is a cognitive process that is less of a dogmatic practice. The focus of the method is the production of true understanding of the phenomenon under study (Wojnar & Swanson, 2007 p. 175; Jonas-Simpson et al. 20011). Moreover, the choice of the right methodological approach vastly depends on the research question and the philosophy grinding the researcher's beliefs on the phenomenon. The question on the impact of autism on single parenthood therefore has the knack for understanding both the essence of the lived experience cum a universal meaning of the phenomena of autism and single parenthood and the context for that lived experience (Simpson, 2007). This explains the choice for a combination of both descriptive and hermeneutical analysis.

While the Van Kaam method utilized as much as possible, a further step was adopted to strengthen the accuracy of the coding process. The Qualitative Data Analysis Program Lab (QDAP) (Coding Analysis Toolkit) from the University Center for Social Science and Urban Research at the University of Pittsburgh and QDAP-UMASS in the College of Social and Behavioral Science at the University of Massachusetts, Amherst came handy (http://cat.ucsur.pitt.edu/default.aspx?ReturnUrl=%2fapp%2fmain.aspx; Burnett, 2009, Pp. 190-199). Essentially, the focus is to present a descriptive account of the phenomena of autism and single parenthood from the lived descriptive experience of the participant through the analytical steps adopted. According to Creswell, researchers could also input their own personal experience of the phenomenon under study. In conducting this research, I will be keen at describing my experience of the participants' manifested emotions in sharing their experience, tone of voice and other non-verbal communication that either resonates with my bias or refutes my assumptions about single parenthood and autism. The transformative analysis will be provided as a concluding part of the data analysis.

## 4.7: Ethical Considerations

Booth, Colomb, & Williams (2008) indicated that research is a "social activity with ethical implications" overlapping issues of honesty, integrity, and justice especially in fair representation of the voice of the research participants in the final document. This consideration guided the process of this research. The two institutions that were directly involved with the research process granted the approval for this research. These institutions included the Montefiore Medical Center Bronx, New York (MMC) serving as the research site and the Nova Southeastern University (NSU) being the principal institution approving the research. MMC is the teaching hospital for The Albert Einstein College of Medicine. Working and conducting a research in a University health institution presented a unique ethical requirement as it pertains to the Health Insurance Portability and Accountability Act of 1996. Specially, the ethical concerns were privacy and the confidentiality of individually identifiable health rule information (www.hhs.gov/ocr/privacy/hipaa). These ethical requirements guaranteed and approved by the Montefiore/Einstein Institutional Review Board (IRB) prior to approval by the Nova Southeastern University IRB at the commencement of the research. These approvals opened the door for selecting and working with identified participants from the outpatient records in MMC.

The choice and selection of research participants often times brings the researcher to working with gatekeepers. Miller and Bell (2008) discussed the complex roles gatekeepers could play in paving the way for researchers to access their research participants for either interviewing or focus group meetings. Some of the dilemma outlined includes the role of power and contending roles of influence over the freedom of participants in their responses and active participation especially when it concerns male gatekeepers versus female participants. The utility of gatekeepers in this research came by way of referral from attending physicians as the MMC policy designed allowed. For the most part participants accessed directly by the research team. Additionally, prior to each interviewing sessions, consent forms pre-approved by participating institutions (NSU & MMC) were discussed and signed by participants. One major aspect that gatekeepers utilized was for language barrier. Some of the participants were Spanish speaking only subjects. Addressing this need, we translated consent and information documents into Spanish language and trained research assistants with bi-lingua ability enlisted into the research staff team with various IRB approvals.

Other ethical considerations include confidentiality, risk, and benefits ratio regarding the research. I did recognize the fact that potential harm could occur if the participant's identity is revealed from the interviewing records. To avoid this confidentiality issue, we undertook procedural designed to secure and protect the identity of participants to prevent potential harm. The following are the procedures used to insure confidentiality:

- Actual names not used for purposes of data analysis or for any aspect of the final research report or any derivative publications that linked to the participant's identity.
- All electronic data saved in a password-protected computer accessible only by the researcher.
- > All hardcopy information saved in a locked cabinet in the PI's office.
- With the exception of the informed consent form, all direct links to identifiers removed for purposes of data analysis or for any aspect of the final published research report or any derivative publications. This will be kept for three years following the completion of research, as the law requires.
- The participants were all informed that their signed information were going to be kept for three years after the completion of the study. On a general note, the anticipated risk is fleeting, low magnitude and very minimal compared to potential benefits.

Finally, Kvale and Brinkmann (2009) in discussing ethics in interviewing analyzed on seven key points on research stages that requires ethical considerations. These include (a) thematizing: understating research as more than knowledge production but a science designed to improve human condition above all. (b) Designing: respecting consent and confidentiality of research participants. (c) Interview situation: morality in research as recognizing the mutual vulnerability of the interviewing situation between the researcher and the participant. (d) Transcription: Being true to the confidentiality agreement and loyal to the interviewee's oral statement in final reports. (e) Analysis: respecting the intent and needs of the participants on how their statements are represented or interpreted in the final analysis. (f) Verification: the research has the onerous task of ensuring presenting a knowledge that is as secured and verified as possible. (g) Reporting this again emphasized the need to respect privacy and confidentiality of the research participants in presenting research documents for public consumption (Kvale & Brinkmann, 2009, p.63). These salient points made represents the modicum of thought intensively processed in engaging the production of this research contributions to knowledge for the upliftment of the condition of life of single parents caring for autistic children.

#### 4.8: Limitation of Study

This research does not pretend to serve either as psychological or clinical purpose. It is rather a social scientific analytical research whose object is to present through a phenomenological interviewing a descriptive and hermeneutical analysis of the lived experience of single parents of autistic children. Therefore, it is limited to qualitative analytical presentation of researched ideas. It is an attempt to open a new way of looking at autism for further research discussion for possible policy resolve. Moreover, the focus is to look at how the field of conflict analysis and resolution could contribute to the art of living with autism. Nevertheless, it does not pretend to answer all the questions there are currently in the field but it is intended to stimulate further research and discussion in the way single parents dealing with autistic children see themselves and the world with or without autism. The analytical report of this research is strictly based on the transcript from the interviewing with the selected nineteen participants in this research process. Lastly, the generalizable information for this research is sole based on information provided by the research participants from enlisted from the outpatients departments at MMC, Bronx New York. While this segment of the population might not represent all there is about the experience of single parents and autism, its objective is to stimulate further research and discussion on the subject of autism and single parenthood for policy realignments.

#### Conclusion

Burton, Lethbridge, and Phipps (2008) argued that it is nearly impossible to fully articulate the health of individuals without equally appreciating the environment that could have played or been playing a significant role in shaping the sum total of the outcome of that individual (p.360). If this argument is anything to hold on to, then McAdams and Pals (2006) contention that various factions of environment and culture factors into individual's identity construction may be applicable to the possible conflict and crisis that single parents entertain in dealing with autistic children. The tenacity of this claim informs my personal bias in going into this research on "conflict and crisis in autism and single parenthood." The focus of this research is what informed the phenomenological method chosen as the right methodological procedure for conducting this research. It is my hope that the research on the phenomenon of autism and single parenthood will either confirm my initial bias or refute it. However, it is it will definitely create further understanding of the phenomenon. This descriptive understanding will

enable policy developments for creating support system that will forestall possible increased conflict and crisis experience of the impact of autism among single parents. Essentially, the underlying variable of this research is the impact of autism on single parenthood. In order words, how does autism impacts single parenthood? The philosophical strategy for attaining that goal is the utility of the phenomenological methods of transcription of interviewing data and qualitative logical reflexivity.

### CHAPTER FIVE: FINDINGS: THE IMPACT OF AUTISM ON SINGLE PARENTS

A brief note on how the method described in the previous chapter operationalized as regards to reporting the findings of the research. This has become relevant given the fact that a qualitative analysis toolkit was used in conjunction with the KAAM method for phenomenological analysis. This begins with horizonalization. Horizonalization: typifies participants' experience and cluster of meaning in unified themes from the research interviewing sessions. In order to appreciate the thematic design for the presentation of the findings, a coding process was generated. Using the Coding Analysis toolkit the interviewing data was grouped into Family (representing Married Couples) and Single parents that were then uploaded to the coding scheme toolkit (See Lu, & Shuman, 2008; Carley, 1998). Following the Kaam method, I selected appropriate codes that best clustered the unit of the phenomenon's experiential analysis and engaged a process of reduction and elimination using the Coding Analysis Scheme Toolkit (Lu, & Shuman, 2008). The codes reflect the invariant constituent labels that group the core themes of the experience (Moustakas, 1994; Carley, 1993). The themes include: 1.) The Daily impact of Caring Burden, 2.) Gaps in the Support System for Parents of Autistic children 3.) The Crisis experience of Dealing with Autism in a Child 4.) Resilience and efficiency model in managing non-compliant behavior 5.) The perennial fear for the future of the autistic child: Fears of the unknown 6.) The Married vs. Single Parent factor in caring for an Autistic Child and 7.) Autistic advocacy in Social and community expectations

Haven identified and validated the themes against the invariant constituents a bar chart was constructed using the coding toolkit for textual description of the experience. The bar chart was based on the clustered codes (See figure 6 below). A total number of 20 codes were used. 1.) Autism and Single Parent experience: This denotes the specific experience that is relative to the experience of single parents with autism. 2.) Community intervention referring to various ways participants got assistance from medical diagnostic interventions to extended family network assistance. 3.) Economic and Career related to financial condition and employment status as it relates to affects from caring for an autistic child. 4.) Family dynamics with Autism captured the nuclear family system relations in the context of the presence of an autistic child with pervasive challenges in the immediate family system. 5.) Gaming and Validation captured the various experience parents used to express attempts to connect, sustained communication, and relationship with their autistic children especially the non-verbal ones. 6.) Married Couple's experience of Autism attempts to represent those essentializing experience that are relative to the dynamics of dealing with autism within a normal family system of both parents actually living together. 7.) Perception of an Autistic Child represents some of the value statements that described how single parents and married couples have come to define an autistic child from their experience.

Others are, 8.) Relative deprivation indicating the curve of attributed human dreams that were missed as an opportunity cost of caring for an autistic child. 9.) Selfefficacy captured unyielding efforts of parents in search of cure and best practice for cure and care. 10.) Social and Behavioral Challenges presents the experience of parents with reference to conflict behaviors of their autistic children either in the public or private cells of their homes. 11.) Community Perception of Autism attempt to capture parents' experience of community reception of and treatment of autistic children and their parents in the wider spectrum of the society. 12.) Dreams about autism attempted to generate information on the wishful thinking about a world with or without autism. 13.) Emotional and Social alienation represented how parents describe their personal pains, loss of social interaction with the rest of the world as they did before and after the birth of a child with autism. 14.) Fears about an autistic child captured the various emotions and worries expressed about the future of their autistic children that represented for the most part their mental crisis stressors or an unresolved challenge. 15.) Lapses in the support system describes their perceived gap in the services they currently receive aiding their care for an autistic child. 16.) Married vs. single in autism attempts to describe how each group attributes and compares their experience with autism with reference to their family status. 17.) Policy changes advocacy are the echoes of what participants perceived as what may minimize their often times conflict situation of dealing with autism. 18.) Resilience and conflict management captured various ways parents used to manage the crisis risk factors associated with communication and behavioral conflict with their autistic child. 19.) Shared meaning of autism also captured the unifying ways that every parent interviewed meaningfully or conceptually defined and internalized their life with autism. 20.) Social and conflict attributions generated data on how parents see their present stress and crisis as relatable to the impact of caring for their autistic child. Please note: all names used in describing participants" are not their real names.

#### 5.1: Research Findings

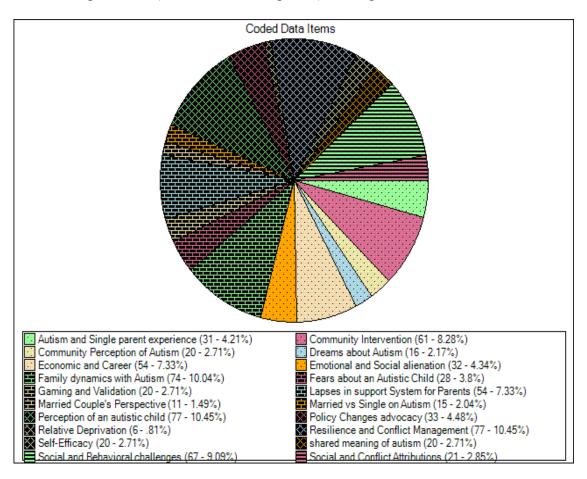
From the research, interviewing investigations conducted between August 2013 and June 2014 with 22 individuals hereafter referred to as19 families participating salient observations generated providing descriptive and hermeneutical themes for consideration towards understanding the impact of autism on single parenthood. The interviewing process zeroed around certain key concepts from the approved interviewing questions (Figure 5.2) conducted in a semi structured dialogical process. The object of the interviewing process maintained to generate sufficient information on how autism and single parents interact. It also focused on how their process of managing crisis and resilience in their ongoing relationship

Participants in this research across board spoke about the challenges of raising an autistic child but emphatically on the fears of the life of an autistic child when they as parents are no longer available to nurture the needs of the child. For example, a parent expressed and described an autistic child as "a lifelong baby." Elizabeth a single mother of one daughter described it as an ambiguous loss of a child. Sophia a married mother with two children expressed this sentiment with deep sigh and emotions this way: "

You know, the greatest challenge is what is going to happen to him when I am not around. That is really the only problem I have with the whole thing (autistic condition). When I am here and capable and able to do it, he is going to be fine. He is going to receive or get what he needs to get. He is going to be loved until I am not here. It is the thought when I am not. And that is the greatest challenge, that no matter what I do he is going to be alone and I cannot fix that. The detail of the interviewing transcripts from individual families interviewed for the most part reinforces previous research findings on the subject of the descriptive impact of autism on single parents and families in general. For instance, Cridland et al. (2014) indicated a family with autism spectrum disorder (ASD) is often fraught with bidirectional and pervasive problems based on the multiple levels of needs and assistance that an autistic family member requires for survival. Schilling et al. (1986) more pointedly affirmed on the significant impact of the presence of an autistic child for a single parent. My research findings for the most part reflect these sentiments while equally demonstrating the positive aspect of autism within the family.

## 5.1.1 Statistical Coded Description of the invariant/Textual experience of the Phenomenon of Autism

Rubin and Rubin (2005) indicated coding of interviewing data for analysis should reflect the pattern that enables the correlation of themes (p.223). Within a phenomenological analysis, the coding system reflects the invariant descriptive pattern that runs through the generated data for understanding. The chart below from the Coding Analysis Toolkit statistically demonstrates the layers of descriptive information on the impact of autism on parents forming their invariant cluster of meanings. Besides, invariant horizon represents "unique quality of experience that stands out during the



interviewing sessions (Moustakas, 1994, p. 128). See figure 6 below.

Figure 6: Coded Data report from Coding Analysis Toolkit: Invariant constituent

From the 19 family participants interviewed only 16 of the data collected uploaded to the software for coding analysis. One eliminated for insufficient data and two of the interviewee could not be included because they were conducted while the coding analysis was already in session. The coding helped to capture in summary the percentage of the salient experience of the phenomenon of autism by participants. Out of the total number of 13 single parents coded about a good number thought autism impacted their lives both negatively and positively (See figure 6 above). Their experience hunted them on conflict questions about their liability as single parents for the disease of their child. These innuendoes often come through judgments from some immediate family members and perceptive stereotyped experience from the community. Beside these attributed stereotypes, they felt trapped with the struggle alone. For example Rebecca s single mother of two captured her experience as follows when asked about her challenges with autism:

Greatest challenge? Hmmm I do not know what to say. I do not know what to say. It never ends. The struggle. Sometimes in life, when you are doing something and your expectations are off, ok maybe in one month I can be able to probably raise money and do this. But with an autistic child, you cannot say that. You cannot, because, it is an ongoing thing. When is it going to end? You ask yourself in the morning you do not even know what to expect. But with other things, you can say, ok, I am going to call in sick today and maybe sleep. But with an autistic child, the day you want to sleep is the day of their tantrum. So it never ends. [this could go on during] morning routine, or during afternoon routine, and at bedtime routine. So you see it never ends. It is not just like today and tomorrow. No! So it is a real struggle. Drained! Emotionally? Ah, I feel like.... emotionally it is a torture. And whom are you going to complain to? Nobody. You got to deal with it.

Another single parent Zera a mother of three described her experience this way:

At the very beginning, it was shameful. It was embarrassing. It was overwhelming. I wish it did not exist. I resisted. I couldn't understand. It was nowhere in my telescope- not culturally, not educationally. It just was not there at the beginning. Also, Sophia a single mother of two corroborated her experience as follows: "it is a lot of work, a lot of tension a lot of responsibilities. My child is 10yrs old. Being a single parent makes it even more complicated because you do not have help and you have to do a lot of things on your own. I have to bathe him, take him to school and help the other child. Some days you are overwhelmed and wondering how much you have to go."

Furthermore, some of the interviewee thought the perception of autism in the community is still evolving and sometimes embarrassing when beholding the various cultural stereotyping labels on both the child and the parent. For example, Zera a single mother of three further described her experience this way:

.... With my mother, it was horrific. She used to say things like, and it was cultural, it really was, "there is nothing wrong with her. You are listening to the Americanos. Just go back to Puerto Rico. And we are going to get that girl cured. You might want to beat her a little bit, give her a nice slap across the face. She can stop that nonsense," *she would say in Spanish*. She was so prideful. She would say, "I don't know why she is like that. It is your fault." And I would say "maybe so." And then I would cry. So the raising was very, very tough. Autism and culture... so much conflict was there. And I think that people of color who have children like ours struggle more than the typical Anglo-Saxon families that have those children, because, genetically, for whatever reason in their research, they seem to have some genetic predisposition somehow. So for a long time, it was just... I had to learn Pavlov, classical conditioning. I taught my daughter and my son how to use the bathroom. It took me six years. I used pictorial, I used

classical conditioning, therapy, and my house looked like an institution with arrows. My kids were always embarrassed; they could not bring friends, because they could not understand why an apartment looked like that. It smelled always like urine or feces. They used to smear the feces because they were so delayed.

Another married coupled family of Sadith with two children observed:

But I think it is very stereotyped. What they do now, they show autistic people on TV, it is stereotyped. My son does not go around going like this (motion). And I really do not like how they present disabled people. I do not like how they represent poor people. I do not like how they represent Latino people on TV. I ... think it is just a stereotype. For Puerto Rican, they always show it as you have to live in the ghetto and you have to be a mechanic, car stealer, car theft or a drug dealer. It is just a stereotype. I try to stay away from that. .... 500 doors get shut to 1 door that is opened. It has always been very difficult to get things. Either he is not too severe enough for the help or he does not qualify because he does not have all 10 of the what they look for in autism, or because he is verbal and before because he was not verbal. It is like they have all these rules to say who can, and cannot be in this thing. And, just like we do not all look alike. I do not believe that any disability not just autism, any disability you can package it in a group. My experiences are not going to be the same as 100 other people who have autistic children.

Furthermore, while about some of those interviewed believed their economic life and career has been negatively affected by the presence of an autistic child in their life, others indicated that their family system structure or dynamics had been greatly defined by their experience of caring for an autistic child (See figure 6 above for statistical representations). In an attempt to navigate the road less travelled with autism, some participants adopted some gaming and validation methods in their efforts at stroking a relationship that will minimize their challenges of putting some of the normative behavioral attitudes of autistic children under control. Out of the five married couples enrolled and interviewed, at least indicated raising a child with autism has either strengthen their bond or taken their marital relationships through rocky paths with some emotional toll. One family described their experience as follows:

It took a while for the father to understand that his son was different. I do not like that word either. But you know, to describe, you know, when he first found out about the autism, it took him longer to get around it. Also, there are not a lot of support groups where there are men. And he hates going to the ones I go to, because he only finds a bunch of women there. But I did find out that autism stresses marriages and a lot of time, the divorce rate with autistic children is higher.

#### What has helped you to stay?

Well, it took a lot. I am not going to say it was perfect. But, umm, we had to work on it, and sometimes, really, marriage is not really the top priority, because everything is around him. Unfortunately, that is how it is. But we have settled into, and have an understanding on it because you get exhausted, and you are just too tired. We have to learn to split things that were commonly, well, I am not saying women's and men's roles, but the cooking and the cleaning- he has to help. So everything is done. And that brought us closer in more areas that before we did not have. So I think that part compensated to what other parts have been diminished to lesser priorities. That is the only way I can describe it *(laughter)*. We prioritize everything. Like I said, there is good times and there are bad times. So in bad times, do not expect me to be more on your need. But then good things come, and our priorities change. We have to put things in priority levels. And it is bad that we have to live like that that is the way it is. We are able to keep ourselves together because of that (Sadith).

Similarly, another married coupled family discussed and described their experience as follow:

Jose (Dad): I am tired. For a child nothing is too much. It is pretty difficult to understand him. He does not know how to express himself. If he needs anything that I am not able to understand, he cries and hurt himself. He is scared of shadows especially at night. If he wants, milk and I give him juice he throws it away. Judith: It frustrates me; I cry and want to fly away. The sister does not understand him and they fight a lot. She fills bothered by him, gets tired and frustrated. The sister who is seven equally wants attention. In the midst, I feel I am losing both ways between him and the older sister. Does it bring tension between parents? Sometimes. Judith: when I get frustrated or nervous, Dad gets upset. It is easier for him as a man. Jose, I pick him up and hug him to calm him down. Judith: But he does not bother him the way he bothers me. Jose: there not much I can do because he goes to her more. Judith: sometimes I get migraine, send him to dad and he send him back to me. There is often tension among the kids about choices with television. When he needs something, he takes you to the room and lays down which means he wants to lie down. He knows what to get from each person anyhow. He has to win a game otherwise, he cries the whole day. If needs something and he cannot find it he cries the whole day, take off his cloth. I do not have privacy with him, even when I am in the bathroom he wants to come. I lost weight because of him (Family #2, See Appendix A).

Another married family of Dora a mother of three with the youngest having autism expressed her experience as follow:

Yes, I am married. Thank god, we stayed together. But they say 85% break up, and I know why.

You know why, Yeah, it is like... we call it like we were in a train wreck. Our entire life was going on this beautiful path and then boom! It was all changed in one diagnosis.... In one diagnosis? Hmmm!

Yeah, and I remember the day Neda (Pseudonym) was diagnosed, I had pulled my husband into one of our bedrooms, and I said, "I want us to make a promise that our other kids lives stay as normal as possible." And that was very important to me and to my husband. And we were very lucky, because we had a lot of people that loved us. And stepped in and made sure that they still went to their activities. Then Neda was still a screaming, crazy mess, so we would always promise if we were ever out and he was causing a scene, that one of us would drop to the floor and say "I have a headache" so that they never blamed him. They blamed us. And that has served us well. That was a good thing we did. But then it just changes, because we put him on a special diet. When my other kids were young... Neda was 17 months, so my next son was 4, my daughter was 6, and they were very young. And they had to really watch what they were eating and make sure... and they had to learn to be aware of him. Because he had no... even when we walked outside, they were very young, but if he would walk into the street... or at that time he was very difficult and screaming and slapping his head and jumping and did not know what danger was. So I would say for those things, it affected them, because they knew that we were a team and we had to protect him. So that was hard. **So what helped you?** 

We stayed together, because... I guess because we are good people and we just knew that we wanted that this was our family. I think we loved each other enough to... try to do whatever we could to keep our family intact. And, you know, I am proud of that. And I know he is too. The early parts of it were very hard though. Because we both were sad, and we both were scared and we both were lashing out when our kids were sleeping I guess. And it was very costly, and I had to close the daycare, so a big part of our income was gone. But we had saved a lot, a lot of money because we were planning to move and buy a house... and we ended up spending every dime of it. So it was hard. And then once my kids stabilize once I went to teach at a school that my kids went to, and my son still had therapy going on here. And so my mom and my father-in-law would come and wait with Neda for the therapist to come. And it was hard. That was a hard... very stressful time. Yeah!

Interestingly, many of those interviewed have evolved an experiential perception of an autistic child that differentiated it from the global current but for the most part endearing to their affectionate view of who and what they have come to vivify in their joint conflicting struggle with the disease. For example, Dora a married mother of three noted, "An autistic child is, like, trapped. Early on, they are in pain, I think. My son was in pain He is just trapped, uncomfortable, and sick... and it is really just unfocused, confused, and scared. That is how I would describe Neda. Later on, as they grow older, they become resolved.... And they are in there, but they just cannot get out.... But they are in there." Sophia a single mother of two described an autistic child "...as endless baby." Serafina a divorced single mother of three described it this way: "The way it was explained to me, it's like their brain is inside of a bottle. But now I see .... Autism is a delay but they do learn but very slow. It is difficult. It takes more time. But at the end, I do know that they understand. I had the desire of wanting to be a mother. I understand that since he knows me, what he did for me, he gave me this child because he knows I would have that maternal instinct to handle it. So to me, it is not any luggage that I am carrying. A child never really grows up- he will always be my child. The others, they will move on, but my son will stay with me. I am lucky! (Laughter)." For Esther a single mother with two children, an autistic child could be described as "a regimented and a predictably hyperactive child that does not get any better with age but different in energy flow whose get nervous with any noise." Dorothy a remarried single mother of three described it as "... a fairy tale...Honestly, I would say that one side would be so shiny and bright, but the other side would be a little cool and dark. Because from my experience with my son, one minute, he can be this so up, up, up but then one-minute he

can be so uh. I mean, there was a point in time, too, that Dibe (*pseudonym*) was so hyper When I found out, I thought that I had failed him somehow, that I did something wrong that he is the way that he is."

From the data analysis also, few of the participants saw their having to care for an autistic child as creating some form of relative deprivation experience in their relationship with either their immediate families or engagement with social relations. For example, a married mother Sadith shared this experience:

Basically, your life is around them. Trips, everything, the minute I wake up in the morning, what we eat- there is certain things he does not like so it is off our menu. It is a routine. Everything has to be explained to him. There is always what if he does not act properly. Special occasions- unfortunately, even with family members. I was not even invited to a wedding because they did not want me to bring him.

#### You are kidding.

They did not want my son to destroy their day. I have also been kicked out of a movie theater because he would not stop making noise- even though they then gave me a pass to come in a matinee when it was just us. But now they even have that some of the movie theaters have an autistic day.

#### Oh, really?

Yeah, they do. But when he was little, they did not have that. I was kicked out of a movie theater. I was kicked out of a restaurant. So things are around him. I have to make sure he is in a good mood and that things are ok. I mean, even on a train, on a bus or a train, he do not like crowded buses. I cannot take public transportation with him at certain hours because he will start barking or making a noise or start acting up.

For a single parent the experience of relative deprivation could be different. As Esther a single mother described her experience:" I cannot do anything else but do what I have to do. There is nothing else to do. I try my best every day. I do not even date. Just like today, last week I have about five friends on my hands, and every month they go out to dinner. They called me last week and asked me to come, and I told them no. And they called me today, because they are at work and they said, "We are going to have dinner in the city. Are you coming?" I said "no" and when they asked why, I said, "I can't. I can't go, I can't come." I don't have anybody to watch my son, but my mom and he would run her crazy". Additionally, Josephine a never married single mother of on child has this experience to tell about inadequate support system. "I do not go to church, and my family has not fully accepted my daughter. I tried to take her out and I was denied the opportunity to travel to Florida with her. You cannot work full time. No one will watch the child for two hours. You have to give up a lot to be there for the child. I always felt isolated. I do not feel my family accepts my child." In the face of these relative deprivation struggles, about some participants indicated they adopted a self-efficacy cognitive consonance of firm determination of hope for their ability to unearth possibilities for their autistic child. Others reported some social and behavioral challenges with their autistic children ranging from random tantrum, poor social skills, sleep disorder, sexual inappropriateness, and inability to use the bathroom even beyond infancy age leading to continuous use of diaper.

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Furthermore, some families participating thought community intervention with regard to medical assistance or extended family and friends' support system was either weak or non-existent. For example, Josephine a single mother claimed: "My mother never accepted it. It was a crazy time. It was always conflicting and confusing information from my mother and doctor. My Mother always claimed the doctor was wrong." For Serafina, a single mother of three, "it was hard following my son when he was younger. Some of the difficulty is that the hospital is not aware of the needs... because when we use to go there, he had issues with having to wait. And that was never accommodated. I have taken notice that there should be some sort of extra consideration for those special needs kids. They could facilitate and speed up the process for them. At the beginning, it was very hard. He wanted to leave and just wanted to go. But he had to wait there. They need to get more help and staffing." Additionally one of the families believed her child evolve autism because of the number of vaccine doses her child got in one day. Thus for this family buttressing their point further explained:

And then you hear now that some of those doctors are being sued because they are just reaping people for money because you are so desperate. I would cut my arms off to make him (child) feel normal. And they are preying on that. And I did not care. It is like "ok! I will do this... I'll do that...everything." We used to pay \$15,000 a visit to Mexico for stem cells and it was clear... it could have been water that they were giving him, and we were doing it... and it was just... I do not know. I do not know if he is better for it or worse. It was hard (Shared by Dora a married mother of three children). Another family indicated that female doctors were more forthcoming with early diagnosis. With further regards to medical intervention, Josephine a single mother believed "right now it is more guess work from the doctors, therefore more specialists on autism is very much needed." For Ruth a single mother of one whose chose not have another children because of her ordeal with an autistic child, therapies have greatly made a difference with the daunting task of being able to communicate with her son. For her:

The beginning was hard. I did not know what he wanted when he was crying. I did not know why he was crying or what he wanted at the time. But as his therapies went further and he has gotten a little older, it is like "ok, you want milk. You want juice? Or something like that. He has made a lot of progress. But it took a lot of work for us to get him comfortable. When he was first diagnosed, even you guys coming here would have like, flipped him out. It would have totally thrown him off.

In the midst of these experiences of contending issues about care for autistic children, some participants in this research romanticized with a dream about autism. They emotionally wished a world without autism or a society that strives to understand the plight of the autistic child in their own world without striving to change or stereotype them. They needed a space to be autistic and accepted that way. Most especially a parent described her dream about autism this way:

I want my son to be able to get a job and get a wife. And I do not care if the wife has autism. But I want him to live a life independently. It is like my father died and I did not die after my father. My mother is alive and she is in Florida. She does not help me out. So I feel proud that I live far away from my family and I am able to deal with my family all by myself. It is the same thing- I want him to be independent. I want him to live his own life. I want him to have an apartment and clean his apartment and do everything that he has to do. So I do not feel like what I do is too much. Now is the time! (Shared by Pereta who described herself as a single mother of two seeking divorce because of an ambiguous dad for her autistic son).

The experience of emotional and social alienation or isolation from being able to engage productively with friends, family, and other social function as a result of caring for an autistic child peaked and resonated with the population interviewed. There was that probable registration of an experience of fears about the future of their autistic child by both single parents and married couple regarding when they are no longer able to provide and attend to their extenuating needs either as a result of death or any other unforeseen catastrophic events. It suffices to note that this fears for the most part brought out deep emotional tears and sighs from respondents. Moreover, there were the shared thoughts that gaps existed in the present services made available to parents of autistic children. The need for more programs tailored to the need of autistic children were describe as very much needed since the provision of such program will invariably create a respite for parents. The need for more information for parents was particularly described as fundamentally needed. For example, Ruth a single mother of two children noted,

I think that there needs to be more information out there. Sometimes it is very hard for us to get information, like where to go for the Respite Care. There is no information out there for that. There are needs to be more, like, awareness- when to get them diagnosed, what agency to go to. We just got very lucky that we have a really good pediatrician, and she recommended and agency. But if it was not for that, we would not have known which agency to go to... or how do we do this... how do we do that. Also, the health insurance part of it- many people do not know that until they are 4 years old, they qualify for diapers from health insurance. We did not know that. We found out because this pediatrician told us.

Another single parent Zera has this to say:

They do not understand. They do not understand. Do you know what we need more of? I am going to tell you what would work. We need to educate the police department. We need to educate the churches that it is not a sin or something I did in my past life [that made my child to have autism]. We need to do things like that. That is what we need to do and stop wishing on a star.... People look at my daughter. You hear it. And no longer... I used to cry about it, but I do not know. If I cry, it is intermittent but I do not feel sorry for myself anymore. I let go of that, it does not work. It is not a good investment. I learned that the outcome was not good enough. So that is it, the church has to learn. We have to train. We have to educate. We have to have a regular conversation about this. Policy, legislatorsit has to be up to date. We need to continue to have this conversation.

More so, single parent Rebecca puts it this way:

I want a lot of changes. I want them to, you know, put their resources out there. Make it easy. Make it easy for the parents to go out and get it, because number one, we did not ask for [autism]. We did not ask for this. And we are not asking [resources] for ourselves. We are asking for the child's sake. And I feel like, they will tell you [where to go for assistance], but when you go out [there] you are on your own. That is how I feel. I am on my own. And that is the point I keep saying. When you go to those support groups, you hear everybody saying, "I'm on my own."

#### So it is like a general consensus.

Yes! I am on my own. The reason why I am telling you I am on my own is that when the school brings "A" back home, you deal with her. That is it! Those resources will be available so that mothers of autistic could have a break. Maybe on Saturdays, a service group could take care of them So that we, parents of autistic children, can feel a little bit loved in the society and say ok so we can have the love and the happiness we deserve. Because they have special needs does not make them different. We are all God's children. They make it look like they are a curse. I see it.

Additionally, on the note of family structure impact, those interviewed compared their marital status in reference to the experience of caring for an autistic child. While a few within this coded category thought having a partner minimized their stressed some others thought they chose to be single as a conflict management strategy in order to be fully available to the child. However, noted was the notion that being single and caring for an autistic child creates a double edge sword experience. Resulting from the lapses in the present support system for parents of autistic children, the interviewed population thought some policy changes and advocacy was need in order to create awareness about the full impact of autism on both single and married couples. When asked about how their resilience and crisis management strategy in dealing with the impact of autism about some respondents indicated the role of efficient family support system, spirituality, *filial* love and the determination not to let the child down as his or her only sure hope keeps them going. Some noted they simply cry and feel all the fears and pains realizing that the journey with autism is like a bottomless tunnel for them. One single parent Rebecca expressed her feelings on resilience thus:

[Simply] because they have special needs, does not make them different. We are all God's children. They make it look like they are a curse. I see it.

#### How do you feel whenever you see that?

Oh God, I am so angry. I get so angry and I get so mad. You know. And that gives me more strength to push forward, to say I am going to make it. If I am doing this and I am feeling this, I still have to do it because Amanda needs me. That is how I look at it. "Tima" (*pseudonym*) needs me. I just want to thank you, because you have made me voice a little of my concern. Even in the support group, everybody is talking, everybody is... you do not really have the time to express how you really feel (*crying*). All of them are feeling the same. So you

know... but when you get somebody to talk to one to one, it makes a difference. The concept of autism from the research interview came across as one that truly cuts across cultural boundaries, racial divide and educational cleavages. The feelings and emotions surrounding the disease remain descriptively same. Arising from this about some of those interviewed described their shared meaning of autism that somewhat represent the current of meanings individuals have experienced about the phenomenon. For example, Sadith a married mother of two presented it this way: "autism is not something bad but a child that needs help attention from the parents. The only thing is that they become a little sad on their face and I do worry but definitely, I do not describe it as something bad. They simply need more attention. He is my heart it does not matter. They represent lov*e (Very affectionate description)*. And Dora a married mother of three noted "Autism is... a scary... confusing... huge umbrella... where people are searching for a needle in a haystack to find a way to trigger their child back into living as we do. And it is just very sad, scary, and large. It encompasses so many different things." For Eileen a single mother of one child, "whatever is odd to us, would be natural and normal to them." Lastly for Rebecca a single mother of two children,

Ah.... With me, I think autism has to do with.... Uh... the mind, you know the memory. Something went wrong to me. Everybody have different meaning, but to me, I think everything has to do with the mind... the way.... Something went wrong, it was not developed or something went wrong along the line.... I mean they are different. And everything has to be with their sensory... the way that they receive message. You know. Because it is like you and me talking now, you understand me. But to them, something... when you talk to them, something blocks- there is a blockage. They do not really understand exactly what you are telling them or what you are asking them. They do not get it. They are in a different world!

Rhoda a single parent caregiver also described it this way:

It is never being able to sit still. It is never being able to understand why the world is not at their feet (*laughter*). You know, it's "why?" Everything is "why?" "Why

auntie?" They need to know why things are not the same every day. Why is the world not smiling at her every day? She wants to know why. Everything in her world has to be exactly the same. If one thing is not the same the next day as it was the day before, then in her world something is wrong and it is not right.

For Pereta who described herself as a single mother seeking divorce from an absent husband,

Autism is like a ghost inside my son. I could say that. For me, autism is that. It is like a ghost that lives with him. I have to love him, and he is a ghost.... Because he is very mysterious. Autism is very mysterious... Sometimes, I look at my son and I go "what is really wrong with him?" I see ok, he can function sometimes. He has these things that shock me, and I go "Wow, you are capable of doing that." But he is only six years old. I do not know what he is thinking. He cannot tell me what he is feeling even if he says, "I'm happy. I love you. You are so cute, Mamma." All those things he can express it to me, but I cannot say I know my son... as if he is transparent to me. I cannot say that, because sometimes there is a block and there is no more than "I love you, Mamma." So it is like two people living together.... It is kind of weird to put together... in real life with a neurotypical kid. Usually they don't pay attention or they say Oh, it's ok. We will go get what is missing. Like, he struggles even for those little tiny things that are not really important... that is why I said it is a ghost. Because nobody can really say, it is here, it is there, and it is this.... It is so many things... so many little things... that is why I say autism for me is like a ghost living inside my son.

Finally, describing their social and conflict attributions about some of the population interviewed believed that the impact of caring for an autistic child engineered mixed feelings in them. For them it has changed their world for the better while for some it brought challenges. Thus, it enlivened certain levels of stress and emotional crisis in their lives. It brought about financial crisis, social isolation, break in family ties and parental worries and concern about the future. One of the respondents for example attributed her divorce to her child's diagnosis.

Her father moved out because he could not handle [the fact that his child is autistic]. Yeah, and most men are like that. Every autistic child, like 95% are all single parent. We do not even know where he is. Having heartbreak and having to deal with an autistic child is like having two at the same time (Shared by Rebecca a single mother of two children).

For the experience of being financial drained with autism Dora a married mother of three children noted the financial turbulence it brought to her family cohesion when they had to spend all their life savings in a bit to find a cure. Pereta a single mother of two children on her part expressed it this way:

These kids are very expensive, that is another thing. Very, very expensive! Because, you know, you can love them, you can hug them and that does not cost money. Sometimes, they are very simple sometimes. But sometimes you are outside in society and you have to deal with that... my son does not like trains or buses. He likes taxis and cars. You can imagine how much money I have to spend in a cab just because he says, "no! I don't want to go on the train." And then you have to choose right there- what do I do? I have to take him to music therapy. It is late, and he does not want to take the train. Do I bring this kid with me like...? It is hard to convince right there- either you convince him with something that you can provide him with. But if you do not convince him, you have to get the cab. Or the show is right there. So it does not matter if you are poor or rich, you have to have money for those situations. And it is like that... I can tell you different things.

For emotional attributions, among others, Briana a married mother with two children shared this experience,

It has been a struggle to accept the reality. It was always conflict situation to deal with. I did not deal with it too good. I blocked it out, did not know how to handle it. I had a lot of shame and guilt. **Why guilt and shame?** I did a lot of drug and I thought it was a reckon. I could not share with anybody and I internalized it. There was no one to talk to. I just did not want to be judged by anybody. I came to realize and got over the self-blame once I heard about the similar situation with celebrities. At first having, an autistic child led me to do more drug. I lost custody to my mother for a year and that was the wakeup call. (Cried with lots *of tears and deep emotions around this subject*).

Additionally Josephine a single mother further shared experience with regards to ability to secure a job, social isolation and family ties:

You cannot work full time. Now one will watch the child for two hours. You have to give up a lot to be there for the child. I always felt isolated. I do not feel family accept my child. As a child, I was more with my grandmother and cousins. But it is not same for my child. They are not in denial but it is easier not to deal with it. It is difficult to explain it. It gives me some concern. I over compensate. She does not ask for much but whatever she wants, I let her have it. Dad is not in her life by his choice

These examples represent a tip of the iceberg of how many of those interviewed attributed their conflict experience of autism in the life to their child. Moreover, some single parents talked about inability to date because of their crisis situation with autism. In the midst of these peculiar experiences, there are exceptional descriptions of how lives have been touched, and changed by the exceptionality of autism. For example, Sarah a single mother of two children went back to school to study for a nursing degree because of her autistic daughter. Elizabeth another single mother described a child with autism this way:

Unique! That is the word. **Say more.** I think she [autistic daughter] teaches us how to be better people. Teach us also how to have more patience, not to critique or judge someone just by looking. To see how much capacity they have to learn and also watching her learn how to live in a society that is not understanding them and coping with that society.

It is important to note however that my personal experience of observation during the interviewing process was many were holding back in defining their personal crisis, social or financial limitations as attributable to the impact of an autistic child. This for me was a way of fighting off the guilt of being perceived like blaming the woes of their life on their already overburdened child. Further analysis on this livid experience will be provided on under the thematic description. The guide from Moustakas, (1994, p.132) on thematic analysis will provide further structural descriptive analysis that engages the heuristic patterns of this experience.

# 5.2: Thematic Description of Impact Experience of Phenomenon of Autism

Thematic description of the experience of a phenomenon attempts to frame the invariant constituents into comprehensible structure for an organic understanding of the textual experience of the phenomenon. Thematic exploration therefore creates a framework for a more organized or unified perspective description of the experience of the phenomenon of autism by participants. It may serve a useful purpose to indicate here that this thematic coding serves to highlight the different types of conflict present in the researched population. Namely, intrapersonal conflict, resulting from caring burden, interpersonal conflict reflective of the competing goals with the child, and group conflict indicative of the universal tensions and social barriers that parents of autistic children experience in trying to assess institutional support services.

1. The Daily impact of Caring Burden:

Information from the interviewing data indicated that parents of autistic children entertained certain levels of caring burden liabilities. These caring burdens came under these conceptualized codes described above with verbatim from the interviews. A.). Community perception of the autistic child with some stereotyped negative and unwelcoming attitude often times complicates parental feelings of esteem and safety. It limits their abilities to meet social needs or restricts potentials for their child within the community and extended family circles. B.) Economic and career: Participants expressed with deep emotions about their inability to keep their jobs and maintain economic stability because of the absence of jobs that accommodates the needs of single parents of an autistic child. This often time leads to either quitting their jobs or being fired from the job. This arises from taking too many timeout from work hours in favor of meeting the multiple appointments for the autistic child. As a curve of their experience, single parents described the challenge of keeping job demands and meeting multiple appointments of an autistic child as daunting and unmanageable for a single individual. Additionally, financial burden comes from some expensive choices often made by autistic children like not being comfortable with ridding on regular public transportation like trains and buses in preference for expensive taxis. This not only limits movements, it taps deeply into the pockets of already financially stretched families.

C.) Perception of an autistic child: Autistic children are for the most part nontransparent, over-regimented or structured, and non-compliant. These often time complicates meeting the needs of the entire family thus leading to the crisis of having to live by multiple layers of life within the same family system. This burden curve of meeting the needs of other siblings and adjusting to the unique need of an autistic child overwhelms and frustrates. D.) Relative deprivation: Having to regulate diet and make choices that aligns only with the needs of the autistic child often times becomes a burden of social and economic opportunity costs for parents. E.) Emotional and social alienation: Caring for an autistic child for the most part re-shapes the life of the parents. In some cases, family gatherings are not attended for the sake of the unpredictable behavior of the autistic child. Single parents find it hard to engage in a sustainable dating relationship. In some severe cases sibling cannot bring their friend home because of some indecency concerns not excluding the use of bathrooms. These are some of the liabilities of caring burden that come with the experience of a family caring for an autistic child. When these burdens reasoned together, it brings about crisis risk factors of self-doubt, emotional exhaustion, and feeling trapped in life.

#### 2. Gaps in the Support System for Parents of Autistic Children:

An African adage holds, "whereas it takes a woman to give birth to a child, it takes a whole village to raise that child." If this adage is anything to go by then it aptly describes the deficiency currently experienced especially by single parents of autistic children. A.) Lapses in the support system for parents: The data generated from the study observed that parents of autistic children feel alone and insufficiently supported in their daunting care for their autistic children. Medically they feel somewhat supported for the needs of the child but socially there are inadequate non-medical support programs. These lapses specifically locate itself in the search for schools to meets the specific needs of their children. What is currently available for the most part applied as one size fits all. This process operates without respecting the differences in the various categorical needs of autistic children. Beyond the school system, there is not after school programs tailored towards the needs of autistic children in the community. In the absence of this, parents are stuck with their children to the point of near emotional suffocation. Additionally, some of the home health aides come unprepared to meet the need of the kind of services they employed to meet for the autistic children and their parents.

Lastly, there was the experience of the inadequacy of information on the subject of autism in communities or location of resources for parents of autistic children. B.) Community intervention: The code on community intervention captures assistance for families of autistic children ranging from support from extended family system to medical facility approach towards meeting the needs of autistic children and their families. The data indicated that emotionally not all families have either fully accepted or dealt with the reality of an autistic child in their family positively. This often times leads to either isolation of the single parent with the father walking out on mother and child. Besides, other members of the extended family structure often lack the emotional or mental capacity to deal with the unpredictable needs of the autistic child. Some cast the burden of faulting the mother for the challenges of her child as selective inattention motif of self-fulfilling prophecy for not accepting the child. Under this circumstance, single parents are excluded from family social gatherings. Furthermore, early intervention appears to play a pivotal role in the effective and efficient management of the condition of autism. Some parents shared the experience of not receiving the early intervention required especially with male physicians. However, in some families that enjoy both the support system of their extended family members and good medical support, the absence of good social programs makes those community supports inconsequential. More importantly, there is the feeling of over emphasis on medical needs of the autistic child leaving aside other human and ecological needs of the child that broadens the crisis curve of most single parents.

#### 3. Crisis experience of Dealing with Autism in a Child: The concept of a crisis

experience in dealing with autism refers to social and psychological reaction to perceived permanent or temporary existential stressors linked to daily abnormal life structural changes influenced by the diagnosis of autism in a child. The data from the interviews pointed to the following as some of the major stress producing experience that engineer crisis related experience in the life of especially single parents. A.) Family dynamics with autism captured data on the experience of the nuclear family structure dealing with autism spectrum disorder. The impact of the disease on family sanity, cohesiveness, serenity, and conflict management process takes a toll. In some cases, it may either lead to divorce, or renewed bonding in the family unit. Whichever way it goes participants expressed the enormous sacrifices they have to make for a child with autism. In families that chose to stick it out, physiological needs of sex, privacy, and home chores are doted around the needs of the autistic child. Among single parents, life is isolation, maimed physiological and safety needs. B.) Gaming and validation data reflected some intransigent negotiation process aimed at problem solving under failed communication process with the autistic child.

The concept of a lifelong baby came from this descriptive data referring to cleaning endlessly after the child and constantly on diaper even though grown. Some families indicated evolving a problem-solving model of rewards for every good behavior as teaching tool. This process could become overwhelmingly hopeless especially when near end is not guaranteed. C.) Social and behavioral challenges represent one of the most challenging experiences that participants indicated as a problematic curve. These behaviors include tantrums, non-compliant behaviors, poor social skills, over structured and unpredictable behaviors. D.) Lapses in the support system for parents came across as one of the key stress exacerbating agents for parents. The absence there off makes the hyperactive activities of the child often times become overwhelming and depressive. It becomes depressive with some of the high functioning autistic children that have no after school program outlets to exercise their energy.

E.) Fears about an autistic child captured the data on what parents felt about the prospect of a future for the autistic child. Thinking about what seem to be a blink and problematic future for the autistic child generated a crisis experience stressor and constant resilient risk factor. This experience anchored on the realization that the child is like going to be dependent on other for the rest of his or her life. F.) Not being able to either date or engage in other social activities with friends and extended family members without fear of the possibilities of unpredictable tantrums or reclusive behavior of the autistic child came across as an emotional and social alienation stressor. G.) Finance and job are often times perceived as one of the most stress generating factors in life. In the light of this, economic and career data came across as a major crisis impact in the life of parents of autistic children across board. Job insecurity was one major angel of stressor for single parents.

H.) Self-efficacy is the psychological tool of indomitable spirit that propels individuals to believe they can attain certain goals. This approach came across as one coping resilient self-assurance strategy that parents indicated aided them through their daily struggle. It is motivated by love for the child. They engaged this by exploring every available possibility for cure and improvement through therapies and educational program for their autistic child. The crisis point here ties with setting too high goals that often lead to spending out their resources and thereby go financial broke and emotional exhausted without attaining the desired result. This in turn may bread marital tension and feeling unrewarded outcome compared to the effort invested in the process. I.) Social and conflict attributions data reveal a connection with other data through a zero sum thinking of what their lot in life could have been in the absence of an autistic child. These noted layers of experience came out of the data as risk factors or borderline experience that trigger stress in the life of single parents. While participants were slow to attribute their difficult experience to the autistic child, their body language had volumes to say about attributive feelings of I wish he/she was not autistic and they did not have to deal with the awkwardness of autism that limit life opportunities.

### 4. Resilience and efficiency model in managing non-compliant behavior:

The interviewing data presented various coping mechanism that parents have adopted to deal with the challenges of the impact of autism in their lives as reflected in the following codes. A.) Self-efficacy: Self-efficacy is the psychological tool of indomitable spirit that propels individuals to believe they can attain a certain goal. This approach presented as one coping resilient self-assurance that parents indicated aided them through their daily struggles. They engaged this by exploring every available possibility for cure and improvement through therapies and educational program for their autistic child. B.) Resilience and conflict management came through the data from the innate sense of hope especially from the understanding that they are not alone in the experience. This provided for the risk factors of caring burden, financial crisis, and emotional drain. Additionally, learning the skills from daily experience of the autistic child and so improve communication strategy became a resilient risk protective factor.

Moreover, resilience and conflict management skill comes from their innate parenting skills that strategically evolve unique skills to manage their difficult child. Lastly seeing positive outcome of their efforts was resilience buffer. C.) Community intervention was one area that some find useful and helpful in positively engaging their experience. Some parents indicated support from their spouse, grandparents, and good relationship with their pediatrician and special need schools that assisted in teaching the autistic child new improved skills. This coded data was particularly tricky because while some find it useful others especially single parents found it inconsequential compared to their level of needs for assistance. D.) Dreams about autism include some form of dreaming linked to selfefficacy of possibility of a better future of assured levels of care for the autistic child in the absence of the caring parent. This came around as the assurance from siblings of the autistic child that they will always care. Besides, also included is the witness of improving skills from therapies for some. E.) Shared meaning of autism presented data of synergistic life pattern that parents know of their autistic child. This somehow energizes them to stay strong and will to do everything possible to be there for the child knowing that no one else may better understand and care the way they as proximate persons of trust in the life of the autistic child can. These factors stimulate resilience and probing conflict management skills for all participants interviewed.

### 5. The perennial fear for the future of the autistic child: Fears of the

Unknown: If there is, any theme in the data that stood out with deep emotional connection through the entire process it was definitely this theme about the future of the autistic child. A.) Fears about an autistic child were more or less about the unsolvable dependency of the autistic child on the parent for all their life circle events. This stimulates emotional crisis of fear about what the future holds for the child. Palpable questions like what happens when the parent figure is not there anymore. Will the child ever get married, have a job or put simply be able to face the brutality of the world out there with their childlike innocence? What is the likelihood that they will not be exploited in the absence of caring parent? Tears flowed whenever this subjected was brokered during the interview. It is a fear that was real and concrete in the experience of all parents interviewed. B.) Social and behavioral challenges grouped the data of common behavioral traits of autistic children like throwing tantrums, poor social skill, noncompliant attitudes, over-structured life, and demands for regimented life style. How these behaviors could integrate in the larger society evokes fear and uncertainty in the experience of parents.

The paramount dilemma for participants was if probability of a comprehensive therapeutic treatment totally reversing these social behavioral challenges. C.) Perception of an autistic child that could go either negative is definitely a baggage that came across as part of the experience fear by parents that impacts their journey with autism. D.) Community perception of autism as a misnomer that could only be tolerated and at best rather not dealt with remains an experiential concern. Social and institutional stereotyping that is fraught with negative connotations was presented as a concern that may serve as a barrier towards fully creating opportunities for autistic children especially in the workforce. Some parents for instance indicated they do not go to places of worship because of the resenting attitudes they get from some members at certain places of worship. These fears represent a major crisis stressor in participant's experience.

## 6. The Married vs. Single Parent factor in Caring for an Autistic Child.

The impact of autism on parents for the most part enjoyed a universal sentiment. However, there are certain layers of differences in presenting the impact factor from the research data. A.) Married couples' perspective holds no doubt that autism is a major blow on marital cohesion. It presents another layer of struggle in the relationship. As some expressed they stayed together in spite of the challenges but they definitely know why a higher percentage experienced divorce. Nonetheless, from their experience it is much easier to have a spouse to share the burden with rather than none at all. Most of the married couples interviewed indicated that they had to devise division of labor model whereby the male spouse works while the mother stay at home with the child to keep all the various medical and social appointment of the autistic child. Having one spouse keep a regular job in turn creates a deep hole in the family financial resources.

There was also the experience that the autistic child attached more to the mother than it does with the father. One father complained that the medical theme only craves for the mother's perspective less than they crave for the dad. B.) Autism and single parent experience revealed the burden felt by single parents who had neither family assistance nor the presence of the autistic child's father to assist. Some shared the experience of being judged and isolated in their world with autism either by family members of the community. They could not date or keep social track with friends in order to be present for the needing child. They indicated that they were unable to keep a full time job and keep appointment for the child at the same time. It requires a multitasking that is inconceivable for one single individual to keep. This therefore compromised their financial strength. When compared to married couple, the married couple is better off given the case that dad works and supports the family. So while the source of income shrinks, it is not totally lost as in the case of the single parents. Some indicated they became single not by choice but a consequence of having an autistic child. Others made a choice for single in order to reduce the tension in their life arising from constant having to deal with emotional crisis from spouse who could not deal with having an autistic child. Summarily therefore, while the stress of autism is mutually real, being single elevates the stress level compared to married couples.

C.) Emotional and social alienation data showed that married couples enjoyed some emotional support that regulates the crisis level compared to single parents. Thus, while some married couples still feel emotionally alienated, having a partner nevertheless minimizes the impact of that experience. Single parents on the other hand lack a teammate and go it all alone in most cases without a helping hand. The emotional toll may seemingly be different but it came across as normative across board. Emotional needs tampered with the esteem and physiological needs of single parents more than it does for married couple. D.) Fears about an autistic child's future was commonly shared at the same experiential levels. E.) Lapses in the support system is made more daunting for the single parents giving the fact that whatever is not given cannot be provided for by a suitable helpmate because there is visibly none. Moreover, when it comes to the need for more programs single parents crave far more than married couples do. One area that stood out as a consensus was in the programming vacuum associated with school placements. This is a consensus that craved for more information and more school programs that attended to specific needs of autistic children compared to the current one-size fits all approach. E.) Married vs. single on autism: Some married couples noted the relief they get with a partner with some challenging situations of getting the child to compliance. Married couples indicated it could have been more difficult if they were single. When compared directly, the dividing line on the impact of autism between married couples and single parents appeared thin but significant.

Precisely when the data is broken down about the actual levels of crisis impact that autism stimulates in the different life style, the differential strength and weaknesses in married couples vs. single parents was enormous. Finally, it suffices to note that significant information was gathering through body language than some single parents were willing to share. For example, it was more common for me to experience tears and cry from single parents with no male presence all than married couples or single parents with minimal male presence during interviews. Single parents were equally more prone to demand why they are not getting assistance or crave for more programs in the community that gives them space to breath from over attachment with the autistic child than married couples. This reveals that the crisis impact level on the single parent was possibly higher than it is on married couples.

### 7. Advocacy on Behalf of Autism in Social and Community Experience:

If there was another consensus that the data revealed it definitely was one on the need for program policy modifications that will benefit autistic children directly and indirectly benefit the parents. A.) Policy changes advocacy: The data revealed parents' need for policy modifications. Community awareness project comes around as needed. Such information will include helping parents locates sources of assistance, kinds of assistance available, education for special needs children, and adjustment of school testing that recognizes the challenges and needs of autistic children. B.) Community intervention in the guise of providing after school programs tailored to the need of autistic children and their parents. C.) Change in Community perception of autism with negative stereotypes. D.) Economic and career: This data assess the problem of inadequate jobs that accommodate the needs of parents of autistic children. E.) Education for a change in the perception of an autistic child as statistical object of research in favor of a child that needs help with the different kind of life pattern. F.) Dreams about Autism: the need to increase prospect for full integration into the workforce and the ability to live normal life in the absence of a dependent parent was of paramount importance to participants as this fed into the fears about the future of the child.

These thematic policy areas presented a grave potential for conflict and crisis in the lives of parents with autistic children. This is because most of them constructed around access to service programs and information on government provided services. In the gap that exists between service program access and poor support system, there are bound to be overburdening feelings of oppression, isolation, and disenfranchisement. It is evidence of a gap between policy governance on autism and implementation of budgeted programs from the avalanche of programs constructed on the policy of combating autism. Arising from poor policy implementations, some parents indicated a belief that many in the medical and non-governmental organizational sectors are taking undue advantage of their pains with an autistic child to benefit their financial interest. What these experiences instigate therefore, is the intensification of intra-conflict behaviors producing risk factors such as emotional and psychological stress. Additionally, it breeds group conflict behavior of a zero sum thinking of parents of autistic children versus the various social service institutions.

### 5.3: Hermeneutical Transformational Approach to Impact Experience

The hermeneutical transformational approach to impact experience accords with the structure of experience by single and married coupled parents of autistic children. Copen (1993) in his research indicates that, "structures are brought into the researcher's awareness through imaginative variation, reflection and analysis, beyond the appearance and into the real meanings or essences of experience (Copen 1993 in Moustakas, 1994, p.135). Thus, what hermeneutics provide is the dynamic feature that underlies the description of the experience of the conflict and crisis impact of autism provided by the data of this research. This framed from the point of view of various theories of knowledge on the subject. The theoretical framing links with generated themes using the transcript from the interview.

# 5.3.1: Theoretical Framed Hermeneutical Analysis of Impact of Autism

Theoretical framing of the experience of autism by single parents and married coupled is a creative and cognitive attempt at understanding the underlying dynamics of participants' experience of autism. Theories in this regard provide the synergistic opportunity to correlate the account given with the various model of reconciling conflicting situations that are both social, psychological, and emotional. Theories in this wise provide the unified wisdom of understanding of the pattern, structure, and process of acquiescing conflict and crisis in the transformation association between single parents and their autistic children.

In "The Effects of Autism on the Family" by Schopler and Mesibov (Ed., 1984), some contributors like DeMyer, (1979), Bristol, (1979), Marcus, (1977), Leighton, (1969), and Berger (1980) all came down with the conclusion that indicated parents of autistic children were markedly impacted emotionally, psychologically, and relationally in negative terms by their encounter with an autistic child in the family. According to these researchers, some of the problems included depressive symptoms from especially the mothers filled with constant fear, worry, anxiety, apprehension... and serious concern about the linguistic and behavioral abnormalities" of the child and how this might impact the life ahead (P.49-49). This analysis is atypical of an intra-conflict behavioral experience of a psychological processing of conflicting comparison of the expected versus the reality. Recent studies on the subject of effects of autism on affected families from Weiss and Lunsky (2011), Hodgetts, Nicholas, and Zwaigenbaum (2013) equally buttress this point. Cridland, Jones, Magee, and Caputi (2014), Solomon and Chung (2012), Vohra, Madhaven, Sambamoorthi, and St. Peter (2013), O'Brien (2007), Weis, Wingsiong, and Lunsky (2013), and Ludlow, Skelly, and Rohleder (2011) all seemingly agreed on the significant negative impact of autism on families like their research predecessors. The ambiguous process that seems to have been missing in these researches cutting across clinical through social analytical framework is the underpinning synergies of the kinesthetic relevance of framing the subject in specific and unified conflict resolution theories. Theoretical framing will build for clarity of wisdom in order to acquire the cognitive structure of experience of autism by families for better interpretational conflict resolution support approaches (also see Atkin & Tozer, 2014).

The structure that fills the experience of the impact of autism on single parents could be reason from the point of view of how these parents perceived their life process living with and caring for an autistic child. These includes the worries and obsessive concern about the future of the autistic child, limited resources to support themselves and the autistic child, unpredictable behaviors of the autistic child, and social and perceptive attributions to their identity as single parents of autistic children. These concerns often bring out tears streaming down the eyes of the parents during the interviewing sessions. The tears and emotional expressions perhaps demonstrates the feelings of losing out of what could have been had the child not been the way he or she is. O'Brien (2007) analyzing on the experience of parents with autistic children "proposed that a diagnosis of an autism spectrum disorder (ASD) is especially likely to be experienced as ambiguous loss." This ambiguity experience supposedly arises from a perspective of a lost dream of the kind of a child the parent had desired. In order words, "the child they thought they had is not the child they must learn to live with" (p.135). This experience of ambiguous loss comes around as constant stressor that mourns a dream lost in medical diagnosis.

The theory of ambiguous loss indicates stress results from changes in the family system not often easily identified and so ambiguous. Additionally when the challenges of the present are measured against, their strength they feel overwhelm. There are lots of variables that could be analyzed as contributing to the experience. Vohra, Madhaven, Sambamoorthi, and St. Peter (2013) observed, that caregivers of children with ASD "were significantly more likely to report difficulty using services, lack of source of care, inadequate insurance coverage, lack of shared decision making and care coordination, and adverse family impact as compared to caregivers of children with other developmental disabilities, mental health conditions, or both" (p.1). From Maslow's hierarchy of human needs' theory, we can categorize the conflict and crisis experience of single parents under deficit (deficiency) needs and growth (being) needs. While deficit needs are lower needs, growth needs are higher and weaker needs. According to Maslow, failure to satisfy higher needs (need for self-actualization, esteem and belongingness) may not necessarily produce crisis but they are nevertheless important for contentment, happiness, improved health, fulfillment, and life survival process.

These existential qualities require environmental contributions for attainment. Hence, they are described as growth or being needs. Moreover, failure to satisfy lower needs (physiological-food, water, and sex- and safety needs –security, order, and stability) leads to deficiency in the body and thus crisis (Schultz, & Schultz, 2013, p.247). In the context of the conflict and crisis impact of autism on single parenthood, the available data from this research indicates some levels of relative deprivation across board on the hierarchy of needs. For example, some single parents and married couples as well expressed their inability to date or engage in sexual satisfaction because of their autistic child. Fear for their autistic child's future, inability to sustain a career, or maintain family stability structure creates arena of experience of some form of safety problems.

The experience of a double stereotype theory of being a single parent with an autistic child could be producing esteem problem from self and others in the community (Konstantareas & Homatidis, 1992). Ludlow, Skelly, & Rochleder, (2012) in their research with 20 parents of autistic children observed the significant impact of the variables of esteem need arising from judgment from others and the lack of support system that could possibly validate this human need. This therefore constituted a valid layer of stress especially for single parents who feel isolated and ignored in their existential plight with an autistic child. This isolation further extends to their inability to secure a job that meets their peculiar needs. Inability to fully engaged and contributes meaningfully to the workforce or engages in an enterprise that will enable the fulfillment of a career dream or the opportunity to fully excise one's talent tended to compromises their self-actualization need. A great deal of single parents in this study indicated how they had to quit their job (Zera a single mother of 3 children for example was a social worker but had to guit her career, Sadith a married mother of 2 children left her job and became homeless at some point, Dora a married mother of 3 children shut down her daycare business.

Josephine a single mother went into drug uses, etc.) in response to the overriding and exogenous needs of autism. Additionally, for belongingness needs, most of the parents felt out of place with their families or even friends who walked out of their lives because of their inability to deal with an autistic child. Inability to score high on these need theory often creates an attributive and zero sum thinking of feeling left out of a dreamed of a good life with family and friends or even a thriving career thanks to autism in a child. This is a comparative feeling of what individuals in these categories feel entitled to from the society or family denied because of the stereotypes of their condition of being single parents of autistic children. Feeling left out of life current is a conflict-producing dilemma that has the potential to exacerbate a crisis experience while engaging the world. "A crisis is any situation in which a person's ability to cope is exceeded" (Lanceley 2003, p.15). Every crisis for the most part is a conflict problem. It could function as either an intra-personal experience or interpersonal conflict. Within these structures of conflict problem from human needs theory, the question is not so much as whether they exist from a clinical point of view, but how they so exist and either reinforce or frustrates functioning resilient abilities in single parents of autistic children.

Another way to engage this process is to access the theories of effective communication between parents and their autistic children. Theory of effective communication presents another significant layer of understanding the structure of relational conflict experience in the association between autism and single parenthood. Communication variable becomes more apparent through non-compliant behavior and tantrums coming from poor reception of mutual communication. It is symptomatic of a breakdown in communication between the child and the parent caregiver manifested in non-compliant and aggressive behaviors form the autistic child. Theory of effective communication holds that poor communication in interpersonal relations often times served as conflict trigger or intensify conflict behaviors escalating break down of rules and order. The problem of ineffective communications was described as more elevated especially at a younger age and particularly from the non-verbal autistic children. When these happens parents cry, feeling frustrated, with an overwhelming feeling of inadequacy as a parent. For the single parents the absence of a partner to serve as rule enforcing significant other or just another person to vent with complicates the experience. To navigate this experience with minimal down turn parents often innately adopt various conflict resolution theoretical skills of problem-solving, effective communication strategy of gaming theory, resilience, and conflict transformation process. Wilmot and Hocker (2007) noted, "the more clearly individuals or groups understand the nature of the problem and what they want to have occur, the more effective they will be in solving problem" (p.63). Therefore recognizing the type of communication problems the child has, parents often resort to attending skills and responding skills. While attending skills helps parents demonstrate love and interest in the autistic child, responding skills produces some measure of parental empathy that reinforces the behavioral change either intended or subscribed to in concert with their therapeutic needs (Katz & Lawyer, 1992, p.29). They game the process through reward and validation for compliant behavior. In this pragmatic gaming theoretical module, effective communication becomes bridging stone for solving relational roadblocks of non-compliant behaviors and tantrums. This transformational method engages resilience and self-efficacy as a conflict management model.

Resilient framework builds on the positive self-efficacy determination of working to engaging a relational growth and transformative adaptation in the realization that the problem of an autistic child is a life-long condition (Walsh, 2002). Through innate selfefficacy resource of parental love for their child regardless of their condition, participants game their resilient risk factors in the hope for positive outcomes at least on the levels of improved communications. The downside of this process as evidenced in the data is that over compensation for fear of what might happen to the child in the absence of the primary caregiver often leaves the parent feeling emotionally overburden thus leading to internalized conflicts of some sort. The theoretical place of resilience from the available data in this research arose from the various synergies of family adaptation process to the extenuating needs of the autistic child. Effort investment, financial investments, investment of emotional capital, and various opportunity costs of caring for an autistic child is calculated as variables of vulnerability, stress, and resilient risk factors that make valuable resilience outcomes of any visible improvement in the life of the child no matter how insignificant a great resource for coping. While resilience may not be confused for a heroic self-determination resource (Begun, 1993), it nevertheless provides conflict adaptation and accommodation for cognitive consonance for single parents in this research.

Finally, the presence of limited resources and inadequate information/ policy advocacy on the phenomenon forms another layer of stressful experience. Not being able to assess the very much-needed resources starved off through poor policy implementation breeds a feeling of hopelessness, isolation, or experience of nobody cares personification. Under such a circumstance, single parents feel constantly at war with the rest of the society on behalf of their autistic child. This is a conflict mentality of a zero-sum thinking theoretical process that is often associated with a mentality of if I do not fight the system or the society to gain access to care, then I will get nothing and so be failing the child as a parent caregiver. Russa, Matthews, & Owen-DeSchryver (2014) in their research, equally observed limitation of access to quality information, poor parental skills, and transitional support as some of those key stress inducing agents for parents of autistic children. On this note, therefore there is the undeniable need for more advocacy and community engagement around the phenomenon of autism. This need could be framed as a mental theoretical crave for emancipations from the seemingly oppressive isolationism with the concept of autism. It is a critical theoretical search for political resolve and happiness through effective communication of their needs to policy makers for effort recognition and esteem affirmation (Kellner 1990). No doubt in recent time, more information around the subject of autism has blossom through various governmental and non-governmental organizations' efforts (Shute, 2010). However, when these efforts are measured against the experience of participants in this research it does appear that a perception of non-inclusiveness abounds. This is a perception that sees various organizational efforts as outlets for budgetary benefits for researchers while leaving the actual daily caregivers on the fringes. It is on the basis of these experiential feelings participants thought a coordinated emancipatory advocacy is needed on behalf of caregivers.

In a nutshell, we could summarize the theoretical model using the cap of the family system theory. The family system theory holds that the family is an ecological system where experiences are either equitably shared, or unequivocally distributed. Besides, the health of a family depends on how it mediates and balances its stressors versus its outcomes. For example, how does a family manage its feelings of an ambiguous loss? Thus, the impact of the various synergistic needs and behavior of an autistic child significantly affect the single parents based on its family ecosystem resources to balance its need vs. outcome. In order words the lower the copying resources in the family ecosystem, the higher the stressors and resilient risk factors. Poverty in copying resources escalates intrapersonal, interpersonal and inter-group conflict behaviors for the single parent of an autistic child. Where there are inadequate provisions for hierarchy of human needs, feelings of relative deprivation, stereotypes and identity issues or zero-sum and attribution feelings will feed the stressor machines and the single parent becomes overwhelmed or in crisis. Resulting from the imbalance in the peculiar circumstance under which the single parents of autistic children abides reliance on resilience and social advocacy resources becomes inevitable (See critical theory and feminist theory above).

#### 5.3.2: Thematic Framed Hermeneutical Analysis of Impact of Autism

Different researchers in recent time have observed the significant impact of autism in the life of families. What has particularly been weak in the research community on the subject that this research attempts to contribute is the unique experience of being a single parent and caring for an autistic child at the same time. The various thematic expressions of single parents in this research about their experience of living and dealing with autism therefore provides that specific window of understanding of the various structures of acquiescing conflict experience as single parents. While most available research data speaks to general family experience, the data from this particular research did not however negate those previous findings. At best, it served to describe an elevated structure of stress experience for single parents compared to regular nuclear family of a father and mother living together with an autistic child. The themes utilized here structured in a way that cognitively unified the experience into structures of experiential epistemology.

### A.) Daily Impact of Caring Burden:

Weiss & Lunsky (2010) identified some of caring burden and stress variables of families dealing with autism to include behavioral problems, education, financial resources, and the child's health-challenges. For these researchers, these variables are significant enough to task the emotional and psychosocial needs of families and thereby lead to crisis. This research finding agrees with the findings of this particular research when the participants identified community perceptions, economic and career challenges, incremental perception of an autistic child, relative deprivation, and emotional/social alienations as some of their most daunting caring burden impacts. What merits attention here is the elasticity of experience of single parents when they tied this particular experience to the absence of stable family support system that could have served as absorbent of their emotional constrain. One cognitive arena for understanding this structure of experience by single parents is plausible from the theory of family system and ambiguous loss. Family organizational structure functions with order, rules, spontaneity, and some psychological bonding ties that keep the cohesive boundaries of the cell together as one single unit of existential experience. The absence of order, rules, and boundaries often make parents to cry and doubt their parenting efficacy. Karst, Vaughan, & Hecke, (2012) equally found similar observation of parents doubting their parenting efficacy in the context of autism within the family from their research as significant stressor.

Another concept for consideration here is the theory of ambiguous loss. Cridland et al. (2014) described ambiguous loss as a "complicated or unclear loss resulting from either physical loss of a person while retaining their psychological presence (e.g. missing person) or the physical presence of a person while experiencing a loss or change in their psychological state (family member with ASD)" (p.216). What stimulates caring burden from autism therefore is the ever changing and unpredictable life process of an autistic child that blurs boundaries in the family norm. More so, the indeterminate needs and emotional absence of the autistic child makes the life of the parent more or less revolved around him or her with little emotional resource for siblings. In the face of this experience, single parents in this research reported being thorn with a feeling of losing both ways (with an unsatisfied autistic child and siblings feeling an ambiguous loss of their mother). This ambiguous loss of a mother by siblings comes from a single parent struggle to understand the autistic child's unique world away from the socially defined normal. In the absence of a significant other to care for other important needs of the family, life becomes chaotic and overwhelming thereby raising the stress levels and crisis boundaries of internalized conflict behaviors. Within this spectrum of experience, selfactualizations becomes a missing fiber in the life of the single parent leading to poor sense of self, weak safety nets, and defied opportunities for meeting physiological needs (Schultz, & Schultz, 2013).

Moreover, daily crisis experience observed from the interviewing session to come from conflict of ineffective communication strategy and non-compliant aggressive behaviors between the autistic child and the rest of the family members. This extenuating experience further tasks the conflict management strategy of the single parent. The research findings of Ludlow, Skelly and Rohleder (2012) seem to have supported this finding when they indicated, "dealing with challenging behavior; dealing with judgments from others; lack of support; impact upon the family; coping and the importance of appropriate support" (p.702) as significant variables of stressful risk factors in their thematic findings. Hodgetts et al. (2013) equally noted managing the aggressive behavior of the autistic child as one of the major burden on families. Single parents in this research indicated non-compliant aggressive conflict behaviors as daunting, frustrating, and overwhelming because of the children's energy level, as they grow older. Finally, while in previous research study Higgins et al. (2005) observed that self-esteem was not particularly a caring burden issue for families except impact on marital happiness, quality of life, and family cohesion, the data from this research found self-esteem to be a caring burden stressor especially for single parents. Lastly, parents both single and married reported across board the caring burden of being sleep deprived and thorn between meeting the obsessive needs of the autistic child and balancing the needs of the siblings. This becomes a major conflict and crisis stressor. Previous research on the subject equally found this variable as significant (refer to Quintero & McIntyre, 2010; Lopez-Wagner, Hoffman, Sweeney, Hodge, & Gilliam, 2008).

B.) Gaps in the Support System for Autistic Families: Silverman (2006) in "A

*Feminist Activist Raises a Son with Autism,*" observed the challenging odds especially single parents faced in trying to access various resources towards the care of their child with disabilities. Quoting from a report from *The Institute for Women's Policy Research*, Silverman noted the significant negative impact having a child with disabilities in the

United States as well as in England, had on mothers in the workforce as comparable to "having a child under one year of age or a preschool child" (p.50). These challenges according to Silverman further exacerbates within the context of inadequate institutional, community, and family support system. In the course of my research, the observations of Silverman was further confirmed when the data revealed that single parents complained of how daunting it was for them to obtain information about how and where to get adequate support resources for their autistic child. Moreover, when they do find one, navigating through the paperwork process of reaching the resource becomes another uphill task. For example, Sadith a married mother of two children noted,

500 doors get shut to 1 door that is opened. It has always been very difficult to get things. Either he is not too severe enough for the help or he doesn't qualify because he doesn't have all 10 of what they look for in autism, or because he is verbal and before because he wasn't verbal. It is like they have all these rules to say who can, and cannot be in this thing. And, just like we don't all look alike. I don't believe that any disability not just autism, any disability you can package it in a group. My experiences are not going to be the same as 100 other people who have autistic children.

Ludlow, Skelly, & Rohleder (2012) equally corroborated this experience from their research findings. Additionally, Vohra, Madhaven, Sambamoorthi, and St. Peter (2013) quantitative study on "Access To Services, Quality Of Care, And Family Impact For Children With Autism, Other Developmental Disabilities, And Other Mental Health Conditions," observed,

*Access to services*. More caregivers of children with ASDs reported difficultyusing services (55.0%) than caregivers of children with DDs (43.7%) and MHCs (36.4%). One-third (33.4%) of caregivers of children with ASDs reported insurance coverage as inadequate, as compared to 23.8% of those with DDs and 21.3% of those with MHCs. *Quality of care*. Greater proportion of caregivers of children with ASDs reported lack of shared decision-making (43.1%), as compared to caregivers of children with DDs (36.4%) and MHCs (31.1%). A significantly greater pro- portion of caregivers of children with ASDs reported lack of coordination (86.7%) as compared to all other groups (82.2% DDs, 61.0% MHCs, and 80.2% both DDs/MHCs) (Vohra, Madhaven, Sambamoorthi, and St. Peter, 2013, p.6).

When the findings of the above study compared to the data from this research, similarities are apparent, but also, some differential outliers are equally evident. Firstly, it was quite evident that levels of education and socialization played a role in the abilities of single parents to access the right resource for their support needs (also see Mandell et al. 2009, p.496). For example, compare Esther a single mother & Pereta another single mother holding a college and graduate degrees with Ruth a single mother with high school diploma or Elizabeth with only a junior high school. Their service information access opportunities varied based on intellectual and social competence abilities. Additionally, the level of access to information for Family #4 with college degree were found higher than those of others in the same category but with different educational background. (Refer to figure 2). Furthermore, the Hispanic population that constituted 45% of the interviewed population of this research tended to report more on inadequate

access to support system from the community or institutions compared to the 22% of Caucasian or 33% of African Americans. Thirdly, African Americans were more prone to judgment and alienation from community and family and thereby lacked their desired support and coordination. More so, the need for information and coordination on how to handle behavioral and educational challenges of autistic children cuts across the spectrum of unmet needs in this research as previous research on the subject also indicated (refer, Brown, Ouellet, et al. 2012; Ausderau, & Juarez, 2013; Higgins, Bailey, & Pearce, 2005; Hodgetts, Nicholas, & Zwaigenbaum, 2013; Reed & Osborne, 2013).

However, single parents seem to possess more problems with navigating various resources for needed support. As Sophia, single mother of 2 children described it: "if you do not have money then there are few choices." Invariably we could interpret this assertion relative to the level of financial muscle a parent has opens more doors of opportunity for support systems as an indictment on existing legislative policies in favor of caring for autistic children. Since single parents have limited access to the job market, then their access to financial strength in order to reach certain threshold of being able to either pay for support services or reach avenues for information is grossly limited. Dora married mother for instance buttressed this idea when they indicated that their ability to explore various therapies and resources both nationally and internationally while legally challenging the board of education over policy adjustment for their autistic child's education only paid off thanks to their financial strength. Most single parents do not have the robust resources that married couples have because as already noted, circumstance their life style makes the odds obvious, limited resource control, shrinking family support network, and limited access to job market.

Lee, Oh, Hertmann, & Gault (2004) in their research, "*The Impact of Disabilities* on Mothers' Work Participation: Examining Differences between Single Mothers and Married Mothers," further indicated that incremental policy changes in the United States are culpable for most of the service access gaps. According to these scholars from *The Institute for Women's Policy Research*, the Welfare Reform legislation of 1996, namely the changes from the existing policy program of *Aid to Families with Dependent Children (AFDC)*, to *Temporary Assistance to Needy Families (TANF)* created negative impact on the income support system for low-income families. Opportunities that were available under the previous policy design (AFDC) came under the bus in the TANF.

Unlike AFDC, TANF imposes strict work requirements, sanctions, and lifetime limits on cash benefits. Some low-income children as well as adults with disabilities are eligible to receive cash assistance under the Supplemental Security Income (SSI) program, but the 1996 welfare reform also restricted the definition of disability for children, eliminating benefits for children with less severe disabilities. Many low-income families who have children with disabilities, therefore, not only lost SSI benefits for their children, but also were subject to TANF work requirements and time limits unless granted an exemption (Karoly, Klerman, and Rogowski 2001; Loprest 1997). While strict work requirements can provide strong incentives for some low-income families to find and maintain a job, they can exacerbate economic hardship for many families where health limitations among mothers or children pose a serious obstacle to employment (Lee, Oh, Hertmann, & Gault, 2004, Pp.1-2).

It is often assume that incremental policy designs facilitates and optimize services to the public. However, in the case for the experience of single parents dealing with autism the TANF policies seemed to be working on the contrary. For some segment of the needy population specifically single parents of autistic children, the stringent and restrictive demands of the TANF adjusted policy tilts the balance somewhat to favor some while others languish. For a single parent caring for a young and evolving autistic child, strict work requirement and limited cash benefits under the TANF is unrealistically harsh given the fact that the circumstance of their current family arrangement makes that improbable. Furthermore, various adjustments to TANF since it came into effect only deals more with monitoring than changing the operational philosophy that single parents described as alienating their needs in the system.

Talking about access to support services under the prescript of the various legislative policies, Esther, single mother with two children talked about the *ZIP code effect* in allocating services. She questioned why someone in Long Island New York with the same condition as her son gets a benefit and she cannot access the same benefit because she lives in Bronx New York. Besides, how was she expected to work in order to meet the threshold of the law and still care for the extenuating demands of her autistic child as a single parent? Moreover, Elizabeth a single mother demanded to know the metrics of validity for defining her child as not disabled enough to get certain benefit that she needs to improve her life with an autistic child. Additionally, Sadith a married mother of 2 children noted even the *Affordable Care Act of 2010* elevated the requirements for obtaining resources for needy parents with complicated paperwork and questions demanding immediate and efficient answers. These policy gaps make otherwise available

support resources unreachable especially for single parents that lack the time and resources to access them. Finally, parents across board indicated the poverty of after school program tailored towards the needs of autistic children and schools that differentiate the varieties in the needs of children within the spectrum. This experience further complicates the feelings of being stuck with the child like being in a Pandora box of no escape. There is therefore a search for a transformational outlet that will not only guarantee a break for the single parent, but also provision that responds to the search for acceptance, esteem, and safety in the community.

### C.) The Crisis experience of Dealing with Autism in a Child:

Crisis experience is Symptomatic of either environmental stimulant or stressor or intra-ventilated feeling that overwhelms the individual's residual ability to deal with those stressors judged unconventional in the individual's social or physiological routine. Solomon & Chung, (2012) observed that families dealing with autistic children are more likely to experience elevated stress level, divorce, and absence of cohesion in the family environment compared to other family types. Similarly, Weiss, Winsiong, and Lunsky (2013) noted on the importance of understanding what crisis means to families dealing with autism in order to design effective and efficient assistance for them. Weiss et al., investigative study of the subjective crisis experience of 155 mothers of autistic children indicated that crisis process evolves from demands, internal capabilities, external resources, and subjective appraisal of those individuals. Olsson & Hwang, (2001) in *"Depression in Mothers and Fathers of Children with Intellectual Disability,"* 

severe depression than mothers living with a partner and even more so with mothers of autistic children (Pp.535 & 536). These studies tend to demonstrate the pervasiveness of an association between crisis and autism for caregivers. The question then is not so much as to if crisis exists at this point but the structure of a variable difference in the investigated population.

One of the clearest ways that this research observed the crisis impact of autism on single Parents was in the emotions displayed when sometimes cautiously providing a response to the interviewing questions. Tears, chuckle, sigh, and deep breath were common manifestations of being overwhelmed with the unconventional present while being frustrated about the uncertainty of the future. The crisis impact comes with the pervasive struggle to understand the unconventional world of the autistic child, and the intentionality behind their emotional tantrums and non-compliant social behaviors. Judith a married mother with three children expressed their experience this way,

He may soil his dipper and he doesn't let us know. Someone who watches over him have to know he is in pain and that is what worries me the most. He has the ability to absorb and live within himself. He just wants to be by himself. We are working on the dipper. He grabs things randomly on the floor and takes to his mouth that could bring in some germ.... It is pretty difficult to understand him. He doesn't know how to express himself. If he needs anything that I am not able to understand, he cries and hurts himself. He is scared of shadows especially at night. If he wants, milk and I give him juice he throws it away. It frustrates me, I cry and wants to fly away. The sister does not understand him and they fight a lot. She feels bothered by him, gets tired and frustrated. The sister who is seven equally wants attention. In the midst of this, I feel I'm losing both ways between him and the older sister.

In a more personal and pointed way that further demonstrates how some single families acquiesce the struggle, A single mother Josephine tearfully noted:

It has been a struggle to accept the reality. It is always a conflict situation to deal with. I did not deal with it too good. I blocked it out, did not know how to handle it. I had a lot of shame and guilt. *Why guilt and shame?* I did a lot of drug and I thought it was my reckon. I could not share with anybody and I internalized it. There was no one to talk to. I just did not want to be judged by anybody. I came to realize and got over the self-blame once I heard about the similar situation with celebrities. At first having, an autistic child led me to do more drug. I lost custody to my mother for a year and that was the wakeup call. (*This participant had lot s of tears and emotional feelings through the entire interviewing process*).

Summarily, the crisis experiences of parents and especially single parents is embedded in the uncertainty about the future of the disease, poverty of information, and communication gap between the autistic child and the rest of family members. There is the evident weakness in accepting the exogenous nature of the personality type of autistic children that often leads to the troubling mental rejections of the reality, internalized blaming, mutual attributions of responsibilities between parents leading to divorce in the realization of the lifelong nature of the challenge. It is the ability to understand this salient and often rejected fundamental of the challenges of the disease (in order not to come across as wicked and unaccepting of the child) that provides the road map for resolving the acquiesced conflict processing. This may come around as a process of selective inattention for cognitive consonance on the part of family member who feel uncomfortable with the idea of having an autistic child as a sibling. This is where opportunities arise for conflict transformational mediation. It is not a problem-solving situation because it is not a one-time problem to be solved, but a lifelong relationship to be re-constructed and sustained (Lederach, 1995).

Furthermore, it is a conflict experience that has various layers - cultural, intellectual, cognitive, social, and economic- yet to be fully mapped and visualized for resolve. It is definitely more than a disease to be cured. It is an existential puzzle requiring different pieces to come together. Temple Grandin (2005) in *"Thinking in Pictures and other Reports from my Life with Autism,"* aptly expressed thus:

I think there are too much emphasis on deficits and not enough emphasis on developing abilities.... (p.105). People are either empathizers or systematizers. Empathizers are people who relate to other people through their emotions. Systematizers are people who are more interested in things than people (p.100). An autistic person's fixations can be their way to achieve some social life and friends (p.105). Quoting Donna Williams, Grandin opined, "I believe that autism results when some sort of mechanism that controls emotions does not function properly, leaving an otherwise relatively normal body and mind unable to express themselves with the depth that they would otherwise be capable of" (p.91).

My observation of the depth of emotions and tears through the interviewing process appears to me as an expression of a conflict of contradictions of love and frustrations. Love for the child and frustrations with the emptiness of the present over-psychologized and medicalized approach to dealing with the concept of autism. Thus leading to some form of cognitive dissonance rife in the autistic family environment. And this is where the conflict and crisis situation resonates and reside inherently with single parents. It is an unsatisfied desire for a cognitive consonant way to relate with the autistic child in a way that accommodates mutual self-actualization, esteem, and safety. A single mother Josephine puts this across this way, "For as long as I am here she is good but I am concern about the future. (Lots of tears and emotions). It makes me feel sad about the future. I want more programs, more research, and better specialists. Right now, I feel it is more of guesswork from the doctors. We need more specialists on autism." In the absence of life processes that guarantees various innate human needs, for self-esteem, security or safety, self-actualization, and other physiological needs life becomes empty. It could also feel depressive, and thus crisis arises in search of hope for autism especially for a single mother feeling isolated and alone in the conundrum of the experience (Confer Olsson & Hwang, 2001; Schilling, Kirkham, Snow, & Schinke, 1986; Patterson & McCubbin, 1983; Lee, Oh, Hartmann, & Gault, 2004; Giallo, Wood, Jellett, & Porter, 2011). Crisis experience here manifest from emotional and cognitive vulnerability, stress resulting from inadequate support structure, and poor social cohesive environment for sustainable resilient coping mechanisms.

### D.) Resilience And Efficiency Model In Managing Non-Compliant

Behavior: The experience of autism and being a single parent from the data would seem a circle of pain and woes. However, in the midst of the crisis of relational conflict and cognitive dissonance of some sort that comes with the search for meaning and resolve, parents of autistic children have equally described a conflict management model that manifests some levels of resilience and self-efficacy strategies. Bekhte et al (2012) observed that autism as a lifelong neurodevelopmental disorder that presents enormous challenging to family members. Thus, they must learn the art of effective and efficient management strategy of the new order to stem possible effects that might complicates family member's mental health. The skill for efficiently managing the pervasively inherent nature of the affect and effects of autism in the family comes across as the innate resilient abilities of caregivers. Resilience is a "dynamic process encompassing positive adaptations within the context of significant adversity." Also, it could be conceived as the "process of coping with adversity, change, or opportunity in a manner that result in the identification, fortification, and enrichment of resilient qualities or protective factors." Furthermore, it is the determined ability to balance risk and protective factors in the face of adversity (Bekhte, Johnson, Zauszniewski, 2012, p.650).

Bekhte and colleagues analyzed benchmarks of resilience theory to include, risk factors, protective factors, indicators of resilience and resilience outcomes (Pp.650-651). I will include self-efficacy as one significant factor in resilience theory. Self-efficacy is an inherent self-motivation belief by individuals about their abilities to manage a given experience. This for me ties up to resilient philosophy of conflict management model that maps crisis experience with faith resolve for possible positive outcome. No doubt over projection of self-efficacy could itself be fraught with crisis if over-confidence fails to yield the desired result. If the resilient benchmark's theoretical foundation from Bekhte is anything to go by, then we can analyze this thematic piece by looking at the risk and opportunity factors for resilience as described by research participants. It is this described risk factors by parents that make them susceptible to distress and crisis. It comes from feeling isolated and not understood by anyone else about the journey with an autistic child. There is the constant fear about the future of their autistic child, obsessive noncompliant behavioral challenges of the child, the child's poor social skills that makes connection with the rest of the world scary, doubt about their parental competence, and insufficient support services network. Those are the angles of stress and vulnerabilities for caregivers. They are the described risk factors from the data that parents perceive as their layers of conflict and crisis experience. The contents of the conflicts describes as identity conflict, verbal aggression/non-compliant behaviors, poor communication model, perceived incompatible goals, perceived scarce resources, zero-sum thinking about the uncertainty of the future, and power-balancing struggle.

Bush and Folger (2005) analyzing on human nature and capacity in conflict transformation opined in human relational theory that "human beings have the inherent capacities for strength (agency autonomy) and responsiveness (connection or understanding). And an inherent social or moral impulse that activates these capacities when people are challenged by negative conflict, working to counteract the tendencies to weakness and self-absorption" (p.54). Human relational theory summarizes the various factors that single parents of autistic children described as their management model resource from the available data (refer to Appendix A). All the parents interviewed held back in describing their experience as negative. They will rather see their experience as caring for a child that is different but challenging. Above all, they feel misunderstood and pre-judged by the rest of the world that do not share their angle of life experience. Staying positive and insulated from negative perceptive attributions are protecting metaphors that form a hermeneutical framing for cognitive coherence of self-efficacy nurturing and a self-fulfilling prophecy for resilience.

Cognitive conflict accommodation metaphors reshaped participants' perceptive model of their routine stressors from negative to the ability for adaptation, and determination for working through the challenge with the hope for a rewarding resilient outcome (confer Walsh, 2002; Bekhte, Johnson, Zauszniewski, 2012; Farmer, & Reupert, 2013; Lerna, Calhoun, Mikami, & Reyes, 2012; Almeida, 2005). This protective factor of resilience pave way for resilient indicators of paternal and maternal empathy and firm determination in the face of child's aggressive and non-compliant behavior, or incompatible goals of trying to teach the child either social skills, or simply insistent push to help the child learn the art of getting along with siblings. From the descriptive account of both married couples and single parents, it is quite evident that what has evolved upon the diagnosis and full blown autistic behavioral manifestation of the child is a change in caring paradigm that absorbs the negative energy for a transformative interactional conflict management model (refer, Roosa, 2000). These change in child caring paradigm also served as moderators of risk factors in the daily experience of incremental stressors from tantrums through inappropriate bathroom usage etiquettes to insistent noncompliant, self-absorbed, and aggressive behaviors. The amount of social support from

extended family members, married partner, and siblings equally provides a safety net for some participants. For those without these enormous support systems the protective nets only came from their caring paradigm shift of taking one day at a time and seeing the child in the child, rather than the autism in the child.

The goal of virtually all the parents interviewed in all their resilient efforts is to see improvement in the life of the child. Roughly, an estimated 30% of the parent calculated the outcome of their resilient effort as positive. This came from the evident improvement in the communication interaction like being able to engage in a more productive interaction with their child, as the child grew older. Additionally, positive outcome came from efforts with securing various trial therapies that worked to improve the skills of the child. The result became rewardingly visible as some of the non-verbal children regain their speech abilities, improved eating habits, minimized tantrum, and non-compliant behaviors. When this happens, parents become less crisis orient and saw reduction in their stressors. For most single parents with their child still at a relatively younger age, the resilient outcome could only be hoped for. Furthermore, evidence of other autistic children manifesting improvement counted for a reason to sustain hope and cave in on self-efficacy process of not giving up on their search for best transformative human theory practice. While previous studies on the associations between parental stress and autism advanced various reasons for the amount of stress that parents acquiesce ranging from severity of the disorder, level of access to education and healthcare (Schieve et al., 2006; Lerner et al, 2012; Almeida, 2005; Karst, et al. 2012; Ludlow et al., 2012; Weiss, et al., 2013). The finding of this research affirms but elevates those stress levels for single parents for the different hermeneutical reasons already analyzed.

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E.) The Married vs. Single Parent factor in Caring for an Autistic Child. On a general note, the experience of married couples and single parents on the phenomenon of autism remain for the most part similar. Nonetheless, the structure of experience presented a nuanced that is existentially different on the levels of reality perception and support system. Just as single parents did not all fit into the same module of structural experience, so also some married couples managed the experience with differential perspectives. Previous research literatures on the experiences of single parents with autism are relatively sparse but a growing number on outcome for normative family structure. However, Freedman, Kalb, Zablotsky, & Stuart, (2012) conducted their research on relationship status among parents of ASD and found no significant association for increased risk factor for children living with single parents. The gap in this study is that it controlled only for children with no emphatic control on the experience of single parent caregivers themselves. Karst, Vaughan, & Hecke, (2012) equally noted this gap in some available literature on autism, indicating that while research on child autism focus could provide evidence for best practice, it is improbable that impact in the life of a child will yield significant result if its effect on the caregiver is not taken into cognizance. The wellbeing of a child is to a large extent predicated on the variables of environment of growth and maturation. Parental caregiving resilience and self-efficacy plays a significant role in that hypothetical environment.

Comparative data from this research presents the following notable differences between married couples of both parents of the child living together and single parents living without the regular presence father or total absence of the child's father. Firstly, not all single parents have the same condition of living status. 51% out of the 14 of those identifying themselves as single parents among the 19 participants interviewed identified themselves as never married, 5.6% divorced, 5.6% divorced and remarried, 5.6% identified as living with current husband but more or less single by all standard and seeking divorce while 5 married couples enrolled and interviewed for this study. As some previous studies already indicated single parents of handicapped children came across as prone to experience of extraordinary stress compared to their married coupled counterpart (Schilling et al. 1986). Some of their stressors include job insecurity, financial constrain, poor support system, and parental self-efficiency dilemma. Single parent participants in this research expressed certain experiences that accords with this previous findings. While some participants attributed their being single to having an autistic child, a good percentage out of the 51% that were never married indicated the father of their child distanced himself from the family because of the autistic child. At least one of the participants expressed poor support system and so seeking a divorce. There was equally the case for a liability factor in guise of the father walking out of the relationship knowing fully well that his side of the child's family has the history of autism. This experience impacted happiness and family satisfaction that probably explains the amount of emotions this segment of the participants displayed as they recount their experience with autism.

For the most part married couple with both partners living together had significant emotional presentation of their experience but nonetheless expressed satisfaction with their family experience. At least two of the participants indicated that their journey with autism solidified their marriage despite the challenging process. They expressed the

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benefit of having a partner in the experience that could have otherwise proved more cumbersome. Significantly, all the married couples interviewed had a stay-home-mom arrangement to care for the multiple medical and educational arrangements for the autistic child. This support and division of labor network provided a resilient proactive factor for the family. It buffered safety, relatively stable financial resources and esteem/coping mechanism. These are the evident resources falling short for the single parents possibly making them more vulnerable to attendant stress and crisis. Moreover, for at least two single parents that had an arrangement for a constant presence of the child's father the resilient protective factor secured as attested (Deborah a single mother, for example, indicated this). While participants expressed the satisfaction and transformative experience they have gained from caring for an autistic child, accounts presented demonstrates an extraordinary and overwhelming experience that take the resilience to task. These ironic expressions of experience were equally observed by Mullins' (1987) research titled, "Authentic Voices from Parents of Exceptional Children." Finally, while the general emotional experience of connection with and worries about the future of the child remains the same for both single parents and married couples, the structure of their resilient methodology differs by the amounts of resources available, and outlet for stressors.

# E.) Advocacy on behalf of Autism in Social And Community Expectations:

Autistic advocacy could be categorized as parental social action about the experience of caring and securing the various needs of their autistic child. The world of autism and caring for an autistic child is described by participants as a free for all and hallowed ground for isolation and exploitation. Isolated for want of understanding and exploited for desperate need for cure and care. Nancy Shute (2010) in "*Desperate for an Autism Cure*", corroborated this idea of isolation and exploitation when she indicated on the myriad of bogus claims for therapies and cure on the subject of autism that have plundered and taking undue advantage of parents of autistic children desperate for cure. Aside from the desperate search for cure, participants in this research indicated their frustrations and challenges with the education provisions for their autistic children. Over the last decade through the "*Education for All Handicapped Children Act, Individuals with Disabilities Education Act (IDEA), Individualized Education Program (IEP), and Free Appropriate Public Education (FAPE)*" (http://www.p12.nysed.gov/specialed/idea/) various opportunities have been created to meet the incremental needs of disabled children. These policy provisions are often implemented to respond to the growing challenges to previously existing educational programs that failed to recognize the special needs of children with disabilities.

The IDEA, IEP, and FAPE aimed at ensuring safety and inclusiveness in all public schools, provision of transportation, and tailoring programs to meet the specific needs of these groups of children in which autistic children are fully recognized. Some of the challenges of parents with these policy provisions are the unilateral application of the provisions. For them, implementation of the policies often fails to recognize the differential needs of disabled children. Autistic children from participants' point of view often placed in a program that does not meet the specific needs of an autistic child. Some participants indicated an experience of having their autistic child placed a school for the mentally disturbed. Therapies and medications that are not appropriate for the child often come with wrongfully placement in a school. Within this experience, parents resort to challenging the system. Dora married with 3 children for example recounted spending \$50.000 annually to challenge the Board of Education in court towards the interest of getting their autistic son for the right program suitable to his needs. 90% of the single parents interviewed narrated harrowed experiences of trying to get their children into the right program. While acknowledging non-denial of the right to be in school with the various transportation provided for the most part, participants indicated inequitable distribution of appropriate schools in the state of New York.

The challenges of getting information and navigating the system for limited programs available for their child's specific need described as daunting and incredibly stressful. For a single parent, this could be a nightmare. It could be philosophically analyzed that the inadequacy of information dissemination process about the amenities available for autistic children remain an Achilles' heel for the various policy provisions otherwise made available to care for autistic children. Secondly, regardless of the various legislations, educational programs are yet to evenly distribute in communities. When such programs are available, they do not take into account the different diagnostic needs of autistic children. From the account of participants, it noted that educational services provided lag behind in the abilities to differentiate between the kinesthetic of autism or the differences between an autistic child and the mentally disturbed child. In order words, blind application of the policy comes with a liability of additional stress for families already over stretched. What is needed therefore, is a comprehensive information package that is easy to access and out there for the entire community and institutional arrangements.

In brief, the data suggests based on the experience of the families with regards to accessing information and services for their needs, they feel ignored, isolated from the social life around them, systemically oppressed and deprived of the services that policy provision guaranteed for them and their autistic children. Despite the poverty in the implementation of the policy provisions, there is that resilience and determination to make a difference in the life of their autistic children. What the cry and call for change implies therefore is a comprehensive framework for social action and emancipation from the perceived cleavages of oppressive denial of access to required services. This is where the combination of the transformative human relational theory, speaking on the inherent capabilities of the human beings for strength and responsiveness for action framework of critical theory is needed. The tools of critical theory could be viewed from the point of view of seeking emancipation from all form of oppressive experience that impinge on human freedom, social needs, psychological powerlessness, political isolationism, happiness and rational ordering of society (Kellner 1990, p.12). These conceptual frames of reference are what single parents of autistic children perceive to be inherently begging for action in their journey with autism. There are enormous legislative provisions that demonstrates government's interest in what happens to the autistic child but there is an enormous gap in policy implementation that directly respond to the daily needs of these families from their experiential perspective.

#### Conclusion

While research on the phenomenon of autism is a field that is constantly evolving, research on the subject for the most part revolves around a knack for cure. From the information gathered above from parent caregivers, it does appear that one layer of needs yet to receive significant attention and capital investment is on the needs of caregivers themselves. This experience apparently complicates what parents consider as effective and efficient care for their autistic child. Single parents especially feel ignored and isolated in the program design for the child. This isolation, judgment, financial liquidation, and emotional capital alienation and extenuating caring burden task their resilience and conflict behavioral experience. Lastly, what appears apparent is the need for a multifaceted layer of response to managing the autism pandemic experience. More especially, while therapies are breaking grounds in improving the life of the autistic child, conflict resolution model is imperative for the various layers of conflict behaviors like aggression, non-compliant behaviors, and conflict communication strategy between the families and the autistic child. Essentially, we could summarize the variable relationship in this research finding to include the presence of an autistic child for a single parent raises the bar of stress and crisis experience. The various variables that stimulate these negative associations described thus: increased caring burden that comes with extenuating needs of the autistic child, inadequate information and support system leading to social alienation, negative psychological impacts, stereotypes and identity /relative deprivation effects raising the resilient risk bar factor thus leading to isolation and helplessness experience. What possibly leads to crisis experience therefore is the excruciating exclusionary feeling of helplessness.

# CHAPTER SIX: General Conclusion: Summary, Implication, and Outcome of Study

The foundational philosophy behind this study was an attempt at understanding the impact of autism in the life of single parents. Interest in this research came from personal experience of single parent of an autistic child who committed homicide and suicide. This harrowed experience created the nudge to know more about the nature of autism and single parenthood and grounded the choice of phenomenological approach for the research.

Over the last decades, several studies have been conducted on the subject of autism and family under different titles and investigative perspective. More prevalent among them is in the field of clinical science and quasi-science. For example, while social scientists focus on the phenomenon predominantly from psychoanalytical perspectives (stress and resilience measurement, impact on siblings, family structural adjustments etc.) the hard sciences (medicine), is nuanced on best practice on finding cure and therapeutic managements of the disease. While these excellent researches have helped to create better understanding of the impact of autism in the life of a child and the family in general, from a psychoanalytical and medical worldview, there has been little investment on the concept of autism from a conflict relational angle. This research therefore attempted to bridge this gap by opening up discussions on the perspective of conflict analysis behaviors of the autistic child and the single parent. The research adopted a phenomenological investigative analytical tool for data generation through structured and unstructured interview process. What is autism? The CDC defines autism as: "...a group of developmental disabilities that often are diagnosed during early childhood and can cause significant social, communication, and behavioral challenges over a lifetime. People with ASDs have a different way of understanding and reacting to people and events in their world. These differences are caused by the way their brain processes information "a group of developmental disabilities that can cause significant social communication and behavioral challenges (CDC ADDM network Community Report 2008, p.2).

For most parents in this research, autism is just another way of life that makes a child different from every other child. This exceptionalism predisposes them towards needing more attention and care that opens up emotional and cognitive potentials of being a lifelong baby. What is a single parenthood? Single parenthood is understood here as an unmarried male or female with no consistent presence of a significant other in his or her life. What defines as consistent presence is relative to the individual as some participants in this study indicated.

#### 6.1 Summary of Study

For a more perspective analytical understanding of the phenomenon a literature review and theoretical analysis was conducted. While the literature review provided background information on the current understanding of the subject of autism and single parenthood the theoretical analysis framed the hermeneutical mindset for lunching into the experiential descriptive thoughts of participants on the phenomenon. Generally, there are populating research on autism and family but with limited emphasis on isolated association with single parenthood. The available literature review seem to come to a conclusive consensus on the increased risk factors, mental health problems, and sustained stress level of parents of autistic children compared to parents with children of other disabilities. (See Olsson et al. 2000, p.540; also see, Solomon, et al. 2012; Brown et al. 2012; Hall et al.; Ślifirczyk, et al. 2013; Weiss et al. 2011; Schieve et al., 2007, p.5114; Reed & Osborne, 2013; Jennings, 2005; Bendixen, Elder, Donaldson, Kairalla, Valcante, & Ferdig, 2011).

Theoretically, the Maslow hierarchy of human needs theory provided analytical tool for looking at the various need assessment background to variables from the data that possibly contributes to the inference of conflict and crisis vulnerability in the life of participants. Resilience theory complimented this human needs theory in correlating the areas of vulnerability, stress, and risk factors, to stimulate further analytical understanding of the resilience outcome and efficacy variables in the experience of the participants of the research. Other theories include stereotypes and identity, relative deprivation, attribution theory, phenomenological theories of autism and single parenthood, critical theory, feminist theory, and family system theory. These theories provided background analytical tool for assessing the different layers of conflict and crisis acquiescing process in what operationalized as a relational conflict between autistic children and their single parents. More specifically, critical theory for example provided a theoretical experiential basis for a social action thinking process on the subject of association of interest between autism and single parenthood and the gap in policy implementation on this relationship constructing layers of vulnerability, risk factors, and conflicts behavioral experience. Finally, a balanced pre-investigative analysis of available

researched information on the subject and theoretical background surgical conferencing on the subject broaden the horizon of possible knowledge areas on the phenomenon under study.

Using the phenomenological method 19 participants, aged 27-52 years enrolled in the study and interviewed for data collection purposes. 51% of those interviewed were single, never married parents, 5.6% were divorced, another 5.6% identified themselves as single and remarried, 5.6% believed they are single though living with a man and processing divorce, 5.6% was non-parent caregiver but single. Additionally, 27.8% represented the married coupled population of participant in the study. While 22% of the participants were Caucasian, 35% were African Americans, and 45% Hispanics. Furthermore, the five stages of phenomenological process of pre-interviewing session, data collection, collation/transcription of interviewing data collection, and analysis of the data gathered guided the process. Research participants were drawn from the data of parents currently taking their autistic children for outpatient treatment at the Montefiore Medical Center facilities in Bronx, New York.

The object of phenomenological investigation is to elucidate both that which appears and the manner in which it appears (Kyale, 1996). Thus, the descriptive and the hermeneutical analytical tools of the philosophy of phenomenology were utilized. Interviewing questions were designed to stimulate the descriptive and hermeneutical prescript in participants for the description of their experience (Confer figure 5.1 & 5.2). While the descriptive framework provided the essential structure of experience of autism (Kumar, 2012), the hermeneutical tool enabled understanding of the environment of the experience (Simpson, 2007). It is the recognition of the environmental influence of the experience that makes theoretical application inevitable for analysis. Analysis of the data adopted the combination of the Van Kaam phenomenological analysis method (Moustakas, 1994, Pp. 40-41) and the Coding analysis toolkit for qualitative research (Burnett, 2009; Lu & Shulman, 2008). Phenomenological methodological intentionality is the production of knowledge or true understanding of a phenomenon through a succinct descriptive account of participants' experience while noting the environmental influence that shapes such experience. The choice of method therefore is reflective of what the researcher judge suitable for the production of the knowledge of the phenomenon intended. Besides, as Wojner & Swanson (2007) noted phenomenological process is less of a dogma as it is a cognitive and qualitative process that gives the researcher the freedom to choose his process in so far true and unbiased understanding of the phenomenon is engaged (P. 175; Jonas-Simpson et al. 2011). While the coding analysis toolkit was utilized to get a sense of the statistical representation of the invariant and textual experience of the phenomenon of autism among single parents and married couples, the Kaam method provide a stage by stage hermeneutical analysis of the data generated from the interviewing process.

The data collected revealed different layers of experience of the phenomenon of autism by single parents and the controlled group of married couples. These include experience of social and emotional isolation, relational conflict, a pervasive noncompliant behaviors from autistic children, poverty of information about needed helping resources, family dissonant experience, ineffective communication model, financial stress, job insecurity, safety problems, fears about the future of the autistic child, esteem and physiological needs, crisis of self-actualization, and ardent desire for public policy modifications. Thematic description and analysis of the structure of experience identified, 1.) Daily impact of caring burden, 2.) Gaps in the support system, 3.) Crisis experience of dealing with an autistic child, 4.) Resilience and efficiency model in managing non-compliant behaviors, 5.) Perennial fear for the future of autistic child, 6.) Married vs. single parent factor experience and 7.) Advocacy on behalf of Autism: These generated themes from the data aptly described the structural details of various kinds of normative experience that work in tandem to engineer conflict and crisis experience of living and caring for an autistic child. While the data revealed for the most part significant crisis and resilience risk factors in the life of single parents of autistic children, there were equally areas of parental satisfactory experience of feeling fulfilled for being present to care and advocate for their child. Significantly also was the fact that comparative experience of caring for an autistic child between married couples and single parents remain similar on the emotional attachment level.

However, on the structure of experience of meeting personal needs of safety and security, financial stress, support system, and physiological needs, single parents presented an elevated level of conflicts and stress. Thus, we could conclude that single parents of autistic children indicatively are more structurally stress from unmet safety needs, physiological, and other theoretical hierarchy of human needs compared to married couples in caring for an autistic child. Lastly, the study revealed a heighten levels of self-fulfilling prophecy of "*without me the child is dead mentality*" that is not only feeding into stress levels but equally stimulating conflict behavior of zero-sum thinking, and attributions leading to a vicious cycle of crisis acquiescing behaviors with minimal

resilient outcomes. This research therefore revealed a negative variable association between an autistic child and a single parent. In order words, raising an autistic child negatively impacts single parents through various synergistic variables of caring burden and gap in the support system. Some of the inherent conflict typologies identified as evident part of the crisis engineering process on the impact of autism on single parents include intrapersonal conflicts arising from caring burden and interpersonal conflict often stimulated by the pariah nature of autism. Others include intergroup conflict being a product of socially constructed experience of stereotypes and poor institutional support system. The research therefore revealed these experiences as defining for the most part the conflict and crisis impact experience of autism on single parents.

## 6.2 Implications of study

Findings from this research presented some research and policy implementation implications for reconsiderations. These research implications arise from the shared experience of participants implying inadequate support system and lack of information on available resources to aid their exclusive journey with autism. When these experiences compared with the depth of research funding and programs from both the federal government and state agencies including non-governmental agencies, the implications are indicative of a gap between policy intentions and its comprehensive results. Some of the reasons identified are: current research practices funded by different agencies in the field of autism lack significant bearings or interest in integrating finding cure for autism with their direct home based parent caregivers. For example, Autism Speaks, one of the leading non-governmental organizational voices for autism, has the following as their core policy conditions for funded research activities:

1.) Identify risk factors for ASD that can lead to prevention and improved diagnosis and treatment, 2.) Reduce age of detection and improve access to early intervention for children with ASD. 3.) Enhance quality of, and access to, medical care for individuals with ASD. 4.) Promote the development of safe, effective interventions and medicines to reduce core and associated symptoms of ASD throughout the lifespan. 5.) Improve the health and outcomes of adults with ASD from a lifetime perspective (http://www.autismspeaks.org/science/grants-program).

Additionally, between 2008 and 2012 Interagency Autism Coordinating Committee (IACC) in their strategic plan objectives recommended and funded 535 projects. 13 projects in 2008, 36 in 2009, 211 in 2010, 137 in 2011, and 138 in 2012 with estimated budgetary allocation of \$123, 816, 730. In all of these research projects only two of those projects focused on impact of autism on parents (http://iacc.hhs.gov/strategic-plan/2013/services.shtml#q5). Incremental policy generation and implementation gaps on the specific needs of parents and especially single parents of autistic children are quite obvious from the current scope of research funding and program interests. As described by participants and Grandin (2005), incremental policy focus is on treating autism as a disease to be cured and less about a life to be fully studied and understood in all its ramifications.

Furthermore, the Combating Autism Act of 2006 reauthorized in 2011 (CAA) that outlined researched and program interest areas for the IACC was not equally inclusive of the needs of parent caregivers of autistic children in all their policy legislative developments cum budgetary allocations for this aspect of autism care. As expected enormous emphasis is placed on finding cure and best practices on autism without realizing the concomitant needs of those who bear the daily burden of autism. IACC under the CAA is the federal advisory committee charged with coordinating all the various efforts aimed at combating ASD. The mandate of IACC under the CAA is "to develop and annually update strategic plan for ASD research, and monitor federal activities related to ASD" (IACC, 2013, Update on strategic Plan). The IACC is charged with providing guidance to Health and Human Services (HHS) on research and enhanced services specific to ASD.

Now, if this umbrella body does not deem it efficient to allocate budgetary resources that will stimulate interest in investigating and incorporating the caring burden of parents in the broader strategic plans for combating autism then such services will be selective and understated if at all given. Thus the information from this research about the experience of single parents of autistic children of being ignored and isolated to be on their own in the battle with autism bears some policy indictment merit. Some of the problem that bedevils most of the policies on disabilities including autism is the exclusive definition of disability from a medical perspective that limits and relativizes service to medical jingoism (Fischer, 1995, p.133). It is this policy over emphasis on cure that sidelines parenting agents of care for autism. In the absence of a broad policy that is

binding and inclusive programs are starved of its clarity of goals and objectives for the common good.

In the New York State where this research was conducted, there is presently no task force on autism. Several attempts at passing laws to that effect have failed just as cases for autism is on the increase in the state. "In [the year] 2000, 6,752 or 1.53% of children ages 3-21 who received special education services in New York have autism. In 2011-2012, 24,533 or 5.42% of children with disabilities ages 3-21 who received special education services have autism" (Easter Seals, Inc., November, 2013). Below is the tabulated breakdown of the statistics.

	Child Count in 1999-2000	Child Count in 2011-2012
Age 3-5	51,665	64,082
Age 6-11	175,186	173,721
Age 12-17	191,385	191,032
Age 18-21	23,097	23,484
Age 6-21	389,668	388,237
Age 3-21	441,333	452,319

*Figure 7: Source: Reported by the State of New York in accordance with Section 618 of IDEA to U.S. Department of Education, Office of Special Education Programs* 

Notwithstanding the aforementioned lapses, there are various but limited

programs in different states that cater for the needs of parents of autistic children across the nation evolved under the CAA and IACC. In New York State for instance, there are

only 13 Special Education Parent Centers across State. This program as good as it is, is

for the most part designed for parent's management of educational needs of the child. The scarcity of inclusive programs under the present circumstance is imperative of an oversight on other incremental needs identified by parents in this research. For example, under the New York State Office of Children and Family Services,

New York State is divided into fifty-eight local social services districts. The five boroughs of New York City comprise one district. Outside of New York City, each district corresponds to one of the fifty-seven counties that make up the remainder of the state. County Departments of Social Services (DSS) provide or administer the full range of publicly funded social services and cash assistance programs. Families whose income meets state guidelines and who meet other criteria may be able to receive a subsidy to offset some of their childcare costs (http://www.ocfs.state.ny.us/main/localdss.asp).

Some of the findings in this research also indicate that participants feel available programs are either inadequate or often time policy clauses eliminate them from being able to access those programs. Some of the programs available include New York Metro chapter of National Autism Association with an inclusive focus on mentoring programs for parents of autistic children. Healthy Families New York, offering visiting programs for at risk parents of autistic children, Fatherhood Initiative helping families maintain strong relationships and enhance father's economic stability, and Center for Parent Information resources, among others. These programmatic frameworks lacked inclusive viabilities of recognizing the exclusiveness of the needs of single parents of autistic children. Once more, we could look at some of the policy problematic goals of caring for the disable that focuses on rehabilitation, employability, and independence. As Shafritz and colleagues (2004) noted good ideas are not lacking in public policies but the ability to make policies benefit its projected audience through its bureaucratic process is the hallmark of effective policy evaluation. According to these scholars, "policy implies theories. Whether stated explicitly, or not, policies point to a chain of causation between initial conditions, and future consequences" (Shafritz, Hyde, & Parkes, 2004, p341). If this policy theoretical presumption is anything to go by, it could be argued that present policy design on combating autism is galvanized more around future consequence. It is calibrated around a world where the autistic child is cured and rehabilitated, and attained the goal of self-dependency, but downplaying the initial condition of the negative impact of the autistic child on its family ecosystem. If the base is weak, then how can the top be sustainable?

The absence of policy inclusiveness framework that stimulates and guide programs therefore sustains stress related vulnerabilities and crisis risk factors for single parents of autistic children that this research finding found to be more impacted by autism. As the saying goes, "a healthy parent breeds a healthy child." The presence of so much risk factors and vulnerabilities in the life of caregivers, especially single parents demonstrates a lacuna in the program design to care for the autism problematic. This study therefore provides yet another opportunity to re-assess the phenomenon of autism away from current clinical frame of reference to include a dimensional contribution from the humanities. This perspective contribution will update policy makers to include the significant importance of looking at the phenomenon of the subject of autism in a more globalized perspective compared to the current over-*clinicalized* neurological research practice. For example, statement for the declaration of World Autism Awareness Day, 2014 by President Barack Obama reflected and confirmed the exclusive policy framework of cure the child let parental caring burden take care of itself. An inclusive caveat will include looking at the full normative environment in which an autistic child is to live and be treated and taught new occupational skills. This inclusive outlook has to be fully funded by IACC. As McAdams et al. (2006) indicated various environmental factors play significant and undeniable role in the evolution and growth of every child. Hence, research and autism program that minimizes or ignores the emotional and caring burden of single parents risk half hazard results.

In brief, the findings of this research challenges policy makers and program providers to reassess the effectiveness and efficiency of their policies and service program on how they better fit and serve the wider population of those impacted by autism. It raises questions that demand ongoing research on the significant impact of autism on the single parent population that serve a greater number of autistic children. According to the U.S. Census Bureau, Statistical Abstract of the United States (2012) as at 2008, 29.5% of all households with children are single parent families. Moreover, between 1980 and 2008, the total percentage of births to unmarried women increased from 18.4% to 40.6%. If the current statistics of population of autistic children in the United States is anything to go by, with 1 in every 68 children diagnosed as autistic then we got to look further. For example, the divorce rate in family with autistic children estimates between 70-80% plus (Freedman, Kalb, Zablotsky & Stuart, 2012). The statistics of autistic children with single parents is not clearly established at this point. However, from what is statistically established, we could conclude reasonable numbers of autistic children live with single parents. Essentially, single parents of autistic children population are underserved, not fully represented in most federally and state funded research and therefore require further investigation to further establish the need of this segment of the population for better service delivery in combating autism pandemic. Lastly, there is the need for more social and clinical advocacy for the vulnerable population of single parents of autistic children. Until this is taken seriously, the plausible needs and conflict and crisis challenges of single parents of autistic children will continue to be ignored to the detriment of the goal of effectively and efficiently combating autism plight.

In the light of the afore analyzed implications of the finding of negative impact of autism on single parenthood there will be need for a sustained and effective advocacy mechanism that carefully articulate those significant issues involved whose policy shift and legislative effort will improve the circumstance of the plight. Firstly, it will be significant to understand the existing concrete gulf between the descriptive experience of the negative impact of autism on single parents and current policy provisions. These include the absence of customized afterschool programs and parks for autistic children in communities. It will add up to improve educational facilities funding for autistic children in public schools that recognizes the individual needs of the various types of autistic disability of a child with trained teachers to handle the type of needs. This imply additionally, enhancing neighborhood public schools with skillful teachers and funding to cater for the needs of autistic children as against present few facility widely dispersed across counties. For the single parents, legislative provisions should be put in place that mandates programs to recognize and includes specific programs that meets the unique

circumstantial needs of single parents. Secondly, beyond the current provision of nondiscriminatory clauses in workplaces, there should be specific provisions that respond to job protection for single parents of autistic children. Additionally, conflict competence training and therapies for single parents should become a policy provision mandated by IACC and CAA in all their research and program funding. Thirdly, to accomplish these enumerated specific goals, certain political will have to be employed both at the federal and state levels. Effective lobby for this desired outcome will require mobilization and galvanization of communities around the high significance of this plight as a cause for the interest of the autistic population and indirectly the health and wellbeing of the entire population as a matter of justice on behalf of the autistic child and single parent. The apparatus of the social media like Facebook, twitter, Television Ads, and other related effective media outlets will have to be employed as a sensitization tool. The message could read: "#Save Autism with Single Parents" or "Autism and Single parents need *your attention.*" I do believe more information like this will force politicians to take a cursory look at the cause for significant attention.

#### 6.3 Outcome of study

In simple term, this study provides significant evidence to the fact that Single parents overtasked in their role as caregivers of autistic children. This experience of being overburden in caregiving at all levels further elevates the stress vulnerability of single parenthood. Thus making them a particularly at risk group for conflict and crisis experience. This supportive research evidence is in accord with previous research finding on the evidence of stress and crisis association in the care-giving role between families and autistic children (See among others, Reed & Osborne, 2012; Schilling, et a., 1986; Kearney & Fulbrook, 2012; Ślifirczyk, Krajewska-Ku, Brayer, & Maciorkowska, 2013; Weiss & Lunsky, 2011; Schopler & Meshibov, 1984). As analyzed above, the conflict and crisis experience of single parents does not necessarily imply the absence of programs but a programmatic structural deficiency that presumably ignores the needs of the exclusive group of single parents with autism in design and implementations. More emphatically it does appears the role of caregivers are not practically factored into a realization that care for the vulnerable needs of especially single parent caregivers represents a very important variable in the care and management of autism.

There are enormous researches that indicate the invaluable role of a good family cultured environment for any child to thrive effectively (Kearney & Fulbrook, 2012; McAdams & Pal. 2006; Hertzman, 2002; Keating & Hertzman, 1999). Environmental factors do not only inform the psychological and physiological wellbeing of a child, it equally speaks to the effect it has on the parent caregiver as well. And there are different factors that could either engineer a favorable environment for the child just as it is for the parent. In the case of a single parent with an autistic child, it does appear the setting is already predetermined for a dual carriageway of stress generating circumstance of living. What is needed therefore is social service network that minimizes the risk factors while boosting the protective factors for the wellbeing of the child and other agents in the family social environment. The absence of such programs further exacerbates the level of stress and mental constrains of single parents whose social leverage is already limited by the condition of being single or without a significant helping other. This absence presuppose a dire need for encompassing system that cares for the needs of the caregiver

and the child not as a defined stigmatized disabled entity but as holistic partners in the community. Current service plan delivery on autism at least as described by participants in this research structures as follows in figure 7 below.

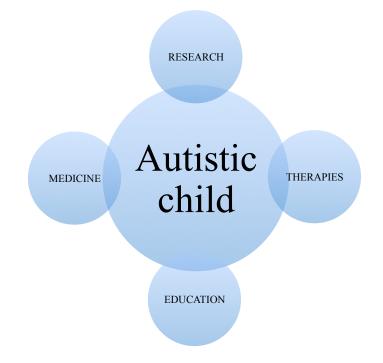


Figure 8: Current Service delivery chart for autism

The above diagram representation from participants shared experience indicates the autistic child is often treated like an incremental research subject. It seemed autistic children viewed by clinicians and researchers are medical statistics needing cure devoid of the needs of the significant parent caregiver variable. Importantly, the parent caregiver variable humanizes the autism subject. As a parent in this research noted, "an autistic child has a right to be autistic and a place to be autistic and my home is that place." Temple Grandin (2005) in *"Thinking in Pictures: And Other Reports from my Life with Autism"* observed, autistic people are systematizers who focus on things rather people as against what emotive people called normal would otherwise do. What this research reveals therefore is the need for a constructivist and transformational social action that not only facilitate the needs of single parents of autistic children who see the other side of autism, but also the need for an inclusive research and supporting program reorientations. Firstly, there is the need for coefficient research activities that will recognize the endemic interactions between parent caregivers and autistic children and so fund and investigate inclusively in order to optimize results that will mutually benefit these interrelated human variables. Thus, an autism inclusive research will optimize both the autistic child and parent caregiver for effective dialogue leading to efficient research outcomes. See diagram below for needed operationalized research design for efficient outcomes.

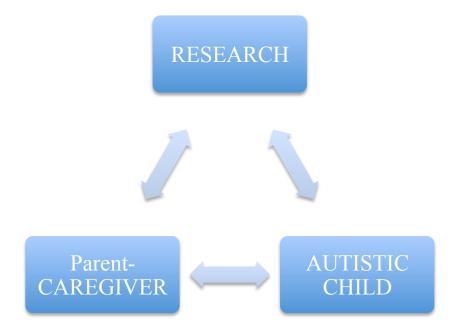


Figure 9: operationalized diagram for autism research outcomes

Secondly, while there are incredible needs for enormous psycho-clinical research activities aimed at discovering effective cure and efficient management of the autism

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epidemic, the research data equally demonstrate the need for an inclusive support system focused on conflict behavioral management quotient for single parents of the autism population. If the CAA and IACC will ultimately meet its target of effectively combating autism, it needs to know that autism is not a variable in isolation as this research reveals. A multi-faceted human experience approach to care will not only influence the child, but parent caregivers as well. Thus, there is the need to start engaging legislative policy advocacy funding allocations in a way that is more inclusive and pervasive. Desired program design for combating autism from this research assessment could look like the following in diagram:

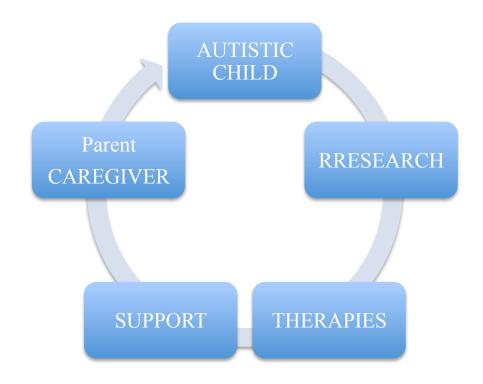


Figure 10: Projected program design for autism care

From the diagram above (figure 9), we have a circle of activities that is inclusive and mutually interactive. The autistic child remains the center of attention informing research activities. Information from research will operationalize therapies/medical interventions. Psychosocial therapies will work in tandem with various support systems that include, education, after-school programs for the autistic child, and conflict resolution tools for parent caregivers to manage various conflict behaviors feeding into risk factors and stressors. The impact of these therapies and effective support systems informed by research will optimize the parent caregiver to stimulate efficient outcomes for the autistic child. While the psychological therapies will build the occupational and social skills of the child, medical team will respond to the medical needs, conflict resolution specialist will work to improve transformational conflict management skills of both the single parent and the autistic child. Fountain, Winter, & Bearman (2012), in "Six Developmental Trajectories Characterize Children With Autism," observed that education and socioeconomic factors influence treatment outcomes for children with autism (Fountain, et al. 2012, p.1112).

What this research finding by Fountain and colleagues indicate therefore, is the impact of the environment of the child, the level of cognitive and economic wellbeing of the mother as significant thriving factors for the autistic child. Thus optimizing programs for single parents will not only positively impact the life of the parent caregiver, it will strongly and positively drive the thriving curve of the autistic child as the Fountain and colleagues research supported. In order words, the fewer the conflict stressors and the more cognitively empowered a single parent is, the more the chances of positive treatment outcome for the autistic child. Additionally, Fountain and colleagues noted, understanding what drives the outcomes of research study is an important piece for optimizing its results (Ibid). Hence, the recommendation to optimize autism research for

the autistic child and caregiver bears eloquent significance. Some of the single parent's conflict incident experiences issues revealed from this research are shown in the following diagram:

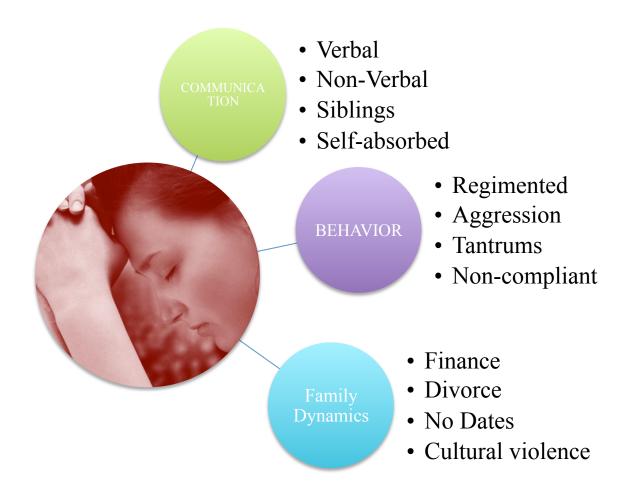


Figure 11: Conflict incident experience

The object of conflict transformational mediation is to reconstruct a relationship that has fallen apart or falling apart as the case may. In the case of single parents' relationship with their autistic child, its object is to empower the single parents to improve on communication and manage the different listed conflict behaviors of the autistic child. Participants expressed mutual frustration experience with non-verbal autistic children when communications becomes near impossible followed by aggressive non-compliant behaviors (see also Hodgetts, Nicholas, & Zwaigenbaum 2013). In this case, a transformational non-violent communication method of observation, feeling, needs, and request becomes relevant for resilient solidifications and enhancement (see Rosenberg, 1999). Through synergistic tools of conflict mapping and conflict coaching, the innate resilient skills of single parents could be strengthen to be strategically more problem solving than acquiescing. Moreover, McKay (2012) noted, context of family cultural dynamics of conflict mediation is paramount to creating an environment of a sustained peaceful family life (McKay, 2012, In Duckworth & Kelley, 2012, p.111). Hence, the more through research the needs of the single parents are unearthed and included in policy and program evolution, the more they better served to fulfill their parental role.

Furthermore, it is impossible within the caveat of the vast amount of issue experienced by single parents with the autistic child to have a one-size-fits-all model approach. Each block of conflict behavior will need either a combination of modules or single problem solving module to respond to a specific need. For example, we could consider problem-solving mediation technique for finance and divorce. For cultural violence, that includes, social judgments by family and community, stereotypes, isolations, emotional alienation, and identity destruction, a transformational mediation module will serve a useful purpose. Transformational mediation appears imperative because of the social constructivist badge on the issues involved. It requires didactic, pedagogical, and critical theoretical approach for community communication around the subject of autism. Additionally, cultural violence evokes the need for social advocacy for structural, linear self-emancipation, and self-identity concept reorientation for relating with the rest of the world. Nonetheless, I am keen at recommending the four-module parent education/support group program developed and adopted by The VOICES Family Outreach Project at the Nova Southeastern University as an ebullient conflict transformation tool resource model that will benefit single parents of autistic children.

The VOICES Family Outreach Project (VFOP) at the Nova Southeastern University, Fort Lauderdale Florida was established in 1979 to deal with trauma reduction for families struggling with recurring conflict and low levels of family violence, (McKay, 2012, In Duckworth & Kelley 2012, p.108). The philosophy behind VFOP is to optimize families' ability through shared action plan to enhance communication and family wellbeing. This anchored on the hypothesis that families could effectively attain sustainable change through mediation and other opportunities for individual and family development (p.109). Notwithstanding the fact that this project designed for curbing entrenched family and community juvenile violence, I do believe the sustainable philosophy and model practice by VFOP could strategically engineered to meet the needs of single families of autistic children that are often traumatized, stressed, and depressed from their shared experience with autism.

Summarily, the VFOP model includes 1.) Family violence and conflict resolution training; 2.) Trauma reduction, conflict intervention and management; 3.) Development of multi-media resources for related professional, 4.) Research and report on the effectiveness of VFOP co-mediation model for the reduction of family violence (Pp.109-

110). This model's methods that integrate family therapies and conflict resolution strategies to meet the needs of families, accords with the suggested program design for autism care in figure 9 above. Additionally where VFOP coordinates with law enforcement agents, various stakeholders of the autism project (IACC and New York State Office of Children and family Support Services) will engage for common outcomes. Moreover, the VFOP model could equally provide social advocacy outlets from in-depth research ability for the autism communities. In this wise, the autistic child will be cared for and the feelings of alienation, isolation, and family stressors will inclusively receive desired attention through the service model. The ultimate goal is to build and strengthen the transformative skills of single parents for problem solving. Such an investment will sustainably meet the incremental needs of a lifelong journey with autism. Based on the shared descriptive experience of participants in this research, it could be inferred that an improved community engagement for single parents with their autistic child (conflict resolutions skills, networking, and afterschool programs). This will on the long and short run, improve the quality of life of both the single parents and the autistic child (Russa, Matthews, & Owen-DeSchryver, 2014; Fountain, Winter, & Bearman, 2012). If the quality of life is improved, chances are high that self-efficacy and positive resilient outcome will optimize research and program investments for autism.

Hence, using the honed skills of conflicts resolution specialists single parents will be trained to efficiently handle evolving issues by: 1.) Building the skills of parents in effective conflict communications strategy to manage poor communication problem with the autistic child. 2.) Train parents on issues of family violence and conflict resolution transformative model to handle tantrums and aggressive behaviors from the autistic child, 3.) Equip single parents for trauma reduction, conflict intervention and management by improving the resilient skills for mediation between the autistic child and siblings, etc. These will be part of the VFOP project.

The VFOP intervention could be incorporated to begin by signing parents and child up at the point of diagnosis. This is under the proviso that VFOP is fully integrated into the combating autism project with policy provision and program design funding under CAA and IACC. Such early intervention will emotionally and systematically, preequip the single parents with the required skills as the autism behavioral manifestations begin to unfold in the coming years. 'A stitch in time as the saying goes saves nine.' For parents and specifically single parents that are already engaged with the experience of autism, they should be encouraged to sign up for the program either through their primary care physician with a referral or through contact with a functional VFOP centers located in the community. By this, it is suggestive that VFOP needed to be different from currently dispersed programs assisting parents under different names and missions. The VFOP should be funded by the IACC under CAA and state governments. It is recommended to have direct link to all health systems, locally with easy accessibility to all parents and single parents of autistic children for an intense support system as described above under VFOP.

## Conclusion

This research began on a note of seeking to uncover the conflict and crisis impact of autism on single parenthood. It progressed through the shared experiences of participants conceptualizing their journey with autism summarized in a metaphor of an ambiguous loss of a child (Cridland et al. 2014; O'Brien, 2007). The metaphoric expression not only draws on the challenges of acceptance of the reality of the disease, equally it presents a picture of an enduring emotional journey with the struggles of an autistic child that is present but distant. The concept of autism as a neurological and developmental deficiency in a child leading to different behavioral and cognitive anomalies remains a page to be fully uncovered. The physiological and cognitive impact of the disease on the child is today assessable through various cutting edged medical breakthroughs in the field improved by significant federal funding investments in research. However, the blurring line on the magnitude of the impact of autism on especially single parents has yet to be given desired attention. This axiomatic gap is an enigmatic fallacy of so much care for the disease without attending to the normative nurturing ecological environment of the disease bearer. The assumptive presupposition that all families can be cared for with a one-size fits all approach defies the essence of public policy that solely defines autism as a medical problem without a wider consideration of the social implication of autism beyond a medical disability frame of reference. The emotional and resilient capital investment in autism by single parents as indicated in this research and other previous researches on the subject calls for policy implementation rearmament. Autism as revealed challenges resilience resources of families.

Patterson (2002) in discussion on family resilience and stress theory noted the differences between family resilience as a capacity and family resilience as a process. Analyzing from the point of view of Family Adjustment Adaptation Response (FAAR) model, Patterson contends,

Families engage in active processes to balance family demands with family capabilities as these interact with family meanings to arrive at a level of family adjustment or adaptation (Patterson, 1 988; 1993;). Family demands are comprised of (a) normative and non-normative stressors (discrete events of change); (b) ongoing family strains (un-resolved, insidious tensions) and (c) daily hassles (minor disruptions of daily life). Family capabilities include (a) tangible and psychosocial resources (what the family has) and (b) coping behaviors (what the family does). There are some obvious parallels between risk factors (resilience language) and demands, as well as between protective factors and capabilities. Both demands and capabilities can emerge from three different levels of the ecosystem: (a) individual family members, (b) a family unit, and (c) from various community contexts. The diagnosis of a child's disabling condition would be an example of an individual level demand; marital conflict about how to manage the child's condition would be a family level demand: and community stigma about

Balancing resilient capacity with resilient process becomes daunting when the resources are scarce and near impossible to attain. Single parents as the name implies is a do it all alone experience laced with enormous ongoing family strain of being single. This is a condition often buffeted by mean resource of tangible protective factors and inadequate

disability will be a community level demand (Patterson, 2002, Pp. 350-351).

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physiological and psychosocial resources tasked for personal needs and overburdened by extensive demands of an autistic child.

What has become visible but elusive to the autism care system of approach is the peculiarity of the family ecosystem where single parents function as a unit of the society. Additionally, it taps on insufficient policy development resource on how single parents' resilient capacity and processes co-functions to meet the need of the autistic child. This policy gap makes the support system appear weak and inefficient as it were. American society has come a long way with the single parenthood phenomenon. Nonetheless, in the eyes of those with lived experience of single parenthood, the institutionalized subtle but progressive community judgment of the condition of being single saddled with an autistic child is double-edged sword of alienating and stereotyping stigma that regularly speaks to the heart of attributive perception of how service is rendered. This perhaps explains while service to this group of persons is yet to be fully ceded into the welfare service and policy lexicon of the American policy society. This field therefore needs further research and social advocacy to bring the discussion to the forefront of policy makers. To ignore the need of single parents in the circumstance, and pretend to care for the autistic child is a public policy suicide of a self-fulfilling prophecy that attempts to justify programs at the level of verification through a capitalist cost and benefit methodology (Fischer, 1995, p.125). That policy generation and implementation approach only serves the interest of an exclusive few.

Finally, we could conclude by looking at the core operational variables of this research namely, 'the impact of autism on single parenthood.' The research findings and analysis raises questions that borders on the core values of scientific research and intended outcomes. It challenged the gaps that currently exist between research, policy, and program development on the autism care accelerations. The shared experience of single parents in this research challenges the logical assumptions behind clinical research that is disease centered and elusive evasiveness of the enabling circumstance of beneficence. The result of negative impact of autism on single parents arises from program oversight and research underestimation of the correlation between environment of managing the diseases and projection of cure. The various types of conflict experience of intrapersonal (caring burden,) interpersonal (competing goals of anti-social behaviors and pervasive non-compliant and aggressive behaviors of autistic children), intergroup (gap in institutional support and dearth of information) represents the core operational variables that enabled risk factors and crisis experience that presently defines the impact of autism on single parents. Effective and efficient management of the autism pandemic will necessarily take into cognizance these attendant variables. Thus, conflict resolution competence training remains an invaluable element for program design in favor of autism. It need to be adopt as part of the combating autism project by the IACC in order to aid parents with managing relationship issues that is a key cornerstone in autistic behavioral pattern.

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## **Biographical Notes**

Andrew A. Ovienloba was born and bred in Edo State, Nigeria. He migrated to the United States to further his education in 2004. Andrew got his Bachelors of Arts in Philosophy from University of Ibadan, Nigeria in 1994. He got his Bachelors of Theology from the Pontifical Urban University, Rome, in 1998. For his graduate studies, Andrew obtained his Masters of Arts in Religious Education, (Education for peace and justice) from the Fordham Jesuit University, Bronx, New York in 2006, and Masters of Arts in Diplomacy and International Relation (Global Health and Human Security), Seton Hall University, South Orange, New Jersey in 2009.

Andrew equally has a post graduate certificate in Bioethics and Medical Humanities from the Montefiore/Einstein Center for Bioethics of the Einstein-Cardozo

Bioethics Graduate Education programs, Bronx New York, in 2010. Andrew served as a Calihan Research Fellow for the Acton University Grand Rapids, Michigan,

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Andrew has received awards from different communities, local and international organizations for his work in Nigeria for democracy and good governance, police and prison reforms, peace and justice initiatives and women empowerment. One of several awards received by Andrew was from the Rotary Club International for honorary membership. Andrew currently works as a religion and culture patient/family and staff relations expert at Montefiore Medical Center, Bronx New York. He is also an adjunct faculty of Religion and Human Experience at Columbia

College of Missouri. Additionally, he serves on various ethics committees for different medical facilities in New York. Andrew previously served as the Director of Justice Development and Peace Commission of the Catholic Archdiocese of Benin City, Benin City, Nigeria and served on the board of various government and academic institutions in Nigeria. He has published researched papers in both medical and social science journals on topical issues. For his research interest, Andrew specialized in conflict and crisis intervention, sociology of religion, social constructivism, epistemological inquiry, bioethics, Peace and justice restorative initiatives. He has flare for medial psychology and social content analysis of human cultural and linguistic conflict behaviors and organizational system designs.