Surviving to Thriving
Terminology and Family Reactions to Disability
A literature review

By
Meghan L Gray

Major paper presented
as partial requirement of the
Master of Interdisciplinary Health (M.A.)

School of Graduate Studies
Laurentian University
Sudbury (Ontario) Canada

Surviving to Thriving:

Terminology and Family Reactions to Disability

A Literature Review

Meghan L. Gray

Laurentian University

TABLE OF CONTENTS

ABSTRACT

This literature review examined the theories and models surrounding the topic of family reaction to disability. Five models were assessed in terms of their structure and their terminology. An historical review has been provided to give context for the models under examination. Concerns with terminology used include the application of the words adjustment and coping within Patterson's (1988) Family Adjustment and Adaptation Response model (FAAR), as well as the applicability of the construct of resilience to the FAAR (Patterson, 2002). The relationship between theories was also discussed with the FAAR and Scorgie, Wilgosh and Sobsey's (2004) Transformational Outcomes model found to be the most complementary.

DEDICATION

Dr. Shelley Watson, without you none of this would have been possible. You have been my torch while I travelled through the dark and misty forests of theoretical analysis, guiding my steps and keeping me on track. You never gave up on me, and for that I am humbled. It has been an honour to work with you.

_____

Jim Gray, you are my rock, I love you.

Caleb, Rory and Malcolm, you boys bring light into my life and inspire me to be my best, thanks for keeping me smiling.

To my family, your emotional support has been incalculably valuable.

That which does not kill us makes us stronger

– Nietzsche

CHAPTER ONE:

INTRODUCTION

Patterson and Garwick (1994b) have defined family as an interactive group of people who either live together, or share close contact and provide care for each other, as well as guidance for members of the group who are dependent, such as children. Raising a child with an intellectual disability places demands upon the whole family. Adaptations need to be made in order to provide proper care for the child with the disability, such as physical and health interventions, rerouting of monies and specialized treatments. Agencies and professionals have traditionally recognized the stressors placed upon the parents of children with disabilities (Perry, 2004). Unfortunately, this view has often focused upon the negative aspects of parenting a child with an intellectual or developmental disability and differs drastically from strength-based analyses that are beginning to emerge (Scorgie, Wilgosh & Sobsey, 2004; Watson, 2008). What this major paper will examine is not how families adapt to having a child with a disability, but how the theories and models that have been created best describe the processes in family reaction to disability and what terminology is most congruent for this area of research. The models that will be discussed include the Hill's (1958) ABCX, McCubbin & Patterson's (1983) Double ABCX, Patterson's (1988) Family Adjustment and Adaptation Response (FAAR), and Scorgie, Wilgosh and Sobsey's (2004) Transformational Outcomes.

The American Association on Intellectual and Developmental Disabilities (2011) has defined developmental disability – an umbrella term that includes intellectual disability –as beginning before the age of 18, and being characterized by significant limitations in both intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. It also incorporates an IQ of less than two standard deviations below the

mean, which typically means an IQ of 70 or below. It also includes disabilities from birth or before the age of 18 (at the latest) such as blindness, deafness and cerebral palsy (AAIDD, 2011). Within Canada there are approximately 202,350 children who have been diagnosed with a disability, though this number is not clear as to whether the disability is physical, developmental or intellectual or a combination of any of the three (Statistics Canada, 2003). When considering this number, one must also consider the impact that the diagnosis of an intellectual disability has had on the family, because therein lies the issue at hand.

In reaching a deeper understanding of the multidimensional processes involved in family response to disability, researchers have developed the Double ABCX model, which can be used to assess a family's stressors and ability to adapt (McCubbin & Patterson, 1983). Hill (1958), a military and family researcher developed a model pertaining to stressors and the family, named the ABCX model of family stress. Hill's (1958) research examined separation and reunion that was war-induced; major variables he established remained nearly unchanged for more than 20 years at the time of the McCubbin et al. article (1980) reviewing family stress theory.

Crisis, which is a key component of the ABCX, Double ABCX and FAAR models, is defined as when the family undergoes a period disorganization, some form of recovery, and a new type of organization (McCubbin et al., 1980). Patterson and Garwick (1994b) go on to define crisis as a state of disequilibrium within the family system that occurs when the demands exceed the family's existing capabilities. This imbalance persists over time and eventually creates a turning point within the family, forcing the system to change and adapt to the stressors that created this crisis (Patterson & Garwick, 1994b).

By taking into account the history and development of stress, families, and family reaction to disability research, a deeper understanding of families of children with intellectual or

developmental disability should evolve. This major paper will incorporate the Family Adjustment and Adaptation Response (FAAR) model. This model was developed by Patterson and McCubbin, which came out of Hill's ABCX and McCubbin and Patterson's Double ABCX model (McCubbin & Patterson, 1983). The FAAR model incorporates two phases, the adjustment phase and the adaptation phase. When challenges are presented in the adjustment phase, the family must meet them using their current capabilities. However, when these challenges are greater than their ability to deal with their crisis, the family system reaches a turning point and begins to move towards the adaptation phase (Patterson & Garwick, 1994b).

Building upon the concept of adaptation is that of transformational outcomes (Scorgie & Sobsey, 2000; Scorgie et al. 2004). Transformation has been defined as a proactive process in an individual's attempt to handle stressful situations beyond their control (Wong, Wong & Scott, 2006). Many families speak of a transformation that they (usually parents) undergo when faced with the realization that their child has a disability (Scorgie & Sobsey, 2000; Scorgie et al., 2004; Watson, 2008). When parents are faced with the reality that they cannot change their child's diagnosis, it appears as though they unconsciously create a new cognition/world view (transformation), allowing them to process this new reality in a way that they can create healthy family and individual functioning. According to Watson (2008), many families are relieved at the diagnosis because it provides them with an understanding of their situation and through this understanding, a platform for personal transformation is created.

Historically, families have been seen negatively, with parents being blamed for exacerbating their child's illness (Kog, Vertommen & Vandereycken, 1987). Unfortunately, this negative view has only recently begun to change in the last decade as researchers seek to examine the strengths and positive aspects of the experience of family members of an individual

with a disability (Sobsey, 2004; Scorgie, Wilgosh, Sobsey & McDonald, 2001). By pulling from the body of literature covering Hill's ABCX (1958), McCubbin and Patterson's (1983) Double ABCX Patterson's FAAR model (1994), literature examining transformational outcomes of parents (Scorgie & Sobsey, 2000), as well as the experience of siblings and extended family members, a complete picture of the experience of having a family member with a disability will hopefully be constructed.

This paper will examine what the above theorists (i.e. Hill, 1958; McCubbin & Patterson, 1983; Patterson, 1988; Scorgie et al., 2004) discussed within the body of this paper mean when they use the words they do. I shall also attempt to answer the question of how this vocabulary affects the understanding of these models. This understanding is directly related to the models' functionality and applicability in the literature on family reaction to disability. Through this analysis I will demonstrate what terms are most congruent with the constructs they are tied with, and which models are most compatible with each other. I postulate that the terminology in these models is not always congruent with its associated constructs. In addition, to increase the clarity and functionality of the models examined in this paper, the terminology used should be as fitting as possible to the constructs and processes involved in family reaction to disability.

CHAPTER TWO:

HISTORY OF DISABILITY

This chapter will examine the historical evolution and settings in which the models discussed throughout this major paper are developed. Furthermore, it is important to note that language use has evolved over time. In a bid to accurately reflect the time periods of the eras to be discussed, the language of the era will be applied in the same manner that it was used when these topics first arose (e.g., mental retardation vs. developmental disability). This language may seem to be strongly biased and negative; however the terminology applied was not necessarily used in a derogatory manner at the time and as such is seen as a reflection of the eras in which these theories were developed. As this chapter journeys from the 1950's to present day, this evolution/change in the language will become evident. Disability has been part of the human experience since time immemorial (Berkson, 2004; Brown & Radford, 2007). Peoples in Antiquity have provided researchers with small snippets of evidence that disability was part of life even then. The ancient Egyptians were known to actually revere individuals with Dwarfism (Brown & Radford, 2007), whereas the ancient Greeks honoured their disabled war veterans and at the same time "disposed" of their infants with noticeable disabilities via exposure (Brown & Radford, 2007). Depending upon the nature of the disability and their place in human history, individuals who were "different" were either seen as important and valued memories of society, scourges and jokes from the gods, objects to be pitied, or objects of ridicule (Berskon, 2004; Wolfensberger, 1972).

It was not until the medieval era that the creation of institutions began as a means of providing care for the "idiots," as the care of others was a moral obligation of the Christian faith (Berkson, 2004). In 11th century England, four types of these early institutions existed:

almshouses, hospices for poor wayfarers and pilgrims, leper houses and hospitals for the infirm and sick poor (Brown & Radford, 2007). From these early beginnings, staffed by religious men and funded via charitable donations, the next few centuries would see an expansion in the arena of charitable care including workhouses, poorhouses, and most important in significance to the history of disability – the asylum.

Within the province of Ontario, at the height of the asylum era (i.e. the majority of the 20th century), there were 20 care facilities, almost half the total number of facilities nationwide (Radford & Park, 2003). Since the early eugenics movement of the late 19th century, many scientists and doctors were of the belief that individuals with disabilities should not reproduce as these so called "undesirables" would only breed more undesirables, causing more impurity within the human species (Brown & Radford, 2007; Kennedy, 1942; Radford & Park, 2003). As a result of this belief, it was thought that individuals with deficiencies belonged in these large-scale care facilities where they could be out of the general population, segregated by gender so they could not reproduce, and removed from society completely (Radford & Park, 2003). It was not until the end of World War II when the German eugenics research and cultural/ethnical cleansing became widely known that the eugenics movement came to a halt. However, within the population of persons with developmental disabilities, sexual and reproductive control remained a constant pillar in their care and treatment.

Though I could continue discussing the minutiae of the history of disability, this will not be the case. The focus for this chapter will be the discussion of the time in which the previously discussed research/theoretical models were developed (e.g., McCubbin & Patterson, 1983) and how this research influenced the evolution of the knowledge base over time. Essentially, the context in which these models were created is as much a part of the model as the particular

theoretical components within the model itself. Many models, as a result of the time and place in which they were created are not applicable today, or may need to be understood within the context of the time to make sense of their processes. The context also informs the congruency of the models in the body of literature over time. Spanning from the late 1950's up to the early 2000's the literature will be examined to help build, within the reader, a deeper understanding of when and as a result why, these theories developed when they did.

1950s

When attempting to understand the development and function of models and theories that assess family functioning, it is necessary to understand where this line of research began. Looking back, Hill (1958) was one of the earliest researchers to examine the effects of stress on the family. Hill's (1958) research focused on families that were experiencing separation due to war. This early research included the development of the ABCX model of family development as a means of allowing researchers to analyze families under stress, as well as their methods of functioning. Hill (1958) explains that families are not themselves a sole source of stress, which can come from the greater sphere in which the family lives, but are also a place of refuge and rebuilding for its members, literally "love in action" (p. 140).

It is this love in action that allows families to build cohesion and face not only the stressors in the family unit, but also those stressors that occur outside of the family's locus of control (e.g., catching an illness, natural disaster). Hill (1958) began to analyze how this functioning happens and developed his ABCX model. Hill (1958) performed this analysis because at this point in history many families had already undergone serious stressful events such as war-induced separation during World War II and many families were facing further separation due to the Korean War. These forced separation situations led to a wide variety of

new stressors as a result of the missing family member. Hill (1958) summarized his research regarding the organization of the family by stating that the, "myth of family self-sufficiency requires discrediting" (p. 148). What he meant by this was that families are not static units, separate and unchanging unto themselves: they are, in fact, dynamic participants within their communities at large. As a result, research into family reaction to disability needs to incorporate not just the family unit itself, but external factors and resources as well, influences that will be touched upon further in this chapter.

Following Hill (1958) came a piece of research that examined family integration as it pertained to mentally retarded children (Farber & Kirk, 1959). The researchers examined how the defective child adversely interferes with the functioning of the family and the cohesion and consensus of the family members re: family values. One reason for doing so was to determine whether the child should be institutionalized (Farber & Kirk, 1959). The 1950's fell during the height of the institutionalization era. Medical professionals believed that children belonged in these specialized facilities where the child could be cared for, allowing the parents to move forward in their lives (Radford & Park, 2003). In contrast to Hill (1958), Farber and Kirk (1959) describe the process of the effect of the child as an arrest in family functioning, whereas Hill describes family functioning in a more dynamic and involved process. This is not to say that Farber and Kirk (1959) dismiss the dynamic nature of family functioning, but rather they have opted to more closely examine the family at one particular moment in time, rather than through a more comprehensive analysis over time. Essentially, Farber and Kirk (1959) take a snapshot of family life and focus on that rather than Hill's (1958) approach, which is more similar to a complex storyboard.

An aspect of family life brought forward by Farber and Kirk (1959) is the acknowledgement of siblings. This acknowledgement of siblings touches upon effects of having a sibling with a disability (how well siblings react to their siblings with disabilities and vice versa) and also the differing roles played by parents when this is the case. The inclusion of siblings as being both affecting and affected could perhaps be one of the earliest dates at which this topic is broached. Sibling research will not become mainstream until later in the 1970s and further into the 80s and 90s, beginning with the authoring of research by San Martino and Newman (1974), which examined the mental health of siblings of children with developmental disabilities.

1960s

Farber and Kirk (1960) continued with their research moving towards the topic of maintenance of family function in families with a severely mentally retarded child. Borrowing from Hill (1958), Farber and Kirk (1960) take the concept of family crisis and apply it specifically to families where there is a child with a disability. This secondment of the concept of family crisis sets the stage for decades of future research where families who have children with disabilities are seen as experiencing crises (Fortier & Wanlass, 1984; Lavee, McCubbin & Olson, 1987; Lavee, McCubbin & Patterson, 1985; McCubbin, 1979). Again, like many of the articles touched upon here, Farber and Kirk (1960) acknowledge that families "do not stop living" (p. 5), and that they adapt. However, Farber and Kirk (1960) dismiss the concept of strength and focus on the weakness and negativity associated with children with mental retardation. Some of the research questions Farber and Kirk (1960) applied include:

> What are the conditions or circumstances, which influence the potential severity of the disintegrative effects of the retarded child on the family? What are the effective

> courses of action that the family may take in order to maintain its integrity? As specific courses of action, (a) Is it necessary to place the retarded child in an institution? (b) How does interaction between normal and retarded siblings affect the normal children? (p. 5)

These research questions quite obviously show a theme of negativity with a definite focus on the challenges associated with having a child with a disability. The means through which Farber and Kirk (1960) investigate these questions will now be discussed.

Farber and Kirk (1960) used a concept of "Games of Strategy," with the family and individuals as players set against "Nature," the opposite player (Farber & Kirk, 1960). In an attempt to possibly provide some form of understanding, game theory, as proposed by economists, is applied to the family. The definition of game theory states that it is the study of "mathematical models of conflict and cooperation between intelligent rational decision-makers" (Myerson, 1991, p. 1). Game theory is applied only to the families within the study and, as such, the researcher is the "judge" of their success during this "game" (Farber & Kirk, 1960).

What Farber and Kirk (1960) are attempting to accomplish is a deeper understanding of what factors can be controlled by the family members, and what factors cannot be controlled. This deeper understanding includes how the choices of one family member influence and guide the choices of another and also how the members react to events outside their direct influence. Reaching a deeper understanding allowed for the researchers to gain knowledge regarding what strategies are used that either do, or do not, allow for success in meeting crises (Farber & Kirk, 1960).

Solnit and Stark published a paper in 1961 entitled, "Mourning and the Birth of a Defective Child." This paper was in many ways a groundbreaking assessment of families'

experiences with the birth of a child with a disability and the parents' (mothers) and professionals' means of dealing with it. Building on a history of research examining the most detrimental effects of individuals with disabilities on their families and society (Brown & Radford, 2007; Danielson, 1912; Jordan, 1913; Key, 1920) Solnit and Stark moved past the old call for the application of eugenics towards one of institutionalization.

The move toward institutionalization was seen as a humane means of caring for both the "defective child" as well as protecting its parents from experience further grief and mourning caused by regular contact (Solnit & Stark, 1961). Initially institutions were created as a means of schooling and training persons with disabilities to re-enter society in a productive manner (Radford & Park, 2003). A significant part of the approach of controlling the population of individuals with disability was to ensure that they could not reproduce. The thoughts behind the prevention of reproduction included the idea that persons with disabilities were innocents and childlike (Brown & Radford, 2007) to being part of the decline of human evolution, thus their reproduction should be prevented to ensure a stronger genetic future for humanity (Kennedy, 1942).

One aspect of Solnit and Stark's (1961) article incorporates a discussion of the mother's experience with having a defective child. More specifically, this discussion does not involve the mother's experience in her own words, but rather the interpretation of the situation from Solnit and Stark's (1961) viewpoint. Essentially, the professionals performing this psychoanalytic analysis are not asking the mother what her experiences are; they are making conclusions solely based on uninformed observation. It also must be noted that it is mostly mothers and not fathers or other family members who are assessed and considered in the birth of a defective child. Fathers were mostly ignored because, according to psychoanalytic theory, it is the mother who

has the most invested in the birth of a healthy child and who will suffer the most once the defective child is born (Solnit & Stark, 1961). This suffering was coined "object-loss" as a means to reflect the loss of the healthy child imagined during pregnancy. It is a reflection of the psychoanalytic approach used during the mid-century to see the expected child termed an object, which would have defined said object as a construct created by the mother (Solnit & Stark, 1961).

Furthermore, the views held by professionals during the 1960s were ones that focused almost solely on the negative aspects of disability (Cummings, Bayley & Rie, 1966; Olshanksy, 1962; Solnit & Stark, 1961). The terminology used is a strong reflection of this view, where children with disabilities are considered to be retarded and have defects, even going so far as to consider the retarded child at birth as a feared, threatening and anger-evoking child (Solnit & Stark, 1961). A mother's reaction was not assessed based on adaptations and positive transformations, but rather on the anxiety and emotionality associated with the birth of a child with disability. Solnit and Stark (1961) explain that the mothers' expectations were crushed and as a result she feels damaged and she cannot adapt to having given birth to a defective organism. Children who were born with disability were seen as a source of stress and damage to the parent.

Family research encompassed not only the focus on grief that parents/mothers experience who received their child's diagnosis at birth, but also in instances where children do not receive a diagnosis of retardation until early childhood (Solnit & Stark, 1961). The grief aspect of Solnit and Starks's (1961) article sets the foundation for researchers to examine families and their functionality while undergoing the experience of grief. A key realization in Solnit and Stark's (1961) work was that it is important for mothers to discuss the child's diagnosis; and to be given the opportunity to do so allows mothers to create an interpretation of the new situation. This

interpretation then would allow the mother to be prepared to deal with her new reality and stave off the development of depression and anxiety. That being said, it is implied that if the child had instead died, the mother's grief would be terminal, whereas the grief associated with a living child would be "unrelenting" (Solnit & Stark, 1961, p. 533). The thought that perhaps the mother would be better off if the child had died is perhaps one of the many reasons why placing a child in an institution and separating it from the family's life was seen as acceptable. This separation would in essence be a type of death and would, theoretically, allow for the mother's grief to come to an end.

In cases where the child is not obviously retarded at birth, but its deficiencies are noted more over time, the mother's mourning reaction would not be as acute (Solnit & Stark, 1961). However, the authors assume denial would be present in these cases and thus it would lead to a more painful and chronic experience of grief (Solnit & Stark, 1961). The experience of chronic mourning and grief associated with the disability of a child that is not apparent until the child is past infancy where it may be associated with diagnoses of disabilities such as autism or other genetic syndromes. Interestingly enough the probability that the depression experienced by mothers after the birth of a child with a disability is most likely not caused by the child's diagnosis as hypothesized by Solnit and Stark (1961), but is instead post-partum depression. The reason for this lack of understanding was that in the 1960s the prevalence of post-partum depression was not acknowledged and the common term for experiencing difficulties after birth was light-handedly termed "baby blues". In fact, little research at all had been done at this time (Hopkins, Marcus & Campbell, 1984).

Building on Solnit and Star's (1961) work involving grief, Olshansky (1962) spoke on the topic of chronic sorrow. Olshansky (1962) stated that parents of children with a mental

deficiency suffer chronic sorrow throughout their lives regardless if the child has been institutionalized or not. This sorrow appears to often be a result of culture, in the sense that those from different cultural backgrounds experience their sorrow in different ways. According to Olshansky (1962), some parents openly display their sorrow, whereas other parents, particularly those of Anglo-Saxon background, apply a "stiff upper lip" (p. 191) in an attempt to conceal their sorrow. In contrast to Solnit and Stark (1961) who claim that the child's mental deficiency causes the grief and thus the damage, Olshansky (1962) states that it is more probable that the denial of the parents' chronic sorrow (grief) is the cause of any neurosis. Furthermore, the experience of sorrow is not abnormal nor is it to be considered the sole experience of parents of a defective child, as parents can also derive satisfaction and joy from their child's "modest" achievements (Olshansky, 1962).

It is clear to this author that Olshansky (1962) has come to realize that there is a tendency for professionals to focus on the negative experiences of parents rather than those of joy. Even though this realization is noted, the effect of the child on the parents is still held in a light that focuses less on the positive and at most on the mediocre. Assessing parental responses to a mentally defective child allows the parents little to look forward to except a continuous burden and a life full of trials, depression, and anxiety (Cummings et al., 1966; Olshanksy, 1962).

With regard to the experience of parents on the issue of their child, it is noted that all parents, not just those with retarded children, experience acceptance and rejection of their children dependent upon circumstances (Cummings et al. 1966; Olshansky, 1962). It appears that the issue of acceptance is key to Olshansky (1962) as being a goal in counseling families of these children. Though the event of having a child deemed defective is labeled tragic, the realization that parents are fully capable of providing care for their children, as well as the importance of

respite for the personal comfort of the parent, are stepping stones towards future research that assesses in a more supportive light the needs and experiences of the family (McCubbin, 1979).

Cummings et al. (1966) stated that there was ample evidence to support the claim that it was the mother's fault that children developed neuroses. The blaming of mothers during this time was not unheard of (Cummings et al., 1966; Solnit & Stark, 1961). Kanner (1949) described the mothers of children with autism using the term "refrigerator mother". Kanner (1949) interpreted the relationship that the parents (mostly the mother) had with their child as being remote and unloving, which led to the child developing autism. The apparent difficulty Cummings et al. (1966) had in ascertaining whether the mother's stress was the cause of, or caused by, the neuroses of the child weakens this claim. What remains constant is the discussion surrounding the negative aspects of parenting a child that has a disability. These aspects include concerns regarding stress, anxiety, self-esteem, and conflict amongst others (Cummings et al., 1966), and continue to be reflected in research of the 1970s.

1970s

The start of the next decade signaled the slow beginnings of the community living movement, without the occurrence of a single large event that would foreshadow the immense changes to come. Pierre Burton, one of Canada's foremost news reporters of the mid 21st century wrote an article on the distressing conditions at the Huronia Regional Centre in Orillia, Ontario (Radford & Park, 2003). When provided with the details of the conditions in Ontario's largest institution the public (e.g., parents, volunteers, advocacy groups), began a push to move the patients from these inhumane conditions to someplace where they would be safe and comfortable, and also be provided with a more normal life (Brown & Radford, 2007; Radford & Park, 2003).

Wolfensberger (1972) published a pivotal book entitled *The Principle of Normalization in Human Services*. This book opened the floodgates for the patients of institutions to move into a community based setting, however, for the individuals living within these institutions as well as some of their families, this move was not always as welcome as one would have hoped. According to Brown and Radford (2007) one of the reasons leading to hesitation and discomfort at the thought of integrating individuals with disabilities with the general population was the risk to the individual themselves. Life poses natural risks at all ages, and as a counter argument to the risk to the individual with disabilities is the concept of dignity of risk (Wolfensberger, 1972).

At the same time that the community living movement was commencing, Birenbaum (1971) examined the cyclical nature of family functioning in families with disabled children over the lifespan. In opening, Birenbaum (1971) discusses the nature of previous research (e.g., Solnit and Stark, 1961) regarding the realities of the parents/families as being either in denial or acceptance (Olshansky, 1962; Solnit & Stark, 1961). Important in Birenbaum's (1971) article is that the strains and stresses of having a child with a disability do not negate the means through which cultural and societal supports are mobilized to provide support (Birenbaum, 1971). The interactions of the families within themselves, and within their community, are what allow these families to successfully navigate the realities of having a child with a disability. That Birenbaum (1971) acknowledged the importance of these interactions will lead to McCubbin (1979) and McCubbin and Patterson (1983) developing the Double ABCX model, which was briefly discussed in the previous chapter, and will be discussed further in Chapter 3.

Furthermore, Birenbaum (1971) speaks of families not being mere recipients of services and support, but also catalysts in the development of novel means of supportive programming. For the first time in the literature, families are noted as being proactive in their approach to

adaptation to life with a disabled child. In addition, the mothers of these children are often noted to be successful parents because they wear many hats. This wearing of hats refers to Birenbaum's (1971) descriptor of the mothers as being involved in roles within the mental retardation community as well as within the "normal" familial community. The involvement within the non-disabled community, however, is referred to by way of being a "polite fiction" (Birenbaum, 1971, p. 56).

In the late adolescent and early adulthood years of the mentally retarded child's life, this polite fiction breaks down, which is said to threaten the family's appearance of conventionality (Birenbaum, 1971). What is occurring is the realization that the child will never live independently and that the mothers will not live forever either, leaving the child with an uncertain future regarding their care. Using a qualitative interview method, Birenbaum (1971) spoke with 103 women of children who were moderately retarded with the majority of the children living at home. Many of the mothers queried in Birenbaum's (1971) article mention the uncertain future of care for their offspring with a disability, and also that they often avoid thinking too far into the future because of the level of uncertainty they are feeling. Birenbaum (1971) concludes that the uncertainty felt by families of children with disabilities is a direct result of the departures from conventional family cycles that occur in families with nondisabled children.

In contrast to Birenbaum's (1971) research into the cycles of family life culminating in the later years of childhood, Parks (1977) examined the parent experience when the child with a handicap is born. The birth of the handicapped child is said to cause a threat to the parents' homeostatic state, causing disequilibrium leading to crisis (Parks, 1977). The work by Parks is an opening of a door towards a change in terminology used (e.g., mentally retarded becomes

mentally handicapped) and potentially signaling a change in direction of research to come. Prior to this work, the majority of the terminology and research surrounded stress, crisis, mental retardation, retardate, defective, chronic sorrow, grief, and burden (e.g., Farber & Kirk, 1959; Hill, 1958; Olshansky, 1962; Solnit & Stark, 1961).

Interestingly, Parks (1977) discusses the psychological stress the mother undergoes when having given birth to a handicapped child as potentially exacerbating depression. Parks (1977) also states that regardless of the diagnosis of her child, any woman can develop depression after the birth. Park's acknowledgment that mothers of children with handicaps have an increased risk for post-partum depression is in stark contrast to previous researchers, who either did not acknowledge post-partum depression, or who placed the blame for mothers' struggles on the handicap of the child (e.g., Olshansky, 1961; Solnit & Stark, 1961). The writings of Parks (1977) are quite different from previous works on the same subject. This difference from other researchers is representative of the progressive change in the area of research pertaining to families with handicapped children, demonstrating a change in the literature toward a more human approach.

Parks' (1977) work informs professionals so they may be better able to help their patients who have a handicapped child process this diagnosis. The need for the acknowledgement of grief, not to shame the parents regarding their grief but to provide support that the birth of the handicapped child was unexpected, is an important step towards the parents reestablishing homeostasis. The parents in Parks' (1977) paper were given the right to grieve, as well as supports and guidance, which allowed them to move forward and establish a new normal for themselves and their new family member (Parks, 1977).

Building upon stress in the family, McCubbin (1979) argued that successful family adaptation to stress includes two resources; 1) internal resources such as integration/adaptability to withstand social and psychological stresses; and 2) a range of coping behaviours directed toward strengthening the family's internal organization/functioning, accessing community/social supports and diverting, reducing or eliminating sources of stress. Coping is examined via family stress theory, guided by Hill's (1958) ABCX model to lead researchers to the conclusion that it is indeed an important dimension in a family's adaptation to stress response.

Furthermore, adaptation is examined within the scope of Hill's (1958) B factor; the family's crisis-meeting resources. Hill and Hansen (cited in McCubbin, 1979) spoke of four propositions that depicted the relationship of adaptation and family characteristics in the B factor: 1) adaptive behaviour is more likely in intact families than in non-intact families; 2) adaptive behaviour is more likely in families which are communicative with each other; 3) adaptive behaviour is more likely in families with flexible authority/status structures; and 4) adaptive behaviour is more likely in families that have been successful in meeting past disasters. It matters not what the stress is but more so how the family can face it and apply its coping resources in a bid to adapt.

1980s

As previously discussed, Wolfensberger's (1972) work on normalization opened the doors for a move of individuals with disabilities out of the institution and into community living. During the 1980's the Ontario government closed 5 institutions, significantly reduced the size of several others, and increased spending on community-based services from $10 million to $181 million (Ontario Ministry of Community and Social Services, 2014). These changes in how the

province dealt with individuals with disabilities and moved towards a system of inclusion is representative of the theory of normalization.

It is from this point forward that the institutions will be shrinking in size and will eventually close completely, with Huronia Regional Centre in Orillia closing its doors in March of 2009 (Ontario Ministry of Community and Social Services, 2014). With the last institutions in the province having closed their doors, individuals with disabilities took up residence in either group homes or returned to live with their families. The family experience of living with a family member with a disability is a key reason for research examining the associated familial processes. As the institutions were reducing their numbers, theories pertaining to family reaction to disability began to develop (e.g., McCubbin & Patterson, 1983; Patterson, 1988, 2002; Scorgie et al., 2004).

The Double ABCX model was developed in 1983 by McCubbin and Patterson out of a need to answer a number of questions that arise when assessing families using Hill's (1958) ABCX model. These questions are: how much and what kind of stressors are present; what are these stressors mediated by (personal, family, community resources and what family coping responses; and what family processes shape the path and the ease of family adjustment and adaptation over time (McCubbin & Patterson, 1983). However, Hill (cited in McCubbin & Patterson, 1983) notes that living systems characteristically evolve toward greater complexity, and, as such, families may naturally facilitate such growth, leading to the question of whether the concept of crisis reduction alone is an adequate measure of the family's post-crisis adjustment.

Family adjustment and adaptation response – FAAR is also explored by McCubbin and Patterson (1983). In an expansion of the Double ABCX, McCubbin and Patterson (1983) speak of observations of families and their adjustments and adaptations to stressors and crises. This is

not the FAAR model that has been discussed previously in Chapter 2, but rather a title given to the process of families progressing through the Double ABCX. Concepts discussed include: pre-crisis, avoidance, elimination, assimilation, adjustment , bon/mal adaptation, coping, restructuring, accommodation and consolidation (McCubbin & Patterson, 1983).

In 1988, Patterson published work on a revised process model – FAAR. This work had the goal of revising and clarifying concepts based on empirical findings as well as creating a model that is more salient for the biopsychosocial researcher (Patterson, 1988). The Double ABCX is enveloped within the FAAR as a means to describe the processes that families under go when achieving pre-crisis adjustment and post-crisis adaptation. This relationship with the Double ABCX and the FAAR is reversed from earlier works where the FAAR was a secondary process analysis to the Double ABCX (McCubbin & Patterson, 1983). Patterson (1988) separated the FAAR from the Double ABCX giving researchers a model with fewer variables, but similar outcome results to the Double ABCX.

The movement within research to examine positive adaptations and family strengths begins in the 1980s (McCubbin & Huang, 1989; Summers, Behr & Turnbull, 1989). The reason for this shift in the literature stems from a pervasive ideal of human dignity and rights that developed via the normalization movement. Works like Parks (1977) where a noted shift in the language is seen, to Wolfensberger (1972) who speaks of the rights of the individual led the way in changing the way researchers and service providers view the family. McCubbin and Huang (1989) examine family strengths in families of handicapped children using the Typology Model of Adjustment and Adaptation. The conclusions reached by McCubbin and Huang (1989) show that use of the Typology Model of Adjustment and Adaptation is not a suitable fit for research on families of handicapped children.

Summers et al. (1989) examined positive adaptations and coping strengths in families of children with disabilities. First noted in the title of this work is the use of person-first language, as well as an open acknowledgement of the facet of positivity not previously seen in the literature. Person first language is a type of "linguistic expression" (p. 146) that involves the use of words, and the ordering of sentences to better reflect the humanity of the individual under discussion, reflecting awareness, creating dignity and building positive attitudes about people with disabilities (Jensen et al., 2013). Summers et al. (1989) speak of how the concepts within the models of the ABCX and Double ABCX are truly beneficial to understanding how families move through time, as well as change and adapt in response to a stressor/crisis event.

Examining coping skills and resources that are predictive of family stress is the next part of the work by Summers et al. (1989). One example of the type of research question that is now asked by researchers is, "what is the impact of the quality of the parents' marriage on the ability of the family to cope with a child with a disability?" rather than, "what is the impact the disability of the child is having upon the quality of the parents' marriage?" (Friedrich & Friedrich, cited in Summers et al. 1989). The concepts examined in the work of Summers et al. (1989) include language such as strengths, positive adaptations, mastery, enhancing self-esteem, and support. This shift towards examining families in a more positive light will become an important aspect in family reaction to disability research; however, the assessment of the more negative aspects of family life will not be forgotten and the majority of the body of literature will continue to be from an approach of negativity (Helff & Masters Glidden, 1998).

1990s – present

Resilience as a construct is defined as including the capacities, aspects and attributes that helps a family to be resistant to disruptions (McCubbin & McCubbin, 1988). Resilience research

in the mid 1990s was used as a means to understanding and facilitating how families both become resilient and are resilient. One such document is a report prepared by Iowa State University. This report defined resiliency as an individual's ability to "bounce back" from stress and crises (Ford Arkin, Frazier, Miller, Blinn Pike, & Reynolds, 1995). Furthermore, Ford Arkin et al. (1995) speak of factors of resilience such as survival, immediate family/kin network, and community factors, for example: relationships with friends, neighbours, teachers and also broader influences like school and the media, all affecting an individual's ability to be resilient.

Within the levels of influence of resilience, there are possible protective factors that, when in place, can aid in an individual, family or child achieving resilience. These protective factors include problem-solving and intellectual abilities, self-esteem, self-efficacy, close relationship with at least one adult, a close friend, positive school experiences, required helpfulness, belonging to a supportive community, as well as bonding to family members and other institutions (Ford Arkin et al., 1995). These protective factors are found in all levels of function for an individual or family, from personal to familial to community. As the concept of resiliency has such a strong family role, it is not surprising that Ford Arkin et al. (1995) apply the Double ABCX to these families when assessing resiliency.

Walsh (1996) as well as Hawley and DeHaan (1996) both put forth publications seeking to define the concept of family resilience. In examining resilience, children with at least one person to whom they can turn, who loves them unconditionally, along with other supportive factors such as positive/hope directed personalities, are often able to withstand extreme stress during childhood and develop into healthy and well-adjusted adults (Hawley & DeHaan, 1996; Walsh, 1996). What researchers have begun writing about is that resiliency often begins in

childhood and, as such, it is important to comprehend its development and presence over the lifespan, particularly because children grown up and often build new families of their own.

Families that are studied are now being examined through a focus of competency-based and strength-oriented paradigms (Hawley & DeHaan, 1996; McCubbin & McCubbin, 1988; Walsh, 1996). This area of focus has enabled researchers to discuss families less from a place of the families being damaged but rather from a place of accepting these families as having challenges (Walsh, 1996). When researchers are able to shift their focus toward more strength-based paradigms, not only does it broaden the scope of the research, it also deepens the understanding of the intricacies involved in family resilience, coping and adaptation, (these terms will be further clarified in Chapter 4).

Patterson (2002) looked at the distinction between family resilience as a capacity versus a process through the use of the FAAR. When assessing family system outcomes with regards to resiliency, the outcome must be at the family system level and a minimum of two family members should be involved (Patterson, 2002). Therefore the outcome is a product of the family relationships (Patterson, 2002). For a family to be assessed with regards to their ability to be resilient, two other factors must be considered. First there is the consideration that there is risk involved, and that the family may not be successful, and second what protective mechanisms are available to prevent a poor outcome (Patterson, 2002). By applying the FAAR model and incorporating these three factors (family-level outcome, risk, and protective mechanisms), one can grasp how the resilience process unfolds in families.

It is the positive changes after crisis that is key in both the analyses of the research examining responses to war as well as those analyses performed by researchers examining the family reaction to disability. Recent work by Watson (2008), as well as Watson, Radford-Paz

and Hayes (2011) examined the experiences of parents who seek out differential diagnosis (e.g., Fetal Alcohol Spectrum Disorder) for their child with a disability; findings included parental sense a relief from guilt, and a sense of increased self-efficacy in their ability to care for their child. Parents often found that once they received their diagnosis they were also better able to relate and care for other people outside of the family unit, people that are undergoing a similar experience that could benefit from the support of others who have already undergone the process (Scorgie & Sobsey, 2000; Scorgie et al., 2004). Transformational outcomes are not solely the positive experiences of the individual, but are, in a sense, a springboard that allows the individual to launch themself to a higher level of functioning than they were at prior to the crisis (Linley, 2003).

It is the positive nature of this type of research that truly signifies the movement in the body of literature to a more strength-based approach on the topic of family reaction to disability. The writings of Scorgie and Sobsey (2000) and Scorgie et al. (2004) are both fitting and representative of the movement towards a more positive theoretical approach in the sphere of family reaction to disability. Furthermore, the findings that families, parents and married couples undergo positive experiences and maintain healthy relationships, is strong evidence to support more research on the subject.

Conclusion

In summation, knowledge of the historical context of family reaction to disability research is beneficial to understanding how these models came to be. Many of the earlier works focused on stress in the family, as well as how children with disability were a cause of such stress. Solnit and Stark (1961) and Olshansky (1962) both focused on shame and sorrow when a child is born with a disability and how this negatively affects the mother. What was not focused

on was how current stress in the family prior to the arrival of a child with a disability would affect the family functioning after the arrival of the child.

As the decades passed, the research began to make a gradual shift, not excluding the negative, but rather adding the positive. Parks (1977) and Wolfensberg (1972) both respectively led the way in bringing forth more positive terminology and respect for the humanity of the individual with a disability. Research on families of children with disabilities now provides readers with both the negative and the positive aspects associated with parenting a child with a disability. Furthermore, more recent work regarding transformational outcomes has shown that parents are able to find a new, more positive meaning in their lives, leading to a better outcome for themselves and their families. This shift in the literature, along with the development of theories designed to assess families of children with disabilities, has led to a change in the use of language over time. The following chapter will discuss the use of the terminology and how it too has evolved over time as a reflection of changing societal norms.

CHAPTER THREE:

MODELS OF FAMILY REACTION TO DISABILITY

Some of the most useful tools to have come out of family reaction to disability research have been the development of a series of models that attempt to provide a picture of the dynamic processes involved within families as they are faced with and experience stress and crisis. The importance of these models cannot be understated as they allow researchers to more closely examine the factors and levels of function within families, potentially leading to improved services and the ability to advise legislation and programming. Models of family function have evolved since the work of Hill (1958). Bronfenbrenner's (1977) Ecological Theory of Human Development was published as both a critique of the present state of research and a movement towards a more holistic understanding of human development and family function. Following Hill's (1958) Family Stress model: ABCX, Patterson and McCubbin (1983) expanded on the ABCX to examine multiple factors over time in the Double ABCX. Further analysis and research by Patterson (1988) lead to publication of the Family Adjustment and Adaptation Response (FAAR) model, which has subsequently been built up further to the FAAR model now in use (Patterson, 1998). The latest model examines transformational outcomes in parents and families of children with developmental disabilities and many of the positive aspects in these outcomes (Scorgie et al., 2004). This chapter focuses on these theories as a means to deepen the readers' understanding of the research base through which family stress and adaptation can be understood.

Family Stress Theory

The first to create a model in understanding family stress process was Reuben Hill. Hill's (1949, 1958) research focused on the family's definition of a major stressor event, in this case

military caused separation. Hill (1958) examined three variable that are involved within the conceptual framework that evolved regarding families in crisis; family, crisis-provoking event, and the meaning that the family ascribes to this event (see Figure 1). In coming to an understanding of Hill's (1958) ABCX model, one must examine each variable in detail to allow for a deeper understanding of the processes and variables involved. By examining and building a foundation of understanding and knowledge around these three variables, Hill (1958) was able to develop a model that became the foundation for later theories and guided research for decades afterwards including work by Patterson, Garwick, McCubbin, (1979; 1985; 1988; 1994) and others.

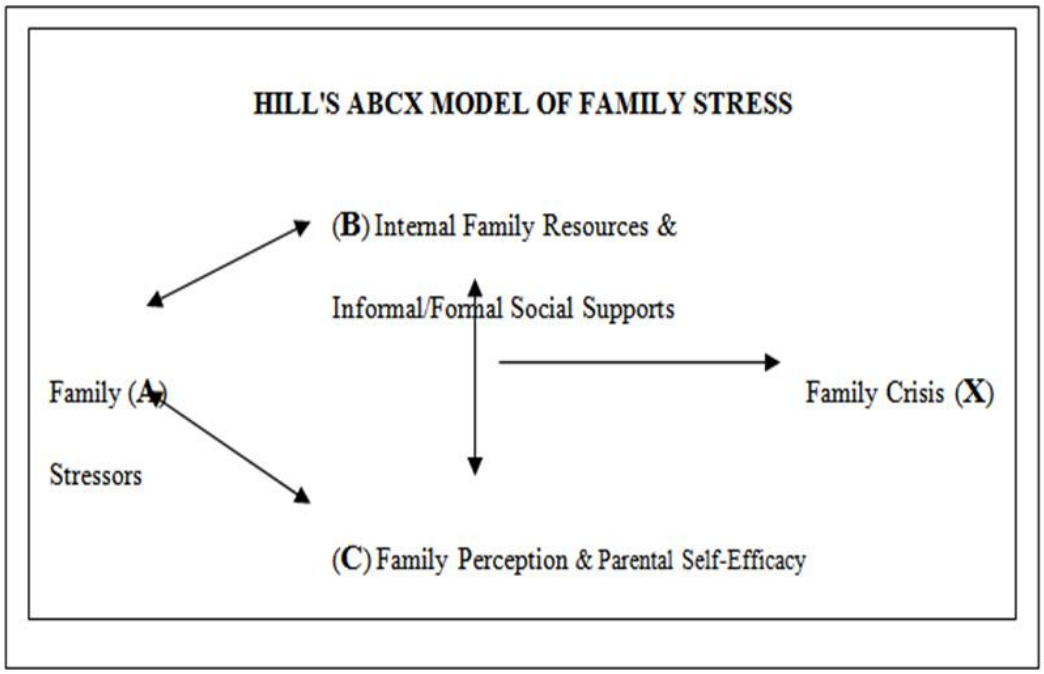

Figure 1. The ABCX model of family stress (Hill, 1958).

variable: a

"A" represents the event itself and this initial stressor can be myriad of occurrences, such as death of a family member, loss of employment, birth of a new child, diagnosis of a disease or

a disability in a child or other family member. To coin something "the event" is a reflection on a family's circumstances. This factor has also been called the "crisis-provoking event" (Hill, 1958). Hill (1958) further defines the stressor in this context as a situation for which the family has had little or no preparation and it is thus viewed as problematic. The definition that the family makes will be assessed through the examination of the "C" factor of Hill's ABCX model.

variable: b

This factor reflects the meeting of the family's resources with the crisis itself (Hill, 1958). McCubbin (1979) has examined the "B" factor of the ABCX model in further detail, listing some resources for handling a crisis as: family discussion, prayer/stronger religious beliefs, and comforting an individual who has a diagnosis even though this person may be seen as the cause of crisis. These resources are examples of coping mechanisms that some families may have in place prior to the development of this new crisis event. However, in an attempt to adapt, families may go on to develop new and novel resources in order to meet the crisis event. Some of these new resources may include consulting with medical experts or even seeking guidance and support from other families who are undergoing a similar experience, as well as reaching out to others such as family and friends for support (McCubbin, 1979). An important aspect of the B factor is that families often recruit other family members to help when, for example, parents must devote their energies to the care of a child that may have a disability or is medically fragile. Unfortunately for the immediate family, overdependence on external resources or coping mechanisms developed prior to said event can be potentially catastrophic to the family's ability to adjust because it can delay the family's ability to develop unique coping strategies that would be more functional in the long term, particularly since this potential for catastrophe can cause further stress within the family (McCubbin, 1979).

Further stress in the family is caused by an overdependence on external resources, and is associated with the types of resources that the family is over dependent upon. For example, when a family requests that an extended family member come and to stay to provide child care which allows the mother to return to work. However, the family is requiring that extended family member to put their own life on hold to help out. In this case the external family member cannot work, and but regardless they are taking on responsibilities that they otherwise would not be required to fulfill.

However, the extended family member will eventually need to return to his or her own life. The loss of help provided by the extended family member leads to the mother needing to attempt to secure affordable childcare and rearrange shifts at work, in addition to other household responsibilities that were being filled by the extended family member's presence. All these events lead to further stress and new crises as the family has to adjust again to the extended member not being present, a lack of income, and all the other complications that come with a lack of support and monies.

variable: c

This variable in the ABCX model is the definition the family has about the event (Hill, 1958). Again, like the event (A), this definition is unique to the family and is created within the context of the family's social sphere and experiences. Hill (1958) goes on to state that both B and C should be seen as lying within the family itself and be viewed in terms of the family's structure and values. Hill and Boulding (cited in Hill, 1949) devised probable definitions of the crisis-precipitating event: (1) an objective definition, which is formulated by an impartial observer; (2) a cultural definition, created by the community; and (3) a subjective definition created by the family. The key factor of the crisis-precipitating event is the subjective meaning created by the

family because if the family does not view this potential crisis-precipitating event as being serious enough to cause serious issues within the family, then the event remains neutral and can be disregarded. However, if the family does define the event as potentially leading to crisis, then the family will experience crisis as a result. It is the definition of the event at the family level that leads to the occurrence of crisis.

x: the crisis

The crisis. The actual occurrence of this event is caused by a combination of the three prior variable (i.e., A, B, & C) involved in the framework developed by Hill. In his writings, Hill (1958) states that, "crisis proneness is in effect the phenomenon of experiencing stressor events (A) with greater frequency and greater severity and defining these (C) more frequently as crises" (p. 143). What Hill is saying is that families that are considered "crisis-prone" tend to be more vulnerable to stressor events. A lack of, or weak, crisis-meeting resources cause this vulnerability. The vulnerability also includes an inability to have learned from past experiences regarding crisis events. As a result, these crisis-prone families will more often define an event as a crisis.

Hill (1958) may have been one of the first to create a model/framework in an attempt at further understanding the reasoning behind families reaching crises in their lives. However, he did not attempt to determine how families managed to move forward from crisis towards a potential return to healthful functioning.

Double ABCX

Building upon Hill's (1958) model, Patterson and McCubbin (1983) developed a new multivariate model coined the Double ABCX (see Figure 2). McCubbin and Patterson (1983)

stated that the central research question pertinent to any work done regarding family stress is to examine how many, and what kinds, of stressors there are. This line of questioning includes what mediates these stressors (personal, family, and community resources), what coping responses the family has, and what family processes occur in shaping the family's adjustment and adaptation in the long term (McCubbin & Patterson, 1983). It is important to keep this central research question, regarding the number and type of stressors, in mind when understanding and grasping the processes within the Double ABCX.

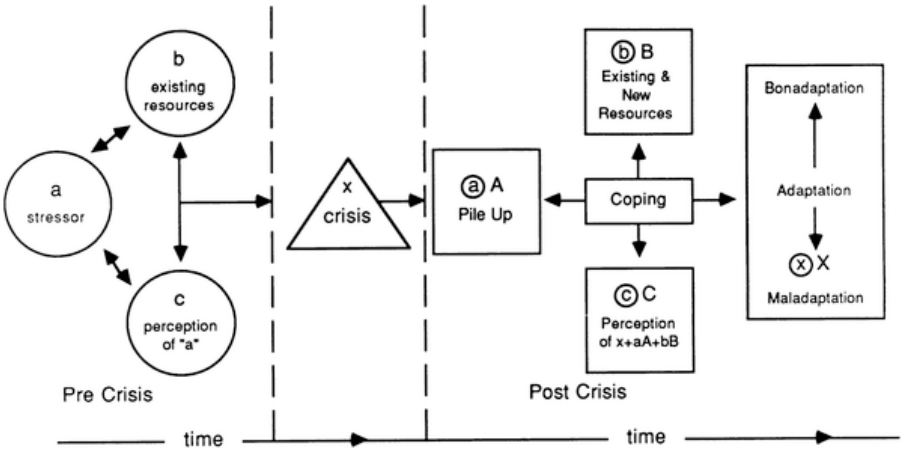

Figure . Double ABCX model of family function *(*McCubbin & Patterson, 1983)

aA factor

To explore the Double ABCX model, it is important to understand how McCubbin and Patterson define key terms such as stressor and hardships. These theorists define a stressor as either a life event or a transition that impacts the family unit and produces or can produce a change in the family social system (McCubbin & Patterson, 1983). Hardships are defined as demands that are placed on the family unit that are specifically associated with a stressor event. The stressor, as defined above, can take place within any number of the family's systems and the

individuals within, as well as the hardships experienced by the family that arises when this occurs.

The “a” factor is essentially the same as Hill’s A factor, but it becomes doubled (aA) within the model of the Double ABCX to reflect a more detailed view. This doubling up of the “a” factor leads to what has been termed the “pile-up” (McCubbin & Patterson, 1983). The pile-up occurs when families experience more than one stressor at a time, which is a realistic view of family life as families do not live in singular moments, but rather within dynamic systems throughout which events and stressors influence and can be influenced by the family at any given time

There are three sources of change or demands that occur during this stage and they come from different sources. The first is (a) individual family members, which in McCubbin and Patterson’s (1983) work the mother as an individual member of the family felt the pile-up of demands because she had to perform the roles of both mother and father. The second source of demands noted is (b) the family system itself, which is when the family as a unit feels the strains of the loss of the father as they try to take care of each other and fulfill the responsibilities held by the father (e.g., sons and daughters perhaps taking on more chores than they can handle on top of school, mother hearing from the school and having to deal with the stress of poor grades in her children; McCubbin & Patterson, 1983). The third source of change/demands is (c) the community that the family is a part of (McCubbin & Patterson, 1983), for example the family is under pressure to maintain appearances of normalcy, such as fulfilling social obligations they can no longer afford to, like a club membership or providing the children with healthy lunches.

Furthermore, there are five types of stressors and strains that contribute to this pile-up. These are (a) the initial stressor and its hardships; (b) normative transitions (life transitions); (c)

previous strains; (d) consequences of the family's efforts to cope; and (e) intra-family and social ambiguity (McCubbin & Patterson, 1983). Examples of these are as follows:

(a) The Initial Stressors and its hardships: Diagnosis of daughter at birth with Down syndrome. The baby has difficulty eating and is not meeting infant developmental milestones. Parents must learn to meet the demands of their other children while being required to spend more time with their daughter, as her needs are higher.

(b) Normative Transitions: Mother's maternity-leave ends and school begins for the siblings.

(c) Previous Strains: finances, marriage, and extended family

(d) Consequences of Effort to Cope: fatigue, weak financial situation, decreased time with family members

(e) Intra-family and Social Ambiguity: Siblings are often asked to take on more responsibility than their peers. Extended family members are asked to be more involved with child-care for the siblings, freeing up time for the parent's to care for their new daughter.

bB factor

This variable of the Double ABCX involves the family's resources as part of a family's capability to meet the demands and needs required, such as (a) individual family members; (b) the family unit as a whole; and (c) the community to which they belong (McCubbin & Patterson, 1983). There appear to be two types of resources a family has: existing resources (old), and expanded family resources (new; McCubbin & Patterson, 1983). These two resource types are where the model evolves from Hill's (1958) B factor to McCubbin and Patterson's (1983) bB factor. McCubbin and Patterson (1983) define Hill's (1958) B factor as the existing resources of

a family and how these resources are used to reduce the initial impact created by a stressor. These resources also reduce the probability that this stressor will lead to crisis.

According to McCubbin and Patterson (1983), the bB factor involves the second type of family resource, "new resources." These new resources are created or strengthened as the family responds to the increasing demands that arise during crisis situations and as a result of pile-up (McCubbin & Patterson, 1983). For example, a new resource for the mother of a child with a disability could be an educational support group. Social groups are important resources within the bB factor. Cobb (cited in McCubbin & Patterson, 1983) has defined socials supports as information that families are (a) cared for and loved; (b) esteemed and valued; and (c) knowing they belong to a network of mutual obligation and understanding. Research has shown that families that are involved with social supports are more resistant to major crises and are also better able to recover when they do experience crisis and thus restore stability to the family (Lavee, McCubbin & Patterson, 1985; McCubbin & Huang, 1987; McCubbin & McCubbin, 1988; McCubbin & Patterson, 1983). Experiences of stressors without social supports may leave individuals and families unable recover from these stressor events. The inability to recover can then lead to personal crisis and potentially a breakdown of the family unit.

cC factor

This factor is the meaning that the family gives to the crisis situation as a whole. It includes the individual stressor believed to have led to crisis, other stressors and strains, old and new resources, and estimations of what needs to be done to return the family to a state of equilibrium (McCubbin & Patterson, 1983). There are three variables involved in a family's ability to be successful in redefining a crisis situation and creating new meaning. These variables are: (a) clarification of the issues, hardships, and tasks in order to make them more manageable

and responsive to problems solving; (b) a decrease in the intensity of emotional burdens that are associated with a crisis situation; and (c) encouraging themselves (the family) to carry on with important tasks of family member social and emotional development, such as careers and caregiving (McCubbin & Patterson, 1983. How the family defines the crisis situation and creates meaning from it directly affects how the family adapts. The process of adaptation, whether the family adapts poorly or healthfully to the crisis is discussed within the xX factor below.

Prior to moving on to the last factor of the Double ABCX model, it must be noted that the differences between Hill's ABCX and McCubbin and Patterson's Double ABCX lie within the interaction of the factors and a move from pre- to post-crisis over time. Within Hill's (1958) model, factors interact in a linear-like manner: a with b, a with c, and b with c leading to the event of the crisis. The interactional processes of the Double ABCX model, including post crisis factors aA, bB, and cC interacting with each other, creating coping (McCubbin & Patterson, 1983) differentiates the Double ABCX from the ABCX. The last process of the Double ABCX model is the xX factor, which shall now be examined.

The xX factor

Adaptation, bonadaptation and maladaptation are three facets of this factor. McCubbin and Patterson (1983) argue that family disruptions (stressors) may potentially be a necessary catalyst toward maintaining healthy family relationships and perhaps even lead to desired changes in family life. By this assumption one could ponder whether the removal or reduction of a stressor or stress event is itself a useful key regarding a family's adjustment post-crisis. To understand further the occurrence of family adaptation, it is necessary to comprehend three elements that are involved within this; (a) individual family members; (b) the family system; and (c) the community in which the family and its members are a part (McCubbin & Patterson,

1983). One should view each of these elements as being composed of both demands and capabilities, thus as they interact one's demands can be offset by another's capabilities, creating adaptation (McCubbin & Patterson, 1983).

This concept of achieving adaptation/balance is exactly what the xX Factor is about. The two opposing ends of the spectrum of adaptation (xX factor) are bonadaptation and maladaptation. These respectively result in:

Bonadaptation

a) Maintenance or strengthening of family integrity: keeping the family cohesive and strong
b) Continued promotion of member development and family unit developed: supporting of family members through their personal achievements and growth and support of the family as a whole as it grows over time.
c) Maintenance of family independence and its sense of control over external influences: the family is able to support itself and feels that it has control over its reality.

Maldaptation

a) Deterioration of family integrity: family roles shift, expectations change and the cohesiveness of the family begins to weaken.
b) Deterioration or curtailment of personal health and development of family members or the well being of the family unit: the family halts the process of personal and familial growth and development and focuses on basic needs, rather than achievements.

c) A decline or a loss in family independence and autonomy: the family becomes dependent on others, perhaps social services, which can include the Children's Aid Society becoming involved and deteriorating some of the family's autonomy regarding the care of the children (McCubbin & Patterson, 1983).

If these three elements cannot maintain a balance through reciprocity, the family falls out of balance, leading to maladaptation, and if they can maintain a balance, bonadaptation. Families also know, by being part of such intricate systems, that there is no such thing as perfect families, and that a healthy ability to manage the stressors and demands presented to them are often the best they can do, and in all practicality, the most that can be expected. Family response to stress/crisis is the central concept of the Double ABCX. Thus the Double ABCX is a useful tool when assessing the family's response to disability. However, the Double ABCX is a highly involved process model with multiple variables. The FAAR model on the other hand has fewer variables and comes directly from work on the Double ABCX and is in essence a natural progression in the literature towards a clearer understanding of family reaction to disability.

Family Adjustment and Adaptation Response – FAAR

The FAAR model developed through research performed by Benson, McCubbin, Dahl, and Hunter, (1974), McCubbin, Dahl, Lester and Ross, (1976), and McCubbin and Metres, (cited in McCubbin & Patterson, 1983; see Figure 3). The longitudinal research by McCubbin and Patterson (1983) examined families that were dealing with prolonged separation due to war and revealed that these families changed over time as a response to this situation. McCubbin and Patterson (1983) noted that there were three particular stages of adaptation, which they have termed resistance, restructuring and consolidation.

1) Resistance: defined as individuals within the family wanting to "wait it out," meaning that they attempt to keep the status quo as long as possible with only mini changes being made. This resistance to change however does not bode well for families, and they most often come to a realization that whatever it is they were hoping would stay the same will not, and their resources are not able to match their needs and a crisis occurs (McCubbin & Patterson, 1983).
2) Restructuring: characterized by a crisis event causing families to make changes in the roles played by family members, often working in tandem. Hill (cited in McCubbin & Patterson, 1983) calls this "closing ranks", in order to manage the demands they face.
3) Consolidation: when the family, even members reluctant to participate in the changes, being to realize that things will not improve unless they work together, noticing that moving forward is necessary (McCubbin & Patterson, 1983).

It was via these three stages, which were "reconceptualized into a process model," (p. 22) that McCubbin and Patterson (1983) were able to create the initial concept of the FAAR model, However, it was not until Patterson (1988) published her initial work on the FAAR that a model separate from the Double ABCX model was applied to FAAR processes. Until that time the FAAR was applied as a deeper analysis for family processes utilizing the Double ABCX model as the avenues through which family stress responses occurred (McCubbin & Patterson, 1983).

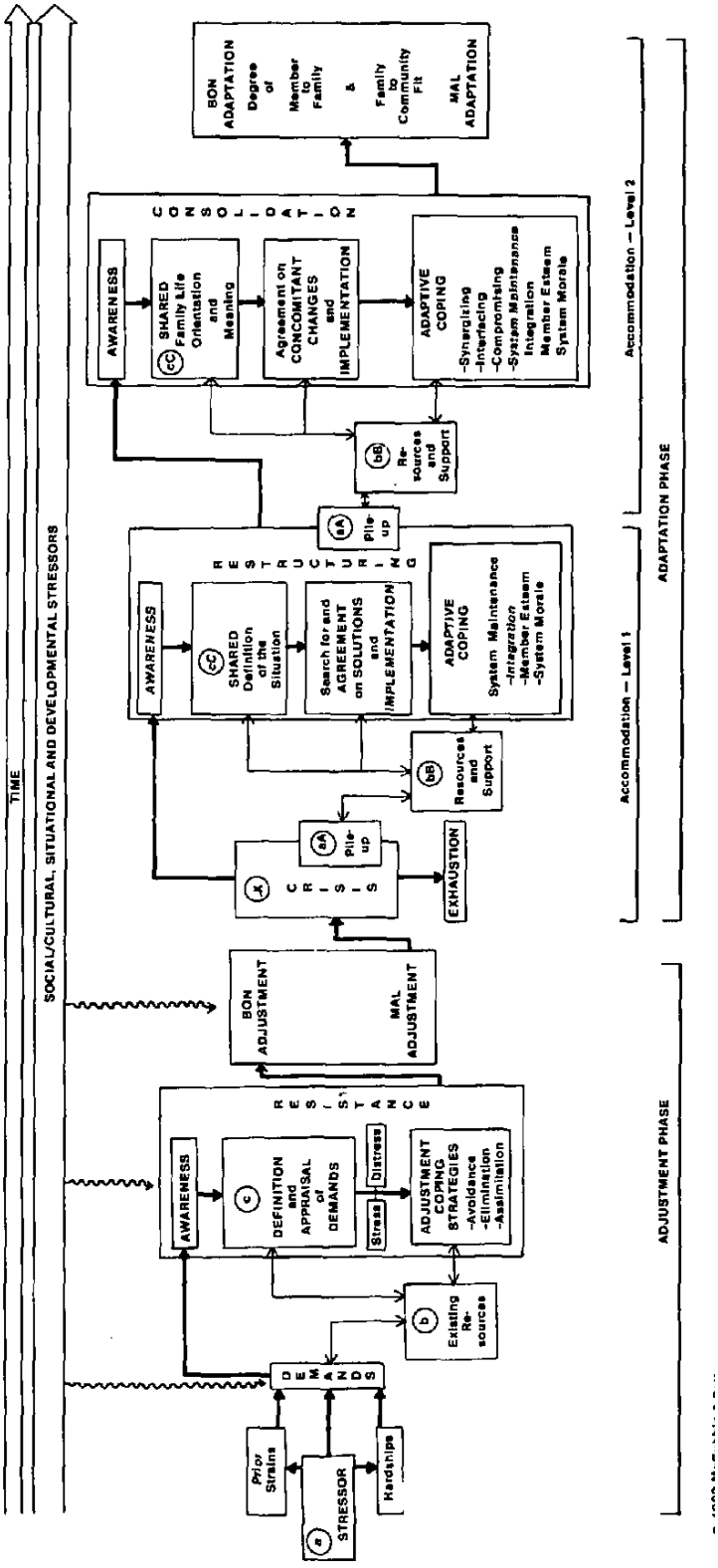

Figure 3. Family Adaptation and Adjustment Response Model (McCubbin & Patterson, 1983).

Patterson (1988) and Patterson and Garwick (1994a; 1994b) went on in later years to create a revised model of the FAAR that is in use to date. Not only did the model change during this revision in the structure of the model, but also in some of the language used, which will be touched upon separately. This newer version of the model is what will now be examined in further detail (See Figure 4). The FAAR is composed of two distinct sections, family adjustment and family adaptation separated by crisis. Families, according to Patterson (1988), are like any other social system in that they are constantly attempting to maintain homeostasis (balance) by using its capabilities (resources and coping behaviours to meet its demands (stressors and strains). Also, the meanings that they ascribe to these demands and the capabilities they have to deal with them are key in a family's ability to achieve homeostasis (Patterson, 1988).

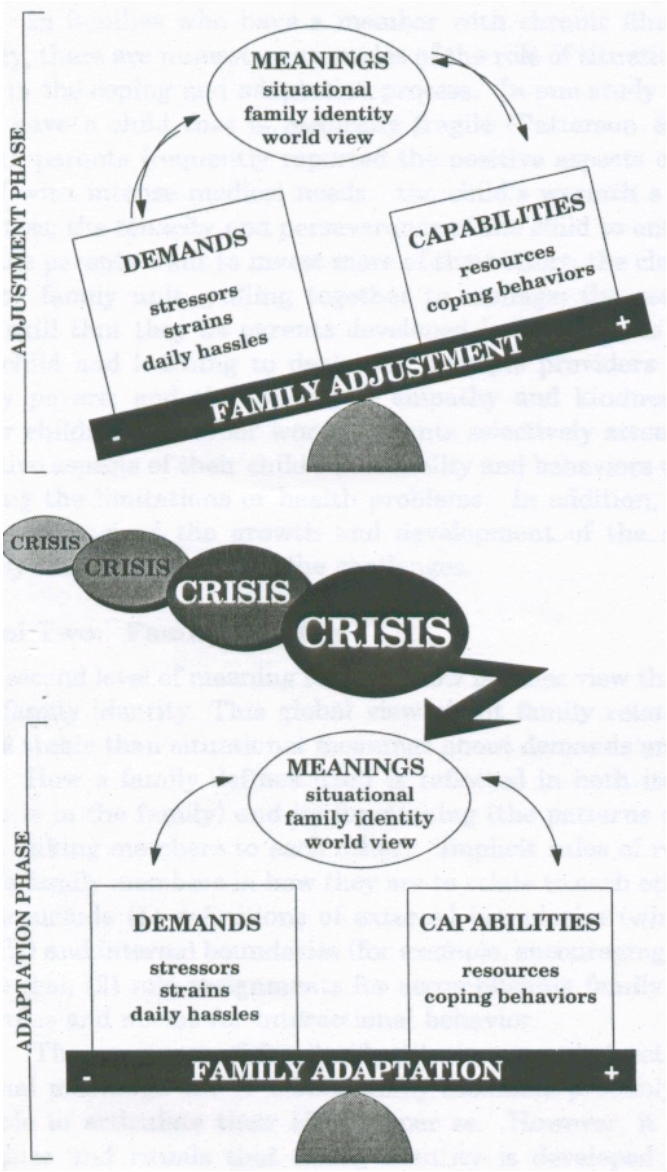

Figure 4. Family Adjustment and Adaptation Response model – FAAR, including meaning with family world view (Patterson & Garwick, 1998)

Patterson (1988) states that the family adjustment phase is meant to represent a relatively stable time in which only small changes are made as a family attempts to face its demands with their existing (resistance) capabilities. The adjustment phase is also the time when a family is encountering these new demands. It is important to note that families are constantly facing new

demands and stressors, as they are not static units within a static environment but are constantly under flux. Each new demand creates either adjustment or adaptation and in the case of the former, can lead to crisis. In a direct quote from Burr (cited in McCubbin & Patterson, 1983) they state that, "the family could be anywhere along the adaptation continuum from bonadaptation to maladaptation. Where families are along the continuum of adaptation influences their vulnerability to the impact of a subsequent stressor event or transition" (p. 22 Crisis arises when families can no longer maintain homeostasis as a result of a culmination of multiple demands that they face across time. A family will experience crisis when their available resources are insufficient to support family functioning once demands being to pile up.

The adaptation phase is when the family begins a return to homeostasis. The renewal of homeostasis can be achieved three ways; (1) acquiring new (adaptive) resources and coping methods (behaviours); (2) reducing the demands that they deal with; and/or (3) altering the way they view their situation (Patterson, 1988). Throughout both phases of the FAAR, there are multiple levels of the family system to be considered as integral to either the family's failure or success. The levels include individual family members, the family unit (and subsystems), and the community in which the family lives – all representing their own set of demands and capabilities (McCubbin & Patterson, 1983; Patterson, 1988). The means by which the family is able to maintain homeostasis varies depending upon what the demands are and what capabilities the family has to respond to the demands. Patterson provides valuable working definitions of key terms involved in the FAAR that are necessary for any further review of this model.

Demands

Demands are, "defined as a stimulus or a condition that produces or calls for change in the family system" (Patterson, 1988, p. 210). Demands are viewed as threats toward a family's

ability to maintain homeostasis, primarily because change, in this sense, is an essential part of the functional definition. As mentioned above, crisis occurs when the family has insufficient resources to meet the increasing number of demands. Stress (stressors) as discrete events and strains, mentioned below, are continuous (Patterson, 1988).

Stressors

Stressors are life events that occur at discrete points in time and produce, or can produce, changes in the family system (Patterson, 1988). Stressors are said to have a discrete onset, meaning one noticeable event, such as death. Even so, adaptation to these events can take an extended period of time. Also, stressors can be normative, such as a child reaching puberty, which is an expected change that occurs over time, or non-normative events such as an unexpected death of a child or natural disaster (Hill, 1958; McCubbin & Patterson, 1983; Patterson, 1988). Essentially, stressors are not equal in their level of severity or life altering ability, as certain events are welcomed and others are not. However, the number of stressors is often one of the concerns that researchers have when assessing family stress (Patterson, 1988).

Strains

Patterson (1988) defines a strain as a condition of perceived tension that is associated with a need or a desire to change something. In essence, a stressor occurs, strain is felt, and change then happens. Strains are already present prior to a stressor event and change is required to remove them (Patterson, 1988). Strains, unlike stressors, do not have a discrete onset and rather are a chronic and insidious facet of family life. Through her research Patterson (1988) states that she has ascertained that there are actually three sources of strain.

Source one.

This strain source may occur as a result of unresolved tensions associated with prior stressors – this could happen as a result of dealing with a chronic health condition of a family member that cannot be resolved or completely removed (Patterson, 1988)

Source two.

Source two strains may arise from ongoing roles played by individuals when their "role performance" is either not meeting their own, or another's expectations An example of this second strain source would be a parent who is dissatisfied with the lack of time available to spend with their children due to work constraints. Both they and their children can be disappointed with regards to the lack of hours spent together. Furthermore, an inability to create change with regards to this situation, such as being unable to find the time to attend the school play, in which their child has a role, (a nonoccurrence of an event) can be a source of strain itself (Patterson, 1988)

Source three.

The third source of strain emerges from outcomes of family adjustment/adaptation efforts. As families proceed through the process of managing and attempting to resolve demands to achieve homeostasis, the patterns of the family behaviours become stabilized. However, this stabilization does not provide a guarantee of homeostasis, and when homeostasis is achieved, even if precariously, this may actually place strain on individual family members' physical/psychological development. This occurrence of strain after homeostasis happens because the family creates maladaptive patterns of behaviours (e.g., depending too much on others) that essentially feed back into a loop that causes a pile-up of demands (Patterson, 1988). It appears that stressors interact with strains creating more demands – and not just in an additive

way – these strains often become demands in and of themselves as the family is aware of them when presented with new stressors (Patterson, 1988).

The FAAR also includes three levels of meaning that are important when considering a family's adaptation to stressful events. According to Patterson and Garwick (1994b) these levels of meaning are: situational meaning, family identity, and family world view.

Level One: Situational Meanings

Situational meanings happen organically as family members talk with each other about the stressor or demand pile-ups and what capacity they have to deal with it. As this discussion occurs new meanings are created (Patterson & Garwick, 1994b). E.g., discussing what the diagnosis of the child involves and how this will affect the family.

Level Two: Family Identity

At this level the family's self identity pertaining to their familial relationships is more stable than at level one: situational meanings yet also more abstract. If family members were asked, they would most likely be unable to articulate their identity within the family (Patterson & Garwick, 1994b).

Level Three: Family World View

The family's worldview involves the family member's orientation to the world outside the family unit and how the family members interpret reality, their core assumptions about their environs and also existential beliefs (e.g., the family's greater purpose/purpose in life, Patterson & Garwick, 1994b).

At these three levels, the family interacts with stressors at all stages of the larger FAAR model. These interactions can either lead towards maladaptation and poorer overall functioning for the family, or benefit the family and help them adapt in a healthy way. The functioning of the

family unit and its members is a complicated process, with myriad variables. The FAAR model has provided researchers and practitioners with a means towards understanding the latent and overlying variables involved in family stress processes.

Ecological Systems Theory

The Ecological Systems theory, or also the theory of Ecology of Human Development, was developed by Urie Bronfenbrenner (1977; 1986; see figure 5). The model of this theory explains why humans behave the way they do in different settings, such as quiet and attentive while in a lecture at school compared to a loud and vivacious nature when at home with family. The overlying tenet of this model is the influence that the environment has upon the individual (Bronfenbrenner, 1977; 1986). The environments that we encounter throughout our lives are posited to have a variety of effects upon the reactions we produce and the behaviours we display when situated within different environs.

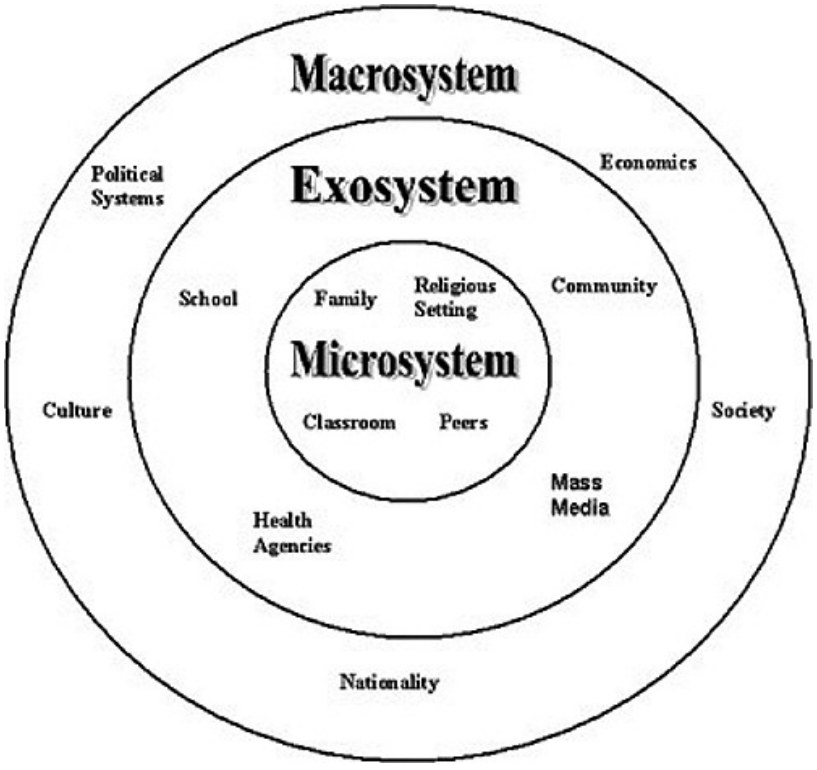

Figure 5. Ecological Systems Theory (Bronfenbrenner, 1977)

The ecological systems (environments) in which we find ourselves have been broken down into five systems of function (Bronfenbrenner, 1977). The five systems are:

1. Microsystem: In this system the individual lives directly within this system. The microsystem includes the family, friends, school (classmates), employers, and neighbours. Any person with whom the individual regularly has direct contact is considered to be a part of the microsystem. At this system level the individual is not mere a recipient of the experiences but also an integral and influential contributing factor in the structure of this system.
2. Mesosystem: This system involves the interaction between different pieces of the microsystem, such as how ones school performance can affect life at home and vice versa. Another example of this interaction could be in an instance when the child is neglected by his or her parents and as a result is not responsive to the teachers at school and withdraws from interactions with other children.
3. Exosystem: This system involves a link between where the person has active participation/interaction (e.g., a tight bond with one parent) and where the person does not have an active role (e.g., the parent they are not tightly bonded with). In this case the child is closely bonded to his or her father and when the father must go away for business, the child's relationship with the mother can either produce conflict or build a stronger bond between mother and child.
4. Macrosystem: The macrosystem is similar to the culture in which the individual resides. The culture can include socio-economic status, religious beliefs, country, city and race. An example of this influence on the individual's life could be the reality of being black in a predominantly white city where racism runs rampant. This experience not only makes it challenge for the individual to find employment, but they also often fear for their safety.

5. Chronosystem: This system includes the transitions that people experience over the course of their lives. These transitions can include moving away from home, marriage, divorce and death. In the case of divorce, not only is the once married couple affected, but the children are also affected, as are other people and systems involved within the family's life. (Bronfenbrenner, 1977; 1986).

The creation of the ecological systems theory was relevant because it allowed researchers who were assessing family stress processes to widen the scope of influence in the families' lives. Researchers could now incorporate these systems/levels within their own projects and theories to create meaning and understanding. Most importantly, this theory informed researchers on why/how participants in their studies behaved differently in different settings, and how this can guide the research process. This knowledge included knowing when it was appropriate to assess subjects in a laboratory setting or when this setting would be detrimental and a more natural setting, such as the home was a better representation of the subject's behaviour/response that was being assessed.

Bronfenbrenner's (1977; 1986) ecological systems theory made so much sense that it has become part of the zeitgeist involving psychological and social work research on families and stress. A prime example of this influence is seen when one examines the models applied to family reaction to disability (discussed in this chapter) and the discussions surrounding the interactions between different levels of the models. It is these levels that tie in directly with the systems of Bronfenbrenner's (1977) theory. Though the researchers in this chapter have not directly quoted Bronfenbrenner (1977), this author is certain that the presence of the ecological systems theory within the zeitgeist is what has driven researchers to develop this line of research, incorporating such integrative processes.

Work by Gallimore, Weisner and Guthrie (1996) as well as Hauser-Cram et al. (2001) assess familial function when there is a child with a disability across various systems. The tenets of the ecological systems theory are present in this research examining the varying levels and systems of function within the family. In support of Bronfenbrenner's (1986) work, Hauser-Cram et al. (2001) state that one of the influences on child cognitive outcomes is that of socioeconomic status, which is associated with the exosystem (e.g., neighbourhood, school, parent's place of work). While Gallimore et al., (1996) does not directly cite Bronfenbrenner, the structure of their familial analysis systems (i.e., school, family, and surrounding environment – exosystem) directly mirrors the structure found within Bronfebrenner's (1977; 1986) work. The fact that Gallimore et al. (1996) mirror the ecological system theory demonstrates an innate presence of Bronfenbrenner's (1977; 1986) theory within the present day zeitgeist of family reaction to disability research.

Parent Transformation - Transformational Outcomes

Scorgie et al. (2004) interviewed parents of children with assorted disability characteristics in a bid to support the model of transformational outcomes (see Figure 6). The model of Parent Transformation illustrates three overlapping processes that are thought to be accountable for the transformation seen in parents of children with disabilities (Scorgie et al., 2004). These three processes are: (1) image making, (2) choice making, and (3) meaning making, within the all encompassing "Environmental Influences" (physical, cultural, social; Scorgie et al., 2004). The model portrays the process by which parents let go of their prior assumptions and self-concept that no longer function, and actively work to create a new self-identity and world views. These changes are in response to receiving a diagnosis for their child. Central to the model is the concept of the bonded relationship. This relationship exists within the parent(s)

when they first discover they are expecting a child. The parents begin to image the life they will have with their child, and after the child's birth the parents continue to attach to a child they already love and life moves forward from there (Scorgie et al., 2004).

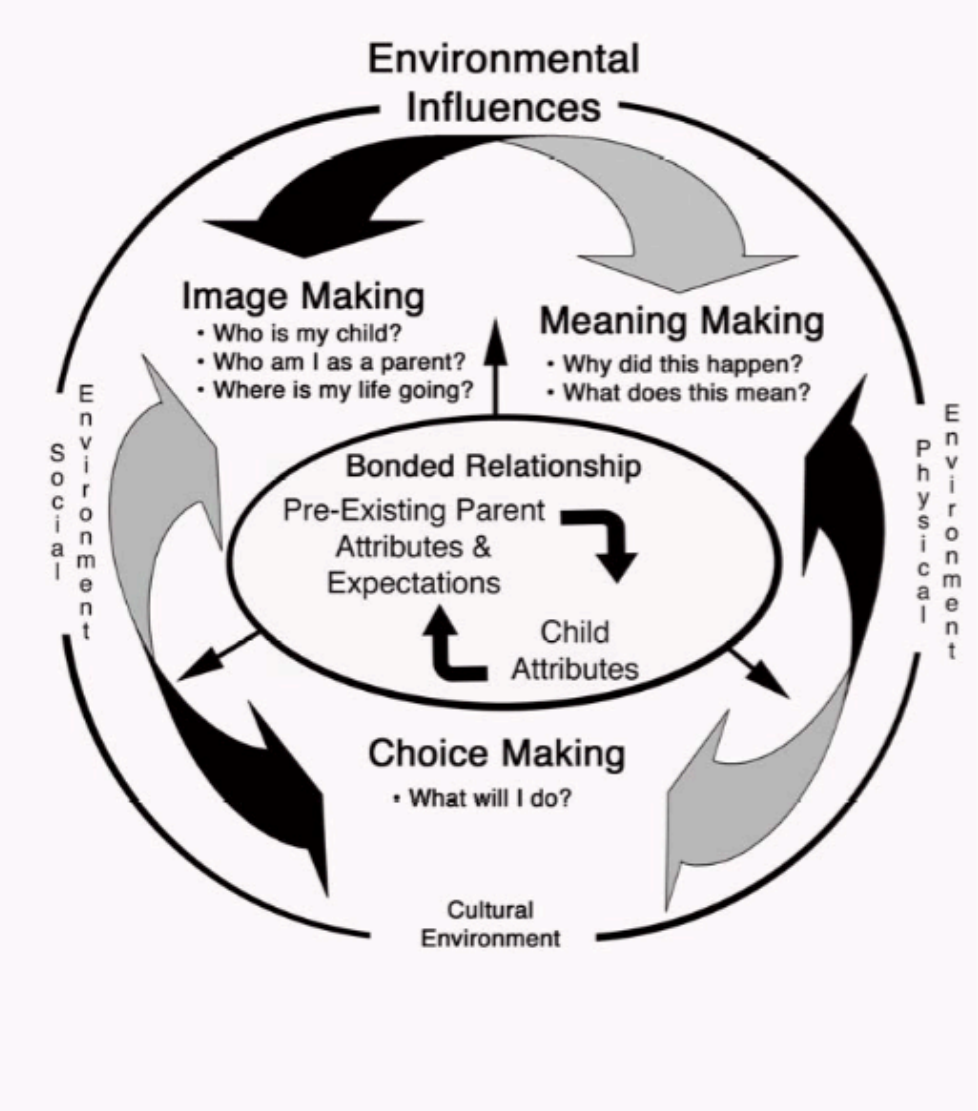

Figure 6. Processes used in achieving a transformational outcome (Scorgie et al., 2004).

However, when a child is either diagnosed at birth or even later on in their infancy/toddler years, the parents experience a "disorienting dilemma" (Scorgie et al., 2004, p. 91). The three processes within the parent transformation model begin to activate via the

emergence of "critical questions" (Scorgie et al., 2004) as a result of the family's sudden change of fate. These critical questions can be loosely categorized into the following categories: life trajectory identity-oriented questions, existential meaning-oriented questions, and personal/family choice-oriented questions (Scorgie et al., 2004). Transformation processes and outcomes occur when the questions can either be answered or they cannot. When they cannot be answered, new self-perceptions and life perspectives can be the result after an intense process of either image making, meaning making or choice making, or any combination of the three (Scorgie et al., 2004).

Within transformational outcomes are three major areas where the individual's self-identity are affected: (a) personal growth; (b) improved relationships with other people; and (c) changes within the individual's spiritual/philosophical values (Scorgie & Sobsey, 2000). Personal growth can involve a parent's new interest in learning more about their child's diagnosis and starting a support group for parents in their community. The improvement of relationships with other people can be seen as a heightened level of compassion towards others, particularly as a result of the parent being required to be more compassionate to the needs of their child and a new understanding of the struggles of others as a result. Finally, changes within an individual's spiritual or philosophical values can be affected such as a renewal of interest in their faith, or contrarily even a realization that maybe their God had nothing to do with their experiences; as a result they may feel free to leave their religion altogether.

Not all parents may necessarily undergo a transformational experience, though for those that do, it is a result of experiencing stress, pain and difficulty (Scorgie et al., 2004). Thus one can see how transformational outcomes are associated with parental experiences that occur with parenting a child with a disability. Parents often seek out differential diagnosis, as it allows them

both to relieve possible guilt, and also as a way for the parents to understand how best to care for their child and move forward in their lives (Watson, Hayes & Radford-Paz, 2011; Watson, 2008). As a result, this model allows researchers and professionals helping families of children with disabilities to understand the processes involved that lead the parent(s) to a new outlook on life.

Resilience Theory

When examining the theory of resilience, it is key to understand where resilience theory developed, how this was done, and where it is going. There is said to be four "waves" of resilience theory study and understanding (Masten, 2007; Richardson, 2002). The waves of inquiry begin with the response to the question, what characteristics do individuals who are exposed to risk factors have that allow them to "bounce back" in the face of their adversity (Masten, 2007; Richardson, 2002). Wave two developed to answer the question how are an individual's resilient qualities acquired (Masten, 2007; Richardson, 2002). Wave three has a strong focus of research and testing ideas of resiliency, plus it is also deeply set within a metaphysical school of though in an attempt to integrate biology, psychology, theology and mysticism in understanding the multifaceted experiences of resilient individuals (Masten, 2007; Richardson, 2002). Wave four is currently in its infancy as it is slowly overtaking and incorporating earlier research and data gleaned through the prior three waves (Masten, 2007). The fourth wave differs from the third as it is characterized by multiple levels of analysis and integrates the study of resilience across disciplines, species, and levels of analysis (Masten & Obradovic, 2006).

The initial inquiry into resilience did not occur from academic theory, but rather began through the assessment of at-risk individuals, most often young people, that overcame hardship

(Fraser & Richman, 1999; Richardson, 2002). According to Keyes (2004), the concept of resilience is a relative newcomer to the field of research in human development. Keyes (2004) states that the initial investigations and uses of the terms risk and resilience were conducted by Garmesy (1973), Werner (1977) and Rutter (1979), though Werner (Werner & Smith, cited in Keyes, 2004) is credited with initiating the use of the world resilience to define this specific phenomenon. Both Garmezy (1984) and Werner and Smith (cited in Keyes, 2004) examined children in at risk environments and how many of them avoided/overcame their hardships, some even quite successfully.

The construct of resilience used in this paper includes many factors and is not based solely on individual traits, but also involves an individual's social and environmental situation. McCubbin and McCubbin (1988) defined resilience as including the capacities, aspects, and attributes of families that help them to be resistant to disruptions as a result of change and crisis. What is also necessary for families to be resistant to disruption is a combination of interactional processes such as cohesion, flexibility, problem-solving skills, and good communication, all facilitating the well being of family members and basic family functioning (Walsh, 1993). Greene, Galambos and Lee (2004) have stated that in regards to resilience theory, there are certain individuals who have the ability to overcome dangerous or disadvantageous situations, though these skills can also be taught to those who do not have this ability, in an effort to protect them from harm.

Patterson (2002) also discussed resilience in a bid to integrate family resilience with family stress (reaction to disability) theory. Resilience as discussed by Patterson (1986) can be either a process or a capacity, with further discussion of these differences in Chapter 4. Resilient families and individuals can demonstrate a dearth of coping strategies that they can apply to

avoid the deleterious effects of crisis, as well as sometimes having an innate ability to be seemingly unaffected by a crisis at all. What Patterson (2002) concluded was that many of the factors of resilience are currently incorporated within the FAAR model and that both resilience and family stress (reaction to disability) theory complement each other, with resilience theory having "much to offer the family science discipline" (p. 358).

Conclusion

As this chapter has progressed, this author has been able to provide the reader with a deeper understanding of the models used in family reaction to disability research. From the early beginnings with Hill (1958) examining how families coped with stress caused by family separation, to the formation of new world view and self views of parents undergoing transformation processes (Scorgie et al., 2004), it has been shown that the understanding of family reaction to disability has changed over time. Not only has this understanding of the stress processes changed, but also the views held by researchers and practitioners towards families of people with disabilities and those with disabilities themselves.

It is hoped that the reader has been able to gain an understanding of these models and how they are applied. What also should be noted is the manner in which the researchers use their terminology to refer to many similar components within each separate theory. This fluid use of the terminology creates a challenge to current researchers as there are no definitively set terms that are consistent across all areas of family reaction to disability research. The following chapter will aim to clarify the issue of fluid terminology and provide a critical analysis of the current body of literature and the language applied within.

CHAPTER FOUR:

TERMINOLOGY

The American Psychological Association (APA) states,

> … authors who write for APA publications avoid perpetuating demeaning attitudes and biased assumptions about people in their writing. Constructions that might imply bias against persons on the basis of gender, sexual orientation, racial or ethnic group, disability or age are unacceptable. (Publication Manual of the American Psychological Association, 2010, p. 61)

The spoken and written word is the means through which the majority of the planet's population communicates with each other. Through millennia of evolution and culture, language has developed, changed, and grown as a reflection of the experiences of its speakers at that present moment. When examining the historical literature in the field of family stress in the prior chapter one can see this evolution in the language from a lexicon steeped in negativity towards one now building upon the value of the individual as more than just a diagnosis; a vocabulary that incorporates the humanity of the subject, and not solely a focus on the disability or an assumption of lesser value.

In the arena of family reaction to disability research, the lexicon includes terms such as stress, stressor, crisis, coping, adaptation, adjustment, resilience, and transformation (Hill, 1958; McCubbin & Patterson, 1983; Patterson, 2002; Scorgie, Wilgosh & Sobsey, 2004). This chapter will attempt to ascertain what the authors' mean when they employ the words they do, and how vocabulary differs between authors and their corresponding models. The chapter will also discuss how the language differs in the interpretation of these models in the literature. Though these words may not intentionally create bias or negativity towards groups or individuals they are

often interchanged in models or research studies. The issues in comprehension lie within the flexibility of word use, and not with the previously discussed potentially derogatory terminology surrounding disability. It is necessary to come to an understanding of what the authors mean when they use these words, and how these words are best used within the context of the models previously discussed. To understand the best use of these words is to reach an understanding of the best model to fit the research and whether or not any of the models previously discussed are consistently used within the literature.

Stress and Crisis

While Hill (1958) may not have overtly defined the word "stress," he did define stressor within the context of the family as a situation for which the family had little to no preparation for, and must then be viewed as problematic. To add to this definition, (Hill, 1958) also refers to the stressor as both the "crisis-provoking event" and "crisis-precipitating event" (p.140) in the span of one paragraph. Fortunately for the reader, these terms are not so obtuse in their meanings as to cause unmanageable confusion. In fact, other authors also use stress terminology interchangeably (Lavee et al., 1985; McCubbin, 1979; McCubbin & Patterson, 1983). What the authors mean by the word stress is an event or lack of an event that can lead to an imbalance in family functioning (Hill, 1958; McCubbin 1979). More specifically, a stressor is defined as a life event or transition that impacts the family, which produced or can produce change in the family social system – goals, patterns of interaction, roles and values (Abery, 2006; McCubbin & Patterson, 1983).

Examples of stressor can include the onset of illness, loss of employment, poor performance or trouble in school to name a few. Family hardships are further defined as demands on the family that are specifically associated with the stressor event (Lavee et al., 1985;

McCubbin & Patterson, 1983). Hill (1958) also states that it is difficult to separate the hardships of the stressful event from the definition of the event created by the family. Furthermore, the hardships of these events are noted to lie outside the family and are an attribute of the event itself, creating a separate variable entirely (Hill, 1958). Hill (1958) refers to these stressors as crisis-precipitating events. What Hill (1958) is saying is that the same event could happen to different families and the families would each create unique definitions regarding the hardships associated with this crisis-precipitating event and how it pertains to them as a family and its comprising individuals.

Hill (1958) provides an example, separation caused by war, which entails the removal of a family member, often a husband or son, through conscription to fight in World War II (Hill, 1958). The loss of a productive and supporting member of the family happened to many families during World War II. However, each family had a unique and individual response to the temporary, but often permanent, loss of their family member. This is where the hardships of the crisis-precipitating event can be seen as lying outside the family as a separate variable, though also creating a unique stress reaction within the context of each differing family.

It is this unique stress that can create a crisis when the family's resources cannot manage the stress caused by the crisis-precipitating event. Hill (1958) noted that crises often involve demoralization of family members' roles and patterns within the family structure. McCubbin and Patterson (1983) define crisis as a family's inability to restore stability and the continuous pressure to make changes within the family structure and its patterns of interaction. A crisis is distinct from stress, which is defined as a demand-capability imbalance (Lavee et al., 1985; McCubbin & Patterson, 1983). At this point in the literature, the definitions and interpretations

of the terms stress, stressor, crisis-precipitating event and crisis appear to be consistent across models and across authors.

Coping

Coping is a frequently used term throughout the family stress process literature related to family reaction to disability (Hill, 1958; Lavee et al., 1985; McCubbin & Patterson 1983; Murray, Kelley-Soderholm & Murray, 2007; Patterson, 1988). Its use varies from initial use when speaking about families that "close ranks" (Hill, cited in McCubbin, 1979), to a stand-alone analyzed factor (McCubbin, 1979), to being an integral factor in the second half of the Double ABCX (Lavee et al., 1985; McCubbin & Patterson, 1983;) involved with pile-up, new resources and meaning prior to becoming strongly associated with Patterson and colleagues' (e.g., Patterson, 2002; Patterson & Garwick, 1994a; 1994b) concept of adjustment. In this section, I will attempt to determine what is meant by coping, what appears to be its most valid definition, and if this understanding is reflected in the literature.

To begin, prior to the Double ABCX model McCubbin (1979) published a work examining the integration of coping behaviours with family stress theory. Coping in this context is described as a strategy used to manage stress, a collection of behaviours that are directed at strengthening the family's internal organization and function, as well as the ability to access supports and sometimes divert, reduce, or eliminate the source of stress itself (McCubbin, 1979). This definition of coping allows for a wide application of the word, which leads an understanding of why so many researchers have adopted it to describe the family's process of managing and responding to stress.

In discussing the analysis of coping and coping strategies, McCubbin(1979) incorporates Hill and Hansen's (1962) proposition of the connection between coping and adaptive behaviour.

In this case Hill and Hansen (1962) have used adaptive (adaptation) behaviour in place of coping behaviours. This interchangeable nature of the words coping and adaptation creates difficulties in separating the two concepts, which continues throughout the literature and will be demonstrated below.

Coping behaviours assessed in McCubbin and Huang (1989) showed that mothers' coping behaviours were directly connected with a positive outcome for herself, her child and her family. These coping behaviours included searching out supports, information, and maintaining family integration and they can also be seen as behaviours associated with both adjustment and adaptation (Lavee et al., 1985; McCubbin & Huang, 1989; McCubbin & Patterson, 1983).

The Double ABCX incorporates coping in the second half of the model (see chapter 3, figure 2) as an interactive facet/process that involves: pile-up of demands (aA); existing and new resources (bB); perception of Aa and bB; (cC); and adaptation (xX; McCubbin & Patterson, 1983). Coping essentially functions as a bridge in this context, connecting a variety of other factors together to create a dynamic and flowing model of function. Interestingly, coping strategies can also cause negative consequences for families as a result of new sources of strains (McCubbin & Patterson, 1983). For example, a mother might have to take on a job outside of the home to afford medical expenses for a child with a disability, leading to more stress being placed on other family members who may not be fully capable of performing all of the duties previously performed by the mother.

Coping as a bridging concept includes cognitive and behavioural components that involve resources, perceptions, as well as behavioural responses of the family as it tries to achieve homeostasis (Lavee et al., 1985; McCubbin & Patterson, 1983). The nature of coping as a concept is such that it can incorporate many unique and varying factors dependent upon the

situation in which it is applied, the model where it is used, and the situational context in which we find the model being applied. An example of coping in the FAAR can include the continued use of an old schema and its associated behaviours, such as the belief that hard work and self-sufficiency are the only way to manage a financial crisis associated with increased medical expenses for the child. Furthermore, coping is not dependent upon specific stressors, but rather is a process through which the families rally their resources etc. in response to ever changing stress and crisis stimuli (Lavee et al., 1985; McCubbin & Patterson, 1983).

Patterson (1988) discusses coping behaviours and responses separately, though it appears that they are essentially interchangeable in their definition. According to Patterson (1988, 2002), coping responses are part of subjective judgments that include capabilities and resources, and coping behaviours involve the family attributing new meaning (either positive or negative) to the situation. This begs the question; are we looking at coping responses or coping behaviours and are they the same thing, or are the slightly different? Further analysis of Patterson (2002) shows that the FAAR employs the term "coping response" and this is defined as the means through which a family copes. Coping is achieved by changing the way they think about the/their situation and often ascribe new meaning to their situation.

It appears that coping is a flexible term in its ability to be adopted by researchers throughout the sphere of family stress research. This flexibility has allowed researchers to carry the term forward through the literature and thus has enabled the evolution of the term coping to fit within the present day. The evolved definition of coping is more in keeping with the reality of present day families and their reaction to disability. From the discussion above it is clear that one of the strongest concepts within the construct of coping is the formation of new meaning that the family ascribes to their situation. This process has evolved from occurring as a standalone

process (Hill, 1949) to a bridging concept (Lavee et al., 1985; McCubbin & Patterson, 1983), to an involved process that allows families to ascribe new meaning to a situation (Patterson, 1988; Patterson, 2002). Furthermore, the coping behaviour/response of the family occurs prior to the adjustment phase in the FAAR, which will now be discussed further.

Adjustment

Looking back into Hill's (1958) theoretical writings on the ABCX model of family stress, Hill only lightly touches upon the concept of adjustment. Using Koos and Fulcomer's (cited Hill, 1958) work as an addendum to the ABCX, adjustment to crisis is discussed pertaining to slowed familial affectional and emotion-satisfying performances. This omission of adjustment within the actual ABCX may be due to the nature of the model, in which there is not a continuation of the family's function past the crisis point. The use of the word adjustment will not be seen until the development of the Double ABCX (McCubbin & Patterson, 1983). Hill (1958) does speak to adjustment as being an important factor in the familial response to stress, as can be seen below, although the term that Hill applies instead of adjustment is integration. Integration, within the scope of the ABCX is defined as, "bonds of coherence and unit running through family life, of which common interests, affection, and a sense of economic interdependence are perhaps the most prominent" (Angell, cited in Hill, 1958, p. 144). What this means is that the B factor of the ABCX involves the family's resources meeting the crisis in a manner that allows the family to function in a reduced capacity prior to the onset of a crisis. An example of reduced capacity could include the need for parents working extra hours outside of the home and away from their child with a disability (not meeting the child's full needs for parental care) in a bid to earn more money to meet increased expenses. As a result, the child does not receive the attention it needs

and becomes more severely ill with an infection, ending up in hospital leading to a crisis for the child and the family.

Using the ABCX model as a starting point, McCubbin and Patterson (1983) developed the Double ABCX by integrating four new factors, with the first half of the new model involved in adjustment and the second half involved in adaptation. This new specified adjustment phase is an interactional process between the family's stressor (a); their current and existing resources (b); their definition and appraisal of the demands caused by the stressor (c); leading to a culmination in crisis prior to the adaptation phase (McCubbin & Patterson, 1983). Furthermore the adjustment phase discusses specific adjustment strategies including coping, avoidance, elimination, and assimilation. Interestingly, within the structure of the Double ABCX McCubbin and Patterson (1983) discussed the Family Adjustment and Adaptation Response (FAAR) process, not as a stand-alone model, but as an integrated process within the structure of the Double ABCX model itself. It will not be until 1988 that Patterson publishes work on the FAAR as a stand-alone model.

Coherence is another often used term when discussing the process of adjustment (Patterson, 2002; Retzlaff, 2007). Retzlaff (2007) speaks of a family's sense of coherence influencing their coping processes and changes how the family perceives (i.e., ascribes meaning to) stressors and utilizes their available resources. This use of coherence applies to the process of the family uniting and working together to adjust to stressors.

The term integration as seen in Hill (1958) has also been applied in a similar manner. The integration in families experiencing crisis is often seen in changes in relative position of role/responsibility of parents and child within the family, this definition being similar to that of Patterson (2002). Contrarily, Angell (cited in Hill, 1958) refers to families that are well

integrated as managing crisis in stride without noticeable change to the family's role-structure or organization, a definition more similar to resilience. The second definition of integration lead Hill (1958) to state, "…unintegrated families are most likely of all to be unpredictable deviants in adjusting to crisis" (p. 148). It appears that integration, pertaining to the ABCX work of Hill (1958) does not match the use of coherence as spoken of by Patterson (2002) and Retzlaff (2007).

Patterson (2002) uses the term coherence in the same manner as Retzlaff (2007). However, Hill (1958) is not consistent with the use of integration and as such Hill's (1958) use of integration is actually more similar to the definition of resilience, which will be discussed below. Hill (1958) clearly should have applied the term resilience instead of integration when creating his theory. It is suggested that the term integration be applied when discussing the adoption of new factors or the taking on of novel and additional coping strategies. Conversely, the term coherence is applied in keeping with its definition that pertains to the process of forming a unified whole when families are facing crisis ("Coherence", 2015). With both coherence and integration as descriptive terms in the process of adjustment, it is clear that language use is often dependent upon the author and less so on the concrete definitions ascribed to specific theoretical functions.

Patterson (1988, 2002) and Patterson and Garwick (1994a, 1994b) employ adjustment as a measure (bonadjustment/maladjustment) of the family's capabilities and demands. Adjustment directly influences the family's meaning (situation, identity, world view) of the stressor they are experience. This interactional process is strongly related to McCubbin and Patterson's (1983) Double ABCX FAAR component. However, the FAAR as a solo entity has a more simple layout and structure of the model than it did as a part of Double ABCX. Even though the FAAR has

been isolated from the Double ABCX and as such has a more streamlined approach, certain researchers have still interchanged the terms adjustment and adaptation (e.g., Murray et al., 2007). This confusion supports the thought that the FAAR still lacks clarity, causing its application in the literature to be stunted.

Coping or Adjustment, which one?

However, if coping were used in place of adjustment, the risk of confusion between adjustment and adaptation would likely almost disappear. I hypothesize that the phonetic similarities and the use of alliteration between the two words, adjustment and adaptation, may be at the root of confusion and misuse. Coping has already been applied as a bridging term in Hill's (1958) ABCX model as well as McCubbin and Patterson's (1983) Double ABCX and the definitions created by these researchers incorporate coping as a necessary component of the model's function. It must be noted that there is little difference between the definition for coping and that of adjustment. It is because of these similarities that exchanging the place of the words within the FAAR would make sense. This exchange of terms would be a benefit first, in lessening confusion, and second more in keeping with the application of coping by McCubbin (1979), acknowledging that coping is less a bridge and more a process.

One suggestion towards clarity of the FAAR model is to completely remove adjustment as a construct. Reason for the removal of adjustment is because it is too flexible in its applicability. The application of adjustment in the FAAR was done as a means to describe how a family made-do with their circumstances. However, the accurate definition of adjustment would actually pertain to a discussion on how a family gets "used" to their new circumstances ("Adjustment", 2015), and this isn't the case in the FAAR. The definition of the word cope involving how an individual effectively deals with something difficult, "his ability to cope with

stress" is a much more applicable definition than that of adjustment ("Cope", 2015). The supplied definition of coping is a much better descriptor of the reality of a family or individual under stress than that of adjustment. As such, coping should take the place of adjustment within the FAAR. This replacement makes sense because coping is a word that is widely used in family reaction to disability research (Lavee, McCubbin & Olson, 1987; McCubbin, 1979; Wilgosh & Scorgie, 2006). The use of coping in the literature is strongly associated with its dictionary definition regarding how a family responds to stress ("Cope", 2015; Lavee et al., 1985; McCubbin & Patterson, 1983).

The replacement of the word adjustment with the word coping would most likely result in lessened confusion and build greater comprehension of the FAAR model. It would be beneficial for researchers to have access to a model that is both clear in meaning as well as has ease of use. If the word adjustment is removed from the FAAR anagram and replaced with coping, the anagram becomes the FCAR. This seemingly simple change can have great implications. The adoption of the word coping will hopefully allow for ease of incorporation of the FCAR into family reaction to disability research. In addition, each letter in the FCAR anagram will be unique, resulting in less confusion. Low confusion and high functionality are two factors that should always be considered by any theorist when developing a novel means of assessing a matter of interest.

Adaptation

The first mention of adaptation by McCubbin and Patterson (1983) involves a three-stage definition. Stage one, resistance, begins as part of adjustment, referring to the family's awareness of the new demands and resisting the change that these new demands require for healthy functioning (leading to crisis and the adaptation phase; McCubbin & Patterson, 1983). Stage two,

restructuring, commences as a result of awareness in the family that their existing structure and strategies are not adequately meeting their demands (McCubbin & Patterson, 1983). The family then changes their definition of the situation, and finds new solutions to their demands. Stage three, consolidation, occur when the family applies their new solutions to the situation to maintain the function of the family as a unit (McCubbin & Patterson, 1983). Together the family resists the change to come, but after a crisis they are willing to redefine their meanings and strategies associated with the stressor and begin to work together. Families consolidate their new beliefs and strategies, in essence changing for the better over time in response to their circumstances in an accurate portrayal of adaptation. However, these stages are not touched upon in later revisions of the model. It is the newest definition of adaptation that will be examined and its use in the literature.

Lavee et al. (1985) defined family adaptation as an outcome of the family's processes in response to a crisis and the associated pile-up of demands (demands defined as stressor/strain). One must also note that Burr (1973) spoke of adaptation, stating that it does not mean that disorganization or changes to the system have occurred, but merely that the system has resumed its prior and usual level of operation after coping with change. Family adaptation is also operationally defined as a composing of the family members' sense of well-being, satisfaction with their family's lifestyle, as well as having low incident rates of health, emotional, marital and legal problems within the family (Lavee et al., 1985).

Within the construct of adaptation are the opposing outcomes of maladaptation and bonadaptation. Summers et al. (1989) described these phenomena as being either a progressively upward spiral of personal/familial growth (bonadaptation) or a downward spiral of dysfunction and crisis (maladaptation). The resulting type of adaptation falls on the Xx factor of the Double

ABCX model and at this point, the family and its individual members either move forward in healthful functioning of bonadaptation or reach new crises and changes as a result of maladaptation.

In research performed by Jones and Passey (2005) using the Double ABCX, very little regarding adaptation is mentioned, rather the authors appear to discuss coping and stress with far more frequency. In actuality Jones and Passey (2005) do not touch upon adjustment, but replace it with coping as it pertains to the process of adaptation. The research by Jones and Passey (2005) supports this author's claim that adjustment is not the most fitting term, but that adaptation in contrast is highly applicable with regards to family outcomes. In contrast, Nachshen and Minnes (2005) almost immediately discuss adaptation as a it pertains to the Double ABCX and these authors define it as a result of a pile-up of family stresses (aA), the family's new and existing resources (bB) and the meaning of the stress to the family (cC). The discussion and examination by Nachschen and Minnes (2005) of adaptation and the family's outcome support the use of adaptation in the theoretical vocabulary.

Patterson (1988) incorporated the Double ABCX into the Family Adjustment and Adaptation Response (FAAR) process model. Within the framework of this new model, adaptation is the final stage, as it is in the Double ABCX. Patterson's (1988) definition of the adaptation phase in the FAAR as it pertains to families is a minimal discrepancy between demands and capabilities across two levels of interaction: individual to family and family to community. The final FAAR stage, often called positive adaptation, is the result of an individual/family's coping strategies that are activated as part of their resources in response to crisis (Patterson, 2002; Retzlaff, 2007). Patterson and Garwick (1994a) best define the adaptation phase as a time when the family attempts to restore homeostasis by a) acquiring new coping

behaviours and resources; b) reducing the demands they face; and/or c) changing the meanings about their situation, themselves as family and/or their world view.

Murray et al. (2007) cited Patterson's FAAR model in their study and unfortunately in doing so switched the terms adjustment and adaptation. This switch and reordering of these words demonstrates an incomplete grasp of the concepts within the FAAR. Furthermore, when the reader would expect discussion regarding adaptation, there is none and the focus falls on Family Systems Theory. In fact, upon deeper analysis it is noted that the authors claim that their research supports the FAAR model, and yet do not discuss any factors other than the processes involved with the Family Systems Model (Murray et al., 2007). The processes of the FAAR discussed in Murray et al. (2007) are relational processes that link the experiences of the family members together. An example of these relational processes can involve a parent losing their job and as a result, their stress and anger at the situation created stress and fear in the other family members. This dismissal is reflected in Retzlaff (2007), where the author also cites Patterson's (1988) FAAR as well as her work associating the FAAR with Resilience theory (2002), yet fails to properly approach the concepts of the FAAR model (see Chapter 3) and focuses solely upon resilience.

It appears that researchers in the field have a challenge when it comes to fully comprehending the defining features of the FAAR concept of adaptation. Researchers examining family reaction to disability that claim to apply the FAAR should, in my opinion, apply the appropriate terminology in their writings. Building on the use of said model, it is also important that researchers truly comprehend the model's processes. This comprehension would prevent researchers from making the assumption that similar models in the literature can be applied in the same manner, with the same language.

As hypothesized above, certain researchers have interchanged the terms adjustment and adaptation because of the strong phonetic similarities between them. These similarities are also seen within the definitions of the words. Adjustment is defined as "1. A small alteration or movement made to achieve a desired fit, appearance, or result and; 1.1 the process of adapting or becoming used to a new situation" ("Adjustment", 2015, para. 1; 1.1). Two out of three definitions for adaptation provided by the Oxford Dictionary (2015) are most suited to the context of family reaction to disability. The first definition pertains to, "1. The action or process of adapting or being adapted: 'the adaptation of teaching strategy to meet student needs'" ("Adaptation", 2015, para. 1). Whereas the second definition of adaptation involves, "1.2 Biology, the process of change by which an organism or species becomes better suited to its environment" and is a better fit with how the word adaptation is applied in the literature ("Adaptation", 2015, para. 1.2). There is most definitely a similarity between these two words, in that they both pertain to changing something to better fit something else. For example, an examination of the adaptation of a family to a child's diagnosis of a developmental disability would demonstrate how the family became "used" to this new situation ("Adjustment", 2015). The family's adaptation would also reflect how they are now better able to manage the strains associated with the disability of the child.

Resilience

Resilience has been a construct long discussed in the literature pertaining to both the individual and also the family (Greene et al., 2003; Walsh, 1996). Seligman (1990) writes about the concept of "learned optimism" as it pertains to resilience in opposition to his earlier work on "learned helplessness". Further research includes Murphy (1987), who speaks of "optimistic biases" where the individual uses any means to hold on to hope and faith, and Kobasa's (1985)

three hardy personality traits that enable an individual to be resilient in the face of adversity. Bronfenbrenner (1979) further states that the family, peer group, work or school setting, and social systems are all nested contexts for social competence of an individual/family and as a result are involved within the processes of resilience.

Greene et al. (2003) defined resilience as an individual/family's ability to overcome adversity, sustain competence under pressure, and the capacity to recover from trauma and be successful in spite of exposure to high risk. Also it cannot be understated that the use of the term resilience, is by researchers, reserved for use where there is an unpredicted and markedly successful adaptation to demanding life events, trauma, or stress (Fraser & Richman, 1999).

Patterson (2002) focused on the integration of family resilience with family reaction to disability. Within the scope of her writing, she aims to distinguish between family resiliency as capacity and family resiliency as process. Resilience as a capacity involves a family's properties, dimensions and characteristics that can help the family to be resistant to disruption when facing change, as well as adaptive when facing crisis (McCubbin & McCubbin, 1988; Patterson, 2002). Resilience has been recommended as the term ascribed to the capacity a family has to adapt to crisis (Luther, Cicchetti & Becker, cited in Patterson, 2002). Resiliency, as suggested in the literature is the desired term to describe the *process* of resilience rather than *capacity* (Luthar et al., cited in Patterson, 2002). The resiliency process according to Patterson (2002) incorporates protective factors as a means through which the individual or family can mediate the risks associated with the crisis they face, leading to good outcomes.

One of the sources of discord in the area of resilience research is the difference in use of the concept between practitioners and researchers. Patterson (2002) explains that researchers are most interested in the outcomes to explain unexpected competent functioning with

individuals/families who have been exposed to significant risk (Fraser & Richman, 1999), whereas practitioners generally use the term to describe an approach focusing on family strengths versus deficits (McCubbin & McCubbin, 1988). Patterson specifically defines resilience as "the phenomenon of doing well in the face of adversity" (Patterson, 2002, p. 350).

In Patterson's (2002) work, she ties together family resilience and family adaptation. Deeper analysis shows that there are certain similarities between constructs in the FAAR and the concept of resilience. These similarities include demands, risk factors (resiliency language), capabilities, and protective factors (Patterson, 2002). With regards to outcome processes, bonadaptation parallels family resilience as an end result with healthy familial outcomes (Patterson, 2002). The construct of resilience shares many of the same factors as the FAAR. Interestingly these similarities involve innate resilience processes found within the individual/family and are seen less with regard to capacity (resiliency) and its associated mediating factors.

Resilience theory with regards to the FAAR demonstrates how interactive the process of becoming/achieving resilience is at the family level. Although, when examining the functional processes of adaptation, resilience should be accepted as a stand-alone concept. Maintaining the separation of resilience from the FAAR is supported by the above discussion involving the innate processes of resilience. The integration of resiliency theory with the FAAR would make more sense if capacity was being integrated rather than innate resilience processes, as resilience capacity involves an individual/family's ability to *develop* traits that lead to bonadaptation. The FAAR was developed to assess the adjustment and adaptation responses to crises caused by stress within the family. Resilience can be discussed as a potential variable, but if the family or any of its members display resiliency traits (i.e., innate resilience processes, already having the

trait), then their response to the crisis should not be considered representative of the processes in the FAAR.

Transformational Outcomes

Historically the literature states that families, when faced with crisis, work to re-established prior homeostasis and level of functioning (Hill, 1958). However, the work surrounding transformational outcomes has shown two previously held assumptions about stress and coping to be false. The first assumption states that stress is by nature a negative consequence, whereas the second is that the primary goal of coping is to return to a prior state of homeostasis (Aldwin, cited in Scorgie et al., 2004; Newman, cited in Scorgie et al., 2004) Both of these assumptions are overturned when the experiences of an individual's transformation outcome are considered.

The transformative experience has been described as, "a life event and its outcome, such that the event is given a central role within a self-narrative in causing, catalyzing, or symbolizing, substantial, lasting psychological change" (Palus, cited in Scorgie & Sobsey, 2000, p. 196). These transformational outcomes are real and meaningful because they lead to a new world view of the individual. Parents queried by Scorgie and Sobsey (2004) often supply statements with topics such as increased compassion towards others, learning to speak up and not remain passive, and gaining new opportunities they would not have had before the birth and life of their child. These statements emphasize the positive nature of the transformational experience.

The model of transformational outcomes and the FAAR truly complement each other, particularly with regards to new meanings and adaptation. The FAAR seeks to understand the changing processes over time within the family's process of adjustment and adaptation. This understanding does not assume that the family's adaptation is a return to their prior normal, but

rather that the family has created a new meaning for the stressor, leading to growth toward a new and hopefully healthier (either bonadaptation or maladaptation) level of functioning that differs from their prior, pre-crisis experience (Patterson, 2002; Scorgie et al., 2004). With transformational outcomes, the change in an individual's world view allows that individual to experience personal growth towards positive functioning. In essence, the new world view of transformational outcome is the same as the supplying of new meaning in the FAAR. Through an understanding of the processes within the FAAR, one can easily come to understand how transformational outcomes are not only possible but also probable.

Transformational outcomes surpass even the adaptation stage of the FAAR as the new schemas that have been created become concrete aspects of the individual/family's identity. Individuals assessed by Scorgie and Sobsey (2000) state that they feel that they have gained new skills and with their new world view they are able to function more efficiently, effectively, and healthfully. In keeping with the definition of transformation, "a metamorphosis during the life cycle of an animal" ("Transformation", 2015, para. 1.2), the work of transformation outcome theorists truly demonstrates this change at the personal and familial levels.

Conclusion

Though the body of research is wide, as has been demonstrated, there is a varied vocabulary in use within the sphere of family reaction to disability research (see Table 1). With terminology such as stress, strain, demand, pre-crisis event, crisis, coherence, integration, adjustment, adaptation, resilience, coping as well as transformational outcomes, it can be overwhelming to decide what term best describes the processes being examined within families and individuals experiencing stress.

Table 1. Definitions of terminology across theories and researchers

	ABCX	Double ABCX	FAAR	Transformational Outcomes
Stressor/Stress	"A situation for which the family has had little or no prior preparation and must therefore be viewed as problematic" - Hill (1958, p. 140)	Can occur in any number of the family's systems and the individuals within, includes the hardships experienced by the family that arise when this occurs - McCubbin & Patterson (1983)	Life events that occur at discrete points in time and can produce changes in the family system. They have discrete onset, meaning one noticeable event, such as death - Patterson (1988)	
Strain		Include unstable finances, marriage maintenance, involvement of extended family – McCubbin & Patterson (1983)	A condition of perceived tension that is associated with a need or a desire to change something - Patterson (1988; 2002)	
Demands		Demands/hardships placed on family unit that are specifically associated with a stressor event - McCubbin & Patterson (1983)	A stimulus or condition producing or calling for change in the family system - Patterson (1988)	
Coping	When a family closes ranks and functions using only their immediate capabilities - Hill (1958)	A bridging concept including cognitive and behavioural components that involve the family's resources - McCubbin & Patterson (1983)	The continued use of an old schema and its associated behaviours. A process through which families rally resources in response to changing stress and crisis - Patterson (1988; 2002)	The primary goal of coping to return to homeostasis does not apply at all to transformational outcomes. – Aldwin (cited in Scorige et al., 2004)
Crisis	A downward slump in organization, "roles are played with less enthusiasm, resentments are smothered or expressed, conflicts are expressed or converted into tensions that make for strained relations" – Hill (1958, p. 146)	A family undergoing a period of disorganization - McCubbin & Patterson (1983) The cC factor gives meaning to the crisis definition and examines how this interacts with the other Double ABCX factors leading to outcome	Unrelenting disequilibrium within the family system that occurs when demands exceed the family's existing capabilities – Patterson & Garwick (1994b)	
Adjustment	The family finds it necessary to work out different patterns and roles. This slows the family function and its affectional and emotion-satisfying performances until the new patterns are worked out – Hill (1958)	Consists of specific strategies including coping, avoidance, elimination, and assimilation. Interactional process between the stressor, the family's current and existing resources, their definition and appraisals of the associated demands, culminating in crisis. – McCubbin & Patterson, (1983)	Family meeting demands using current capabilities. Also involves coherence: influences the family's coping processes and changes their meaning of stressors and the application of available resources. - – Patterson (1988)	

	ABCX	Double ABCX	FAAR	Transformational Outcomes
Adaptation	Integration – Used in place of adaptation, "bonds of coherence and unit running through family life, of which common interests, affection, and a sense of economic interdependence are perhaps the most prominent" – Angell (cited in Hill, 1958, p. 144)	Two outcomes, bonadaptation and maladaptation result from the family response to crisis. Bonadaptation is a balanced outcome. Maldaptation is an inability to maintain balance in the family leading to further crises - McCubbin & Patterson (1983)	Result of an individual/family's coping strategies that are activated as part of their resources in response to crisis - Patterson (1988; 2002) The family attempts to restore homeostasis by acquiring new coping behaviours, reducing their demands, and changing the meanings of their situation, themselves and or their world view. – Patterson & Garwick, (1994a)	
Resilience			Resilience as capacity = family's properties, dimensions and characteristics to help the family resist disruption when facing change and adapt when facing crisis. Resiliency as process = protective factors as a means through which the individual/family can mediate the risks associated with crisis, leading to good outcomes. - Patterson (2002)	
Transformation				"A life event and its outcome, such that the event is given a central role within a self-narrative in causing, catalyzing, or symbolizing, substantial, lasting psychological change" – Palus (cited in Scorgie et al., 2004)

The most congruent and complementary representations of family reaction to disability and the processes involved – as demonstrated above – are seen in both the FAAR and Transformational Outcome models. Terminology associated with these models includes adaptation and coping. As discussed above, I suggest coping replace the word adjustment within the FAAR model. This suggestion is a result of the postulation that confusion is a result of the phonetic similarities between adjustment and adaptation, reinforcing the suggestion of the change in terminology. Furthermore, the process of transformational outcomes appears to follow a natural progression of personal/familial growth after the adaptation phase of the FAAR.

Resilience as a stand-alone concept is completely functional. However, it does not fit well within the FAAR model as it corresponds more with innate resilience processes rather than the capacity of resiliency, which involves the use of external supports. Unique to resilience theory is an individual or family's ability to bounce back from a trauma or crisis, seemingly unaffected. Essentially, because the theory of resilience does not involve processes such as those represented within the FAAR (e.g., ascribing new meaning), it is not necessarily a good fit when discussing the process of family reaction to disability.

In summary, the terminology applied in the literature is directly representative of the constructs that theorists are attempting to define. When the vocabulary of these theorists becomes muddied with flexible words that can be applied to multiple events the levels of clarity and functionality of the models are drastically reduced. By coming to a consensus as to the most fitting terminology and potentially restructuring certain models as a result, it is hoped that the usefulness of these theories can be applied to the topic of family reaction to disability for many years to come.

CHAPTER FIVE:

CONCLUSION

This paper attempted to clarify which model of family reaction to disability is most congruent in its explanation of this experience. The use of language within the models and theories examined in this paper is a key factor in determining what the researchers mean when they use the vocabulary they do, plus what words are easily confused. In Chapter 4, I attempted to determine if there are more fitting words that can be applied to research on family reaction to disability. The importance of understanding how language used in the models affects the type of conclusions drawn by researchers cannot be understated. Furthermore, by delving into the topic of language use with regards to models and theories, I hope to guide future researchers in the arena of family reaction to disability research toward the application of clear and concise terminology that best represents the reality of their subject of research.

By examining the historical time periods when the models and theories in this paper were developed, context was provided in order to understand perhaps how the researchers expounded their theories and what influenced their development. Context is essential when a researcher is examining family experience as well as the models and theories involved because the environment influences not only the family and individual in research, but also the researchers authoring their work. Furthermore, family process models and theories that were examined in this document were organized chronologically from the earliest years to present day. This chronological timeline of the research enabled me to build a clear and effective explanation of the development of the newer models, as they often built upon earlier works by other family reaction to disability researchers. The relationship between the context noted in the historical chapter (Chapter 2) and the chapter examining the family stress models and theories (Chapter 3) provides

support for the claim that who, what, when, and where equals why when it comes to family function.

It is unfortunate that the FAAR has had limited application within the literature, particularly because the application of the Double ABCX in the literature did not include the FAAR as a process within the larger model, in the manner it was originally published. This omission ignores what McCubbin and Patterson (1983) wrote about the FAAR as a process of stress response in conjunction with the Double ABCX. A more accurate application of the Double ABCX would ensure that researchers were fully utilizing the model when examining family reaction to disability. This application would include both the variables within the Double ABCX and the FAAR in a combined approach to understanding family function. This concurrent application would be in keeping with the original work of McCubbin and Patterson (1983) and provide greater utility to the Double ABCX.

Both Transformational Outcomes and the FAAR have been demonstrated to have a complementary relationship, though this has not been examined within the literature on family reaction to disability. Though limited, there is potentially a benefit to the relationship between the FAAR and Transformational Outcomes in expanding the understanding of what bonadaptation looks like in families and individuals. When Patterson (1988) separated the FAAR from the Double ABCX, she streamlined the variables and created clarity and ease of function. The FAAR model accurately follows the family's process in response to stress and crisis. One noticeable issue with clarity however is associated with the ease with which certain researchers have confused adaptation with adjustment, as is the case with Murray et al. (2007), where the words adjustment and adaptation were actually written in the wrong order.

As highlighted previously, one of the more prominent features within the literature reviewed for this paper was the use of language. Historical terminology surrounding people with disabilities included words such as idiot, feebleminded, moron, retardate, and defective to name a few. It is important to note that the use of these terms was not always done so derogatorily. Though the eugenics movement recommended the euthanization if not sterilization of individuals with disabilities (Kennedy, 1942), the derogatory usage in general society developed because these words described a population of individuals that were undesired and seen as less valuable. Language has always been a key part of identifying the era in which a piece of writing was created, for example most disability related writings of the 2000s include the use of person first language, a concept not embraced prior to the turn of the century.

The major focus of this paper was the use of language pertaining to the terminology that is applied in the family reaction to disability models and theories that were reviewed. Spanning from the ABCX to the FAAR model, and most recently Transformational Outcomes, the constructs in these models are designated with specific words describing specific processes, at least that was the goal of the researchers who developed these models and theories in the first place. The terms involved in the analysis included crisis, coping, stress/stressor/strain/demands, adjustment, adaptation, resilience, and transformation. Complications arise when researchers begin using different terms interchangeably or do not properly grasp the meaning behind the model and its associated terminology.

As demonstrated in Chapter 4, the construct of resilience does not belong as part of the processes involved with the FAAR. The reason for this is that resilience is a stand-alone theory that does not demonstrate the development of the family and individual as they respond to crisis and adapt. Though resilience and resiliency behaviours can be a part of the family's response to

stress and crisis, the process behind these behaviours does not follow suite with the processes within the FAAR model. To explain, resilience as previously discussed involves an ability to be seemingly unaffected by negative circumstances/events, demonstrating how traits within a family/individual and the associated behaviours enable the family/individual to bypass the more challenging processes that they would otherwise have undergone, as seen in the FAAR.

Coping however should remain within the FAAR because of its strong association with the adjustment processes where the individual/family is in a survival type mode of function by just getting by. As a matter of fact, in Chapter 4, coping has been suggested to replace the term adjustment, creating a new anagram, the FCAR. This replacement in the terminology would create more clarity with regards to the processes of the FAAR model and would limit confusion between the words adjustment and adaptation. Furthermore, by employing coping to describe the processes of a family in the pre-crisis stage - a term seen throughout the literature - comprehension of models across theorists will result, as well as simplification of future analyses of family reactions to disability.

A model that develops the concept of adaptation further is the personal experience of transformational outcomes. The definition of adaptation, involves a successful or unsuccessful new way of functioning for the family (Patterson, 1988; 2002). With unsuccessful functioning, the family is prone to further crisis and will process through the steps of the FAAR cyclically until reaching bonadaptation. Positive adaptation (bonadaptation) flows directly into the concept of Transformational Outcomes and can be assessed further via the Transformational Outcomes model. In Scorgie and Sobsey's (2000) work, parents of children with disability queried with regards to their positive transformational outcomes responded with stories of positive personal

growth and development. This personal growth came after they reached a state of adaptation in response to the crisis of experiencing their child's diagnosis.

The FAAR and Transformational Outcome models complement each other in an almost poetic manner. Where the FAAR concludes on the subject of adaptation, the Transformational Outcomes model picks up and carries forward on the subject of personal growth. Transformational Outcomes demonstrates how adaptation leads to an individual's growth out of the reaction to disability responses assessed by the FAAR. Due to the structure of the FAAR model it can always be reapplied after transformational outcomes have occurred in a bid to analyze the new stressors and crises that can arise as life progresses. It is this cyclical relationship between the FAAR and Transformational Outcomes models that supports the conclusion that these models work well together.

Where do we go from here?

The theories examined in this paper all had one thing in common, the experiences of families reacting to disability. In order to quantify the language use and prevalence of theories applied in the literature, it is suggested that a statistical analysis of the use of terminology within the literature be performed. This would involve a meta-analysis regarding frequency of specific terms and their associated variables. A meta-study would provide key data to analyze how often specific terms are being applied and the accuracy of the applied terminology. Furthermore, it would inform on which models/theories are most often applied in the literature. This study would allow future researchers to accurately determine what theories are being applied, what areas of family reaction to disability research are being examined, and the terminology associated with both of these variables. In addition this type of study could provide support for the unification of

the FAAR and Transformational Outcomes models and/or support the creation of a new, more functional model to assess family reaction to disability.

It is my hope that the critical review of the literature in this paper has brought clarity to the constructs of the theories assessed. Also, that there is a need for more present day researchers to utilize the most applicable and current model in their analyses of family reaction to disability. To do justice to the field of family reaction to disability, these theorists should be employing a model that is both function and uncomplicated as they approach the subject of family function. I conclude that most congruent model(s) to apply to the subject of family reaction to disability are the FAAR: to examine the process of adjustment and adaptation, and Transformational Outcomes: to build on the construct of adaptation, pertaining to personal growth.

Family reaction to disability research began many years ago with Hill (1958) examining the function of families undergoing war-induced separation. It is from these very specific beginnings long ago that the entire field of family reaction to disability research has grown to encompass a variety of families and diagnoses. Today, theorists and researchers have reached a deeper understanding of the family's reaction to disability and the myriad of processes involved. With future research building upon the body of literature currently available, theorists can continue to move forward, hopefully one day developing a theory that is both theoretically sound, but also highly applicable. It is hoped that this literature review has spoken to the importance of this subject and can inform future work on the development of family reaction to disability theory.

REFERENCES

Adaptation. (2015). In Oxford Dictionaries: Language Matters. Retrieved August 27, 2015, from http://www.oxforddictionaries.com/definition/english/adaptation?q=Adaptation

Adjustment. (2015). In Oxford Dictionaries: Language Matters. Retrieved August 27, 2015, from http://www.oxforddictionaries.com/definition/english/adjustment

American Association on Intellectual and Developmental Disabilities. (2011). *Definition of Intellectual Disability.* Retrieved http://www.aamr.org/content_100.cfm?navID=21

American Psychiatric Association. (2002). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author

Berkson, G. (2004). Intellectual and physical disabilities in prehistory and early civilization. *Mental Retardation*, 42, 195-208.

Birenbaum, A. (1971). The mentally retarded child in the home and the family cycle. *Journal of Health and Social Behavior, 12*(1), 55-65.

Bristol, M. M. (1987). Mothers of children with autism or communication disorders: Successful adaptation and the double ABCX model. *Journal of Autism and Developmental Disorders, 17*(4), 469-486.

Bronfenbrenner, U. (1986). Ecology of the Family as a Context for Human Development: Research Perspectives. *Developmental Psychology*, *22*(6), 723-742.

Bronfenbrenner, U. (1979). Toward an Experimental Ecology of Human Development. *American Psychologist*, *32*, 513-531.

Brown, I., Radford, J.P. (2007). Historical Overview of Intellectual and Developmental Disabilities. In I. Brown & M. Percy (Eds.), *A Comprehensive Guide to Intellectual and Developmental Disabilities* (pp. 17-33). Baltimore: Brookes.

Burr, W. R. (1973). *Theory construction and the sociology of the family*. New York, NY: Wiley.

Coherence. (2015). In Oxford Dictionaries: Language Matters. Retrieved August 27, 2015, from http://www.oxforddictionaries.com/definition/english/coherence?q=Coherence

Cope. (2015). In Oxford Dictionaries: Language Matters. Retrieved August 27, 2015, from http://www.oxforddictionaries.com/definition/english/cope?q=Cope

Cummings, S. T., Bayley, H. C., & Rie, H. E. (1966). Effects of the child's deficiency on the mother: A study of mothers of mentally retarded, chronically ill and neurotic children. *American Journal of Orthopsychiatry, 36*, 595-608.

Danielson, F.H. (1912). *The Hill Folk: Report on a Rural Community of Hereditary Defectives*. Long Island: Eugenics Record Office.

Erickson, M. T. (1968). MMPI comparisons between parents of young emotionally disturbed and organically retarded children. *Journal of Consulting and Clinical Psychology, 32*(6), 701-706.

Farber, B., & Kirk, S. A. (1959). Effects of a severely mentally retarded child on family integration. *Monographs of the Society for Research in Child Development, 24*(2), 1-112.

Farber, B., & Kirk, S. A. (1960). Family organization and crisis: Maintenance of integration in families with a secretly mentally retarded child. *Monographs of the Society for Research in Child Development, 25*(1), 1-95.

Ford Arkin, C., Frazier, B., Miller, M. E., Blinn Pike, L., & Reynolds, M. (1995). *Family resiliency: Building strengths to meet life's challenges.* Retrieved November 6, 2010 from Iowa State University Extention website http://www.extension.iastate.edu/publications/EDC53.pdf

Fraser, M.W. & Richmand, J.M. (1999). Risk, production, and resilience: Toward a conceptual framework for social work practice. *Social Work Research, 23*(3), 131-154.

Gallimore, R.S., Weisner, T., Guthrie, D. (1996). Family responses to children with developmental delays II: Accommodation intensity and activity in early and middle childhood. *American Journal of Mental Retardation, 101*(3), 215-232.

Greene, R.R., Galambos, C., & Lee, Y. (2004). Resilience theory. *Journal of Human Behavior in the Social Environment, 8*(4), 75-91.

Hauser-Cram, P., Warfield, M.E., Shonkoff, J. P. (2001). The Development of Children with Disabilities and the Adaptation of their Parents: Theoretical Perspectives and Empirical Evidence. *Monographs of the Society for Research in Child Development, 66*(3), 6-21.

Helff, C. M., & Masters Glidden, L. (1998). More positive or less negative? Trends in research on adjustment of families rearing children with developmental disabilities. *Mental Retardation, 36*(6), 457-464.

Hill, R. (1958). Social stresses on the family. *Social Casework, 39*(2), 139.

Hopkins, J., Marcus, M., Campbell, S.B. (1981). Postpartum Depression: A Critical Review. *Psychological Bulleting*, *95*(3), 498-515.

Jordan, D.S. (1913). *The Heredity of Richard Roe: A Discussion of Eugenics*. Boston: American Unitarian Association.

Kanner, L. (1949). Problems of Nosology and Psychodynamics of Infantile Autism. *American Journal of Orthopsychiatry, 19*(3), 416-426.

Kennedy, F. (1942). Social control of the congenital defective: Education, sterilization, euthanasia. *American Journal of Psychiatry, 99*, 13-16

Key, W.E. (1920). *Heredity and Social Fitness: A Study of Differential Mating in a Pennsylvania Family*. Washington: Carnegie Institution of Washington.

Keyes, C.L.M. (2004). Risk and Resilience in Human Development: An Introduction. *Research in Human Development, 1*(4), 223-227.

Kog, E., Vertommen, H., Vandereycken, W. (1987). Minuchin's Psychosomatic Family Model Revised: A Concept-Validation Study Using a Multitrait-Multimethod Approach. *Family Process, 26*, 235-253.

Lavee, Y., McCubbin, H.I., Patterson, J.M. (1987) The effect of Stressful Life Events and Transitions on Family Functioning and Well-Being. *Journal of Marriage and Family*,*49*(4), 857-873.

Lavee, Y., McCubbin, H. I., Patterson, J. M. (1985). The double ABCX model of family stress and adaptation: An empirical test by analysis of structural equations with latent variables. *Journal of Marriage and Family, 47*(4), 811-825.

Lavee, Y., McCubbin, H.I., Olson, D.H. (1987). The Effect of Stressful Life Events and Transitions on Family Functioning and Well-Being. *Journal of Marriage and Family, 49*(4), 857-873.

Linley, P.A. (2003). Positive Adaptation to Trauma: Wisdom as Both Process and Outcome. *Journal of Traumatic Stress, 16*(6), 601-610.

Masten,A.S. (2007). Resilience in developing systems: Progress and promise as the fourth wave rises. *Development and Psychopathology, 19*, 921-930.

Masten, A. S., & Obradovic, J. (2006). Competence and Resilience in Development. *Annals of the New York Academy of Sciences*, *1094*, 13-27.

McCubbin, M.A., Huang, S.T.T. (1989). Family Strengths in the Care of Handicapped Children: Targets for Intervention. *Family Relations, 38*(4), 436-443.

McCubbin, H.I., Joy, C.B., Cauble, E., Comeau, J.K., Patterson, J.M. & Needle, R.H. (1980). Family Stress and Coping: A Decade Review. *Journal of Marriage and Family, 42*(3), 855-871.

McCubbin, H.I.& Patterson, J.M. (1983) The family stress process: the double ABCX model of adjustment and adaptation. In H.I. McCubbin, M.B. Sussman & J.M. Patterson (Eds.). *Social stress and the family: Advances and developments in family stress theory and research (*pp. 7-37). New York: Haworth.

McCubbin, H. I. (1979). Integrating coping behavior in family stress theory. *Journal of Marriage and Family, 41*(2), 237-244.

McCubbin, H. I., & McCubbin, M. A. (1988). Typologies of Resilient families: Emerging roles of social class and ethnicity. *Family Relations, 37*(3), 247-254.

McCubbin, H. I., & Patterson, J. M. (1983). The family stress process. *Marriage & Family Review, 6*(1-2), 7-37.

McCubbin, M. A., & Huang, S. T. T. (1989). Family strengths in the care of handicapped children: Targets for intervention. *Family Relations, 38*(4), 436.

Myerson, R. B. (1991). *Game theory: Analysis of conflict* (p. 1). Cambridge Massachusetts: Harvard University Press.

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework,43*, 190-193.

Ontario Ministry of Community and Social Services. (2014). *History of Developmental Services.* Retrieved August 12, 2015 from http://www.mcss.gov.on.ca/en/mcss/programs/developmental/improving/ds_history.aspx

Parks, R. M. (1977). Parental reactions to the birth of a handicapped child. *Health and Social Work, 2*(3), 51-66.

Patterson, J. M. (1988). Families experiences stress: I. the family adjustment and adaptation response model, II. applying the FAAR model to health-related Issues for intervention and research. *Family Systems Medicine, 6*(2), 202-237.

Patterson, J.M., & Garwick, A.W. (1994a) The Impact of Chronic Illness on Families: A Family Systems Perspective. *Annals of Behavioural Medicine*, *16*(2), 131-142.

Patterson, J. M., & Garwick, A. W. (1994b). Special section: Chronic illness and the family - levels of meaning in family stress theory. *Family Process, 33*, 287-304.

Radford, I., Park, D.C. (2003). Historical Overview of Developmental Disabilities in Ontario. In I. Brown & M. Percy (Eds.), *Developmental Disabilities in Ontario* (3-18). Toronto: Ontario Association on Developmental Disabilities.

Richardson, G.E. (2002). The Metatheory of Resilience and Resiliency. *Journal of Clinical Psychology, 58*(3), 307-321.

Risdal, D., Singer, G.H.S. (2004). Marital Adjustment in Parents of Children with Disabilities: A Historical Review and Meta-Analysis. *Research and Practice for Persons with Severe Disabilities*, *29*(2), 95-103.

Seligman, M.E.P., & Csikszentmihalyi, M. (2000). Positive Psychology: An Introduction. *American Psychology, 55*(1), 5-14.

Sobsey, D. (2004). Marital stability and marital satisfaction in families of children with disabilities: Chicken or egg?. *Developmental Disabilities Bulletin*, *32*(1), 62-83.

Scorgie, K. & Sobsey, D. (2000). Transformational Outcomes Associated with Parenting Children who have Disabilities. *Mental Retardation, 38*(3), 195-206.

Scorgie, K., Wilgosh, L., Sobsey, D. & McDonald, J. (2001). Parent Life Management and Transformational Outcomes when a Child has Down Syndrome. *International Journal of Special Education, 16*(2), 57-67.

Scorgie, K., Wilgosh, L., & Sobsey, D. (2004). The experience of transformation in parents of children with disabilities: Theoretical considerations. *Developmental Disabilities Bulletin, 32*(1), 84-110.

Solnit, A. J., & Stark, M. H. (1961). Mourning and the birth of a defective child. In A.J. Solnit & M.H. Stark (Eds.), *An Anthology of the Psychoanalytic Study of the Child: Physical Illness and Handicap in Childhood* (pp. 181-184). Newhaven, NJ: Yale University Press.

Statistics Canada. (2003). *2001 Participation and Activity Limitation Survey.* (Catalogue number 89-586-XWE). Retrieved November 5, 2010 from Statistics Canada: http://www.statcan.gc.ca/pub/89-628-X/89-628-x2009009-eng.pdf

Summers, J. A., Behr, S. K., & Turnbull, A. P. (1989). Positive adaptation and coping strengths of families who have children with disabilities. In G. H. S. Singer, & L. K. Irving (Eds.), *Support for caregiving families: Enabling positive adaptation to disability* (pp. 27). Baltimore, MD: Paul H Brookes Publishing Co.

Transformation. (2015). In Oxford Dictionaries: Language Matters. Retrieved August 27, 2015, from http://www.oxforddictionaries.com/definition/english/transformation?q=Transformation

Trent, J.W. (1994). Inventing the feeble mind: a history of mental retardation in the United States. Berkeley: University of California Press.

Walsh, F. (1993). Conceptualization of normal family processes. In F. Walsh (Ed.), *Normal Family Processes* (2nd ed., pp. 3-69). New York: Guilford Press.

Walsh, F. (1996). The concept of family resilience: crisis and challenge. *Family Process, 35*, 261-281.

Watson, S. (2008). "Something you have to do" - why do parents of children with developmental disabilities seek a differential diagnosis. *Developmental Disabilities Bulletin, 36*(1 & 2), 168-198.

Watson, S., Hayes, S. A., & Radford-Paz, E. (2011). "Diagnose me please!": A review of research about the journey and initial impact of parents seeking a diagnosis of developmental disability for their child. In R. M. Hodapp (Ed.), *International review of research in developmental disabilities* (41st ed., pp. 31-71). Oxford: Elsevier.

Wilgosh, L., & Scorgie, K. (2006). Theoretical model of conceptualizing cross-cultural applications and intervention strategies for Parents of children with disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 3*(4), 211-218.

Wong, P.T.P., Wong, L.C.J., Scott, C. (2006). Beyond stress and coping: the positive psychology of transformation. In Wong, P.T.P., & Wong, L.C.J. (Eds.), *Handbook of Multicultural Perspectives on Stress and Coping.* New York: Springer. Retrieved September 18, 2010 from, http://DrPaulWong.com/index.php?option=com_content&view=category&layout=blog&id=47&Itemid=119.