This item was submitted to Loughborough University as a PhD thesis by the author and is made available in the Institutional Repository (https://dspace.lboro.ac.uk/) under the following Creative Commons Licence conditions.

For the full text of this licence, please go to: http://creativecommons.org/licenses/by-nc-nd/2.5/
THE FAMILIES' PERSPECTIVE: RAISING A CHILD OR YOUNG ADULT WITH DOWN SYNDROME

by

Iris S. Drower

A Thesis
Submitted in partial fulfillment of the requirements for the award of
Doctor of Philosophy of the Loughborough University

Supervisors:
Dr. Brian Stratford
Dr. John Thomas

June 1996
© by Iris S. Drower 1996
IN MEMORY OF:

SIDNEY DEUTCH

who believed in human condition
# TABLE OF CONTENTS

List of Tables.......................................................................................... vi
Appendix Listing.................................................................................... vii
Preface................................................................................................. viii
Abstract .............................................................................................. ix
Chapter I: Introduction ........................................................................ 1
Chapter II: Down syndrome Past and Present ..................................... 11
Chapter III: Impact Upon Family When Raising A Child with Mental Retardation .. 39
Chapter IV: Raising A Child With Down Syndrome............................. 70
Chapter V: Methodology ................................................................. 91
Chapter VI: Introduction to the Results ............................................. 105
Chapter VII: Theme One and Two .................................................... 125
Chapter VIII: Theme Three and Four .............................................. 146
Chapter IX: Theme Five .................................................................... 167
Chapter X: Themes Six-Eight ......................................................... 176
Chapter XI: Meta Themes ............................................................... 187
Chapter XII: Discussion ................................................................. 196
Bibliography ...................................................................................... 226
Appendix ........................................................................................... 258
# LIST OF TABLES

Break Down of Themes .......................................................... Table 1, p 104.1
Break Down of Schooling ....................................................... Table 2, p 104.2
Marital Status ...................................................................... Table 3, p 107.1
Current Ages of Family Members ............................................... Table 4, p 107.2
Sibling Rank....................................................................... Table 5, p 107.3
Time of Diagnosis..................................................................... Table 6, p 107.4
Person Making Initial Diagnosis ................................................ Table 7, p 107.4
Parent's Ages When the Child Was Born................................. Table 8, p108.1
Ethnic Background ................................................................ Table 9, p 108.2
Religious Background ............................................................ Table 10, p 108.2
Educational Background ......................................................... Table 11, p 108.3
Financial Background ............................................................ Table 12, p 108.3
APPENDIX LISTING

Recruitment Letter............................................................. Appendix A, p. 258
Letter of Consent............................................................. Appendix B, p. 259
Demographics ................................................................. Appendix C, p. 261
Letter of Confirmation ........................................................ Appendix D, p. 263
Probe Questions.............................................................. Appendix E, p. 264
Validity Check Letter ........................................................ Appendix F, p. 265
Sample Interview.............................................................. Appendix G, p. 266
Map of East Croydon, England (Pilot Study) ......................... Appendix H, p. 275
Map of Phoenix, Arizona, USA........................................ Appendix I, p. 276
Terms and Definitions ....................................................... Appendix J, p. 277
Sometimes a researcher has to travel thousands of miles away in order to make and further comprehend that what is "strange" is truly very "familiar".

Loughborough University has provided this researcher with an international experience by linking two countries different yet equal together within one world. For maintaining high academic standards is truly synonymous with the provision of meaningful learning experiences for every research student. This University under the expert direction and innovative supervision of Dr. John Thomas and Dr. Brian Stratford has provided this researcher with an opportunity for personal and academic growth, i.e. a broadening of horizons, regular exposure to and growing appreciation for cultural patterns different from one’s own culture, and a heightened self-confidence, and independence, toward obtaining this most prestigious degree.

For education is a “partnership”. Education is a cooperative and collaborate endeavor between the research student, supervisor, director, the department or college of education, the institution or university, and staff who by working together can then seek future designs for making a valuable impact and contribution to our “global community”.

viii
THE FAMILIES' PERSPECTIVE: RAISING A CHILD OR YOUNG ADULT WITH DOWN SYNDROME

IRIS S. DROWER

LOUGHBOROUGH UNIVERSITY, JUNE 1996

SUPERVISOR: Brian Stratford, Ph.D.
SUPERVISOR: John Thomas, Ph.D.

ABSTRACT

Down syndrome (referenced in USA) or Down's syndrome throughout the world, the most common genetic birth defect is a chromosomal anomaly. It affects all races and economic levels equally throughout the world.

It has only been over the past twenty years that significant advances in human genetics have compounded a move toward the future needs and potential of children and young adults with Down syndrome. Henceforth, individuals with Down syndrome can now be seen more within the confines of their neighboring schools, homes and communities.

The role and impact from the families' perspective when raising a child or young adult with Down syndrome has been an overlooked complex phenomenon. It is then the intention of this exploratory study to address and further explore a description by looking directly at a sample of fifteen families (within the State of Arizona, USA) who have a child or young adults with Down syndrome. These families represent a diverse cross-section of social, economic, religious, ethnic, and traditional and nontraditional lifestyles. One-and-one half hour audio-taped family interviews were conducted to describe their individual needs, concerns and views of this experience. These families were then recontacted six weeks to validate findings which emerged through thematic analysis.
Eight themes or key areas were shared by all participants. These themes included the following: 1). Diagnosis issues; 2). Adjustment issues; 3). Family issues; 4). Social issues; 5). Educational concerns and beyond school years; 6). Parental experiences and needs; 7). Advice and issues for new parents; and 8). Advice for society. In addition three meta or universal themes were consistently threaded throughout the fifteen interviews. These were described under the headings of: 1). Living one day at a time, 2). Seeing the person first as being 'included' in society, and 3). Advocacy..being their voice. The findings indicated that there is a complex (varies from day-to-day as well as an individualized) effect upon the family related to raising a child or young adult with Down syndrome.

The findings of this study provide a means to learn and share, in light of the current body of literature, the families' perspective when raising a child or young adult with Down syndrome. In addition it is a further intent of this study to offer a challenge to the medical and health professions, psychologists, counselors, educators, social workers and all helping professions along with our "global community" to foster a greater mutual understanding of what it is like to raise a child or young adult with Down syndrome.
CHAPTER I
Introduction

Before Billie was born I was a different person. Billie had Down syndrome. I was active as an officer in Junior League. I was involved in bridge circles, and I regularly attended country club activities with my husband. I still go to country club activities once in a while. But something happened to me—my image—so that Junior League and bridge circles did not mean as much. It’s like some things had to die in me...some myths I believed about myself...some ways I saw myself. They had to die and I had to let them die. Now I’m glad. But at the time I fought against it. (Perske & Perske 1988 p. 15)

Introduction and Overview

In the past, it was a common practice for physicians and other human service professionals to recommend institutional placement for children with mental retardation, including those with Down syndrome (DS) formerly termed “Mongolism” (Close & Keating 1988; Edgerton 1975a; Paul 1981; Seligman 1983; Shields 1977; United States Presidents' Committee 1967; Wolfensberger 1969a, 1969b).

With the significant shift in care, biomedical advances, parent advocacy groups and advancement of progressive legislation at both federal and state levels, a vast majority of children with Down syndrome now grow up and are educated and or included in their home communities.

Presently, Down syndrome poses challenges to geneticists, physicians, educators, counselors, and challenges of an infinite proportion to parents. The area of Down syndrome and the movement of ‘total inclusion’ of these children has developed a heightened sense of community awareness. This area has graced all avenues of the media (T.V. series Life Goes On... whose star actor, Chris Burke has Down syndrome portrayed life as a young adult with Down syndrome) as well as professional and current journals.

Even though problems with the definition of Down syndrome (referred to as mental retardation) abound, particularly among disciplines, the incidence and life expectancy rate nonetheless have grown to a concernable degree.
Down syndrome (the term Down syndrome has changed within the past several years in the USA from Down's Syndrome to this current form) the most common genetic birth defect is a chromosomal anomaly.

The significance of Down syndrome lies in the fact that this genetic defect produces the largest single and easily identifiable group of individuals with mental retardation (Koch, Fishler, & Melnik 1971). It affects all races and economic levels equally throughout the world. The incidence of children in the USA born with Down syndrome is approximately one in 800 to one in 1,000 live births. In the USA there are according to the National Down Syndrome Congress report in 1993, approximately 250,000 individuals with Down syndrome. Down syndrome is as prevalent as cerebral palsy and ten times more prevalent than muscular dystrophy or autism (March of Dimes 1994). According to the estimations of Steele and Stratford (1995) Stratford (1989) there are approximately 30,000 individuals with Down syndrome in the United Kingdom. In Australia the annual incidence is pronounced (Collmann & Stroller 1962, 1963). Neither class nor culture, mixed marriages, religion, environment or anything else influences the natural birth incidence of Down syndrome all over the world. Survival or prevalence, however depends on the quality of medical and social services (Stratford 1989).

Life expectancy among adults with Down syndrome is 55 years at the maximum but this varies (Dyke, Lang, Heide, & Van Duyne 1986; Patterson 1987; March of Dimes 1994; Straus 1965).

Obtaining accurate data will differ from state to state or country to country due to the inadequate documentation as well as false negative and false positive diagnoses (Huether & Gummere 1981). Therefore figures may under represent the number of individuals in need and not fully reflect the needs of the individual or the actual child. Statistics alone provide only a limited standpoint of the child or individual with Down syndrome and the family.

It has been only over the past twenty years that dramatic improvements have been seen in the areas of genetics and education toward the understanding of the whole child with
Down syndrome within the confines of an interdisciplinary, cooperative and outcome based approach (Gartner & Lipsky 1987; Johnson, Johnson, & Maruyama 1983; Rynders 1982; Schmaker & Wilson 1993; Wehmeyer 1992).

These advances have meant that nearly every child born with Down syndrome can now expect to live into adolescence and adulthood. Of equal significance there has been an evolution in the life options (Edgerton 1975b; Goldstein 1983; Farber & Royce 1977), greater awareness and determination led by parents (Perske & Perske 1981; Turnbull, Rutherford, & Turnbull 1985; Turnbull & Turnbull 1982; Wolfensberger 1983, 1991), educational reform (Clark & Astuto 1994), and the phenomena of change in our everyday lives (Crocker 1988; Darling-Hammond 1993).

These significant advances in human genetics have also compounded a move toward future needs and potential of children with Down syndrome to be seen more within the confines of their neighboring school, home and community.

Given a deeper understanding of both cognitive development and learning principles, intertwined with seeing Down syndrome as a person first and as a viable part of our rich biological inheritance, can we then begin to recognize the part these individuals play in our own development (Stratford 1987).

Regardless of how the area of Down syndrome is played out this will have a major impact upon all aspects of children with Down syndrome, their families and society as a whole.

Rarely is a child labeled with Down syndrome clear cut with respect to achievement or ability level. Rarely does a child with Down syndrome represent or fit into any assumed group or traditional placement solely by the term Down syndrome (Mercer 1973). Society's perceptions of Down syndrome has changed significantly, since the first historic publication by Langdon Down over 127 years ago. However, even though it is clear that there is more realization that individuals with Down syndrome have value and give value to
their families, schools, and communities serious setbacks still occur through stigma and public attitude.

Therefore the definition which characterizes or describes an individual with Down syndrome is more meaningful and more fully representative of that individual rather than one which places or defines an individual within a general group or category. Such categorization would only pinpoint the traits or conditions of a person verses the individual differences within an individual with Down syndrome and their families.

Issues regarding the definition and use of the term Down syndrome will be further addressed and discussed in more detail in Chapter II.

However, for the purpose of this study Down syndrome is defined as a genetic anomaly (scientifically referred to as Trisomy 21), encompassing individuals with inter/intra-individual differences and with substantial limitations in several of the following adaptive skill areas: communication, self care, home living, social skills community use, self-direction, health and safety, functional academics, leisure and work, as well as the role the individual plays as they interact with their environment (American Association on Mental Retardation 1993).

The role and the impact of the family having a child with Down syndrome and the families' ability to meet his or her needs is a complex phenomenon. The literature addressing this area appears to be based on negative deficit-orientated views, evasive, and limited in scope by being unimodal or unidimensional in nature. It is an erroneous assumption to say that raising a child with Down syndrome is all problems and a child without Down syndrome to be all but fun and games.

Further research indicates that the needs of families of young children are quite different than those with older ones. This transition to a new stage of life is at times of greater stress for families (Terkelsen 1980). It therefore, is not so uncommon to see an increase and rise in the parent network and support groups. Their purpose is to alleviate stress, by sharing
information, discussing common concerns, providing emotional and practical support and understanding the life concerns of their child.

These gatherings as well as organized professional affiliations have sprung up across the USA as well as around the world. While these parents learn how to become more empowered, their voices and experiences are frequently heard outside these circles.

Even while conducting a Pilot study, (Drower 1988) on Parent’s Expectations of their young adult with Down syndrome in East Croydon, England, parents raised many eyebrows and displayed emotions of surprise, excitement, and frustration that this researcher was willing to write down their accounts to unearth new findings and place a more meaningful interpretation on existing knowledge in the area of Down syndrome.

Parents also see the value of their role to be one of a decision-maker. With the Amendments to Public Law 94-142 the Individuals Disabilities Education Act (IDEA), Public Law 101-476, a stage was set for current values and assumptions regarding actual parent involvement.

Yet, considering the endless amount of professional time dedicated to Individual Educational Programs (IEP) for each child or young adult (Price & Goodman 1980), and the “lip service” given to the importance of the parents’ role, it is alarming to see the limited amount the parents take in deciding what, when or how their child with Down syndrome will be taught (Drower & Hansen 1991, 1993).

These accounts further back up the scarcity of literature which does not give attention to or display verbal accounts of the families' perceptions of raising a child with Down syndrome. Much of the literature is very limited and very disconcerting due to the fact that data about individuals who are handicapped, disabled, or mentally retarded have not been kept separate and therefore the statements made by and about families with children with one kind of problem or another have been generalized to families with children who have other problems (Allen & Affleck 1985; Chinn, Winn, & Walter 1978; Noland 1970).
While the literature is however, full of data on the families' experience of having a child who is disabled, handicapped, exceptional or mentally retarded, the child with Down syndrome is specifically not fully included or represented and has therefore been subjected to general categorization and placed in a homogenous group negating his or her individual differences.

As an educator, almost all systematic studies relating to the mentally retarded or disabled (few specifically to the area of Down syndrome) stress a need for more descriptive studies and actual dialogue from the families' perspective.

Failure to understand the nature and implications specific to Down syndrome from the families' perspective have caused great concern. For far too many professionals working in the broad field of mental retardation continue to hide their own interpersonal inadequacies in test results, "medical jargon," labels, and educational "wisdom" of the past. We appear to have abandoned the child with Down syndrome and their families to past resources. Therefore, these parents have been left to discover their own solutions, suffer their own fears, and experience their own despair. It is time that their stories be told.

In the eighteen years as a professional, the researcher has spent endless days educating young adults with varying abilities along with their families. During this time the researcher has gained much insight into them and their unique needs.

On a more personal side it has only been over the past six years as a proud Aunt of a nephew with Down syndrome and a member of a Phoenix based parent support group called "Sharing" in the state of Arizona, that the researcher has gained further insight into the unique and real concerns of children and young adults with Down syndrome. The researcher has found these parents to be strong, persistent, sensitive and intellectual. The researcher has experienced their joys, their disappointments, their triumphs, and their growth. They have in turn taught the researcher a great deal about human strength and dignity and the wonders of being an Aunt.
The researcher was then presented with a challenge and compelled to ascertain the following research questions:

1. Are all family problems for the disabled, or for the child with Down syndrome interpreted in one set of terms?

2. From the perspective of the family, what are the experiences like for raising a child with Down syndrome?

3. How are these life situations (values and needs) perceived from the standpoint of the parent with a child with Down syndrome?

It is regrettable that time has not offered many answers to these questions or substantial improvements to this situation.

It is appalling how so little attention is given, still by the medical doctors, psychologists, and educators to identify, encourage, and disseminate current research and information about the area of Down syndrome. This fact becomes even more astounding when one investigates the available literature and pertinent research in this area. With the exception of a few books, mostly of dated readings, literature mainly pertains in a general manner to the field of mental retardation, (some inconclusive and often contradictory) one is hard pressed to find meaningful, reflective, and descriptive literature in the area of families with children and young adults with Down syndrome. In addition, children and young adults with Down syndrome offer challenges through the role and impact they play upon their family, their community and society as a whole. Until now, research on families of the mentally retarded, limited in scope for the area of Down syndrome have been largely organized around one major premise: the impact of the child with mental retardation on his or her family (Schwartz 1970).

Assumptions, that the birth of a child who is mentally retarded is a traumatic event, the initial reaction to the diagnosis seen as a “family crisis” (Farber 1959, 1960a 1960b; Farber, Jenne, & Toigo 1960; Kramm 1963; Wolfensberger 1967), specific hardships or limitations (Holt 1958) have focused on one component of such a complex phenomenon.
This exclusively focuses on personal and social impact of the family and excludes from consideration the illumination of the families rich experiences and perceptions on raising a child with Down syndrome.

This thesis is not meant to be an end, but rather, a most humble beginning. It is, for the researcher, acceptance of a challenge. In a larger sense the purpose of this study, is to offer a challenge to medical doctors, psychologists, counselors, educators, social workers, and all helping professions, as well as society at large, to foster a greater mutual understanding of what it is like to raise a child with Down syndrome. It is, an attempt for parents to shed light onto other parents of their rich variety of experiences, their concerns, and their weight of experiences that characterize the different families who have children with Down syndrome. It is, to view in the broadest and most human sense a multidisciplinary process, to help the family with a child with Down syndrome through the complicated processes necessary for them to meet and confront the unique emotional, mental, and physical adjustments. It is, for these parents to acquire the necessary hope, insight and strength for them to take up as their own, the greatest of all human challenges, the inalienable right of every person, disabled or not to self-actualization (Buscaglia 1983).
An Overview of the Chapters Ahead

The following chapter, Chapter II, will review three areas on literature relevant to this study. The first area of literature will examine the historical journey of what is presently classified as mental retardation to the specific area of Down syndrome. The changes and development of classifications and terms, as well as the underpinnings of the etiology, epistemology, epidemiology, and genetic framework will be incorporated in this review.

While there have been long-standing, ongoing difficulties in defining the term ‘Down syndrome’, an operational definition will be provided. As there is a limited body of literature addressing the experience of the family when raising a child with Down syndrome, the second portion of the Review of literature, Chapter III will present an overview of the comparative literature of the effect upon the family when raising a child who is disabled, exceptional, handicap or mentally retarded. The distinction between these terms will be defined further.

The final section of the Review of literature, Chapter IV will conclude with a Review of the literature that most directly addresses the experiences of the family when raising a child with Down syndrome (this will also include implications of a Pilot study, Drower 1988).

The next chapter, Chapter V, will describe the rationale, method, and design of this study. An exploratory phenomenological/heuristic approach will be utilized to elicit descriptions of subjects'/parents perceptions and impact on the family, individually and collectively, of raising a child with Down syndrome.

It is the hope and challenge of this investigation that the knowledge generated by this study will expand the information in the area which is presently so limited in scope.

Chapter VI will present an introduction to the results. This chapter will entail an overview of the twenty-seven (27) participants as a collective group and display fifteen individual portraits as distinct family units.
Chapter VII through Chapter X will present the results of this study via analysis and thematic representation created from the language and the phenomena of the study's subjects. Their words, stories, rich day to day experience, feelings and behaviors will be shared with the reader. Any unexpected difficulties and biases that influenced this study will also be described.

Chapter XI will highlight three meta-themes or universal themes that were threaded throughout each interview.

The results will be discussed in Chapter XII highlighting the major findings and contrasting them to the Review of Literature within the field of mental retardation as well as within the area of Down syndrome. A critique of the method will also be included, followed by implications for practice and further research. This discussion will also attempt to suggest ways that major findings of this study can be applied to the medical, clinical, social, economical, political and educational professions. Personal reflection regarding this journey and the experience of conducting this method will then be summarized.
CHAPTER II
Down syndrome Past and Present

Introduction

The purpose of this Review of literature is to examine and integrate the most relevant literature which addresses how a child with Down syndrome is perceived within the family unit. This review will be comprised of three distinct areas: historical, contextual, and “real” life experiences. These are pertinent to the present-day view of how a child with Down syndrome is perceived within his or her family.

The first area of the Review of literature will address the field of mental retardation seen within the area of Down syndrome. In order to move through the literature appropriately, it is necessary to begin with the historical perspective (the past and where we have been) in order to formulate a direct link between the field of mental retardation and the area of Down syndrome. This will allow the reader to better understand the present position surrounding the area of Down syndrome.

This portion of the Review of literature will begin with a historical perspective (underpinnings from the past to the present) leading to an operational definition of the term Down syndrome.

Research on families of the mentally retarded to date, has been mostly organized early around the impact of the mentally retarded upon the family unit (Schwartz 1970).

With respect to research the results within a collection (limited in range) of data can not shed true light onto the rich variety of experiences, the different types of concerns, thoughts, and feelings of each family. This includes the centrality of the mentally retarded in the families life that characterize the individual differences of families raising children with mental retardation. The literature with exception of a few books, as indicated in Chapter I is largely flawed and limited in scope.

In order to present an appropriate and useful perspective the second portion of the Review of literature will entail an overview of the comparative literature on the impact upon
the family when raising a child with mental retardation (i.e. mental deficiencies disability, exceptionality, special needs, and or handicaps). While there is an infinite amount of literature relating to the field of mental retardation, the literature has not specifically included the area of Down syndrome as a separate and distinct category and or entity.

In the context of this study, the terms 'mental retardation,' 'mental deficiency,' 'developmental disability,' 'disability,' 'exceptionality,' 'special needs' and 'handicap' are interchangeable. Furthermore the term 'mental retardation' is classified as a field because it covers at least thirteen types or theoretician definitions (Jordon 1972). Whereas, the term 'Down syndrome' is classified as a specific area within the field of mental retardation.

The final section of the Review of literature will address the families' perceptions (experience) on raising a child with Down syndrome. Due to the limited literature regarding the families' perception as told by parents, (along with the Review of literature) will be posed a broader spectrum incorporating inter/intra-individual differences as seen through peers, schools, community interaction as well as through the relationship of self. The literature about the child with mental retardation and its history abounds with data regarding difficult interpersonal social skills, these may be gleaned as seen through the family experience.

**Definition of Mental Retardation a Historical Perspective**

One of the most striking aspects of human nature is its endless variability. Rarely do we see two individuals who look alike, carry the same stature or have the same limbs or fingers. Mental retardation however, illustrates the extent to which one individual can differ in intellectual differences. Ironically, one of the major areas of controversy and uncertainty is the definition of mental retardation. Even though the AAMD (American Association on Mental Deficiency) as cited by Grossman (1973) includes both intellectual (IQ) and behavioral criteria, and is widely accepted in many countries throughout the world, it is not broadly applied clinically or in epidemiological research (Begab 1976).
The lack of standardization in relation to Intelligence has made cross-cultural comparisons and efforts to identify relevant social and cultural variables a tenuous one. Furthermore, the failure to include adaptive behavioral measures for diagnostic placement can be attributed to numerous factors. Some authorities felt that impairments in adaptive behavior are attributable to low intelligence and that this distinguished the mentally retarded from other forms of social incompetence (i.e. mentally ill and delinquency). It is also important to note that at one time, mental retardation was not differentiated from mental illness (Hynd & Obrzut 1986). Even though matters have improved considerably throughout society (i.e. economical, socially, politically, and environmentally), the public and or the media still confuse and have yet to come to grips with these two issues.

Another perennial source of confusion and conflict, as seen through the definition of mental retardation, arises from the doubtful terminology (Grossman 1973; Jordon 1972; Kirk 1972) within this field. A wide range of intellectual and social impairments are subsumed under the rubric of “mental retardation”. The mentally retarded according to Ashmore (1975) can then be viewed as mild, moderate or severely retarded, slow learners and as having genetic abnormalities (i.e. Mongolism). At the level of mild retardation, the correlation between intelligence and adaptive behavior is less than perfect yet some individuals below 70 IQ are more socially adequate than others (Begab 1976). An individual who is mentally retarded with an IQ score, according to Zigler and Balla (1982) can provide more precise information if the individuals are differentiated on the basis of etiology as well as intelligence.

The phenomenon of mental retardation attempts to give a broader meaning to independent observations. Efforts of writers and researchers have provided endless opportunities for criticism. Late in the 1960’s Clausen presented a series of observations on the development of mental retardation (Clausen 1967). Noteworthy in his review was calling attention to the value of a psychometric definition “insufficient, lack of precision, and evade of definition” (Clausen p.743).
The occurrence of mental retardation as measured, identifiable in nature, fluctuates in the population; therefore the standards which measure intelligence adequacy are empirical and differ from one social context to another. As the field of mental retardation moves from the context of the home, school, to the community (Berg 1984; Buscaglia 1983; Darling-Hammond 1993; Gottwald 1970; Heal & Fujima 1984; Sigelman 1976; Wolfensberger 1991) the demands will change. Therefore, in view of the environmental demands and expectations as a vital part of the assessment process the American Association on Mental Retardation, 1993 redefined the term mental retardation. This new definition is no longer viewed as an absolute trait, but as a condition which can be improved with the right support. In addition to intelligence (IQ), the new definition considers how an individual functions in his or her everyday life. For purposes of this investigation, mental retardation is defined as the interaction between an individual and his or her environment with both having equal roles (AAMR 1993; National Down Syndrome Congress 1993a).

Today, we are more aware of factors that contribute to mental retardation (mental deficiency) and can now differentiate as those of genetic origin (i.e. Down syndrome) or environmental (i.e. rubella).

Scientific analysis about mental retardation began in the last century. Langdon Down in his classical description of the "mongolism" type or "idiot" as he referred to it (Wolstenholme & Porter 1967), attempted to formulate an area within the field of mental retardation. He believed that certain individuals born with mental retardation showed resemblance to the appearance of Asian people, henceforth termed ‘Mongolism.’ While the concept had been rejected, the label still plagues us today (Cranefield 1966). The conflict is not merely an academic debate over classification and terminology, but also an issue of great social and practical importance to the families, children with mental retardation and our social institutions. Such classifications envisioned all individuals who were retarded to be "defective" from their individuals with normal intelligence. Therefore such euphemisms
and attached labels characterized and conveyed a strong image that this population was incapable of functioning and or contributing to our society.

The physicians have perceived individuals with mental retardation mainly through the utilization of a medical model. Hence, their primary focus has been to cure acute illnesses for a typical child. Sometimes the emphasis on curing has even led physicians to refuse and traditionally neglect the treatment of children with severe disabilities (Centerwall & Centerwall 1959; Darling 1983; Duff & Cambell 1973; Lorber 1971).

The educators primary focus can be characterized by the traits of achievement of every child, universality, functionality, and affected neutrality (Parsons 1951). In the past, educators focused on a medical point of view, regarding and classifying mental retardation as a result of some underlying disease or defective condition. Therefore individual differences were not a sought out practice. Instead placement was determined by degree of mental retardation (i.e. mild, moderate, severe, and profound). Many educators and rehabilitation counselors believe that the elimination of the borderline category of intelligence as proposed by the AAMD, denies service to a large number of individuals with special needs (Braun 1976).

Most professionals, on the other hand, according to Mercer (1973) employ a clinical perspective in terms of the mentally retarded. Thus, mental retardation specifically presents a problem or symptom which become paramount and other roles within the community for the mentally retarded are then ignored.

The difficulty then lies with the translation which stems across disciplines from the confusion and discrepancies of the terminology but also from the unidimensional perspective within each discipline (Schwartz 1970).

Others view this label of mental retardation as stigmatizing (MacMillian, Jones, & Aloia 1974; Mercer 1977). Even members of minority groups, in whose ranks mental retardation is heavily represented by socioeconomic factors, see the terminology process as
discriminatory and having genetic overtones (Lilly 1971; Scarr 1981; Van den Berghe 1967).

Origins or etiology of the mentally retarded development can be found in the rich biological and social domain (Berg 1985, Jordon 1972). In some cases, the subject/object is a statement about a particular child. The term 'Down’s syndrome,' 'Down syndrome,' 'Mongolism,' 'Congenital Acromicria,' 'Trisomy 21,' is a chromosomal anomaly describing many children which have similar characteristics, apart from their own individual traits. The terms 'Down’s Syndrome,' 'Down syndrome' (used in the possessive world-wide and in the non-possessive form within the United States), 'mongolism,' 'Mongol,' 'mongoloid' are inconsistently used throughout the literature. Concerning the use of possessive or non possessive forms in the eponym of syndromes, one of the standard medical dictionaries (Blakiston’s New Gould Medical Dictionary 1949), list one-hundred forty eponyms for just syndromes. Of these sixty-seven are possessive and seventy-three are not. For the purposes of this study 'Down syndrome' (non-possessive form) will be consistently used emphasizing the individual verses the syndrome. However, references will be made to “mongolism” as cited throughout the literature. Even though there is a need for a new dynamic concept (term) to further our scientific research, the term ‘Down syndrome’ will be the one this researcher will use for now.

Down syndrome is the most common genetic birth defect, which includes some degree of mental retardation. Approximately thirty to fifty percent of children born with Down syndrome have congenital heart defects and many have some visual, hearing, and speech impairments (March of Dimes 1994, Elkins 1994). The severity varies greatly in category and interpretation. The degree of mental retardation varies from mild to moderate to severe. The term ‘Down syndrome’ as displayed in the literature, has been subjected to general categorization, and any means of dividing children into such categories is arbitrary and disputable especially at the confluence of category discrepancies (Fewell & Gelb 1983).
“On the other hand, it may be an instance of ‘variation’ though there seems to be a difficulty in applying such a term to a condition comprising so many widely different correlated peculiarities and recurring with such frequency” (Langdon-Down 1906,188-189).

Warkany, (1960) points out that there are no less than thirty-nine different explanations to the origins of ‘Mongolism.’ He groups them into four categories; reversion/primitive, genetic, environmental and changes within the child. However, the irony is that our present state of knowledge is still as uncertain as Down was over one-hundred years ago, but only at a higher level.

In order to fully understand how the origin of Down syndrome came to full term, a Review of the major clinical and theoretical constructs which contributed to the past will be presented. These will have an impact on our present understanding of the term ‘Down syndrome.’

**Etiology of Down syndrome**

Many steps leading up to the discovery of Down syndrome and the various movements throughout time will add to the perceived definition of Down syndrome. It is the investigator's attempt to then offer an operational definition to be used within this study.

The term “Mongolism” is a familiar term to most people but few lay persons understand the implications of this term. “Mongolism”, “Acromicria”, “Down syndrome”, “Trisomy 21” has been known as a clinical entity since Langdon Down described the clinical picture back in 1866. He described the clinical features of patients as a regression to his “more primitive Mongolian race” (Down 1866). The term ‘Down syndrome’ then became more commonly used, with racist overtones of mongolism (Gibson 1978).

The story of Down syndrome (referenced in Stratford 1989; Zellweger 1977), begins about 1500 BC to 300 AD with the Olmecs tribes of Mexico. Indications (i.e. artifacts,
cave paintings) by many anthropologists have suggested that people with Down syndrome were part of this population.

The existence of Down syndrome is older than the family of mankind. According to Brothwell, a microcephalic skull was discovered from the 11th century. His description of the skull from an Anglo Saxon burial grave, its capacity and shape, lead many anthropologists to the conclusion that this child of nine had mongolism (Callaghan 1962, Callman 1960). According to Stratford (1989), the skull had a shape and valiance well outside the range that would be expected to be normal within the Saxon population. It would however, fall within the range of a modern European Down’s population.

The first extensive description of Down syndrome (as reported by Korenberg, Pulst, & Gerwekr 1992) was provided in a report of sixty-two cases of “Kalmuc Idiocy” by Fraser and Mitchell (1876). This provided a complete physical description noting increase risk of Down syndrome with maternal age and described Down syndrome neuropathology. Further observations by Garrod and Thompson (1898) rounded out the basis for a clinical description by the turn of the century as cited in (Korenberg, Pulst, & Gerwekr 1992).

The next major advancement came sixty years later, with a deeper understanding of the biological basis of human heredity. For decades, long before chromosome basis was discovered Down syndrome was viewed as immutable to and uninfluenced by the environment. With distinctive physical appearance of children and the decline in development lending to the notion that children with severe retardation was predetermined, most were placed in institution at early ages due their low cognitive levels of functioning.

It has been recorded that as early as 1932 Dutch ophthalmologist Waardenbury suggested that Down syndrome (Lott & McCoy 1992) might be caused by a chromosome aberration.

1 Both studies by Fraser & Mitchell (1876) and Garrod & Thompson (1898) were only reported and read in context of the article. Neither study was fully cited in the reference section of the article written by Korenberg et al (1992).
However, even though the abnormality of the chromosome number suspected earlier, it was only in (1959) that French scientists Lejeune and Gautier, and Turpin described the finding of an extra chromosome called 21. Ford and colleagues and Jacobs and colleagues (1959) confirmed these findings.

The understanding of Down syndrome resulting from duplication of genes on chromosome 21 was focused by suggestion of Niebuhr (1974) that "the typical Down syndrome phenotype" might be caused by duplication of only a part of the chromosome 21. The observation of Down syndrome in a chimpanzee (McClure et al 1969) provided compelling evidence to support a further understanding that specific phenotypic features of Down syndrome was caused by the duplication of specific genes located on chromosome 21. Also translocation (inherited and de Novo) involving an extra chromosome 21 were described as well as balanced carriers with 45 chromosomes observed (Franccaro, Kajser & Lindsten 1960; Polani, Briggs, Ford, Clarke, & Berg 1960). Translocation is defined when part of the chromosome (46 in total) is broken and the broken part then fuses with another. A third type is mosaic. This accounts for four to five percent of individuals with Down syndrome (Lilienfield 1969). The three types most common in Trisomy 21 according to Koch, Fishler, & Melnik (1971) are:

1. **Trisomy 21**, where all cells have 47 chromosome (know as "full or complete") this occurs when an egg or sperm undergoes faulty cell 23 division during its formation (meiosis). Then an extra 21 chromosome gets included in the package. This occurs before conception.

2. **Translocation Down syndrome** where the 21 chromosome is fused "piggy backed" with another and is frequently inherited. This occurs before conception in either the egg or the sperm. In this type a number 21 chromosome is actually stuck "piggy back" to another chromosome (usually #14). This forms one large chromosome but is actually two in one (#21 and #14). Accompanying by the normal #21 it is then united with the other spouse's germ cell.

3. **Translocation mosaicism 45/46** phenotypically occurs after conception so the infant starts our with all normal chromosomes. Then during the cell division (mitosis) nondisjunction can occur leading to an abnormal cell division with an extra #21 chromosome. Therefore, the fetus will be "mosaic" and have two different types of chromosomes (one normal and one causing Down syndrome). This is further due to the mixture of normal and Trisomy 21 cell groupings.
It is important to note that each of these classes carries different implications in parent counseling, and each case should be analyzed separately.

The literary pace of knowledge quickens as time progressed. The rise of modern science led to higher standards. The establishment of the Royal Society established under the Stuart restoration; at the end of the 17th century began to raise the conscious level of the masses. Even though the Royal Society did not deal with mental retardation directly, the remaining years revealed a strong interest in abnormal development.

Treatment of deaf children was well thought out and members went to great pains to communicate on the subject, as recorded by Jordon in (1961).

Education and Training

The 18th century’s germination of ideas led to favored care and treatment of the retarded. While Rousseau set the stage for public philosophy favorable to education the treatment of the mentally retarded (mentally ill) began to emerge. From 1825-1835 evidence became available of the first attempt toward treatment for patients with hydrocephalus. This reported treatment was conducted by tapping the ventricles. Although English physician Dr. Conquest successfully treated two cases, Meindl indicated such a practice was not widespread and much criticized (Meindl 1962).

The first written description of a person with Down syndrome was done by French physician Jean Etienne Esquirol (Stratford 1989). The word of Itard in the late 1700s and Seguin in the mid 1800s laid the basis for programs for individuals with mental retardation for the next one-hundred years. Itard’s work to educate the “wild boy of Aveyron” showed the promise and training of the mentally retarded and its significance in the degree further generated more attention to society as a whole.

The physician, Edward Seguin began his efforts at educating individuals with mental retardation, with special attention to cretinism. His educational premise was by means of a systematic approach. Esquirol, Itard, and Seguin all recognized the need for some objective
measure of ability to accurately identify individuals with mental retardation. While Esquirol and Itard’s work suggest that beyond a certain young age ability was immutable, Seguin's efforts demonstrated that individuals with mental retardation can be treated and trained.

Parallel to Seguin's ideas on treatment lay Herbart's pedagogy. He established a method of teaching which spread throughout the world. This was the movement of 'normalizing' instruction (Ferrara 1979; Horstmeier 1988; Nirje 1976; Rose-Ackerman 1982; Stratford & Tse 1989; Wolfensberger et al 1972). The relevance to mental retardation lies not in Herbart's method, but in the movement which provided public education around the world with a means to 'normalize instruction.' For instance at the height of this movement, it embraced elements of education from the art of teaching to the cultural history of man.

Other mid 19th century contributions included Guggenbuhl's work on cretinism with Greek refugees, Horace Mann's care for the disabled, and Howe's establishment of the first state supported organizations toward caring for the mentally retarded (mentally ill) in the United States (Kirk 1972). Institutions in Western countries served individuals with mental retardation (i.e. mentally ill, Down syndrome) for more than 1,500 years (Stevens 1977). Yet during the 18th century more knowledge concerning the "idiot" and "imbecile" referred to those who were mentally retarded or mentally ill were acquired.

Morel in 1853, introduced the ideas that mental retardation was a form of evolutionary regression. This phenomenon consisted of a progression over several generations with heredity leading to extinction of the genetic type. Then Langdon Down propounded his ethnic theory of mental retardation in which the "mongoloid" branch of mankind was illustrated. However, Down's name with the condition is best combated by exposition. Originally Down's syndrome because of appearance of the slanting eyes was called "Mongolism". Unfortunately the term has no resemblance to the Mongolian race except for the epicanthic fold in the eyelids (Kirk 1972). Cranefield observed that Seguin presented a
clinical account in the same year, 1866 without the inanity present in the Down's paper (Cranefield 1966).

By the end of the 19th century we saw a rise of the psychometric movement. Measurement of intellect by Alfred Binet and Theodore Simon introduced quantitative measurement. Binet over the years emerged as a scholar of individual differences producing a scale of mental development known as the Stanford-Binet. It should be noted that Intelligence (IQ) development, as seen throughout the literature is dependent upon many factors besides intellect; behavioral and physical should also be considered (Johnson & Albelsen 1973; Drillien 1970).

In consideration of the chronology and historical perspective of individuals with mental retardation throughout the literature several observations can be made. First, there is a noticeable rhythm to the patterns of innovation and neglect. Individuals with mental retardation appear to have benefited as a secondary effect of developments in the welfare of humankind. This however, was not as a result or direct concern for the actual individual with mental retardation (i.e. mentally ill and Down syndrome were not differentiated from the broad field of mental retardation). Second, individuals with mental retardation seem to have provided a site for examining propositions about the perfectibility of man and woman kind. Finally, individuals with mental retardation, in widespread neglect provides us with a model for current and future examination of a series of questions pertaining to our own social, medical, economical, and political philosophies.

Trends in the Field of Mental Retardation

As we move out of the past and closer to present times many trends and theoretical underpinnings prevail within and outside the field of mental retardation. These trends maybe more difficult to discern today than ever before due to the social-economical, political, and psychological factors surrounding the treatment of individuals with mental
retardation. However in order to receive a more thorough understanding of this field, several trends and the interactions of these trends will be highlighted.

Associations; professional, educational, and parent-orientated, became a vital social movement and trend throughout the United States as well as abroad.

Much of the practice to institutionalize children and young adults who were considered mentally ill or retarded was based on the premise that the care and nurturance of these individuals presented an insurmountable burden for their parents. Wolfsenberger, (1967) description of this viewpoint, based on a paper by Aldrick (1947) confirms this point that:

> When the physician attending at birth recognized the baby as mongoloid, the baby is withheld from the mother under the pretext that it is weak. In the meantime the father is called and other relatives and instructed to institutionalize the baby immediately. After all is done the mother is told and informed of this decision which had been made without her being consulted. All is done because a mongoloid child is seen as having a destructive impact upon the family. Therefore the child would be happier in an institution (p. 369).

This passage suggests that institutionalization is a form of treatment to promote positive outcomes for the family (i.e. a mongoloid child as having a destructive impact upon the family) as well as a positive outcome for the child (i.e. "happier").

The role of the parent was to then adhere to the physician rather than actively participate in the decision-making process. It is not surprising, then that a major force causing the pendulum to swing in support of deinstitutionalization, public school programs in the community setting and participation of parents in the decision making process, that a political advocacy movement and trend began to engulf parent groups (i.e. National Association for Retarded Citizens (NARC), National March of Dimes, National Down Syndrome Congress (NDSC), National Information Center for Children and Youth with Disabilities (NICHCY)) (Mickenberg 1980; Parke 1979; Straus 1965; Wieck 1988). NARC and other activist groups were exerting pressure on Judicial and Legislative arenas to have their preferences for active involvement be enacted into law, a concomitant force in shaping both policy and practice was compensatory education programs for the
economically disadvantaged. The goal of such parent intervention (Hunt 1971) was seen as a strategy for remediation and improvement of a child’s environment and for societal integration of poor families. Hence, the design of Head Start programs (Zigler & Valentine 1979) was based on these two strategies. Public Law (PL) 89-794 required parents to participate not only as learner and teacher but as decision makers. This legislation reflected the first policy of parent involvement (Wiegerink, Hocutt, Posanti-Loro, & Bristo 1980).

This movement continued with the passage of numerous laws providing further assistance to handicapped preschoolers (PL 90-538, Handicapped Children’s Early Education Program/HCEEP).

Legislation in the 1970s emphasized the role of parents as decision-makers and further empowered them as advocates to ensure their child with disabilities receive the services they were entitled. For the first time parent’s role as co-partners in the assessment of needs and planning of services at the state level was recognized publicly (Wiegerink et al 1980). Such a movement continued to explode in the decade of the seventies and eighties with the provision for a ‘Least Restrictive Environment’ (Public Law (PL) 94-142). This provided an impetus and lead to the concept of mainstreaming (Kirk & Gallagher 1979), testing and placement, recognition of ‘normal’ peers and that of special classes.

The focus of this movement among parents within the schools was toward abandoning special classes for those with mental retardation and in turn place them in regular classes with supplemented special services (Reynolds & Birch 1977).

The effects of mainstreaming have been reported by numerous investigators. Positive results have been found in studies from preschool to the primary levels of individuals with mild, visual, auditory and gifted disabilities (Cantrell & Cantrell 1976; Gottlieb & Backer 1975; Kaufman, Agardi, & Semmel 1978; Shotel, Iano, & McGettigan 1972).

Based on the Review of literature of the legislative history of parent involvement policy of PL 94-142, Turnbull, Turnbull, and Wheat (1982) speculated that Congress believed parents could make no assumptions concerning the education of their children with
disabilities. This no assumption perspective was emanated from the fact that Congress could not guarantee that schools would provide an appropriate education to students with handicaps unless they were held accountable by empowered agents (Turnbull & Winston 1984).

The role of parents as decision-makers and as learners is clearly predominant in the (IEP) Individualized Education Plan of the child (Turnbull & Winston, 1984; Zigmond & Miller 1986). Yet in light of the pervasive policy expectations for parents of children with handicap conditions, there is lack of and need for research and evaluation to substantiate the extent of these outcomes and practices (Foster, Berger, & McLean 1981; Goldstein, Strickland, Turnbull, & Curry 1980; Karnes & Zehrbach 1975; MacMillian & Turnbull 1983; Turnbull & Turnbull 1982; Turnbull & Winston 1984).

The 1960s and 70s was a period of maximum intellectual effort to study the social problems and interactions of families with mental retardation. Farbers analysis has been of sociological value and used as a model of how much light can be generated on this topic (Farber 1968).

During this period the field of mental retardation received vivid national recognition during the Kennedy Administration whose leadership in combating this perplexing disability sustained others to follow in his footsteps. For on October 30, 1970 President Nixon signed into law the Developmental Disability Act, (Adams 1971) which was directed toward meeting the gaps in existing services (p.2).

Private associations working with children who were crippled, who had cerebral palsy and or mental retardation were fairly effective at the time in dealing with the needs of the disabled at the local level. Nationally, the Association for Retarded Children reported in 1971 that its first members consisted of 60% parents, 15% professionals and 25% of a variety of other clients were overwhelmingly white and of white collar workers (Jordon 1972). In the 1970's this Associations membership was comprised of over 100,000 individuals (Adams 1971).
Associations began to spring up of parents (Down Syndrome Association; National Down Syndrome Congress), and other professionals (i.e., Council for Exceptional Children) interested persons for the disabled throughout the United States. It is worthy of mention, that the National Down Syndrome Congress formed in 1973 almost eleven years later dropped the possessive form (i.e., Down’s) because Down did not "own" the condition. Also due to the national growing status it then became National Down Syndrome Congress (Rynder 1987). Further evidence of the neglect of the human problems by government and professionals led parents on their continued plight. They showed that the government may have opened the doors to needed services but was inept at raising the awareness of the United States. Organizations fluctuated in quality of leadership and reflected the interest of persons whose children were in need of service.

A complete understanding of the mentally retarded within the area of Down syndrome and hence an efficient and workable definition is not possible as long as we are not in a position to define mental retardation (specifically Down syndrome), its present course of development as seen through its universal framework; substantive problems on which those who describe it have entailed value judgments or evaluations, interactions of theories, counseling and programs as well as the specification of the margin of inter/intra individual differences within this group.

The concept of inter/intra individual differences is one characteristic of a child with mental retardation. According to Kirk (1972) classification is based upon an assessment which determines that one individual is significantly different from another; intra-individual differences incorporate ability level. In terms of assessment, as seen throughout the literature, individuals with mental retardation (a field with a heterogeneous grouping of people) can further be divided into the following universal frameworks: medical, statistical or mental testing, behavioral, environmental and social.

The medical framework identifies biological pathology through specifying symptoms. Since pathologies are defined by their symptoms, this framework has been seen as a deficit
one. "Normal" remains a residual, undefined category consisting of those persons who do not have biological symptoms. Distinct biomedical causes of a deficiency which throughout the literature were elucidated though studies of individuals with severe retardation or groups can frequently have a wide range of phenotypic consequences including mild or minimal deficits (Berg, Clarke, & Clarke 1977). Indeed some etiological factors, commonly resulting in mental disability have no adverse effects. This is so for genetic and environmental influences. Since many causes of mental retardation produce characteristic; physical as well as mental effects, it is not surprising that a large number of syndromes have been recognized among those classified as mental retardation.

The term 'syndrome' is widely used in medicine to refer to a concurrence of clinical/other phenotypic manifestations which despite variability results in a resemblance between persons. Down syndrome can then be definable (by an extra chromosome), as a homogeneous group by trait. Trisomy 21 corresponds to three etiological categories: standard Trisomy, translocation, and mosaicism. In these last cases, the embryo develops with a mosaic of cells counting 46 chromosomes and abnormal cells each one with three normal chromosomes 21. Each etiological sub category of Trisomy 21, the inter-intra individual differences is far from negligible both developmentally and in terms of ultimate level of development (Rondal 1988).

Down syndrome occurs when a child is born with three number 21 chromosomes instead of the normal two. This genetic condition is known as Trisomy 21 (Gibson 1978). At the present there are three known causes of Trisomy 21. The most frequent cause is non-disjunction. This accounts for 90-95 percent of the diagnosed cases (Weiss & Weiss 1992). In non-disjunction the child receives an extra chromosome 21 from one parent, usually the mother (Uchida 1973).
Epidemiology of Down syndrome

The incidence observed in chromosome studies as noted earlier in Chapter I occurs internationally according to estimates in the USA as well as throughout the world.

Advanced maternal age in Down syndrome is a well established fact (Ferguson-Smith & Yates 1984; Hook, Cross, & Schreinemachers 1983; Hook 1981 Thompson & Thompson 1980). Already twenty-five years before the chromosomal basis for Down syndrome was known Penrose, (1933) established the relationship between advanced maternal age and Down syndrome. Subsequently an effect of advanced maternal age has been demonstrated in all population studies, regardless of geographic location (national or international) ethnic group or social-economic status (Ferguson-Smith & Yates 1984; Penrose & Smith, 1966; Sigler et al 1965). Down syndrome and some other anomalies also appear to increase with paternal age independent of maternal age (Mikkelson, Hallberg, & Poulsen 1976; Erickson 1979).

Only five to eight percent of pregnancies occur in women in age 35 and over, but they account for twenty percent of Down syndrome births. Therefore approximately 80% of children with Down syndrome are born to women less than 35 years of age and who do not have any identifiable increased risks for delivering a child (Adams, Erickson, Layde, & Oakley 1981; Steel & Stratford 1996).

Two forms of Down syndrome Translocation occurs in 3.3% of the cases and Mosaicism in about 2.4%. Statistics indicate that the likelihood of finding a person born with Down syndrome to a mother under 30 is approximately 6%. Having excluded the parents as a translocation carrier, the risk for recurrence is about 1% (National Down Syndrome Congress 1993 b). This again occurs when the #21 chromosome pair fails to divide properly after the first cell division subsequent to fertilization. In contrast to non-disjunction only a portion of the child's cell will have three #21 chromosomes (Rynders, Spiker, & Horrobin 1978).
However, in recent years there has been a decrease in incidence due to decrease of women over 35 having children Penrose, (1967) and prenatal screening, (Elkins & Brown 1993) and abortion reform laws Hansen (1978).

The greatest risk factor in Down syndrome, is still an unsolved problem where we do not truly understand the underlying mechanism (Mikkelsen 1967). The problem then, is not what causes Down syndrome but what causes non-disjunction.

It has then been suggested throughout the literature that intensive research, combining the cytogenetic data with epidemiological methods might bring us closer to the underlying mechanism of non-disjunction (Jacobs, Baikie, Brown, & Strong 1959; Mikkelsen 1967, 1982a, 1985; Licznerski & Lindsten 1972; Wolstenholme & Porter 1967).

Cognitive, Behavioral, and Social Issues

Intra-individual differences are detected through the mental development for individuals with mental retardation. The usual diagnosis is slow and can be divided into three broad stages (i.e. no stage theory for Down syndrome has been proposed). Gibson, (1978) identifies mental age (MA) into three growth periods. Within these periods a temporary plateau is maintained for the first and second while a slow and gradual decline occurs in the third. Plateau 1 is reached between 4 and 6 years chronological age (CA) with an MA of 18 months. Plateau 2 is reached between 8 and 11 years CA with an MA of 30 months. Plateau 3 (not attained by all individuals with Down syndrome) is reached between 13 and 17 years CA with an MA of 48 months. For a majority of years, MA according to most experts seemed to be the realistic limit of mental growth (Rondal 1988). The developmental delays for individuals with Down syndrome in comparison to normally developed individuals are considered to be moderate during the first 15 months. Mental decline and functional deterioration are sometimes observable from early adulthood and on.

In terms of mental and statistical framework, although controversial in nature Reynolds, (1986) proclaims that: various issues were addressed by some thirty-two
reviewers, with substantial agreement, leaving aside the question of the origins of individual differences, mental tests remain useful tools which should not be disregarded lightly (Berg, Clarke, & Clarke 1977).

Statistical testing, conceptualizes that individuals with mental retardation are significantly below average intellectually. Therefore, such an individual who receives the label "mentally retarded" if his or her score on an IQ test is below the mean. However, it is known that mental testing is not necessarily a reliable predictor of future adult functioning (Begab 1976; Jensen 1980b; Mercer 1977).

As for intelligence and non-verbal cognitive abilities, overall research findings suggest in Gibson's Review of literature that mosaic subjects tend to be less severely retarded than translocation who display less intellectual deficit than standard Trisomy. However, the extent of agreement between studies is far from perfect.

The behavioral framework according to Clarke and Clarke (1984) may reflect individual development. Individuals with mental retardation are identifiable administratively because of behavioral differences as compared to the rest of the population (Belmont 1971). In the past such concepts as social incompetence have been used in a vague matter, with the result of labeling and institutionalizing the mentally retarded, even though they were of normal potential (Grossman 1977). Stedman and Eichorn (1964) showed evidence that a supportive environment through early intervention marked benefit to intelligence. A variety of programs designed to provide extra stimulation (Kopp & Parmelee 1979) showed significant impact on children with Down syndrome. Children with Down syndrome displayed a wide range of reactions to variations in their environment. Early stimulation and enrichment along with support for children in the mild to moderate range proved to be a positive and developmental outcome. Recent studies on individuals with mental retardation in community group care settings indicate that environmental variables predict an individuals current behavior than do personal variables (Landesman-Dwyer 1981).
Socially, (social framework) Gottlieb, in Ashmore's Review of attitudes, (1975) distinguishes three groups whose attitudes toward individuals with mental retardation are unique: general public, professionals (i.e. doctors, teachers, social workers) and peers (i.e. "normal" children in the same class or classrooms with other children).

He conveys a wide array of intellectual social impairments as a means of dividing children into special needs of such as the mild, moderate and severe categories provide further fuel toward igniting attitudes toward individuals with mental retardation. First most people view individuals with mental retardation within the moderate or severe range as having abnormalities (i.e. mongolism). Second attitudes toward individuals with mental retardation within the severe range are generally negative toward the individual while those labeled "slow learner" (i.e. the mild mentally retarded) more positive. Finally the public is generally ignorant regarding individuals with mental retardation and societal concerns.

Being associated and attached with the label of "mentally retarded" or "mongoloid" to a child has sparked much debate and controversy among disciplines. The problems inherent in labeling are compounded when the label takes on different meanings across disciplines, agencies, and geographic locations.

Gottwald's (1970) survey of public beliefs about the mentally retarded and a study by Connaughton (1974) of physician's beliefs were aimed at determining the appropriateness of knowledge and help the retarded as well as favorable attitudes. Connaughton reports that almost all pediatricians and a majority of practitioners are well informed about certain aspects of mental retardation, a substantial minority of general practitioners have very negative attitudes and serious misunderstandings in this area. These practitioners in turn have been giving inappropriate advice to parents of the mentally retarded. Such findings have significant practical applications for education of the physicians.

A somewhat related study, investigates stereotypes or beliefs held about categories of individuals with mental retardation. Thus, an opinion survey such as Gottwald's (1970) determined whether or not there is a consensus on the traits assigned to the mentally
retarded. However, except for Gottwald, most investigations of stereotypes have not been carried out with a large sample representation.

Willey and McCandless (1973) found traits commonly assigned to special classes. The educable mentally retarded (EMR) children as viewed by regular class children in the same school were far more negative in their descriptions than that of children in other regular classes.

Rosenthal and Jacobson (1968) effects of teacher expectancy on behavior, as well as Smith and Greenberg (1975) found teachers tend to more readily accept a diagnosis of an individual with mental retardation if they are from a low-income family. There are critiques of Rosenthal and Jacobson's efforts which raise doubts about generalization of the expectancy phenomenon (Elashoff & Snow 1971; Gottlieb 1974; Kirk 1974).

Gillung and Rucker (1977) found that some regular and special educators have lower expectations of children labeled than for children with identifiable behaviors not labeled. Similar labeling efforts have been documented throughout the literature (Bates et al 1984; Foster, Ysseldyke, & Reese 1974; Pieper & Turnbull 1979; Reschly & Lamprecht 1979). Labels also have a way of guiding the behavior expectancy levels of those who hear or use them. A significant amount of research has substantiated the effects of labels, especially in regards to the population of individuals with mental retardation (Braun 1976; Brophy & Good 1974; Dusek 1975; Levinson & Starling 1981; Rosenthal & Jacobson 1968).

Mercer (1973) believes that a person is labeled "mentally retarded" as a punishment for inadequate social role performance and views mental retardation as an acquired social role, rather than an attribute of an individual. Within this framework the role or label of "mentally retarded" is construed as a specific social system. Other societies have defined different roles, such as prophet or idiot, for persons with the label "mentally retarded" throughout our Western culture. In an industrialized society persons who are mentally retarded would not necessarily be seen as performing their social skills inadequately and might not be labeled deviant (Maloney & Ward 1979). Thus mental retardation involves
relationships of individuals to their society. From this perspective it is important to study not only the characteristics of people but also the basis and the society doing the labeling.

More specifically, a study that follows the actual phenomenon over time has been particularly noteworthy. Edgerton, in an early study (1967), showed that adults living in their community for sometime displayed a great deal of anxiety about the label (mentally retarded) and a feeling of degradation associated with it.

In contrast ten years later these issues had little salience for them (Edgerton 1975b). It is then not surprising to find that the definition for the term mental retardation to be truly controversial and one of uncertainty (Begab 1976).

Educational and Community Trends

The concern with the adverse effects of labeling has influenced this definition but also concepts of education and normalization as well. The growing trend then to decertify children with mild forms of mental retardation from special education is reminiscent in some aspects already seen in the legislative movements (i.e. Head Start).

The rationale for mainstreaming stems in part from dissatisfaction with special education programs but also perhaps primarily from the allegedly detrimental effects of labeling (Rynders, Spiker, & Horrobin 1978; Weisz 1981b; Yeates & Weisz 1985). The focus of a child’s (with Down syndrome) education and training will depend upon the unique needs and learning characteristics of that child. Education programs should reflect those areas which will facilitate post-school success and adulthood (Wehmeyer 1992).

Efficacy studies, show no significant difference between groups on measure of academic achievement, although children in special classes appear better in social adjustment (Budoff & Gottlieb 1976; Corman & Gottlieb 1976). The majority of children in special classes are identified and referred for placement by teachers because of substantial behavioral and learning problems. Their subsequent labeling through IQ testing, only confirms what the teacher suspects from other behavioral indices. Labeling of children has
also left many unanswered questions about who does the labeling, how broadly is it applied and what prompts it in the first place.

From various studies Gottlieb (1976) the child with mental retardation labels himself and that his self-concept is the mirror image of how he is perceived by others.

Speaking in qualitative terms (quality of life issues) are rarely addressed in the literature about the mentally retarded with specific reference to Down syndrome. This is partly due to the life expectancy level of individuals with Down syndrome and coupled with the increasing practice of deinstitutionalization. However, findings of Halpern et al (1986) offer a challenge to all who seek to design better living options for individuals with Down syndrome. Not surprisingly numerous studies (Berkson & Romer 1981; Canning & Pueschell 1978; Edgerton 1975a, 1977; Halpern et al 1986; Landesman-Dwyer & Berkson 1984) have noted friendships and other social support are highly valued by adults with disabilities and are positively correlated with the enhancement of quality of life.

In an attempt to bring the definition and inclusion of individuals with Down syndrome to a further level of understanding parents and professionals began to organize themselves around this issue. Parents, in particular as seen in the political movement came together and sought information and consultation, creating what became a powerful, innovative and advocacy movement just specifically for children with Down syndrome. It all began in 1975 with the Education for all handicap children and PL 94-142 which mandated a free and appropriate public education in the least restrictive environment. This act laid the foundation of a “second revolution” for individuals with Down syndrome in the 1980’s because, according to the act, children with Down syndrome do not have to enter institutions; children with Down syndrome can remain in their home communities; and children with Down syndrome can be ‘included’ and educated with non-disabled peers. These basic facts, as we look toward the year 2000 are responsible for the new demands for an “integrated imperative” for individuals with Down syndrome and other disabilities.
Such an imperative in Wieck’s Policy Issues and Human Rights, 1988 include the following objectives:

1. Individuals with Down syndrome and others live, work and spend leisure time in their community and environment.

2. Individuals with Down syndrome should be provided with an array of options and alternatives to meet their needs.

3. Individuals with Down syndrome should be taught functional life skills for work and social interaction in community living.

4. Individuals with Down syndrome should have work and living environmentally adapted to accommodate their individual needs.

Current Definition

Breakthroughs can also be seen in a new definition of mental retardation which is more precise and behavioral orientated. This new definition revised in 1983, provides a clearer more practical approach to the diagnosis and habilitation of individuals with mental retardation. At the same time it focuses on improving functioning in specific areas of behavior. Individuals with mental retardation are no longer viewed as an absolute trait, but as a condition which can be improved with the right support.

Previously, the AAMR (American Association on Mental Retardation), a 117 year old international multidisciplinary association of professionals organized to define mental retardation since 1876, was often determined by a single IQ test score. Now mental retardation is diagnosed by looking at IQ and behavior. For parents this definition offers a shift away from the emphasis on a single criterion (i.e. IQ and its implications) to a definition which considers how an individual functions in his or her everyday life by looking at a set of adaptive behavior skills. This expanded and redefined definition incorporates mental retardation as an interaction between the individual and his or her environment with both having an equal role.
Despite the legacy of labeling and categorization, support provides that an individual can improve how he or she functions (or even change the diagnosis of mental retardation) and can come from the environment or from the individual as well.

Given a more holistic view of the term 'mental retardation' an individual with Down syndrome has yet to fit or and be specifically defined under this generalized category/framework. So for the purpose of this study, an individual with Down syndrome is understood to be one who has a genetic anomaly (homogeneous in trait only) of which encompassing inter-individual differences (within a heterogeneous group of ability levels) with substantial limitation in several of the following adaptive skill areas: communication, social skills, community use, self-care, work, community living, health and safety, leisure, self direction and functional academics (American Association on Mental Retardation 1993).

The severity of Down syndrome also depends upon the number of processes affected and the degree of severity in each deficiency area. The variation in combinations can affect a wide variety of abnormalities, both anatomical and biochemical. Approximately 40% of individuals with Down syndrome are born with congenital heart defects, many have increased risk for developing cataracts, hearing and other vision impairments (National Down Syndrome Congress 1992, March of Dimes 1994).

Biochemically individuals with Down syndrome may suffer from elevated levels of purine, a condition that by itself could lead to neurological impairment, mental retardation and immune system deficiencies (National Down Syndrome Congress 1992, March of Dimes 1994). In addition (as Reviewed in Epstein 1986a; Pueschel & Rynders 1982; Patterson 1987) Down syndrome is associated with a characteristic set of facial and physical features, increase risk of leukemia, endocrine abnormalities and Alzheimer's disease.

It was then not surprising for individuals with Down syndrome to typically have shortened life spans. In 1929 their estimated life expectancy was only nine years of age.
By 1980, with improved medical care, their life span increased to more than thirty years and now some individuals live to fifty-five and older (Dyke, Lang, Heide, & Van Duyne 1986; Patterson 1987; March of Dimes 1994; Straus 1965). Down syndrome is associated as a chromosomal non-disjunction reflecting a malfunction in the cell division. This takes place when failure of chromosomes separate properly during meiosis (process of cell division that leads to the production of the egg and sperm cells). Trisomic fetuses seldom live, and those that do survive affected by a variety of biochemical and physical defects. Down syndrome Trisomy 21 is thus the commonest human Trisomy seen in such live births.

Trisomy of at least part of chromosome 21 has so far proved to be an infallible determinant of Down syndrome. No individuals with clinical symptoms of Down syndrome exist who do not have at least partial Trisomy of chromosome 21. There are no known cases of individuals with Trisomy 21, according to Patterson (1987) who do not have Down syndrome.

One can only surmise that the final road that directs itself in the movement and in terms of the individual with Down syndrome is comprised of a very complex interactive system between the individual biologically, socially (family setting), political, environmentally/behaviorally as well as the individuals own repertoire of cognitive strengths and weaknesses.

The path thus far despite the progress that has been achieved in treatment, bio-medical advancement and in the behavioral science still shows residues of negative attitudes, exclusion, sequestration, rejection and actions stagnated by ignorance, stereotyping and superstition.

Gellman, (1950) states that the existing prejudices have been long rooted and are present on all social-economic levels and in all regions. Research studies throughout the literature have indicated that a disability (i.e. mental retardation, Down syndrome) like any other characteristics that is different is negatively tinged and stigmatized (Siller 1976).
Rarely is an individual with Down syndrome singular in nature or phenotype but rather, one that touches many aspects of the individual's life especially academically and interpersonally. Even along the way, causes or occurrences have been determined, no one theory has yet to explain the why or how such a homogeneous genetic trait creates such inter-intra-individual differences and ability levels among the development of each person. It then becomes critical that practitioners from the various disciplines be able to draw upon content, methods, techniques and theory and intertwine them within each unique individual with Down syndrome.

For legislation by itself does not automatically ensure the right that individuals with Down syndrome are secured or adhered to. Laws do not enforce themselves and the implementation of legislation and the judicial mandates require persistent monitoring (Soskin 1980).

Over and beyond the etiology, epistemology, epidemiology, diagnosis and remediation, and understanding of how to raise a child with Down syndrome the family requires total collaboration. Just as the field of education is beginning to advocate a "collaboratively shared-inclusive responsibility" between regular and special education, a more cooperative, collective and meaningful shared responsibility between professionals, schools, and parents needs to take place (Bailey 1987; Dukmak 1994; Giangreco & Putnman 1991; Nichcy 1988,1993; Thousand & Villa 1990; Jenkins, Pious, & Jewell 1990; Lipsky & Gartner 1987; Schunk 1985; Sonnenschein 1981; Turnbull &Turnbull 1985).

As a final note, it appears to this investigator that over the last decade many questions have been raised about the responsibility of individuals with Down syndrome. It is ironic that that these appear to be the same ones as seen throughout our past travels, almost a century ago.
CHAPTER III
The Impact Upon The Family When Raising A Child With Mental Retardation

Review of Literature

Several initial comments addressing the general aspects of the literature to be presented in this section are necessary, in order to build a stronger understanding of the contemporary dynamics of the family unit. Regardless of the classification or terminology utilized, i.e. disabled, autistic, handicap, mentally and emotionally retarded, developmental, or exceptional, it is important to keep in mind that children are diagnosed at different stages in their development. These stages, in turn are perceived differently by their parents, educators, community members as well as during different stages within the family unit (Carter & McGoldrick 1980; McConachie 1986). All of this creates an experience relevant to both the individual (child), the family unit and the time of development. Day to day each of these experiences begin to change but continue to be built upon and a new piece of the family foundation emerges. The organizations, textures and highlights of the family experience then begin to develop depth, complexity and magnitude beyond the human reach. For as a social system, the family unit begins to interchange with each other, its environment and other systems (Ross 1964).

Paul (Ed.1981) in a comprehensive review of the literature on parents with children who have disabilities argues that it is in the family that we first learn about the world and about ourselves. He further points out that there is a correlation between parental roles, adaptation, attitudes and behavior of individuals within the family as a reflection of the interactional process. He continues to stress that parents of children with disabilities function in a double bind. They, like all parents, are not only involved in the behavioral and genetic raising of their children, but must also deal with a myriad of feelings, transactions, and interactions with their specific child with particular characteristics and attributes.

In turn, parents and families in general, come with their own characteristics, histories, goals, talents, and past experiences resulting in a dynamic interchange with one another as
a system, as well as within their environment. That is to say that the family is not a closed system rather an open, interactive one. This is also reflected in Minuchin's view on family relationships (1974):

An individual influences his or her context and is influenced by it in constantly recurring sequences of interactions. An individual who lives within a family is a member of a social system to which he or she must adapt. His or her actions are governed by the characteristics of the system. These characteristics include the effects of his or her past actions. An individual responds to stresses in other parts of this system to which he adapt. An individual can be approached as a subsystem, or part, of the system, but the whole must be taken into account (p.9).

Even though, over the last two decades, it has been commonplace to perceive families as interactive and dynamic units (Minuchin 1974; Nichols 1984; McGoldrick & Genson 1985) the impact of this conceptualization upon research remains limited.

In order to group the dynamic nature of the family unit it is therefore, imperative to view the existing ecological or 'eclectic' network within which includes such factors as ethnicity, culture, class, social-economical and political status (Bronfenbrenner 1977; Brim 1975; Crnic, Friedrich, & Greenberg 1983; Hunt 1974; Grossman 1972; Turnbull, Summers, & Brothersons 1986; Zuk 1962). This perspective adds to the complexity and more intricate network and presents a broad standpoint from which families in general and profoundly accentuate the experiences of families with a child who is mentally retarded.

Turnbull and colleagues (1986) illustrate this by stating how cultural beliefs are the most static component of the family unit and play an important role in shaping its ideological style, interactional patterns, and functional status. Cultural style they imply may further be influenced by ethnic, racial, or religious factors along with social economic status.

Zuk (1962) points out that the cultural dilemma stems from the fact that our culture implies that it is a good thing to be a parent but a bad thing to be a parent of a defective child. In her review of literature, Schorr-Ribera (1987) further concludes that cultural based beliefs affect the way in which families adapt to a child with a disability (i.e. mental
retardation). These beliefs can further influence their usage of and level of trust on caregivers and caregiving institutions.

The following section will present an overview of the significant findings and relevant interpretations of the impact upon raising a child with mental retardation. The literature reviewed herewithin refers to a handicap or disability such as mental retardation, or physical disability, such as cerebral palsy. This researcher is fully cognizant of the sophisticated usage of these terms and a differentiation of etiology for each (Sarason 1953). Such diagnostic refinements are of little use to parents whose needs are engulfed around his or her feelings about having a child with mental deficiencies which prevent him or her from learning the skills other kids his or her age are capable of mastering (Patterson 1956).

It should be pointed out that a great majority of the literature that focuses on the impact or effect of raising a child who is disabled comes from studies and clinical findings of families within the broad field of mental retardation. However, given close examination of the literature on the child with a disabilities reveals that these studies or theoretical studies gather data primarily from observation and or perceptions of the mother via interviews. Much of the data on parental emotional status is poorly designed, unimodal (questionnaires), impressionistic, short termed, poorly controlled and represents sampling biases. The majority of the research focuses on the mother, occasionally the father and most recently on the siblings and extended members of which is further interest to this study. Although most studies are based upon a two-parent unit, a few include single parents, primarily the mothers.

The confounding factors surrounding the change in the family unit, being a single parent, or being raised by grandparents are rarely incorporated into most of the studies. Palfrey et al (1989), Seligman and Darling (1989), and Vadasy (1986) however, included specific reference to single mothers. Since the majority of the literature addressing families with a child who is disabled focuses on a two parent unit the review that follows may be considered to be from the view point of a two parent family unit.
It is important to note that the literature documents the pressures and strains these families undertake. The views on marital relationship and marriage in general; the level of stratification, longevity, and theoretical points of views are mixed in review.

Several studies reflect that marital integration or discord has been seen in these families as either a reaction to the handicap or a mediating variable affecting the experience. Such findings published prior to 1980 (Boles 1959; Gath 1978; Kanner 1953; Tew, Payne, & Laurence 1974) found an increase in marital conflict and higher divorce rates. Parents, from a clinically-based perspective of having a child with mental retardation appeared to be the most vulnerable group as far as marriage is concerned (Martin 1986; Mikkelson 1967; Mussen, Conger, & Kagan 1963; Schild 1971).

Some assumptive generalizations may be ventured concerning the marital discord and divorce rate among families with children who are disabled. First, the parental functions of the marital role may become superordinate to other martial functions and bind the marital ties around the child with the disability. Second, such disruption and discord may be related to the emergence of other conflicts which were not dealt with since the disabled are now at home.

In contrast, there are several more recent studies that have proclaimed little difference in the quality of the marital relationship or divorce rate of these families as compared to the general population (Buscaglia 1983; Bernard 1974; Crnic, Friedrich, & Greenberg 1983; Featherstone 1981; Waisbren 1980).

Featherstone (1981) describes marital stress as an everyday occurrence in our daily lives to having a child with a disability:

A child’s handicap attacks the fabric of a marriage in four ways. It excites powerful emotions in both parents. It acts as a dispiriting symbol of shared failure. It reshapes the organization of the family. It creates fertile ground for conflict... At the magical and metaphorical level where so much of the emotional life is lived, a child’s disability calls the union into question. Practical reality reinforces the tendency to confuse the health of the children and the health of the marriage, for the disability touches most of what parents do together (p.91).

42
Paul and Beckman-Bell (1981) collective writings of 'Parents Perspectives' on the issue of marriage recall the meaning as seen through the experiences of Mrs. A.:

*My husband and I agree that having a handicapped child has had a detrimental effect on our marriage and family... No one is more vulnerable than the parent of a handicapped child. It has been harder to deal with the normal tensions of marriage and family.*

Parents accounts of their experiences and the effect upon their marriages range from "super human perspective" to "why me" to "hard core truths." The pressures seem to operate subtle and may be cumulative, and yet, the feelings and interactions that emerge may not be very much unlike those in families without children who have disabilities. Buscaglia (1983) summarizes this perspective as:

*The role of the family of the disabled person can best be understood in a sociopsychological context. It is one, as with the normal family, in which there are continual reciprocal effects, family-child, family-culture-child, each upon the other. Any change in any one family member affects each in turn, depending upon the psychological state of the family. The major difference in the family with the child who is disabled is that their problems are intensified by many special needs, attitudes and requirements which are put upon them, due to the presence of their disability (p.75).*

The early research on parents who had a disabled child commonly displayed themes of recurrent stress, reactions (i.e. diagnosis) and high levels of emotional conflicts. The birth of a child with a disability is a stressful event for a parent. The literature abounds with studies of the negative impact a child's birth precipitates upon the family functioning (Bristol & Schopler 1983; Collins & Watts 1986; Cummings, Bayley, & Rie 1966; Carr 1974; Donovan 1988; Farber 1960a, 1960b, 1962, 1975; Gallagher, Beckman-Bell, & Cross 1983; Holroyd 1974; Holroyd & McArthur 1976; Roskies 1972). Here the child is perceived as an initial event that affects the social-emotional health of the family. Innumerable other events in the family unit are perceived to interact with the presence of a child with a disability to produce further stress or to facilitate coping and adaptation. An increase in family stress to some critical level, is presumed to be different for each family and becomes the mediating variable affecting the child's outcome (Zigler & Yando 1984).
According to Blacher (1984) in nearly all case a child with a disability is reported as affecting in a negative way all or some of the following: marital relationship, siblings, finances, relationships with friends and relatives, planning daily activities and vocations. Thus presumably when the impact of a child with a disability on the above function is negative one outcome is increased stress for the family unit.

Stress also manifests itself in varying degrees due to the disability (Cummings 1976; Holroyd & McArthur 1976) and is related to the amount of stress they experience. A number of reports suggest that limited intelligence, educational background and verbal skills are frequently associated with the child and family stress (Rabkin & Strueing 1976; Rosenberg 1977). Other factors according to Pearlin and Schooler (1978) found psychological resources such as self-reliance and self-esteem helpful in coping with stress. However, other studies have not always reported similar findings. One such study Bradshaw and Lawton (1978) investigated stress in families of Thalidomide children using the Malaise Inventory (Rutter, Tizard, & Whitmore 1970). These authors discovered that mothers were significantly higher on the scale than of mothers in the general population. These higher scores, it should be noted were not related to the child's degree of mobility, type of disability or age.

At this point it is critical to note that not all families respond negatively toward having a child with a disability. Hewett (1970) pointed out that much has been written about the problems that beleaguer families with children who have disabilities and little about "families who meet the crisis" (Lonsdale 1978, p 101). Ferguson and Watt (1980) examined aspects of motherhood in 87 families with children who were mentally retarded and found them to be realistic, adaptable, and resourceful. Even though this study involved a single contact with the families, included mothers of equal numbers of severely, moderate and nondisabled range of the working class, it did reveal mothers perception of the problem a child could create for the family and yet not be directly related to the level of the disability.
Based on interviews of over 400 families in rural Alabama, this classic study of Dunlap and Hollinsworth (1977) also found families did not necessarily perceive a negative effect of having a developmentally disabled child as a family member. This study further indicated that those having additional or secondary disabilities such as cerebral palsy were viewed as requiring extra time, physical assistance, and financial help.

These conflicting findings suggest that the relationship between the characteristics of the individual family members and stress is not necessarily a direct one. It may be that these characteristics take on their importance only when considered in light of other dimensions of the social system. One such dimension entails a transactional one, in which what happens to one family member affects the others directly.

Extending this perspective according to Fewell and Gelb (1983) there is a mutual interdependence between persons, their behaviors, and their environment. How a family operates as a unit and the ways which family members relate to one another will have a major impact on the outcome and intervention for the young child with a disability. Belsky (1981) proposes that the family system is viewed not just in terms of parent-child relations but in regards to how marital relationships and others within the family affect the child. These relationships can not be studied in isolation but must be viewed as they influence and shape the behavior of the family unit. Gabel and Kotsh (1981) extended Belsky's analysis to include grandparent-parent relations within the context of the extended family.

Parental reactions to the diagnosis of having a child that is disabled usually conceptualized as a "family crisis" are highly individualistic. For some it is relief, amazement, shock, disbelief or anger (Farber, Jenne, & Toigo 1960; Wolfensberger 1976). Despite the wide range of reactions described in the literature, some are noted to be more prevalent than others: guilt, ambivalence, disappointment, frustration, anger, shame, and sorrow (Burden 1978). Writings from a personal clinical perspective Schild (1971) suggests that no matter "the intensity of the parental reaction to the diagnosis has often been misconstrued to characterize the parents of the mentally retarded as psychologically
disturbed individuals" (p. 436). When parents are reviewed as actors in a reality crisis situation their behavior takes on rationality. The disorganized behavior which occurs frequently reflects the upset in the equilibrium of the families involved.

On the other hand, derived from psychological and sociological literature, many writers have suggested that parents pass through a series of stages (Drotar et al 1975; Solnit & Stark 1961) while others (Wikler, Wason, & Hatfield 1981) have suggested that although the reactions described by the stage theorists may be present in families with children who are disabled, these are not necessarily experienced sequentially. For instance Gargiulo's study of 1985 identifies three major stages of reactions that parents pass through when they find out their child has a disability. These are the Primary (i.e. shock, denial, grief), Secondary (i.e. ambivalence, guilt and anger), and the Tertiary (i.e. adaptation, reorganization and adjustment) stages. While other writers have suggested that a similarity lies between the sequence of the stages in the acceptance of death and dying to that found in parents with disabilities.

Osmar (1979) reports that parents go through an emotional stage similar to those experiencing a severe loss or death of a family member. Even before they are given truthful diagnosis many parents of congenitally disabled children feel a great deal of anomie in the form of meaninglessness. They know something is wrong and they fear the worst. When professionals refuse to confirm their suspicions they sometimes develop pathologic reactions, such as blaming the child's delay development on their own inadequacies as parents. He continues to report that rarely do parents challenge the physicians because they have been socialized to respect the professional dominance.

Characteristically the first contact with the medical profession are the general practitioner and the pediatricians. Early diagnosis of a child who is mentally retarded is often not possible. However, even when it is, families frequently are not acquainted with the nature of the child's difficulties until considerable time has passed. In Blumenthal's study of parents who had children with severe retardation (intelligence around 25) 46%
viewed the first physician as having failed to make a diagnosis or having made an erroneous one. In Schwartz (1970) review, what seems to occur is the fear of difficulties of diagnosis, uncertainly of prognosis or limited medical treatment. Physicians, she further contends tend to fall back on "medical" technique for handling lack of knowledge, medical uncertainly or emotionally charged situations. These physicians cut short their initial contact with the parents, make abrupt and brief pronouncements and refer parents to someone else.

Even though the social and psychological considerations are the paramount considerations, the mentally retarded continues to be recast as a function within a strict medical model. Thus the mere recommendation of institutionalization in the past as well as the present is done as if this were the medicine. The way institutionalization is described according to the review of literature is the source of many parents complaints about "hardheartedness", "coldness" and "inhumanness" of the mentally retarded. In the end, parent's confidence in the physician is likely to erode (Blumenthal 1969, Kramm 1963). It should also be noted that other studies have shown some satisfaction among parents (Koch, Graliker, Sands, & Parmalee 1959).

In contrast, Olshanky's classic article (1962) "Chronic Sorrow" based upon his personal and professional experiences, proposes that most parents who have children with disabilities suffer from a psychological reactions called "chronic sorrow." He considers this a natural reaction and one of continuing presence many years after the child's birth not to be pathological. He further illustrates this point by stating that:

*The permanent day to day dependence of the child, the interminable frustrations resulting from the child's relative changelessness, the unesthetic quality of mental defectiveness, the deep symbolism buried in the process of giving birth to a defective child, all of these join together to produce the parent's chronic sorrow* (p. 192).

This phenomenon of "chronic sorrow" further attributes to parental denial and to added stress placed by professionals on 'acceptance' of the child's disability. Moreover he views the reactions of parents reported in the literature, such as guilt, anger and shame as intertwined within the experience of chronic sorrow.
Seligman and Darling (1989) further speculate that chronic sorrow and the acceptance of a child’s disability may co-exist as apart of the normal, long-term process of a families’ adjustment. Due to the diversity among families Seligman and Darling (1989) further conclude that the implications of Olshanky’s work for counseling allow parents time to adjust and reorganize. The accessibility to counseling over a long period of time also provided an innovative way of thinking. This further allows emerging crisis over a period of time, greater comfort for mothers and caretakers as well as time for parents to discuss their feelings and problems.

Wilder, Wasow, and Hatfield (1981) re-evaluated Olshanky’s proposition and conducted qualitative research with parents and social workers in order to assess whether or not Olshansky’s concept of chronic sorrow was operating over such long periods of time. Utilizing a questionnaire method and asking participants to formulate a graph depicting their adjustment process and respond to how they felt during their child’s development, they indicated that parents and social workers did not differ significantly on how upsetting it was to have a child with a disability. However, social workers did underestimate how difficult later experiences did become as compared to earlier ones (i.e. puberty, adolescence, high school, independence). The results of this study support the view that grieving for parents of the disabled or mentally retarded is not a time-related adjustment nor a predicable one, but rather a chronic, periodic phenomenal experience. It should be pointed out that the concept of chronic sorrow was not meant to eliminate parent’s feelings of joy and satisfaction but to address the genuine feeling of these parents rather than viewing them as pathological.

In Barsh’s (1968) review addressing the burden of stigma (based upon the clinical records of parents over a 15 year period), he rightfully points out that regardless of parents’ anxieties, feelings of stress, attitudes, regardless of etiology, therapy or prognosis and of diagnosis the parent still remains charged with the obligation of society to transmit a culture pattern, to teach a language, to establish social adequacy and to differentiate right from
wrong. In short, the identification of a child as handicap does not serve to absolve the parent from the obligation imposed upon them by society. Thus the course of a parent who has a child with a handicap as cited in Barsh (1968) is:

*First to accept the shock of having a child who is different from other children and yet the same; second, set in motion through child-rearing practices those actions and activities which will build a foundation of physical, social, emotional, intellectual achievements to serve as a base for future services of the therapist and teachers and to finally develop conformity behaviors at progressive levels of complexity (p.9).*

The experience of having a child with a disability in the family provides further implications for three major findings. In terms of task demands, a child whose development is atypical generally will require special attention, special services, special education, and alternatives in their daily routines. Second, the problem for parents of the disabled is complicated by the need to learn a new role which they have to integrate as a piece within an existing and defined parental role. Third, the emotional difficulties involved may be reason enough for some families to choose not to participate in regular activities (i.e. religious outings, picnics) resulting from feelings of isolation and feelings of alienation by others (Schild 1971; Love 1972; Wolfensberger 1967) at the emotional level.

In contrast to the empirical research, two views are offered in a more human experience rather than a didactic, textbook style. Diamond (1981) so eloquently articulates the perspective or ‘slice of life’ of having cerebral palsy otherwise not captured.

*My father was the experimenter, adventurer, and friend. Marshmallows, white bread and velvet. My mother was the law-maker and disciplinarian. My father always introspective; at age of 70 spoke to me about the guilt feelings that a parent has as a result of having a child with a disability under his care. He said he understood his guilt... It was not in terms of having done something wrong by bearing or siring a disabled child, but rather of not having done the best. He used such examples as: feeling that he could have gone to more doctors, explored more treatments, and feeling he could have smoothed more of the hurt that I was exposed to as a result of being disabled (1981, p.24).*

Mrs. D. cited in Paul and Beckman-Bell 1981 perspective of the impact on relationships with the larger social community relates that:

*One card I received in the hospital (when Sara was born) meant more to me than others. It was a congratulatory baby card; but at the bottom, “We are thinking of*
you." I resented those who sent sympathy cards and was grateful for the few baby cards I got. I was so grateful Sara was alive (my mother had lost a baby born at home with the cord around its neck when I was 14) and I have always been grateful that when she was first brought into me I did not from her but readily accepted her. This is something you can not predict, nor can you bear guilt for it if you reject a handicapped child at birth. That's why I've tried to be understanding of friends and neighbors, and others...No matter how hard you work at it, mothers (and I suppose fathers too) are extremely sensitive during those early adjustments days. A close relative hurt terribly when she told another, in my presence, that underneath the pins and pretty little cape were little wing-like arms. Another told me she did not see how I could bear it. They were all sympathetic, but that was not what I needed. Most of our friends were kind and helpful as Sara grew older...one kept her three weeks, others drove here to and from school, she was invited to parties...at no time did we feel rejection. However, I did resent the sister-in-law who had X-rays to be sure her baby would be "all right" and so notified me. Our pastor wanted my husband to baptize Sara (by immersion) because he was not quite sure how to hold her (she was 10). We insisted that she would not be any different form any other small child and that it would not be in order for her father to do it since he was not ordained. The pastor did it and had no problems of course. However, a church experience we had when Sara was in high school was very bad and represents how adults need more awareness.

She went with the young people for a week to a camp. She took a crate of drinks with her to spare her having to get to the canteen to buy drinks...She took two dollars with her which was probably stolen when she was out of the room. After a week was over, we were asked not to let Sara go back to camp unless a special attendant was provided; that Sara had no money and (after the children drank her drinks) had to borrow money for drinks; that it was too difficult for the children to push her (these were high school age and the paths were paved). We tried to check and all we could learn was that the kids fought over who would take a turn pushing (1981, p. 132-135).

In a more public dimension much of the awareness and consciousness-raising about the day to day and emotional experiences of families with a child who is disabled has been conveyed powerfully and dynamically by the parents (mostly mothers) via shared experiences (Buck 1950; Buscaglia 1983; Feathersone 1981). Such accounts provide a cluster of intimate human interests, resources and needs thereby referencing the interactions with the child, the family and the consequences of family life (Paul & Beckman-Bell 1981). In addition such accounts have assisted to refocus the myopic perspectives of many professionals as well as society as a whole (Kelman 1958; Singer et al 1984; Searl 1978).

McConachie (1985) provides another dimension through the "personal construct theory" of how parents with children who have handicaps construe their role as seen through the fundamental aspects of:
1. The birth and becoming a parent,
2. Initial reactions,
3. Expectations,
4. The role of the family structure,
5. Acceptance, and

She conveys that parents need to reconstruct their perceptions and expectations of
themselves and their lives. They need to construct a picture of their child labeled “mentally
retarded.” Here they are seen as becoming more actively involved in their role as an
enabler. This added dimension is important for the future of parents because it is tailored to
interpersonal style of the child, realizes the variety of people and disabilities and provides
professionals with more insights into becoming more versatile (McConachie 1985).

Throughout the literature group generalizations about the reaction of the parents, their
stress, stages of emotional development give little or no guidance to the understanding of
the complexity of the process of adjustment of an individual within the family unit.
Isolating particular variables does not suggest how professionals can most appropriately
work with a religious family, a parent of a boy, etc. More useful understanding of the
complexity of a parent’s view relates to an individual analysis of the total family
functioning. Such functions may involve economics, education, health, socialization,
affections, guidance, or vocational elements (McConachie 1983, 1985; Russell 1983;
Shotter 1974; World Heath Organization 1983).

On the other hand, Widerstom and Dudley-Marling (1986) thorough review of the
myths surrounding a child with a disability (i.e. high stress, economic hardships, poor
adjustment) reported that research does not confirm these elements singular in nature
attributing to a reduced quality of life. In Dunlap and Hollinsworth (1977) comprehensive
study with the developmentally disabled their findings concluded that a large majority of
families felt that such a child created no additional stress in their daily lives.
While Waisbren's (1980) international study, comparing life of families with children who have disabilities in the USA to those in Denmark (included nondisabled control group in both families) concluded that families having children with disabilities were similar to those not having children with disabilities. He extended the single element of stress to conclude that the dimensions of child birth, health, influence of the baby upon the marriage, relationship to siblings, support networks and future plans were similar among both groups.

A majority of studies, recent ones emphasize "...in most respects that these families resemble others in our society. Most of their roles and values are drawn from and are sustained in a flow of events similar to that experienced by other families" (Farber 1975, p. 247).

Whether families "accept" or adapt to raising a child with a disability is still a much debated issues. It is interesting to note that women have been more accepting of the disabled then men (Fletcher 1974).

The concept and dimension of "social support" has an extensive history in reference to disability and crisis intervention (as seen in the reviews of Gottlieb 1981 and Haggerty 1980) and is well documented in the literature. Additional literature specific to families with children who have disabilities also supports the concept that maintenance of healthy social networks and support groups have been found to be tied to successful family functioning (Crnic, Friedrich, & Greenberg 1983; Reynolds 1979; Sonnenschien 1981; Trute & Hauch 1988). Social support and personal coping strategies are each important but, when linked together, they become powerful means of attaining and maintaining the functioning of a healthy family.

These articles, in general, have revealed that the family strategy for coping with the experience of raising a child with a disability is not created in a single instant or due to the results of having successfully passed through stages of grieving. It is progressively modified over a period of time.
The family, individually and collectively, is then simultaneously involved in the management, negotiations, and balance of various dimensions simultaneously during the families lifetime (McCubbin, et al 1980). A few recent articles (Pearson & Sternberg 1986; Trute & Hauch 1988) have begun to report cases in which the family has found positive mechanisms for coping and has built upon their strengths through the process of sharing. Pearson and Sternberg (1986) suggest that salient issues are uncovered and such interpersonal relationships within the family unit are formed to gain more information on attitudes, values and beliefs of having a child with a disability.

The research review here suggests that there is no easy solution to meeting families' needs through the provision of counseling, guidance and general services. Service providers and planners must view families as functional systems so that what they provide fits with the families resources. In short, services can then be tailored to meet the individual needs of families and to complement the families' own 'structure for coping'. It is only in this way that research can ultimately be of value to the families (Byrne & Cunningham 1985).

**Subsystems within the Family Unit**

The family unit is more than the sum total of its parts. The participants who make up those "parts"...mothers, fathers, siblings, and extended family are also important in their own right. A better understanding of the impact upon raising a child with a disability upon these members (typically studied in the dyadic relationships) allows for a clearer understanding of how the family is a representative of its parts. Therefore, the literature pertaining to mothers, fathers, siblings and extended family members will be presented.

**Mothers**

The literature addressing the impact upon the family when raising a child with a disability rarely has gone beyond the parent-child dyad. Research strategies in turn have
frequently concentrated on only one component of the interactive family unit (i.e. the child and the mother). A great majority of data on the parent-child dyad has been gathered from observations, interview, and or experimentation dealing with mothers and their children. Similar to much of the early dynamic and family systems findings in the literature the portrayal of mothers raising children who are disabled has been far from complimentary.

Mothers being blamed for their children’s problems or for the families’ difficulties has a long and respected history. As cited in Holt (1958); Levy (1943); Symond (1939), mothers of the disabled have been documented as being “overprotective” “a failure”, “inadequate parents”, and “blind and unreasonable in their feelings”. With this kind of beginning orientation of mothers who have children who are disabled, it then becomes extremely difficult to view the literature about mothers in an objective and unbiased fashion. For mothers, the primary caregivers have been expected and are expected to provide the most basic relationship of all-a human one (Buscaglia 1980; Paul & Beckman-Bell 1981). Mothers who have children that are disabled frequently have greater demands on their time and energy with respect to direct child care, but also spend an inordinate amount of time “shopping” for help from professionals and agencies. It should be noted that parents often “shop” around twice, the first time as a result of the denial process and the second time to find appropriate services and help for their child to maximize his or her potential (Russell 1980). In addition, due to the sex role division in society, it is the mother in most cases who seeks out professional help for the child. The mother may spend years shuffling from one professional to another in order to pinpoint the cause of her child’s difficulty or proper services. Imagine the frustration when a diagnosis results conclude that your child has a “delayed development of unknown etiology” (Kupfer 1980).

Again because the primary role of child care falls upon the mother, it is she who must find someone to care for her child at home, take on a new role, suffers the burden and stigma placed upon her by society or embarrassing questions from friends and neighbors within her own community. There are numerous studies that support this point of view
leading further to increased stress and unhappiness (Beckman 1983; Farber 1962; Worchel & Worchel 1961) and identify the ‘tragic crisis’ and role reorganization crisis the mother faces when raising a child with a disability. Telford and Sawry (1977) describe the mothers denial of the reality of having a child with a disability, as ambivalence toward or rejection of the child and projection of hostility and feelings of guilt and shame.

In Buscaglia’s Review (1983) of the literature pertaining to children with disabilities, he reveals that the role of the mother is part of a larger social context within the family unit. Mothers greatly influence the family as to whether the child is accepted or rejected. It is therefore, the mothers behavior and attitude that sets the path the family unit will travel. Parents of children with disabilities (especially mothers) have great responsibility laid on them when they feel an extra burden and a sense of powerlessness (Dupont 1980; Ehlers 1966; Erickson & Upshur 1989). The cultural assumption that mothers are responsible for fostering their children’s development through interaction would seem to have potentially harmful effects upon the mother whose children are not going to achieve quickly and compete with others. This pressure could therefore, distract from the individual family member’s goals and ignore the subculture values of child-rearing (McConachie 1986). The effects on the mother’s personality as a result of having a child who is mentally retarded has been investigated extensively (Agathonos & Valaes 1982; Cummings, Bayley, & Rie 1966). Subjects in this study showed that mothers who had a child with mentally retardation as compared with mothers of only normal children had significantly greater feelings of depression and anger at the child. The mothers sense of maternal competence was also low along with loss of self-esteem. It should be noted that the results underestimate the extent of the psychological stress on the mother due to method of collecting data. This is in reference to the choice of intact families as subjects and the self administration of a battery of tests. Further, the emotional and social development of a child is dependent upon the mothers response to a child’s disability (Bentovim 1972; Feinman & Lewis 1984).
It can therefore be speculated that prior to the 1960s, mothers were perceived on the assumption that in the typical USA family (two parent) the mother served as the chief socializer of the infant and the young. This observation was even more true for the mother of a child with a disability. The mother was considered the primary caregiver who had a limited amount of outside resources. However, the perception of raising a child with a disability over time, has taken on additional dimensions due to demographic trends, the amount of time parents (mothers) spend at home, the changes in the size of the family, its structure and the roles of the family unit (more single parent run families after 1974) along with the changing picture (both in adjustment and management) of the world of work (Waite 1981, Yankelovich 1981).

More recent work of the 1980s tend to incorporate a more contextual point of view highlighting "real-life" issues (i.e. child care, infant stimulation, social competence levels). In one study on the perception of mothers with disabled and normal children (Smith et al 1985) concluded that mothers of children with disabilities had a good sense of the developmental milestones of a typical child. These milestones did not differ from what was expected of those children within the norm. Mothers of children with disabilities, in addition, were more determined in the child-rearing practices than compared with the norm. Mothers of the children with disabilities were still capable of making realistic assessments in regards to social competence.

"Overprotection" in contrast to past studies, resulted from the mother's perception of "others" having a less than positive or supportive attitude toward their child. This could have predisposed mothers to believe in the need to protect their child from possible rejection. Manifestations of such overprotection may be further understood in the light of the child behavioral deficiencies and the interactions between the mother and others in her social environment (Watson & Midlarsky 1979). In addition, Eheart (1982) found that mothers of children with mental retardation tend to dominate free play session more often than mothers who did not have children with disabilities. The differences focused on the
conditions under which the experience of each individual arises. Mothers may have experienced for example stress factors and unknowns when the first signs of her child’s delay appeared. Further these perceptions of their children as delayed fostered expectations that children could gradually internalize.

An interesting difference was found in the amount of variance between the mother and father dyad which reduced the generalization of these findings. Mother’s perceptions were then supported by her exposure to disabilities, birth order, and diagnosis. In support of these findings Kearsley (1979) proposes that developmental delays in young children can be attributed solely to biological insults. He states: “It is the continuing dynamic interaction of the biological heritage that accompanies the child entry into the world with physical, social and psychological environmental that provides the conceptual framework needed to examine the phenomena associated with the process of development” (p.178). For very young children with a disability as well as those without, their physical, social, and psychological environment revolves around their families, particularly their mother. Without the knowledge of the dynamics of the interactions we can not truly understand the child’s development. Even the report from the President’s panel, reminds us that “No mother can be expected to carry the responsibility of a child who is mentally retarded without outside support” (U.S. President’s Committee 1969, p. 89).

In contrast, positive maternal perceptions of infant activity have been associated with less optimal mother-child outcomes. As reviewed in Affleck, Allen, McGrade, & McQueeny (1984) and Ramey et al (1980), mothers who viewed their infant with developmental disabilities as more active provided more stimulating home environments. This relationship may be due to positive contributions which more active infants may make to the quality of the caregiving environment but also be mediated by subjective influences in maternal perception. Another perspective, is that overestimation of the infants activity may be a form of denial or to some extent an adaptation in coping with the crisis of raising an impaired infant (Moos & Tsu 1977).
The hypothesis that attitudes of parents, especially mothers and quality of the relationships a child enjoys play an important role etiologically (at least as precipitating or perpetuating factors) in childhood psychosis has been stated by many authors (Cohen 1962; Gumz & Gubrium 1972; Judson & Burden 1980; Strom, Daniels, Wurster, Rees, & Goldman 1984). Erikson (1963) best summarizes this position when he states: "The role which 'maternal rejection' or special circumstances of abandonment plays... is still debatable."

In discussing the mother-child interaction one must always keep in mind the interaction that takes place in the social matrix of the family which the mother and child are one unit. Brim (1975) suggested that the mother and child is conceived as a separate social system embedded in the more general system, and that whatever happens within any one of these sub-systems will affect not only the other subsystems but also the system as a whole. Conversely whatever affects the system of the family as a whole will in turn result in repercussions in any one of the subsystems. From this profound point of view the child can't be viewed in isolation; but must be seen in the context of the family system.

Fathers

In the past, the role of the father in child-rearing and socialization has received comparatively little empirical attention as a result of three major considerations. First, fathers are generally less available than mothers for participation in research studies (Gardner 1943). Second, the sex role division in our society has allowed the father to "escape" from many of the direct care responsibilities for his child. Third, and perhaps more important, the theoretical framework employed in child-rearing research has placed little stress on the importance of the father's role (Bristol & Gallagher 1986).

However, with the growing demands of mothers to maintain a career outside the home coupled with the mothers demands that the child care is a shared responsibility, now focuses on a more active role for the father (Lamb 1986; Russell 1980). This new focus,
in recent debate, highlights a shift from a concern with fathers as persons primarily involved in the economic support of the family and perhaps in the discipline and control of older children (Benson 1968, Bowlby 1951) to a view that places increase stress on the role that fathers play in the direct care of children of all ages.

The conceptual frameworks for most research in this area have been generally derived from the learning or psychoanalytic theory. In fact, since the mother has had more frequent contact with the child theorists followed along with the above orientation to discount or minimize the role of the father. Amid the explosion of research on fathers in the last decade, fathers of children with disabilities have been relatively ignored. In a review of 24 studies of parents’ adjustment to a child with a disability Blacher (1984) found that fathers were rarely assessed. This failure to include fathers has led to overreliance on maternal information and a subsequent assumption that what is valid for mothers is also valid for fathers (Wolfensberger 1967). Little research has been done directly on the father; however a comparison study on fathers to the research turned up some interesting findings. Cummings (1976), conducted the largest representative study in terms of number of subjects from two-parent families to include 240 fathers of children who were mentally retarded, chronically ill, neurotic and healthy children (60 fathers in each group). Of the 240 fathers who completed a battery of four self-administered tests. Test measures were chosen to permit assessment of four categories of personality variables: fathers current mood, self-esteem, interpersonal satisfactions in relation to family members and others; and child-rearing attitudes. The results showed that fathers of children with mental retardation as compared with fathers of normal children had significantly greater feelings of depression and preoccupation with the child. Since fathers are playing a larger role with their children, “there is increasing likelihood of fathers experiencing the handicaps more immediately and sensitivity than did fathers only two generations ago” (p.247). The fathers general self-esteem was lower, the fathers showed little enjoyment for their child and this generalized to their normal children and wives. Finally, fathers had feelings of rejection toward their
child. Fathers have often perceived the child with a disability as a threat to their self-concept. Fathers who viewed their child with a disability as an extension of their egos are apt to become more isolated, or withdrawn from social interactions.

Several researchers have used the theoretical perspective of Tallman (1965) to suggest that the processes of adaptation to having a child with a disability are different for fathers and for mothers. The prime advantage of the Parson-Bales approach was that it conceptualized the family as a social system involving complementary roles. The findings tended to support the predictions that fathers would show themselves to be more adaptable than mothers and would be more vulnerable to social stigma and extrafamilial influences (i.e. child’s physical appearance, sex). The theoretical formulation presented in this paper suggest a number of additional hypothesis. These were: 1). That the fathers may experience greater frustration during different parts of the life cycle, 2). The father may be more sensitive to social stigma than the mother, and 3). That the social prestige and social image of the family are important to the father’s orientation as seen as part of his occupational structure. It is difficult to evaluate such studies in the light of the change in expectations about the practice of parental roles, and of the changes in theorizing about parent’s attitudes. There are also similar studies which do not find mother-father differences (e.g. Staton 1972). Lamb (1976) has noted that many studies on child-rearing have found paternal warmth a vital variable and suggested that the instrumental role of the father had been overstressed. He also noted that the importance of the expressive component of the relationship between father and child had been overlooked.

In contrast to Price-Bonham and Addison’s (1978) review of literature on the family (i.e. mentally retarded) with emphasis on the father, the fathers exhibit more knowledge relative to their child who is mentally retarded, are more objective, less emotionally involved with the child and tend to show more concern over the future problem (economic and social dependency). This review further indicates that research has found that fathers tend to react in extremes of total involvement and withdrawal if the child is a boy verses a
girl. Fathers are often less skillful in coping with the child who is mentally retarded (physical appearance) which stigmatize the families social and community image. Fathers are more often concerned about the child in roles outside the family (i.e. being a “leader” or “winner”). Therefore a son appears to have a greater emotional impact on the father. More fathers (26%) than mothers (18%) have reported having to alter their social life (p.226). However, this review does present much ambiguity and discrepancies as reflected by Wikler (1979). Studies were not distinguished on a “clinical” or sociocultural or experimental basis. Gallagher, Cross, and Scharfman (1981) caution against assuming that fathers of children with disabilities are under debilitating stress.

Indeed, in the research reviewed, the behavior of fathers resembles in many ways that of fathers of nonhandicap children. Yet as Turnbull and Turnbull (1978) pointed out parents have a lifelong period to adjust continually to their child’s handicap or disability. Wikler, Wasow, and Hatfield’s (1981) findings which report that social workers overestimate parents’ early stresses and underestimate the stresses that occur later in the family cycle are indicative of the perceptions of those working with exceptional children and their families.

In order for the father to be more involved in the development of his child it is therefore necessary to directly and immediately reflect the concerns of the father. By providing fathers with options, professionals who serve families will not only address fathers’ concerns and need for support but also offer the child’s mother needed respite and support toward her efforts.

**Siblings**

There have been plenty of theories, guesses and hypotheses about how siblings influence each other, but until recently, relatively little careful research on early childhood Farber’s work (1959, 1960a) drawing on sociological traditions is largely an exception. The attitudes of siblings themselves have been receiving more attention (yet still restricted by the
general focus of the mother). However, researchers have for the most part, relied on mother's 'reports of siblings' feelings and have tended to assume from the onset that the presence of a child with a disability will have a detrimental effect upon other family members (Seligman 1983, Trevino 1979). The initial stimulus for research on siblings of persons with mental retardation appeared to come from clinicians who discovered the siblings were having problems. Hence, negative psychological outcomes were noted in these case studies (Kaplan 1979; San Martino & Newman 1974; Schild 1971; Travis 1976). While other studies found positive effects for siblings (Graliker, Fishler, & Koch 1962; Grossman 1972).

More recently however, there has been a growing interest in the experiences of persons who have brothers and sisters with disabilities (Adams 1966; Brody & Stoneman 1993; Dunn 1984; Fischer & Roberts 1983; Lobato 1983; Powell & Gallagher 1993; Simeonsson & McHale 1981; Skrtic, Summer, Brotherson, & Turnbull 1984).

One of the most ambitious studies of siblings was conducted by Grossman (1972) who collected data on 83 college students each of whom had a brother or sister who was mentally retarded. A matched control sample of students with normal brothers and sisters was used for comparison. Each student was interviewed individually about his or her own experiences. Tests were given to obtain additional information. Taped interviews were transcribed and scored on 50 measures relating to the siblings' experience. Grossman's data revealed: 1). a number of subjects benefited from the experience, were more tolerant and aware of the consequences of prejudice, 2). some were harmed showing resentment to the family situation; guilt & fear, 3). female siblings were more actively involved than males, 4). the strongest single factor affecting the normal siblings acceptance of his brother or sister was parental feelings and reactions, especially the mother, 5). upper income families, had more opportunity for care, but not without consequences of guilt, and 6). lower income families had more hardship, especially since the young normal women were to assume a major role. Grossman's research indicates the impact of sociocultural status as it affects the
families' ability to secure relief from the burden of having a child that is mentally retarded.

Grossman further emphasizes that it is the families who determine their definition of problems as well as the ability of each individual member within this unit to adjust. The presence of a child who is disabled could enhance a family's normal development, and not hinder it (p. 104).

In an extensive review of the literature over a thirty year period on siblings of persons with mental disabilities, Boyce and Barnett (1993) have alluded to several themes throughout this development. The variables that have been studied as indicated throughout their most comprehensive review can then be divided into the five categories: 1). psychological distress/well being, 2). self-concept, 3). activities/time use, 4). the siblings interactional relationship between the siblings with and without disabilities, and 5). stress and coping. In addition this review displayed how much of the research has been concerned with the child and the family characteristics that influence the effect of the presence of a child with disabilities upon the family unit. Examples of these mediating variables include age and gender of the siblings, functional level of the child with the disability and the family size. The psychological adjustment of siblings of children with mental disabilities has long been a primary focus of research on siblings. Farber, in his landmark study (Farber 1959, 1960a; Farber & Jenne 1963) specifically investigated siblings' feelings and the conditions that affected the amount of role tension siblings felt. He defined role tension to represent feelings of frustration, tension or anxiety. The amount of tension that siblings experience was based on maternal reactions of ten personality traits (i.e. stubborn, jealous, irritable). Farber (1959) found that siblings had higher role-tension scores when the child with disabilities was highly dependent upon him and those who interacted frequently scored higher. Sisters experienced higher scores when the child with mental disabilities lived at home and older sisters had greater role tension scores than older brothers. Fowle's (1968) findings confirmed that siblings' role tension was higher when the child with mental disabilities lived at home. It should be noted that Farber's studies
contradict Grossman's results, which suggest that the family socioeconomic status was indeed related to adjustment. As Farber (1959) points out, normal siblings assume a more superordinate role with respect to the child who is mentally disabled and tend to take on increasing responsibility for this child. According to Travis (1976) the burden of siblings with care of the children who are chronically physically ill seem to be common. Travis indicates that siblings who have been excessively burdened often leave home about age 16. She further notes that in close-knit large families, the care of a child who is disabled is viewed as a shared responsibility. Schild (1971) notes that normal siblings may be burdened by excessively high parental aspirations to compensate for parental disappointments and frustrations about raising a child with a disability. In spite of the rather negative observations about sibling responsibility and dire consequences of excessive responsibility, Graliker, Fishler, and Koch (1962) as consequence of their interviews of normal teenage siblings concluded that "in no case did the teenager feel burdened with responsibility for the retarded child" (p 84). It should be pointed out that the siblings with disabilities were quite young (ten months to five and one half years of age). Other studies, as hinted upon in Grossman (1972) further investigate the question of overall identification such as describing the characteristics of the child with the disability (Grossman 1972; Kaplan 1979). However it was not until the late 1980s as reviewed by Boyce and Barnett (1993), that studies using sample of preschool children (Labato, 1983) and school age siblings (Dyson et al 1989; McHale & Gamble 1989) began to come to light. In studies by Dyson and her associates (Dyson, et al 1989) no differences were found in self-concept for siblings of children who were disabled and nondisabled. Conversely, in McHale and Gamble (Gamble & McHale 1989; McHale & Gamble 1989) school-age siblings of younger children with disabilities had lower self-esteem as measured by the Perceived Competence Scale (Harter 1982). The gender findings also differed from previous studies. Sisters of children who were disabled had significantly low self-esteem scores than brothers or brothers or sisters of children who were not disabled. The cause of the negative
effects upon the siblings of having a brother or sister with a disability has been reacted to the burden of physical care. The research forementioned by Farber (1959, 1960a) and Grossman (1972) have indicated that the time spent performing household tasks and the actual caring for a sibling with mental retardation as being related to this negative effect. Several studies investigated the activities of either older (Stoneman et al. 1983) or younger (Stoneman et al. 1991) siblings of children with and without retardation participating in household tasks. Findings followed traditional sex role patterns, with older sisters in both groups having significantly more responsibilities in personal and adaptive tasks and meal preparation brothers having significantly more response in outside yard work. Correlational analysis revealed that for siblings of children with disabilities more childcare responsibilities were associated with less observed positive interaction and more conflict between siblings. This further indicated a relationship between child and by the siblings to have a negative outcome. Another consideration is the amount of time siblings of children with disabilities spent providing childcare. McHale and Gamble (1989) reported that siblings of children with disabilities spent about twice as much time caring for their younger brothers or sisters as in comparison of other siblings who did not have a brother or sister with a disability in the family. Boyce and Barnett (1993) agreed with these findings, as indicated in their study that siblings of children with disabilities spent almost three times as long providing childcare as in comparison to other siblings who did not have a brother or sister with a disability. Studies and reports on sibling relationships range from childhood through adulthood.

Several studies examined the adulthood perspective (Seltzer et al. 1991; Zeltin 1986) where siblings were viewed with their adult brother and sister while others viewed these relationships as being similar to their relationships with their other siblings in terms of affections and companionship (Begun 1989). Seltzer and associates (1991) reported that within the adult sibling relationship the mothers perceived that more affective support than instrumental help was given. Only one investigation (Gamble & McHale 1989) conveyed
how older siblings of children with and without disabilities coped with stress in the sibling relationship. The stresses were reported as being generally similar in kind for both groups, except that the younger children in the comparison group "teased or bugged" (Gamble & McHale 1989, p.361) their older siblings significantly more often than did the younger children with disabilities. Differences were also found in coping behaviors. Siblings of children with disabilities and sisters (in comparison of sisters vs. brothers) used "other directed cognition" (Gamble & McHale 1989, p.368) more frequently than did siblings of nondisabled children or brothers (i.e. placing blame on others). Group differences should also be noted in the area of adjustment for the variables of depression, anxiety and general self-worth, with the siblings of children who were disabled being more depressed and anxious. With younger children Featherstone (1981) points out that in the wake of a disability, young children may be concerned about "catching" the disability. She notes that anxiety about this is exacerbated when normal sibling learn that the disability was caused by a disease such as rubella or meningitis. Marion (1981) substantiates Featherstone's observations by pointing out that younger normal siblings may have anxieties that they will become blind or death in the future.

In summary to specify variables responsible for positive and negative outcome of sibling relationships, the effects of variables such as parent attitude, family characteristics on sibling adjustment or the mediating variables of age, sex, religion, developmental stages and culture need further investigation. In this light, the quality of interaction between children with disabilities and their siblings more direct assessment is needed (i.e. direct observation). Direct observations of family interactions can further be used to validate parent, teacher and self reports and may generate new hypotheses about individual environment interactions that contributes to long term family outcomes (Vadasy, Fewell, Meyer, & Schell 1984). In this regard the emphasis would shift from studies (socioeconomic status) to the processes (social interaction) emphasizing cultural and individual differences. The studies thus far have primarily investigated sibling relationships
in Caucasian families. Cultural expectations may differ across ethnic groups as well as abroad. In regards to siblings relationship of children with disabilities assessment should be conducted in a bi-directional matter in which the effects on the children with disabilities as well as on their siblings are assessed. Finally, sibling dyad have usually been based on consecutive birth order and often same sex. Many families include more than two siblings and patterns of interactions should be documented.

**Extended Family Members**

Although extended family members may no longer live near each other and friends and neighbors may change over time, this does not necessary mean that such relationships are of no significance to the family unit. At the same time extended family members influence the development of a child with a disability in direct interactions with them and through the nature of support provided to their parents (Cochran & Brassard 1979). In a recent review Uzoka (1979) presented convincing evidence to dispel the myth of the isolated nuclear family. The empirical data strongly indicated that despite social classes and ethnic subculture differences, family life in America is typified by extensive intergenerational relationships.

A kinship network, termed a modified extended family by Litwak (1960) is linked together by a system of mutual assistance and reciprocal exchange of resources, shared social and recreational activities, and by psychological and emotional support (Cohler & Grunebaum 1981; Sussman 1959, 1960; Sussman & Burchinal 1962a; Uzoka 1979). Grandparents and other extended family members also play critical roles in the development and validation of parents’ identities. Cohler and Grunebaum (1981) particularly emphasize the role of the grandmother as identification figures for their daughters. They assert that a woman’s identification with her mother is enhanced by a continuing intergenerational relationship and “represent the most significant of the factors which influence the mothers’ adaptation to the task of caring for they young child” (p.17). Though contact with the
mother's parents may be a more usual source of support, at least two studies have emphasized the important potential contributions of the father's parents in supporting the family. Both Lonsdale (1978) and Waisbren (1980) have found an association between perceived support of paternal grandparents and fathers positive motivation toward the child with a disability.

It is the cumulative evidence accompanied by Sussman (1959); Caplan (1976); Uzoka (1979); and Cohler & Grunebaum (1981) that indicates extended family members throughout time maintain important functional links with one another and exchange emotional support as well as material aid. Since the birth of a child with a disability is often experienced as a family crisis (Solnit & Stark 1961) it is particularly noteworthy that during this time relatives are the most likely group to support them. Studies have shown that reactions of extended family members (especially grandparents) vary due to the time they have lived where mental retardation was not well understood, to stigma for the family, and limited services (Gabel & Kotsh 1981). There are several anecdotal report in the literature of grandparents consistently denying that the child is disabled and putting a strain on relations with the child parents (Cunningham 1982; Glendinning 1983). Glendinning (1983) during an interview with Mrs. Eastwood about her extended members support conveyed:

*My husband’s parents just won’t accept it. Don gets mad too, he gets just as mad as I do…His mothers thinks that if we go to church every Sunday then everything’s going to come all right again (p. 99).*

Although the level of support that parents of children with disabilities receive from their extended families is diminished, it is still substantial. The findings of both Birenbaum (1975) and Shanas (1973) are consistent with the notion that these parents maintain some important connections with the portion of their extended family network.

**Reflection and Summary**

No parent is ever prepared to be a parent of a child with a disability. The identification of a mother and father in that role always comes as a painful surprise. There are initial feelings of shock, grief, shame, depression, low self esteem and frustration when raising a
child with a disability. With few exceptions most of the research prior to 1970 examined the effects of the family having a child with a disability utilizing a "pathological approach." This approach assumed that such families are subject to high levels of stress along with some psychological dysfunctioning. The assumption that such psychological impairment evolved as a consequence for family members, led to many generalizations that families with children with disabilities represent a homogenous group.

Whatever have been the individual parental attitudes toward people with disabilities throughout their preparental lives provides a certain textile to be woven into that fabric of role identification. Whatever degree of psychological or social maturity within each parent another textile begins to surface. Such textiles (variables) as socioeconomic status, size of family, age of the disabled, type of disability, demand of or care, have not been considered extensively in the literature as impacting the family unit. The lack of these variables, together with inadequate control groups, translation of data into statistical aggregates allow for further assumptions to indicate that families with children who are disabled result in the dysfunction of the family unit.

The focus of the majority of studies and articles written about the impact or effect of raising a child that is disabled upon the family reflect numerous dyadic relationships (i.e. mother-child, father-child, sibling-disabled, grandparent-disabled). As stated earlier a majority of the literature focused on the mothers perceptions of having a child with a disability. Fathers have been significantly overlooked, along with siblings and grandparents. The basic nature of living as an integral part of a whole family for the disabled has not been well addressed.

Qualitative and phenomenological studies are few. Viewing the family from the families' rich day to day experiences seems to be a missing link. No matter what threads or coloring are finally woven into the fabric of the family there still remains many contradictions, biases, and no clear cut perspective for families when raising a child with a disability.
CHAPTER IV
Raising A Child With Down syndrome

Review of literature

After reviewing the historical underpinnings and present understanding of what comprised a child with mental retardation and the effect upon the family when raising a child with a mental disability or handicap, the final section of the literature review now focuses on the child with Down syndrome. The qualities or attributes pertaining to this population will be presented as a new path to travel leading down that final road to the family experience. Although much of the literature focuses on the child with Down syndrome under the “rubric” of mental retardation or in comparison with other categories (i.e. severely mentally retarded, trainable), for the purposes of this study the child with Down syndrome is transitioned as well as ‘included’ within the home, school, community, and society at large. It is possible to look at Down syndrome from a number of perspectives. For example, medicine and education are fields that study the facts, conditions, and findings gathered from ongoing professional experiences that can assist in the understanding of the general and specific concerns clustered around the term Down syndrome. This identification and adaptation may not be possible in relation to psychosocial aspects. The psychological situation and the social situation are unique for each individual in that they relate to daily, informal, personal interactions rather than the organized delivery of services from a professional. Each individual has his or her own perceptions and mental and behavioral characteristics.

Each individual has his or her own social status among the people with whom he or she interacts, and each develops his or her own companions and interdependent relationships. Although there are times when people of the same family are similar, even children raised in similar situations respond to persons with Down syndrome with individual patterns. Therefore, an integral perspective where behaviors, communications, and relationships are
interactional, and reciprocal in nature is the underlining framework that incorporate the psychosocial needs that follow.

A child with Down syndrome is not an inhuman entity caused by the ubiquitous nature of geography, socioeconomic conditions, parents age, and ethnicity. Clearly this is not a human problem that is restricted to one population. Down syndrome is a complex, multifaceted term, a covert process that changes over time, along with the human individual to whom this label is attached. When one refers to Down syndrome one only sees the syndrome and not the child or product of genetic endowment, culture and environment shaped by the living experience of the person within. Attached to that child are significant others, mostly parents and siblings. Not unlike the child with Down syndrome the parents and siblings do not emerge from the family experience of living with a child with Down syndrome shattered and less of a family unit (Brown, Goodman, & Kupper 1993; Dickman 1993; Featherstone 1981; Pueschel 1978; Smith 1993; Sutton 1982).

Statistics alone as cited previously in Chapter I and II provide only a limited standpoint of the child or individual with Down syndrome and the family. In the past decades most individuals with Down syndrome were usual not afforded adequate medical care and appropriate educational services. Many were institutionalized and were often deprived of all but the most elementary medical services (i.e. incomplete immunizations, infections rampant). This resulted in a high mortality rate where only 50% of children with Down syndrome survived their first decade (Pueschel 1987). It has only been over the past twenty years that dramatic medical advances have been made so that nearly every child with Down syndrome can now expect to live into adolescence and adulthood. With the further participation and contribution of these individuals in their homes, schools, communities, and as part of society it is striking, to see how little has been written documenting the effect upon the family when raising a child with Down syndrome.

An extensive search throughout the literature in the fields of education, psychology, and medicine spanning over the past two decades, has found only a handful of studies
addressing the family experience. An evaluation of these studies revealed significant methodological flaws, negative views, limitation in scope, and grouping children with Down syndrome as a homogeneous group. In addition, the mother’s perception mostly relating to infants and small children were typically translated into the families’ experience.

The literature pertaining to the child with Down syndrome presents a grim portrayal and a far cry from an adored child. Here the child was described as ‘severely retarded’ an ‘idiot’, short, obese, open mouthed, protruding tongue and unattractive. Unfortunately until recently noted by most articles and reports preceded data predominately came from institution populations with the result that parents were provided with poor prognosis. Work to dispel such reports champion such frameworks (trends) as early intervention, appropriate and ‘included’ education, environment enrichment and parent advocacy as vehicles to follow the path toward quality of life for all children and young adults with Down syndrome.

Biological and Environmental Factors

Studies on the effects of early experiences—both nurturing and traumatic have focused attention on interaction of biological and environmental factors as determinants of the child’s developmental outcome. The model used in reference to Down syndrome is a transactional model as articulated by Sameroff and Chandler (1975). In brief, this model stresses the active role the child plays in interacting with his or her world and describes the child as a “perpetual state of active reorganization.” (p.235). It further highlights the “continual and progressive interplay between the organism and its environment.” In reference to Down syndrome (Sameroff & Chandler 1975) suggest that developmental predictions can not be made from a purely medical or main effects model. The diagnosis at birth and the presence of a biologically based disability resulting from a chromosomal anomaly fails to explain or predict the child’s future development (phenotype). In part this is because the child interactions with the environment is not a static phenomenon, but a
constantly changing one, which mitigates a totally environmental explanation of the subsequent outcome.

The literature has attested to the effectiveness of early educational experience (intervention) for infants with Down syndrome (Abroms & Bennett 1983; Bjorck-Akesson & Granlund 1995; Clunies-Ross 1979; Connolly & Russell 1976; Sloper et al 1983; Ludlow & Allen 1979). While on the other hand given the problem of a positive impact of early intervention, most researchers can not ethically support the use of control groups which receive no treatment. Therefore, the emphasis of early intervention have focused traditionally on making the child more competent. This is similar to and not uncommon in special education where practices have tended to focus on the disability itself and not its effects.

The literature in developmental psychology however has typically looked at the influence of the parent on the developing child. It has only been within the last two decades though Bell's (1968) landmark article has served to shift attention to the relevancy of the child's contributions in this intervention process. Here, the emphasis is now on the effects of both the parent and the child on one another and on the dynamics of the family unit. A wide range of models and roles that parents play in early intervention efforts, range from teachers to advocates (Berkowitz & Graziano 1972; Blackard & Barsh 1982; Brody & Abbott 1983; Johnson & Katz 1973; Lillie & Trohanis 1976; Moreland, Schwebel, Beck, & Wells 1982; Richard 1986) have been identified. However most studies find few group differences in mother infant interactions when mothers of infants with Down syndrome are compared with mothers of normally developing infants (Hanson 1984). The importance of the early years subsequent to development is well documented. The foundations for social relationships, basic skills, and the learning processes are established during this crucial period. However, a statement from a mother of a child with Down syndrome best summarizes the effects of early intervention for her child as:

*We have learned the answers to three important questions that we asked and that we have been asked many times: 1) What does a baby do? 2) What can you do with a*
handicap baby, 3) How do you get a baby to do things? We have learned there is a great deal of work involved with a handicapped child but also the rewards are worth it. This program has helped us know Tony better and to know him as an individual with a great deal of potential. I think it has helped me personally to know that I am capable of helping both my child and the other children. Most of all it has helped us to hang in there and not give up on Tony or give up hope (Hanson 1984, p.5).

A child with Down syndrome does everything a normal child does, but at times more slowly. The diversity of biological factors, functions and accomplishments that exist in all human beings also exist in children with Down syndrome. The physical characteristics of children with Down syndrome are shaped by the influences from their genetic makeup. Yet because of additional genetic material on the extra chromosome #21 the child with Down syndrome will have characteristics that make his or her look different. Similar genes, however from the extra chromosome will also be responsible in altering the development of certain body parts. We are still unsure of how the changes come about or what way the genes from the extra chromosome interferes with the normal development sequences (Pueschel 1990). However we do know their is a greater variation in nearly all aspects of their lives. Their physical patterns range from short to tall, their intellectual abilities and development span a wide range, behavior, and emotional disposition vary significantly...some placid, others aggressive and hyperactive (Pueschel 1978). Hence the stereotype once portrayed is not currently representative of this unique and individual population.

Educational Issues

A Review of literature on academic performance, school placement, and integration reveals very little about the characteristics of children with Down syndrome at this age and little about their capabilities. The extent of the literature states that the educational capabilities of children with Down syndrome have been underestimated (Rydners, Spiker, & Horrobin 1978). However little has been reported that systematically describes their educational or academic capabilities.
Anecdotal reports of unexpectedly high academic progress in individual children with Down syndrome are numerous. One only needs to look in issues of Down syndrome News and Exceptional Parent to see such reports. The popular literature actually appears to be more understanding and supportive of these children and their families than in the professional literature. Therefore popular literature (as well as current sources) provides another important perspective and a welcome addition to both the clinicians and non-clinicians (i.e. parents, educators, community members) and will be incorporated into this portion of the literature review.

A Review of literature in the three academic areas of reading, writing, and mathematics have revealed the following. There were no reported studies of teaching writing to children with Down syndrome. In the area of reading only one study focused on children with Down syndrome (Brown, Jones, Troccolo, & Heiser 1972) while in the area of math (Dalton, Rubino, & Hslop 1973). Thus it is evident that little information has been gathered systematically about the academic abilities of elementary age children with Down syndrome. This paucity of research is disturbing; but as Rynders (1982) states, "it is probably due to the generally low expectations held for persons with Down syndrome until recent times" (p.425).

Even though students with Down syndrome (Dunn 1968, 1973) are an identifiable group, the literature specifically focused on high school students with Down syndrome is virtually nonexistent. However many studies report the participation of adolescents with Down syndrome in participatory activities in their adolescent years (i.e. Nietupski et al 1983; Wheeler et al; 1980). Authors of theoretical papers often focus on more broad educational concerns of all youth with disabilities, including those with Down syndrome. The fact that students with Down syndrome function across a range of ability levels may serve to make them less visible in the literature than in the classroom.

Including students with Down syndrome in the regular elementary and high school classes has currently flooded the literature and has taken on a vital and controversial stand
throughout the United States. The term “inclusion” is not mentioned in the United States federal law; it is a state-of-the-art term that refers placing children with disabilities in integrated sites. Inclusion differs from mainstreaming in that the latter term usually refers to integrating children with disabilities and nondisabled children for only a portion of the day. In the fully inclusive model, students with disabilities, no matter how severe, are taught in the regular classroom of their home school with their age and grade peers for the full day with support services provided within the class (National Down Syndrome Congress 1992). Most of the national debate regarding the appropriateness of general class placement for all students has remained theoretical and speculative. On a more concrete level, there is increasing availability and growing support for the placement of students with severe disabilities into the regular classrooms (Giangreco & Putnam 1991; Lipsky & Gartner 1987; Stainback & Stainback 1990; Thousand & Villa 1990). While at the same time there are those less supportive (Jenkins, Pious, & Jewell 1990; Smelter, Rasch, & Yudowitz 1994).

Support for inclusion is not universal within the special education community, teacher associations and within the Federal court system. In reference to parent groups this however is a key issue (National Down Syndrome Congress 1992, 1993a ) especially for parents who have children with Down syndrome (studies have once again not distinguished between categories of disabilities and therefore there is not significant evidence to conclude the results of such placement).

Issues within the Family Unit

The evolution of parent involvement and the family unit can now be seen as taken on additional roles as decision-makers and intervenors. These roles are well documented in the empirical literature and conclude that parents can be effective teachers and trainers of their children (Baker, Clark, & Yasuda 1981; Bruder 1987; Cunningham 1985; Johnson & Katz 1973; Strom, Wurster, & Rees 1983).
Beyond the mother-child dyad (so often reported in the literature) families can be viewed infinite in scope and diversity. Families vary in number of parents, children, extended family and or in friends. They vary in ethnic background, religion, income, occupation, and location. They vary in values and beliefs they hold and in types of coping strategies they employ to reduce their feelings of stress (Turnbull, Summers, & Brotherson 1986).

Further the characteristics of families have changed substantially over the last 25 years and will continue to change in the future. As cited in Turnbull and Summers, (1987) reported by the Joint Center for Urban Studies of MIT and Harvard University:

"In 1978 over half the women with children were employed. Between 1975 and 1990 over 75% of new households will be headed by persons who have never married are divorced or are widowed rather than the traditional pattern headed by married couples.  

In addition one must realize that families are an interactive system. To a greater or lesser extent, what one person does affects everyone else in the family. They also learn their own particular type of cohesion that is how close or distant different subgroups within the family are with each other" (Olson, Sprengle, & Russell 1978).

Service providers need to be very sure that their recommendations are consistent with the families priorities and are reasonable in light of the many competing time demands they face (Baker 1977). Some families needs are tangible, related to economics, caregiving, education and vocational development. Others are much more intangible. Such as rest, socialization, affections, developing a sense of self-identity and self-direction. When this investigator begins to list or ponder what things are necessary she wonders how families survive at all. Janet Bennett (1985) a mother of a daughter with Down syndrome relays her daily responsibilities during an ARC (Association for Retarded Citizens) meeting:

"At the time of Kathryn’s birth I also had to manage the school schedules of Amanda, who was in sixth grade and Peter in second grade; both were timed to overlap and consequently conflict with Martha’s kindergarten hours. Between 11:30 and 12:30 each day I had to feed a child, pick up two, drop off one, feed two, drop off two. Kathryn’s naps had to fit in whenever they could; breast-feeding was a challenge."
If I had an unretarded baby, I'd never in a million years have thought of volunteering for anything during that period. Now that I had Kathryn, why in the world would I be expected to do anything of the kind? Yet in the face of minimal help from the organization, it was telling me I should help it. And numb from shock and diminished self-confidence, I did my best to comply" (p.164).

In reality as in the previous Review of literature on families with children who are disabled, mothers of children with Down syndrome rather than the families are expected to perform in a heroic manner in attending to the extraordinary needs of children and the expectations of the service delivery system. Therefore the impact of raising a child with Down syndrome upon the families' ability to meet his or her needs is a complex phenomenon. How families experience this experience has been looked at very little from the families' perspective. Mothers have been studied through mostly clinical experiences, (McConachie 1986; Stoneman, Brody, & Abbott 1983) while fathers have been later included as well (Lamb 1983; Meyer 1986; Radin & Russell 1983).

Recently, siblings have been noted, especially in the popular literature, to complete the families' experience. These reports respond in varied ways to their sister or brother with Down syndrome; however their behaviors are only briefly mentioned in these writings (Binkard et al 1987; Dunn 1984; Gath 1974).

Research therefore, appears to be based on one dyad, a negative, deficit oriented view of the individual with Down syndrome. It should also be reiterated from the previous chapters that research has been largely organized around one major premise of the impact or effect of having a child with mental retardation (Schwartz 1970). Research is therefore needed on the positive and negative contributions to the entire family unit (interactively) as compared to with the positive and negative contributions in families where children do not experience Down syndrome. It is erroneous that a mother of eight the youngest of whom had Down syndrome reflected that "she felt some relief when she came to grips with the fact that her child had Down syndrome, because she knew she did not have the coping skills for another normal adolescence" (Turnbull &Summers 1987, p.300).
Although each individual develops in his or her personal way it has been possible through the observation of the development of many different individuals over time to see that there are certain skills and a certain order of development that occurs for most individuals with Down syndrome (Erikson 1963, Flavell 1963). In the early discussions of persons with Down syndrome, L. Langdon Down described the ability of individuals with Down syndrome to imitate what others were doing (Brenda 1969). Bandura (1977) described the young child’s imitation as a strategy for developing adult skills. However the intent of this imitation is not clear. It would be important to study the development of individuals in home, school, and community environments as reflected by the perspective of those around them; driving a car, working, volunteering in their community, going to the grocery store, etc. Concepts of development and definitions of maturation used to describe the process of development and the steps toward maturation achieved by the general population may have limited relevance in describing the development of individuals with Down syndrome. However through observation and evaluation in the form of a procedure that is designed not to see where differences occur but to see what characteristics are actually present may have more relevance. It is important to know what characteristics are present in order to nurture social behavior. It is highly possible that such an investigation could find that persons with Down syndrome posses characteristics that demonstrate not the usual kind of maturity, but a deeper more holistic respect for human worth.

The literature pertaining to the child with Down syndrome concerning their individual attributes, behaviors and interpersonal characteristics is not of such a nature that will lead one to conclude that the development in the areas of academics, interpersonal skills, community acceptance will easily be resolved and completely understood. Certainly these needs should be described. Anecdotally these descriptions are valuable and should not be dismissed because it captures the phenomenological side of the experience by parents, families and for the child. It “tells it like it is.”
Parents have described as cited in the Review of literature, changes in their perspective, value systems and mode of life after birth of a child with Down syndrome (Carr 1975; Michaelis 1977, 1981). Parents respond in different ways and at different times to learning that their child has Down syndrome. A whole gamut of emotions and behaviors are described and writings in this area also, frequently focus on a set of stages toward acceptance of a child born with Down syndrome. However in retrospect, according to Hooshyar (1986) parents feel that the shock could have been less traumatic had physicians and hospital staff handled the situation more positively and with a greater source of information concerning community resources.

Issues within the Medical Profession

One study was conducted on the attitudes of pediatricians, genetic counselors and nurses toward individuals with Down syndrome (Cooley & others 1989). In this study a film was presented showing parents discussing their experiences with Down syndrome to mothers who had children with Down syndrome, genetic counselors and nurses. Their reactions were then compared. In light of the methodological flaws relating to sample selection and size the findings, the differences noted were significant. The genetic counselors held a more negative view of the family life of a child with Down syndrome than the mothers or in some cases than the nurses. When viewing the film 89% of the mothers believed that the film was an accurate portrayal of parental attitudes as compared with 14% of the genetic counselors and 40% of the nurses. Further, 48% of the genetic counselors believed that the problems outweigh the benefits in parenting a child with Down syndrome, but 94% of the mothers and 83% of the nurses thought that the benefits predominated. About 56% of the genetic counselors believed that the parents of a child with Down syndrome would choose to abort. The addition of a child with Down syndrome to the family was not a neutral event. Even though the literature on the impact of having a child with a disability is full of conflicting conclusions, there is general agreement that
unique stresses are involved (Freidrich, Greenberg, & Crnic 1983; Murphy 1982). The initial diagnosis of a newborn with Down syndrome, usually is an unanticipated tragedy for families, and may be accompanied by intense feelings of shock, grief, guilt and despair (Trainer 1995). The ensuing adjustment period has been called a "values crisis" and has often been noted as a period of high risk for marital discord (Wolfensberger 1967). Other studies previously mentioned have found no differences in the physical or emotional health of the parents (Gath 1977; Gath & Gumley 1984) as well as no negative impact on family relations (Feingold & O'Brien 1989).

Marital and family conditions before the birth of a child with Down syndrome must be determined retrospectively in most cases, but some studies do indicate that the impact of a child is determined by prior characteristics within the family (Korn, Chess, & Fernandez 1978). In addition, siblings grow up with a sense of purpose that can not be described in the usual developmental stages (Grossman 1972, Michaelis 1980).

**Labeling, Stigma, and Attitudes of Society**

Frequently the data about families with Down syndrome have been lumped together as previously cited in Chapters I-III as if to indicate that the response of a family to one kind of condition is similar to the response to another condition (Allen & Affleck 1985; Chinn, Winn & Walters 1978). Researchers for the most part have been taught to examine each variable (reason) separately and to be certain that the conclusions are directly related to the condition being studied (Tingey 1988). Therefore data about families with disabilities have not been kept separate, contributing to unwarranted conclusions (i.e. all children with muscular dystrophy face the same concerns as those with Down syndrome), and statements about one kind of family have been generalized to that of another. Therefore, the family as a system has been studied infrequently (Crnic, Friedrick, & Greenberg 1983) and it therefore, becomes necessary to look at each variable in that system more carefully such as those suggested by Turnbull and Summers (1987) to be; impact on immediate
identification, adjustment of parents, siblings, professionals, participation in school, community activities, etc. There are also according to Gath and Gumley (1984) additional concerns that need to be investigated in relation to raising a child with Down syndrome. These are the time and closeness spent with the mother, father, maternal grandparents, paternal grandparents, sisters and brothers.

What is not known about raising a child with Down syndrome all of the time is exactly how that experience predicts or is correlated with developmental events, attitudes, and family life. It stands to reason, then, that the difficulties in living and the initial pain, felt by the family and its members who have a child with Down syndrome would set off an array of feelings. These might in turn cause a further dilemma between the family, school and the community.

As a result of the more professional or clinically based literature on the impact or effect a child with Down syndrome has upon the family unit many questions still are not resolved. Different forms of education and interpretations have emerged, mostly due to the appeals from professionals and parents. The forum for professional discussion concerning the effect a child with Down syndrome has upon the family has been conveyed through symposiums and conferences. Every year the National Down Syndrome Congress has an annual conference (bringing parents, children and young adults with Down syndrome, siblings, extended family members, professionals as and society at large from throughout the United States as well as abroad) join together to ‘share’ and make their visions a reality. Each state association also provides avenues for parents to share and gain more information on crucial issues such as medical, health, employment, living options, friendships, advocacy, communication, ageing, etc. So while little is being documented in the professional literature, there appears to be a growing awareness from the clinical work that these families share, focusing on significant concerns and issues over and above what is generally acknowledged.
While attending a conference in Chicago of 1990 sponsored by the local Down Syndrome Association, the researcher was overwhelmed at the magnitude, intensity, and common bond these parents and children had upon one another. For the experience of raising a child with Down syndrome was a true celebration. Here parents and professionals collected and gained preventative and thought provoking information, a heightened sense of awareness of the commonality of interests and pursuits, how to be imaginative in an unimaginative system, and to discover the unimagined and unrealized potential of children and young adults with Down syndrome. The researcher was extremely impressed by a young man and actor in his own series Chris Burke, star of ABC-TV series Life Goes on. Burke's own hurdle to success as he explains is quite amazing. He is the first actor with Down syndrome. This series and the role Chris portrayed as a middle child of a working class family made a significant impact upon the American public. By viewing the day to day experiences of this family, the public was better able to see that there may be adversities in life and what you have to do is face them the best you can. The TV series presented weekly situations and the interactions that could take place. Here Chris Burke faced typical adolescent problems (often not displayed in the current literature) and often more dramatic because of the individual challenges arising from Down syndrome. There were conflicts with family members, teasing from school bullies, and the emotional pain of being "left out." This one episode categorized a teenager with Down syndrome, an extremely bright/accelerated teenager (with big ream glasses) and a fairly obese teenager all in the same grouping as being outcasts. As Chris Burke, when asked to further explain his feelings toward this episode recapped and translated by an audience member as:

*It appears that our American culture values perfection, self-sufficiency and not celebrating differences. For the children and young adults with Down syndrome as well as the other visible disabilities compassion and acceptance were a far cry from being socially accepted due to their physical differences.*
Current and Popular Literature

Literature for the lay public focusing on the child and young adult with Down syndrome has only been available in the last ten years. Books geared to parents dealing with educational information, advocacy support and personal sharing are now more visible in bookstores and libraries. In more recent form are articles in magazines and newspapers on stories that discuss Down syndrome and the issues pertaining to these children. While there are articles appearing that present personal retrospective accounts of raising a child with Down syndrome, most are "success stories" and even a recent television series on "how life goes on" verbalized by the efforts of the parent.

Within these articles and books is frequently found the families' experience or the effect upon raising a child with Down syndrome. Many current books (Burke & McDaniel 1991; Edwards & Dawson 1987; Kingsley & Levitz 1994; Perske & Perske 1981, 1988; Pueschel 1990; Stray-Gundersen 1995; Stratford 1989) addressing children with Down syndrome across developmental domains and into adulthood. Even though these resources are geared to lay people, particularly the parents, they offer a great deal of practical and valuable information that many professionals could find useful. In a recent issue of People Magazine (1994 September) written by (Farrel & Sugden) two adults with Down syndrome were featured. In this article these two young adults Kingsley, 19 and Levitz, 23 provided a poignant account of coming to terms with their disability by writing a book. Even the title "Growing Up Down. What's life like when it's lived with Down syndrome?" depicts two courageous friends redefining and overcoming the stereotype that followed them throughout their lives. However, as conveyed in this article they have not focused on the "down side" but on the goals and aspirations they wish to achieve such as continuing acting attending college, and maybe even running for public office.

In reference to the quality of life three interrelated factors are relevant for individuals with Down syndrome. They are where they live, where they work, and where they spend their leisure time.
In a pilot study investigating parents' perceptions toward employment of their adolescent with Down syndrome (Drower 1988) seven parent groups aging from 33-60 from East Croydon, London were interviewed on the issue of employment and the future of their son or daughter with Down syndrome. Their teenagers ranged in age from 12-18 (representing four males and three females). The parents general occupations ranged from homemaking to volunteer work, to teaching to that of self-employment. Both parents were present on four out of the seven sessions. The investigation was conducted by interview and documented in written and tape recorded format. Each parent was given a brief description of the study and then asked to respond to a three page questionnaire. The questionnaire consisted of the following: a). parents background, b). attitudes within the family setting, c). account of their teenagers job status and expectations toward future employment. The results were consistent with the previously reviewed literature on initial reactions and acceptance. All parents did engage in a wide range of early intervention programs; nursery school, play-home environment, opportunity group, Montessori and Down's baby association. The outside support received up to school age by these parents at the time, ranged from nothing to minimal. In regards to employment all (7) parents wanted some type of open employment for their son or daughter. When looking at job prospects for their teenagers ten years down the road the responses incorporated such comments as: whatever makes him or her happy, more schooling, and something new and stimulating. In response to when they expected their teenager to leave home the average age came to 20. The type of expectations given for their teenagers future accommodations ranged from (5) seeking a group home arrangement, (1) living in a flat, and (1) living in a flat within a home with minimal supervision. Further inquiry into parents' prospects and or concerns for their teenagers future encompassed a wide array of responses. These included: 1). job situations, 2). further education and training, 3). independence (travel), 4). general safety, 5). accommodation, 6). opposite sex, 7). society in general (expectations and readiness level) and 8). loneliness. In final response, to the question on driving training, all of the
parents never considered this as a possibility for their teenager, but were quite excited by the prospect toward such an opportunity for further independence, mobility, and employment. While this pilot study may be bias and consist of a sampling of one small area in the United Kingdom, there are still a number of fairly clear conclusions that can be drawn from the data collected. First, are the parents perceptions on educational aims. These can be broken down into two sections: 1). early stimulation or intervention and 2). further education and training. In regards to early stimulation all (7) parents considered this extremely important. As indicated in the mixed review of literature those that did support this view found the rewards to be of positive nature.

By the time adolescents leave school, their habits and expectations are for the most part firmly laid. However the relevant adult skills and preparation for new lifestyles then become ever so apparent as to make or break a situation once the adolescent leaves school and enters the world of work. Schools therefore, here and abroad need to equip the adolescent with Down syndrome with better coping skills (Landesman-Dwyer 1984). While, on the other hand it appears quite evident that it is the parent who continues to explore and pursue all possible avenues. Parents daily continue their role and plight as advocates to ensure jobs; to make themselves more familiar with local resources, to maintain links with training establishments and to provide a co-operational system between themselves and other professionals. Such opportunities to display real understanding of the parents’ needs and concerns are jettisoned over and over again, frequently owning to a lack of understanding of the family situations (Tingey Ed. 1988). More sensitivity on the part of the professional as expressed by these parents is necessary in order to facilitate cooperation and form an actual partnership for the adolescents education (Michaelis 1980). Professionals who are not led to understand the importance of the independent steps as perceived by the parents will not make decisions that promote these young adults development toward that independence.
This pilot study further indicated that parents wanted their teenagers to grow up happy, content, confident, and with a sense of self-worth. Happiness and acceptance (being treated as everyone else) were two responses frequently conveyed throughout this study.

Finally the parents perceptions on independence indicated that they see their teenager as moving away from being dependent upon society. They see their teenager as a more active participant in leisure activities; scouts, choir, family outings, and clubs. They are open minded(yet at time over-protective)when it comes to their teenager taking public transportation and or possibly driving a car. Independence is sought by parents with adolescents and basically depicts what adulthood is all about. It is not easy to obtain due to the members of society who believe that adolescents with Down syndrome can not operate independently. This also becomes a source of concern for many of the siblings who have a brother and sister with Down syndrome (Grossman 1972).

The right to passage for children and young adults whether it be learning to drive a vehicle (Anderson 1995), working and living in their communities (Joseph 1990) receiving religious confirmation (Creno 1993) being a role model (Farrel & Sugden 1993) or getting married should be given the same equal opportunity as everyone else. For traditionally our culture has taught us that individuals with Down syndrome are weak and have only a limited ability to act independently. It is only through the individual and their families that we can fully learn about their strengths and special values, their growing up verses their impact or effect and the meaningfulness of their existence. For acceptance by society depends on the frequency which children with Down syndrome come in contact with society at large. What has come across to parents via the books and literature on children and young adults with Down syndrome is that these families are not alone. There is a certain validation for the feelings, the confusion and the frustration. It appears that over a period of time, more and more support services, agencies and professionals have become more available through a kind of ‘Sharing’ network. Albeit, few writings include these actual experiences and at times sadness as told by parents.
Useful support can be found with other parents, independent or professional groups, counselors, educators, preschool, daycare, camps, boy or girl scouts or churches.

**Reflection and Summary**

Working daily with families, being an Aunt of a wonderful nephew with Down syndrome, and especially an active participant of a parent network called “Sharing” for these families with children and young adults with Down syndrome only then, did this investigator begin to see how valuable a resource they can be. This of course is reflected by the name that depicts the true meaning of its name “Sharing”, their stories of daily challenge and conflict, struggle and joy, anger and frustrations as well as utter delight. For families with children with Down syndrome as reflected throughout the last four years need to establish routines to keep stress more manageable. In any case the stress, strain, and the commitment of the family for their child does not reflect the child itself. It is an extended stress produced by a larger unit called ‘society.’ The burden as so well put by one parent “is not the child, for the child is a source of joy and love. It is dealing with the lack of normalization, inclusion in the school, workplace and society, as a whole that cause this extended stress.” The pressures or stresses, unfortunately come from many directions via the neighborhood, the community, family members or the school.

On a positive note, one parent recalled the thrilling experience that their son encountered while waiting for his first bus ride to school along with the other neighborhood children. By taking this step he now has become a part of his immediate community. Until, this experience he had never come in contact with his own neighbors and natural classmates. He soon developed age appropriate friends and socially appropriate pastimes. His inclusion provided an additional sense of belonging for his parents who since they had no other children had been condemned to the same segregation as their son. Parents with children with Down syndrome like everyone else want their children to be productive, independent,
confident and happy individuals. They need to be realistic with what they expect from their children and be equally as aware of allowing their children to make their own choices.

Individuals with Down syndrome is exactly that an individual or person first, and individual or person with a disability last. The right to live and the right for a quality of life should no longer be in doubt for persons with Down syndrome (Brannan 1988; Johnson, Johnson, & Maruyama 1983).

Persons with Down syndrome today are being raised in family homes to live and work in their communities. Due to the current interdisciplinary commitment, personal opportunities for persons with Down syndrome is evident (Bellamy, Sheehan, Horner, & Boles 1980; Kiernan 1988; O'Connor, Giombetti, & Williams 1988; Parent et al 1988; Putnam, Pueschel, & Gorder-Holman 1988; Snell 1987; Volgelsberg, Williams, & Bellamy 1982; Wehman 1981).

It is the hope of this investigator that in the future, instead of “lip service”, adults with Down syndrome will be offered a status that observes their rights and privileges as citizens in their society and preserves their human dignity. There still remains limited cursory knowledge of the feelings and dialogue in the lives of persons with Down syndrome and their families (Crutcher 1986). However the ultimate method we do have is to coordinate all facets of Down syndrome as it touches the lives of the child, family, friends, community, and professionals by dissemination of parent perspectives on raising a child with Down syndrome. Above all families of children with Down syndrome should be respectfully heard, and allowed to take a journey down that road with new bends, a few curves and dips and maybe a “pot-hole” or two in order to get to their final destination (expectation, aspiration, or goal).

Even though this journey may start out say in Italy but it may end up in Holland it was well worth the adventure just the same. Emily Perl Kingsley so eloquently describes and captivates her experiential journey (as it may reflect upon others) when raising a child with a disability to be:
"When you are going to have a baby, it is like planning a fabulous vacation trip to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, Michelangelo's David, the gondolas in Venice.

You may learn some handy phrases in Italian. It's very exciting. "After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, 'Welcome to Holland.' Holland?? you say. 'What do you mean Holland? I signed up for Italy! I'm suppose to be in Italy. All my life I've dreamed of going to Italy. But there's been a change in the flight plan. They've landed in Holland, and there you must stay.

The important thing is that they haven't taken you to a horrible place, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips. Holland even has Rembrandt. But everyone you know is coming and going from Italy and bragging about the wonderful time they had there. And for the rest of your life, you will say, 'Yes that's where I was supposed to go. That's what I had planned. 'The pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss. But if you spend your life mourning the fact that you didn't get to go to Italy, you may never be free to enjoy the very special, the very lovely things about Holland" (Crutcher 1986).
CHAPTER V
Methodology

Qualitative inquiry cultivates the most useful of all human capacities—the capacity to learn from others.

For there is no burden of proof. There is only the world to experience and understand. Shed the burden of proof to lighten the load for the journey of experience. — From Halcolm’s Evaluation Laws (Patton 1990).

Restatement of Purpose

The intent of this exploratory study was to learn from parents their perspective when raising a child or young adult with Down syndrome. A combined phenomenological/heuristic approach was chosen in order to describe, understand, and provide a voice for the ‘lived’ experiences of these families.

This chapter will begin by explaining the rationale for choosing this method, its’ principles and techniques, along with those who have used this approach and how it is applies to the area of Down syndrome. A Pilot study conducted in England leading up to the design of this study and the logistics it entailed will also be stated.

Rationale

An exploratory study using an integrated approach has allowed the investigator to search for a more comprehensive and elaborate interpretation intellectualized by families about their inner and daily experiences when raising a child and or young adult with Down syndrome. Further, this method has allowed the investigator to reconstruct these experiences and viewpoints to its full range of possibilities. This did not limit the findings by any preconceived bounds that might be established using a more traditional paradigm such as a structured questionnaire or rating scale.

On the contrary this approach allowed such a study to reflect the family situation individually and collectively by focusing and representing individuals rather than a composite of numbers and calculated figures.
Background To Method

The researcher's journey, leading toward the theoretical components of this method, will be synthesized in this section. The synthesis has been tabulated by numerous resources in the field of phenomenological/heuristic research: Colaizzi (1978); Code (1991); Giorgi (1971, 1972); Moustakas (1990); Patton (1990); Polanyi (1962, 1969); Popper (1970); Polkinghorne (1984); Reinharz (1983); Taylor & Bogan (1984); and Van Hesteren (1986). This particular selection has appealed and been useful for numerous reasons.

These references made up a variety of styles which collectively represent aspects of the method entailing the 'big picture' while at the same time, complementing each other. The array of writing styles, usage of technical and practical language from the more traditional standpoints, to the philosophical and to that of the feminist encompass an extensive representation and understanding of human phenomena in light of its parts.

The researcher's journey then began in earnest in the year 1988. The year prior had been a year of seeking a personal challenge, while questioning and self-dialoging, in search of inner understanding and the world in which we live.

As a teacher in special education and a newly acclaimed Aunt of a beautiful nephew with Down syndrome the researcher engaged in a scientific quest aimed at discovering underlining meanings toward the experience of living as an individual with Down syndrome in this world. Without the use of a particular map, the stages in this journey lead the sojourner to Nottingham, England. As a post-graduate student with the supervision of the renown international authority of Down syndrome (Dr. Brian Stratford) a new course of study soon developed. For this new course became clear, as thoughts and layers of issues began to evolve with a more collaborative and mutually developed method. The researcher therefore, took a road down a path of the parents point of view, their experiences, beliefs, and perceptions when raising a child or young adult with Down syndrome. Henceforth the focus was on a dialectic relationship between knowledge and
action along with theory and practice. One aspect of life's experience was pinpointed, that of employment. A pilot study was then conducted (Drower 1988) in East Croydon, England on Parent's Perceptions Toward Employment of Their Adolescent with Down syndrome (see Appendix H). The parent participants were obtained randomly through the cooperation of the Down's Syndrome Association in East Croydon, England (Mrs. Daphine Jones).

The investigation consisted of a parent group of 7 whose ages ranged from 33-60 years. Their teenagers ranged in age from 12-18 (representing 4 males and 3 females). Both parents were present on 4 out of 7 sessions as cited in Chapter IV.

Even though the investigation was limited by a structured interview design, a small sampling of one borough (area) and pertained to one outcome of interest (employment) the value of this sort of journey and the response it generated by the participants lay in the awareness of the following implications:

1. A need to understand all aspects of the parents perspective; work, kinds of dilemma, day to day issues, essential for an equitable, mutually educate and authentic collaborative research.
2. A need to understand the 'total' individual with Down syndrome as seen through the everyday experiences of the parents on local, national and international levels.
3. A need to understand and discover the full potential that each individual with Down syndrome can achieve toward employment and as contributing members of society.
4. A need to incorporate a richer and more reflective approach than represented in the current literature and research in the area of Down syndrome.

Following this pilot study the investigator realized that too many dimensions of life and experiences were not actually being captured by language. So in 1990 until the present, the researcher undertook a new direction and challenge in attempt to enrich the world through
the voices of parents about their experiences when raising a child or young adult with Down syndrome. This challenge has lead the researcher down a new path toward exploring dialogue and by finally putting a human face on the detached and impartial nature of standardized educational assessment.

The researcher began by becoming a co-inquirer and a participant-observer of a parent support network for parents with children and young adults with Down syndrome ("Sharing") in Phoenix, Arizona, USA. This provided the researcher with a solid sense of being useful, purposeful, and more comprehensive way to discover, understand, and experience the meaning as it unfolds through the utilization of the phenomenological/heuristic research method.

Before this researcher began to articulate the synthesis of these integrated approaches it is important to consider Giorgi’s (1970) comment that "...even those who understand the phenomenological approach have not been able to translate it into praxis in a systematic and sustained way" (p. 77). While Douglas and Moustakas (1985) add that "phenomenology ends with the essence of experiences; heuristic retains the essence of the person in the experience" (p. 43). The researcher too, does not claim to be bound by any one structure or any one separate approach. In this work the researcher did attempt to make a case that both methodologies contribute significantly to the understanding of the area of Down syndrome, and indeed, are interrelated.

Therefore, the goal is to describe multiple perspectives (Patton 1990), while retaining the essence of each participant (Moustakas 1990) through ongoing dialogue in order to seek understanding instead of just truth seeking (Taylor & Bogdan 1984). Dimensions such as the reciprocal interaction between the family and systems of which they are part, the extent to which the families experience and produce their own development and the cultural, social-economical, political, and historical underpinnings can then begin to evolve. The subjective experiences of these dimensions is represented in the phenomenology method as a process of dialoging and unfolding the 'lived' experiences. Heuristic allows for further
interpretation of the context of actions and narratives which might have been otherwise missed. These can be represented in open-ended stories and examples of these ‘lived’ experiences.

Phenomenology can then be classified as a type of qualitative research method whose aim is to provide understanding of the constructs of interest (phenomena) as they are experienced by the persons in the sample of interest. To conduct phenomenological research is to attempt to experience the research question from others’ point of view. The choice of this research methodology has important implications as expressed by Taylor and Bogdan (1984):

_The methods by which we study people of necessity affect how we view them. When we reduce people to statistical aggregates, we lose sight of the subjective nature of human behavior. Qualitative methods allow us to know people personally and to see them as they are developing their own definitions of the world. We experience what they experience in their daily struggles with their society....qualitative methods enable us to explore concepts whose essence is lost in other research approaches (pp. 4-5)._ 

Heuristic research on the other hand refers to the internal search through which one discovers the nature and meaning of experiences. It is the complete and full depicting of the experience from the reference point of the experiencing person (Moustakas 1990).

Polanyi (1969) adds that it is “customary today to represent the process of scientific inquiry as the setting up of a hypothesis followed by its subsequent testing. I can not accept these terms. All true scientific research starts with hitting on a deep and promising problems and this is half the discovery.” Yet he points out that “to see a problem is to see something hidden that may yet be accessible…” (118, 131-132).

Subsequential phenomenology/heuristic research is a method, a philosophy, an attitude and an approach with an aim to describe the ‘lived experiences’ while still retaining the essence of the person(s) in the experience. Heuristic research epitomizes the phenomenological emphasis on meanings and knowing through personal experience as well as challenges in the extreme traditional scientific concern about researcher objectivity.
and detachment. While at the same time it resituates people in their true habitat, of the world in which we all continue to journey and reside (Patton 1990).

**Principles**

As a research method, a combined five (5) key principles emerge from the extensions of references as cited in background to this method. These principles are by no means isolated entities for this is an integrated approach. There is an intertwining required in order to create a sense of completeness:

1). Phenomenology/heuristic is an alternative paradigm, a “human science”, a systematic guide to achieving correct interpretations and understandings with linguistic data as a means to access the consciousness and the experience (Polkinghorne 1989, Van Hesteren 1986). The investigator approaches the phenomenon from a holistic standpoint. Instead of being set at the outset parameters and a mapped research direction unfold during the course of this investigation. All aspects of the phenomena are considered valid and valuable in the “meaning-making” process. This inquiry is characterized by an open attitude as well as freed from any previous psychological theories, preconceptions, assumptions and judgements.

The method of this investigation can only be achieved by description through dialoging “...participating being-in-the-world with others”(Colaizzi 1978, p. 132). Descriptions are generated by open-ended interviews where often develop a richer written data requiring research to be attentive to the participants nuances of speech as well as gestures. Suspensions from one’s preconception and biases are done by bracketing. Dialogue involves cooperative sharing in which the participants or co-researchers open pathways to each other by explication the phenomenon being investigated. Such a technique further encourages expression, elucidation, and disclosures of the experience.

2). The data generated is dependent upon empathic listening. Moustakas (1990) expresses that “...it is necessary to be open to oneself, be flexible, and skillful in creating a
climate that encourages the co-researcher/participant to respond comfortable and comprehensively” (p. 48). In this way the researcher must interpret and depict the experience in accurate, rich and comprehensive terms. Such depiction's may also include stories, examples, conversations and analogies.

3). Immersion in the participant's experience and the language. The language used flows and is grounded in each participant's own words to the extent that, others may become knowledgeable of the existence to this phenomenon (Code 1991; Colaizzi 1978; Reinharz 1981). Each participant's own language will be depicted in the narrative. When ever possible, each participant’s own language and style, stories and examples will be presented in order to offer insight and reflect the data itself. Each participant is therefore represented as a co-researcher, a holder of his or her own world as defined in his or her own reality.

The researcher then becomes the tool, the means, an integral voice, and a partner confident in reflecting the degree and meaning articulated by each participant. Henceforth capturing, translating and encompassing an intellectual and multi-dimensional perspective of the ‘lived’ human experience.

4). The role of the co-constituency (researcher and co-researcher) is valued and encouraged. The researcher must realize that his or her subject is more than merely a source of data; he or she is exquisitely a person, and the full richness of a person and his verbalized experiences can be contacted only when the researcher listens to him with more than just ears; he must listen with the totality of his being...only then can one be present to the totality of a person by being totally present to him (Colaizzi 1978, p. 64).

Therefore, what the researcher experiences is more than a subject-relationship that encompasses the subject and the experience as separate entities. On the contrary, it emphasizes the connectiveness and the relationship allowing the participant in the process to remain visible in the examination of data eliminated from their experience.
The phenomenologist/heurist is an adventurer, an explorer, a co-discoverer who seeks to find meaningful descriptions at the heart and depths of each participant’s (so-journeyer) experiences in a collaborative manner. What is significant and unique to this combined method is that which the researcher is present throughout the process, while exploring the understanding of the phenomenon, the research also experiences growing self-awareness and self-knowledge.

5). The phenomenologist/heurist researcher emphasizes the importance of making an impact as well as a difference upon society (Popper 1979; Sarason & Doris 1979; Reinharz 1981). Sarason and Doris (1979) in particular address that “mental retardation is never a thing or a characteristic of an individual but rather a social invention...where the obstacles to change are rooted in the habits of thinking, professional training and economic-political structure of human services” (p. 417-418). Reinharz adds further that “when one’s critique is articulated and made public, others will find resonance in their own experiences. Thus one’s private concerns will be redefined as shared” (p. 166). It takes courage as Reinharz continues to make your private concerns public. However, the true challenge lies in converting your private concerns into a public issue. The importance of any informed understanding of the nature of human phenomenon is then not just an individual concern but a collective, communal and rigorously perpetual one.

**Subjects**

Fifteen families (N=15) who have a child or young adult with Down syndrome were recruited to participate in this study. The criteria for participation in this study were the following:

1. These families have raised a child or young adult with Down syndrome. No specification was applied in reference to single parents, divorced, remarried,
adoption, or cultural background. This was done in order to glean a richer cross-cultural perspective on the current family unit.

2). These families have an infant, school aged child, teenager, or adult with Down syndrome. The scope and stages of development (through a cross-section of ages) will allow the investigator to incorporate an all encompassing perspective.

3). These families were familiar with "Sharing" (A Down syndrome Parent network) or Pilot Parents (A parent support group for a cross-section of disabilities such as slow learners, physically and mentally challenged (handicap), attention deficient disorders, etc.).

Procedure

The "Sharing" (Down Syndrome Parent Support Network) was contacted and recruitment letters (see Appendix A) were sent out requesting any interesting families to contact the investigator directly. Each letter upon contact, was then followed up by a telephone call.

Approximately 175 letters were randomly sent out (utilizing both East Valley and Statewide lists) from the Down syndrome parent support network. The investigator previously contacted the President of the Down syndrome parent network and a representative from the East Valley to further explain this study.

The investigator received 31 phone calls which included three referrals from other parents who they considered to be interested participants and one from a colleague.

The investigator then talked with these parents by telephone before considering them appropriate for the study. Subjects were considered appropriate for this study if they were able to be reflective and intellectualize their experiences along with meeting the above mentioned criteria. All subjects were interviewed. Later the researcher chose 15 that best reflected the experiences of a person with Down syndrome from birth to adulthood.
There were two families who declined because they were not ready to share their experiences. Both families had just given birth to a child with Down syndrome ranging in age from 8 to 11 months. They were however, interested in reading the final results.

One family contacted by a colleague had a child with a rare chromosome anomaly called 9P plus. Even though this anomaly was not Down syndrome the investigator believed this families unique perspective and experiences may parallel with families within this study.

In addition, both parent(s) had to be willing to participate (Bender 1985) and to complete an Informed Consent Form (see Appendix B) and a Demographic Questionnaire (see Appendix C).

A follow-up letter (see Appendix D) reviewing the criteria and the commitment involved was then sent to all parents deemed appropriate for this research study. The meetings took place in the families home or at the families place of work. At the time of the interview, the completed Informed Consent Form and the Demographic Questionnaire were filled out and collected. Any further questions that the parents may have had were answered before beginning the interview.

Approximately one and one-half hours were scheduled for each interview; however the time varied, depending upon the subject’s degree of spontaneity and comfort with the area being discussed. The average time for an interview was 2 hours. All interviews were audiotaped using a tape recorder. Interviews were conducted with both parent(s) together. One interview was held in the parent(s) office and the rest (N=14) were held at the parent(s)’ homes.

Parent interviews and in some cases family interviews were conducted depending on how comfortable they felt with the situation. The interview was open-ended and consisted of a general introduction and question at the beginning of each interview. Several probe questions were used if necessary to clarify and or to explore the subjects’ ideas (Appendix E). The introduction and main question were as follows:
I am interested in learning from your point-of-view the experiences you have and are currently going through when raising a child/young adult with Down syndrome. I am interested in your feelings, thoughts, and concerns about raising a child/young adult with Down syndrome in modern day society.

I would like you to first start off by defining Down syndrome.

Unless these areas were spontaneously addressed by parents, the following questions were asked in order to further elicit the family dynamics and feelings:

1). How were you told?
2). What was your reaction when you were told the news?
3). Where did you first obtain the information about Down syndrome?
4). How did your tell your other children?

At the end of the interview the investigator asked the parents if there was anything they would like to add or share about their experience. The interview was completed by “checking” with the parents and asking how the experience of discussing their perspective has been for them. Time was then made available to answer any further questions they may have had and or of the process.

Validity Check

Parents were then re-contacted within six weeks following the interview in order to review the major points expressed and to clarify any ambiguities (see Appendix F). At this point, the investigator transcribed their interview and had done some preliminary analysis (content analysis) for thematic material. Each family received a report on the formulations of their descriptions and the ongoing dialogue. Each family was then invited to make any corrections to their perceptions and or make additional comments. This allowed the investigator to both speak consistently in the language of the subjects and provided validation to their private and now shared experiences. Due to time constraints, scheduling and the need to synthesize their thoughts within a time that best suited each family, the
follow-up was completed by fax, mail, and or telephone conversations. Changes or additions to the data will be included in the results (see sample Appendix G).

**Pilot Study**

A Pilot study previously mentioned in Chapter IV was conducted in order to demonstrate a need for further qualitative research methods utilizing open-interviewing techniques.

The intent of the pilot study was to gain more data on one specific issue, that of employment for a young adult with Down syndrome.

The questionnaire utilized during this study was regarded and treated as self-administered. The questionnaire consisted of twelve (N=12) questions requiring a yes, no or short answers. These questions covered the areas of jobs, skills, education and current employment status. Several of the questions (N =5) allowed for short or open answers. This pilot however left little room for elaboration. The interviewing style lead to predetermined answers. The investigator was in control and imposed a structure that set the stage for the questions and issues to be studied. It was only after the completion of this standardized questionnaire format that the participants began to reflect on other issues, concerns, and feelings also important for their young adult with Down syndrome. Stories of the treatment by the medical profession, school, economics, politics, and even religious affiliations emerged. It was from the nature of the Pilot that the investigator decided to take a more subordinate role with this current study. Here the interviewee would be more responsible by initiating and directing the situation at hand.

An unstructured interview was designed to further obtain additional and pertinent data regarding all issues when raising a child with Down syndrome. There was no presuppositions about the data. It was conducted in a conversational open-dialogue style.
Analysis and Synthesis of Data

The information gathered from the Demographic Questionnaires was utilized for descriptive purposes, framing the group as well as serving to describe each family. Each family was assigned a self-selected pseudonym.

All of the interviews and validity checks were audiotaped and fully transcribed. Since audio-tapes "select out" a certain amount of material, i.e. non-verbal language, facial expressions, physical interactions between the parents, interviewer and family, notes were taken during and after (within 24 hours). The interview was reviewed and incorporated into the data. Hence, the researcher's notes were meant to enhance and add description to the dialogue.

This process of working with all aspects of the data is well articulated by Bender (1985). To ensure thorough familiarity with the data before data analysis, the investigator listened to all interview tapes, reread each transcribed interview and kept in mind the undulating process...the continual swinging back and forth from one activity to the other (Bender p.37).

After weeks of listening to and becoming immersed with the recordings of each interview and working from complete sets of over 2,000 typewritten transcriptions and notes those quotations, blind spots, and experiences that appeared to be most noteworthy of these families were identified.

Through the open-dialogue new questions were asked and answered which illuminated blind spots. For "Anything which can be called a study, whether arithmetic, history, geography or one of natural science must be derived from materials which at the outset fall within the scope of ordinary life-experiences (Dewey 1938/1963, p. 73).
This data was then grouped into content areas. The content areas were further "broken down" into related groups, identified themes and subthemes. A further breakdown of themes and frequency of responses is shown in Table 1 and Table 2.

These themes emerged within the identified areas and groupings of selected quotes and life experiences. The terminology utilized by these families in the area of education (as referenced in the USA) was further defined as seen in Appendix J.
### TABLE #1
BREAK DOWN OF THEMES

<table>
<thead>
<tr>
<th>THEME</th>
<th>FREQUENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived future goals and aspirations for their child or young adult.</td>
<td>11 / 15</td>
</tr>
<tr>
<td>Dissatisfied with the educational profession.</td>
<td>12 / 15</td>
</tr>
<tr>
<td>Dissatisfied with medical profession.</td>
<td>13 / 15</td>
</tr>
<tr>
<td>Perceived additional stress due to society, daily routines, cost and unavailability of services.</td>
<td>13 / 15</td>
</tr>
<tr>
<td>Perceived services to be limited in the areas of speech, occupational and physical therapy.</td>
<td>15 / 15</td>
</tr>
<tr>
<td>Perceived support groups as being beneficial.</td>
<td>15 / 15</td>
</tr>
<tr>
<td>Perceived early intervention/infant stimulation as being beneficial.</td>
<td>15 / 15</td>
</tr>
<tr>
<td>Perceived the child first, took one day at a time, and advocated for their child.</td>
<td>15 / 15</td>
</tr>
<tr>
<td>Perceived inclusion to be important.</td>
<td>15 / 15</td>
</tr>
</tbody>
</table>
TABLE #2
BREAK DOWN OF SCHOOLING

<table>
<thead>
<tr>
<th>TYPE OF SCHOOLING</th>
<th>FREQUENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attended a special school.</td>
<td>1 / 15</td>
</tr>
<tr>
<td>Attended school in special classes/regular classes</td>
<td>4 / 15</td>
</tr>
<tr>
<td>(mainstreamed).</td>
<td></td>
</tr>
<tr>
<td>Attended school in a regular or included class setting</td>
<td>6 / 15</td>
</tr>
<tr>
<td>Are not of school age but parents advocate</td>
<td>4 / 15</td>
</tr>
<tr>
<td>included class settings.</td>
<td></td>
</tr>
</tbody>
</table>
CHAPTERS VI
Introduction to the Results

The purpose of this exploratory study as stated in Chapter V was to learn from parents’ their perspective and the manner this phenomena is explained when raising a child or young adult with Down syndrome. The goal was to collect data about the families “lived” experiences through intellectualized thoughts, feelings, and descriptive language as told by parents.

Out of 31 responses, 29 were interviewed. Two declined prior to an interview because they were not ready due to the newness of the experience (their children were 8 and 11 months old). One family who responded had a child who had a another rare anomaly called 9Pplus.

This exploratory study was conducted by joint interviews in which families discussed their experience in an unstructured and open format. Fifteen families were then selected from the original base of 29 to represent this individual yet collective group.

A one page demographic questionnaire also provided additional descriptive detail (Appendix C). Families were then recontacted within 6 weeks after the interview in order to validate major findings from the initial interview.

These chapters (VII-XI) will provide the results of the interviews, organized by thematic headings which will be articulated and enhanced through the families’ own words. The data presented here is a combination of the interview and the validity check. The validity check added greater depth, definition, and individual reflection to the initial family interview. Chapter VI will be divided into two sections. The first section of Chapter VI will contain an overview of the twenty-seven (27) participants as a collective group. The second section will entail a more in-depth portrait of each of the fifteen families as individual family units. A description of each family is provided to capture a sense of uniqueness and to offer
the reader an essence of the actual interview. The Chapters (to follow) will incorporate the eight (8) identified themes or content areas:

Chapter VII will discuss themes one and two.
Chapter VIII will discuss themes three and four.
Chapter IX will discuss theme five.
Chapter X will discuss themes six through eight.

The order in which these themes present themselves does not represent any specific order of importance. Themes were then sequenced to allow the investigator to present a "story" these families described about giving birth, a new life, and the development of their child. Therefore one theme flowed naturally into the other.

The Eight themes presented are:
1). Diagnosis issues
2). Adjustment issues
3). Family issues
4). Social issues
5). Educational concerns/And Beyond
6). Parental experiences and needs
7). Advice and issues for new parents
8). Advice for society

The final Chapter XI will discuss three meta-themes which were identified by the researcher not only as a continual concept shared by all the families, but ones which bounded them cohesively together as a supportive structure. These meta-themes emerged from the individual data as universal in nature. They can be described under the headings of: 1). Living One day at a time, 2). See the person first as being treated and included like everyone else, and 3). Advocacy...being their voice.

Throughout these chapters, various quotations will be presented to illicit the spirit of what was actually said. To ensure anonymity the last names of the participants and their children have been changed.

Quotations are occasionally signed by both parent's names. When this occurs it is meant to represent a way of sharing thoughts which were intertwined or interrelated rather than stated as separate thoughts. There were times when the dialogue flowed back and forth and distinct "breaks" were not apparent. Parents would at these times look at each other and
concur for agreement or dissent. There was more of a sense of "we feel" in contrast to other times when a parent was speaking more from a position of "I". It should also be noted that once the interview was completed and the tape recorder turned off more intimate and provocative thoughts were shared. Capricious notes and written detail supplemented these thoughts within a 24 hour period.

Section I
An Overview

Thirty-one families responded to this study. Twenty-nine were interviewed. Fifteen families were then selected to participate in this study. Families are defined as single parent male or female with one or more children, a two career couple, a two parent family where the male is the career person, divorced, remarried with a combination of children from two previous marriages or unmarried families with a partnership which included children (see Table 3). Two single parent families consisted of one child a female with Down syndrome whose ages were 6 and 11. One single parent (in partnership not officially married whose husband is the father of her children) has five children where the son with Down syndrome represented the third child. Three families consisted of fraternal twins, one girl and two boys ranging in age from 3-13. Within those families two families had other children ranging in age from 22-15. The children and young adults of this study with Down syndrome ranged in age from 10 months to 40 years old (see Table 4). Their siblings ranged in age from 2-50 years old. The ranking of the 15 children with Down syndrome represented 7 being the youngest, 3 being the middle child, 2 being third out of four, 2 being only children and 1 being the forth out of seven (see Table 5). One family adopted two children, while another had two children from previous marriage. Eight of the fifteen families had a girl diagnosed with Down syndrome while seven were boys. Fourteen out of fifteen were diagnosed with Trisomy 21 while one had translocation. Nine of the families were diagnosed at birth while the others ranged from one hour to thirty days (see Table 6). Eleven out of fifteen families were diagnosed by their doctors. However four families
TABLE #3
MARITAL STATUS OF COUPLES IN STUDY

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Number in Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unmarried</td>
<td>3</td>
</tr>
<tr>
<td>Married</td>
<td>11</td>
</tr>
<tr>
<td>Remarried</td>
<td>1</td>
</tr>
</tbody>
</table>
TABLE #4
CURRENT AGES OF FAMILY MEMBERS

<table>
<thead>
<tr>
<th>Family Number</th>
<th>Mother Age</th>
<th>Father Age</th>
<th>Child Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>30</td>
<td>40</td>
<td>50</td>
</tr>
<tr>
<td>2</td>
<td>35</td>
<td>50</td>
<td>10</td>
</tr>
<tr>
<td>3</td>
<td>40</td>
<td>60</td>
<td>20</td>
</tr>
<tr>
<td>4</td>
<td>45</td>
<td>70</td>
<td>30</td>
</tr>
<tr>
<td>5</td>
<td>50</td>
<td>80</td>
<td>40</td>
</tr>
<tr>
<td>6</td>
<td>55</td>
<td>90</td>
<td>50</td>
</tr>
<tr>
<td>7</td>
<td>60</td>
<td>100</td>
<td>60</td>
</tr>
<tr>
<td>8</td>
<td>65</td>
<td>110</td>
<td>70</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Family Number</th>
<th>Mother Age</th>
<th>Father Age</th>
<th>Child Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>25</td>
<td>35</td>
<td>15</td>
</tr>
<tr>
<td>10</td>
<td>30</td>
<td>45</td>
<td>20</td>
</tr>
<tr>
<td>11</td>
<td>35</td>
<td>55</td>
<td>25</td>
</tr>
<tr>
<td>12</td>
<td>40</td>
<td>65</td>
<td>30</td>
</tr>
<tr>
<td>13</td>
<td>45</td>
<td>75</td>
<td>35</td>
</tr>
<tr>
<td>14</td>
<td>50</td>
<td>85</td>
<td>40</td>
</tr>
<tr>
<td>15</td>
<td>55</td>
<td>95</td>
<td>45</td>
</tr>
</tbody>
</table>
TABLE #5
SIBLING RANK

<table>
<thead>
<tr>
<th>Family Number</th>
<th>Number of Children / Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>8</td>
<td>5</td>
</tr>
</tbody>
</table>

NOTE: Rank of the first born child in family = 1

- Number of children in family
- Rank of D.S. child in family
TABLE #6
TIME OF DIAGNOSIS

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>At Birth</td>
<td>9</td>
</tr>
<tr>
<td>Within 1 Hour</td>
<td>1</td>
</tr>
<tr>
<td>Within 2-3 Days</td>
<td>3</td>
</tr>
<tr>
<td>Within 10 Days</td>
<td>1</td>
</tr>
<tr>
<td>Within 30 Days</td>
<td>1</td>
</tr>
</tbody>
</table>

TABLE #7
PERSON MAKING INITIAL DIAGNOSIS

<table>
<thead>
<tr>
<th>Person</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor</td>
<td>11</td>
</tr>
<tr>
<td>Nurse</td>
<td>1</td>
</tr>
<tr>
<td>Social Worker</td>
<td>1</td>
</tr>
<tr>
<td>Parent</td>
<td>1</td>
</tr>
<tr>
<td>Specialist</td>
<td>1</td>
</tr>
</tbody>
</table>
diagnosis ranged from a nurse to that of a parent (see Table 7). Eleven out of 15 families had children with additional medical problems and complications at birth and after. All children were delayed in speech.

Ten out of 15 mothers were under the age of 35 when they gave birth to their child. The mean age for the mother was 32 while for the father was 35 (Table 8). It is worthy to mention that even though mothers over 35 years of age are at greater risk (cited throughout Chapters I-IV of this study) at least 80% of babies with Down syndrome are born to women who are under the age of 35. Reasons cited by the March of Dimes, 1995 and numerous sources are that younger women have far more babies. This current study correlated with this fact.

Eight out of 15 families (20 parents) were Caucasian. Other ethnic backgrounds included American Indian (Native), Hispanic, Cuban and Israeli (See table 9).

In regards to religious affiliations; 15 parents are Catholic, 3 Protestant, 2 Jewish, 5 Latter Day Saints (Mormon) and 2 Other (refer to Table 10). It is also interesting to note that out of the total (N=54) base of interviewed participants, 8 represented the Catholic affiliation while 19 represented other religious denominations.

Educational background entailed: 13 parents had earned graduate degrees; 11 bachelors, 2 masters, 4 technical schooling; 2 additional medical schooling, 2 vocational training, 4 Junior college and all had high school diplomas (see Table 11).

Even though a majority of participants were Caucasian, married, and of the Catholic religion differences in parent-child relationships did not directly attribute to any significant differences in the raising of the child. However, differences may have been reinforced through the families' individual make-up as well as through how well the family unit related to one another.

Parents ranged in age from 28 to 82 years old. The parent's age alone (having a child at 24 versus 40) was not a significant or compelling factor when raising a child with Down syndrome. Only over a period of time (forty years ago versus today) as to what was known
TABLE #8
AGES OF PARENTS WHEN CHILD WAS BORN

NOTE:
Mean age of mother = 32
Mean age of father = 35
TABLE #9
ETHNIC BACKGROUND OF PARENTS IN STUDY

<table>
<thead>
<tr>
<th>Ethnic Background</th>
<th>Number in Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>American</td>
<td>20</td>
</tr>
<tr>
<td>Hispanic</td>
<td>3</td>
</tr>
<tr>
<td>Caucasian</td>
<td>1</td>
</tr>
<tr>
<td>Cuban</td>
<td>2</td>
</tr>
<tr>
<td>Indian</td>
<td>1</td>
</tr>
<tr>
<td>Israeli</td>
<td></td>
</tr>
</tbody>
</table>

TABLE #10
RELIGIOUS BACKGROUND OF PARENTS IN STUDY

<table>
<thead>
<tr>
<th>Religion</th>
<th>Number in Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protestant</td>
<td>3</td>
</tr>
<tr>
<td>Jewish</td>
<td>2</td>
</tr>
<tr>
<td>Catholic</td>
<td>15</td>
</tr>
<tr>
<td>Mormon</td>
<td>5</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
</tbody>
</table>
**TABLE #11**  
EDUCATIONAL BACKGROUND OF PARENTS IN STUDY

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>High School</td>
<td>15</td>
</tr>
<tr>
<td>Junior College</td>
<td>4</td>
</tr>
<tr>
<td>Vocational</td>
<td>2</td>
</tr>
<tr>
<td>Technology</td>
<td>4</td>
</tr>
<tr>
<td>Bachelor's</td>
<td>11</td>
</tr>
<tr>
<td>Master's</td>
<td>2</td>
</tr>
</tbody>
</table>

**TABLE #12**  
FINANCIAL BACKGROUND OF FAMILIES IN STUDY  
(U.S. $)

<table>
<thead>
<tr>
<th>Income Range</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-20k</td>
<td>2</td>
</tr>
<tr>
<td>20-40k</td>
<td>3</td>
</tr>
<tr>
<td>40-60k</td>
<td>5</td>
</tr>
<tr>
<td>60-80k</td>
<td>2</td>
</tr>
<tr>
<td>80-100k</td>
<td>1</td>
</tr>
<tr>
<td>100k+</td>
<td>1</td>
</tr>
<tr>
<td>Retired</td>
<td>1</td>
</tr>
</tbody>
</table>

* income not disclosed
or available medically or socially for children with Down syndrome along with attitudes of society were perhaps far more significant than age alone. The mean family income fell in $40,000-$60,000 bracket (25,000-38,000 pounds) with 5 families below 4 above this range, and one as retired (see table 12).

Currently eight out of 15 mothers are homemakers. Of the eight that work outside the home five have careers with flexible hours.

Since a significant issue for many of the families in their daily lives is cost and the amount of services and medical care for their child, the following information is presented to give the reader a broader span of what his issue might entail.

Therapies, Occupational (OT) Physical (PT), speech, early infant stimulation range from $40.00-60.00 dollars or 25.00 to 38.00 approximate pounds per hour. Children can go up to twice a week, with speech once a week. In addition private tutoring can run $10.00-20.00 dollars or approximately 6.00-25.00 pounds per hour. This may take place depending on the need of the child two to three times a week.

Preschools which are private facilities where the parents are not subsidized by the government or state and must pay for out of their own funds. In Arizona preschools can start from 6 weeks till 12 years in age. For a pre-school without a curriculum, run by the state, costs incurred are approximately $90.00 per week or 57.00 pounds. If you send your child to a family run pre-school then the cost could run $50.00 per week or 31.00 pounds.

For a special curriculum like Montessori for ages 2 1/2 years going half days will cost $235.00 per month or 149.00 pounds. For full days this would cost approximately $410.00 dollars per month or 260.00 pounds.

In addition surgeries, heart operations, genetic counseling, and additional medical complications will depend on the families insurance companies coverage.

Other health needs that families may incur include the duration of child care, after school programs for working mothers, transportation to and from (if available costs could run $6.00 or 4.00 pounds an hour). For Arizona, geographically, traveling from city to city
could encompass a great amount of distance and time. In the Greater Phoenix area (two million people) one could travel thirty miles one way just to central Phoenix. As shown in (Appendix I) Phoenix also incorporates many neighboring and outlining cities: Mesa, Tempe, Higley, Scottsdale, Chandler, Gilbert, and Bapchule. These families also resided in a wide spectrum of cities throughout the Greater Phoenix area.

Family Portraits

The Mack Family #1

Nancy and Sean Mack have three children; a son Connor age 10 months, and two sons ages 5 and 2 1/2. Connor was diagnosed a few days after birth by his doctor. All Children attend private schools (preschool). Connor attends special classes and therapies. Connor just recently had tubes in his ears and is going to have heart surgery.

Nancy is in sales and Sean is a system analyst. Both parents have bachelors degrees.

Nancy's job allows her more flexible hours to work out of her home.

My initial contact was by telephone. They were referred to by another parent. Nancy and Sean were very open and straight forward, to discuss this new experience of what it is like to raise a newborn with Down syndrome. Two other interested participants with infants from 8-11 months decided that they were not ready to convey their most private and emotional shattering feelings to another at this time.

We met at their home during the lunch hour. This was the best time to meet the needs of their schedule. The home was located in Phoenix, Arizona. It was single level, spacious with toys, computers, and a very homey atmosphere prevailed. Rooms were situated with the family in mind; books, children’s chairs, patenting books on the coffee table and even a Golden retriever.
Both parents were very receptive and equally commented on what their first ten months have been like. It appeared difficult but also important for this family to express their most recent feelings, concerns and beliefs.

Sean was more soft spoken while Nancy more vivid in her tones and expressions.

The investigator was also approached as a source for this family to ask more questions and inquire new and updated information on this area.

All the other children were at school at the time.

The Hughes Family #2

Elizabeth and Tom have two daughters, Kinney age 2 and another daughter age 5. Kinney was diagnosed with Trisomy 21 at birth by her physician. Kinney attends a private (preschool) and therapies. Her sister also attends preschool.

Elizabeth and Tom both have Bachelors degrees. Tom also holds a Masters degree. Elizabeth is a estate agent (Realtor) and Tom is an engineer.

My first contact was by telephone. We met in their home in Tempe, Arizona. The atmosphere was very relaxed. The environment was child related with toys, bikes, books and play tables disbursed among the family decor.

Elizabeth was very outspoken, vivacious, and packed full of energy and candor. She was direct, got to the foundation of things and pulled no punches. She was expressive as seen through her hand, body and facial gestures. She possesses a grand sense of humor. Tom on the other hand was very reserved and intellectualized his thoughts internally. A very critical listener with active thoughts moving and turning to every word that was being said. The investigator had to motivate and address him to pull his thoughts out. He was very analytical and soft spoken.

This interview started out a bit stiff and formal but with Elizabeth interjecting here and there along with having an effervescent personality the conversation then became a most natural one. The children played in and around us during this interview.
The McClaren Family #3

Beverely and Benson McClaren have four children. Two children are fraternal twins. Morgan age 3 a twin, two sons age 22, and 17 and one daughter a twin age 3.

The eldest son attends University while the other children attend public schools.

Morgan and his sister Megan are fraternal twins. Morgan was diagnosed with Trisomy 21 after birth by his doctor. Both parents have completed high school education. Bev completed her bachelors degree and is working on her Masters.

Bev used to work a night job, but now is a homemaker and a student. Ben is a police officer.

The primary language is English with sign language as marked as other.

My initial contact was by telephone. Without any hesitation she was delighted to participate and share a deep interest in providing the best possible world for her son.

The interview was conducted in their home. They live in a spacious one level home in the city of Mesa. Even though the interview started out as a serious venture (first interview), the setting (sitting around the kitchen table where the family spends a lot of time sharing) lent itself to a very spontaneous, free-moving and informal dialoguing. Both parents equally participated. Benson expressed thoughts and feelings that were apparently new or not remembered by his wife Bev.

Bev was very animated, open, and provocative in her descriptions and body language.

Introductions to the family members as they arrived, along with the three kittens added to the already apparent warmth and friendly environment. Being included and treated like everyone else was evident as Morgan sat with us at the table drawing and eating a snack while the interview proceeded in a most natural format.
The Conrad Family #4

Maria and Brian Conrad have four children: Levi, age 4, two sons age 10 and 2 and one daughter age 9. Levi was diagnosed with Trisomy 21 at birth by his doctor. Levi has a slight hearing loss, intestinal blockage at birth and heart surgery.

Levi and his siblings attend public school (state) Levi is in an integrated preschool.

Both parents graduated from high school and from vocational schools. Maria is a homemaker and Brian is a mechanic. The primary language is English, but Levi understands Spanish and sign language.

My initial contact was by telephone. A time was set for both parents to be present. However, due to the demands at work, Brian was called away. So Maria was interviewed separately. Brian was then rescheduled for the following week. Both parents were present this second time.

The Conrads reside in Higley, Arizona. The interview as conducted in a large family room. The children were all home doing chores, wanting mother's attention, watching television and / or playing outside. Maria was very articulate, honest, down-to-earth and very pragmatic about her concerns and experiences. Her major focus is that her son not be treated any different than the other children. Both parents conveyed that it was important to live their lives every day and just to see where it takes them.

A recap was given about what Maria had said and then the father gave his perspective. Maria also provided additional feedback and revalidated issues previously mentioned but allowed Brian to speak freely about his experiences as well. Brian was sensitive, caring and shared similar views as his wife. Brian delved more into personal overcomings, shortcomings in school, and the realization that “it is not me personally that will have to deal with Down syndrome...it is my son.”

An ongoing dialogue of additional stories and experiences also prevailed when the interview was complete and the tape recorder was off.
The Stella Family #5

Paula and James have fraternal twins. Julia age 5 and 1/2 and a son age 5 and 1/2. Julia was diagnosed at birth with Trisomy 21 by her mother. Both children attend regular classes at a public school.

Paula and James both have their bachelors degrees. Paula in addition has training as a cardiovascular nurse specialist. She is both a homemaker and a nurse. James is a health care consultant.

The Stella family resided in New Hampshire until 1990. The twins were born in Boston Massachusetts. They were premature babies. The initial contact was by phone with James. His wife was on vacation with her children back East. Upon return an evening interview was set up.

The Stellas live in a ranch home behind a Phoenix resort. The home environment was warm and inviting. Toys; blocks, paper goods, games and artwork were displayed throughout the house. The interview began with Paula and followed with James. She was open, candid, honest, vivacious and very informative. Her feelings and reflections were described with such detail it was like being there. Her Eastern accent added more flavor and spice to her stories. She displayed a mixed array of emotions. James arrived and was equally intuitive and expressive about his feelings and concerns. He was very much the opposite of his wife.

For he was more subtle, soft spoken, and viewed many situations from a "hands on" approach. Words by themselves and or simply pictures were not as affective for him as the actual experience. However, he did beam as he showed me a picture of his proud bundles of joy.
The Thomas Family #6

Lyrae has one daughter Sydney age 6. She was born and diagnosed in the state of Texas with Trisomy 21. She was diagnosed by the doctor 10 days after birth. Sydney attends public school in a special needs classroom in Chandler, Arizona.

Lyrae had completed high school and Junior College degree. She is a secretary. Lyrae lived in the state of Texas from 1989-1992. She moved to Chandler Arizona in 1992 to the present.

As a single mother managing time for this interview took some arranging. For Lyrae goes to school four nights a week, has many interests like becoming a Chef and aspires to start a non-profit organization to help other parents like herself get better services.

We met in her two bedroom apartment in Chandler, Arizona. It was very cozy, down to earth, adorned with pictures, a piano, children’s toys and books. The interview started out very rigid at the beginning but later comments became more open and candid. Sydney was there playing in her room with her toys.

We did a lot of interchanging of information throughout the interview.

Lyrae was at the stage where she was thirsting for as much knowledge as possible.

Enos Family #7

Tricia is a single parent with five children. A son Brian Jr., 6 years, another son 11, and three daughters ages 7, 5, and 2. Brian was diagnosed with Trisomy 21 at birth by his doctors.

Tricia lives in a two room adobe traditional house (made of mud and cactus ribbing) on the Pima Indian Reservation. The reservation is divided up into seven districts. Tricia lives in District Five which is the largest approximately 15,000 people. In Arizona there are over 72 tribes. Tricia lives with her boyfriend who is the father of her children. Even though she is classified as single she can also be classified as single in partnership.
Tricia has a high school education. Her boyfriend went to school up to the 9th grade. Tricia is a housewife and her boyfriend Kristo is a maintenance mechanic. Even though they are not officially married he does pay for child support however Tricia is still considered the primary caregiver.

The main language is English and the secondary is Pima.

Brian attends a special school in Coolidge, Arizona. All her other children attend school run by the Indian reservation except the 2 year old. She was at home at the time.

The initial contact was by letter. Tricia would call when a phone became available and leave messages. She finally got a mobile phone and an interview was established during the day.

Going to the Indian Reservation was like traveling to a foreign country. It took the investigator one and one half hours to arrive at her home. The investigator traveled through endless open fields and uncultivated land, numerous dirt roads and even past a one room school house until she spotted the barking dog and pick-up truck in front of Tricia's house. Tricia greeted the investigator with a warm welcome and a firm handshake.

We passed though the kitchen area, walking on stone floors and into the sitting combined bedroom area. All five portraits of her children were hanging on the wall. The interview was conducted while sitting on the bed with the tape recorder between us.

Going home made one feel very humble and as the investigator arrived outside the reservation and suddenly civilization appeared closer than the investigator had anticipated. So journey back due the modern development of the freeway (motorway) took only fifteen minutes!

Uzily Family #8

Ilana and Shafrir have three children: A son Oren age 7, a son age 14 and a daughter age 12 and 1/2. Oren was diagnosed with Trisomy 21 at birth by a doctor and social worker. Oren is in regular classes(held back a year). All children attend public schools.
Both parents completed their bachelors degrees. Llana is a software analyst and Shafrir is an industrial engineer. The entire family are here in the country from Israel due to a job exchange with Intel Corporation since 1994.

The primary language is Hebrew with English being the secondary one.

The atmosphere was very friendly, open warm and inviting. After numerous phone calls back and forth (due to children's schedule, work, etc.) a time was established for this interview.

The interview was held in their home in Tempe, Arizona. The home was two levels, open and full of life. I was greeted by their daughter. The father was giving a shower to their son Oren after swimming lesson. Throughout the interview certain words and phrases were difficult to remember in English. So there were many conversations (translations) from Hebrew to English or to confer or clarify a word or meaning. Their grasp and extensive use of the English language both conversationally and technically was outstanding. Llana was very dramatic, uninhibited, expressive in her thoughts and reflections when talking about her son. Sharfir provided a more serious, inward approach with fortitude and depth of color sprinkled with many gentle tones.

The interview was informal free flowing and there was no holding back. The dialoguing continued each sharing their most unique experiences and moments. All of their stories were so vividly told. Each moment was like a reading a picture story book. Each moment in time was captured as if you were living it. Just like a Hallmark moment in time.

The Cook Family #9

Kelly is a single mother. She has one daughter Megan age 11. Megan was born in Phoenix, Arizona and relocated to Globe when she was five days old. Kelly and her daughter resided there for six years. Megan was diagnosed at birth with translocation by her doctor and nurse. She has two chromosomes that are hooked together on the 21st chromosome. This was not lost as is usually the case, but kept. Kelly and Megan moved to
Mesa, Arizona in 1989. Megan is the only child. Megan attends a public school in a special self-contained class.

Kelly had a high school and Junior college education. Kelly chose to meet at her office (court building) to ensure privacy. Kelly is an officer manager for the court system. Due to being a single parent and her concern and general safety we decided to meet in her office. I sensed with the security of the Court building and knowing that there were people around she would have a better comfort zone.

My initial contact was by telephone. Kelly expressed an interest in the study and was curious as to whether other single mothers were interviewed.

Her desk was piled with court cases and mounds of paper work and occasionally judges went in and out of their chambers. A picture of her daughter was displayed on her desk. She proudly showed me this picture prior to the interview. Kelly was very business-like.

The interview started out very serious and a bit somber. Kelly appeared to be nervous at the beginning and focused more on the tape recording instead of dialoguing with the investigator. With the issues of her divorce, a second marriage and her general beginnings her emotions ignited and silence at times fell with small pauses and “breaks” in-between each issue.

The Kennedy Family #10

Kathy and Ramone have three children. A daughter, Vanessa age 12, another daughter 14, and a son 10.

Vanessa was diagnosed with Trisomy 21 a few days after birth by her doctor. Her mother after the birth suspected that her daughter had Down syndrome. Vanessa has a visual impairment and has gone through numerous surgeries. Vanessa and her siblings go to regular classes in their neighboring school.
Kathy and Ramone both have their Bachelors degrees. Kathy has a Masters degree. Both parents are interpreters. The main language is English with the secondary being Spanish.

My first contact with Kathy and her family was over five years ago at my first "Sharing" meeting. I was enthralled at her grace, demure and articulation of the area of Down syndrome. She could reflect upon and communicate to a vast audience on any issue or concern from due process (tribunals), to inclusion, to sexuality, and to general awareness of this area with the utmost detail. It was then that the researcher knew that parents had so much more to say and were such a valuable and untapped resource. We then began to share and this is only the beginning.

I remember feeling like an outsider (in my mind) but soon I put all my prior misconceptions aside and began to see Kathy like she saw me...as a person first. Simply my job as a educator was just that nothing more or less. We have since over the years shared, collaborated, advocated and got involved in the core of the "Sharing" organization.

I am still elated and honored to this day to not only be accepted but an instrumental part of my 'adopted' family.

Kathy and Ramone both were present. Vanessa and her brother were in their rooms. Kathy dominated the conversation and Ramone added where he deemed necessary. Both communicate on a daily basis so what Kathy expressed had already been discussed and represented both as a solid unit.

The interview took place in their newly remodeled two-level home in central Phoenix. The rooms flowed into one another and the entire atmosphere was open and relaxed. Usually it is like Grand central station with kids coming and going, activities galore from soccer basketball practice, scouts, sleep overs, camping and the lot.

Tonight was an exceptional night. It was actually quiet.
The Campbell Family #11

Gina and Curt Campbell have seven children. A son David, age 12; three daughters, ages 5, 8, and 19; and three sons, ages 14, 16, and 17. David was diagnosed with Trisomy 21 at birth by a neonatal doctor. Prior to this birth the mother did sense something was wrong. David was born in the state of Utah and now resides with his family in Gilbert, Arizona. David and his siblings attend public school. David has been in a regular class setting up to this year. He is now in a resource class.

Gina and Curt have their high school diplomas. Curt has two years of College and a D.D.S. (schooling for dentistry). Gina is a homemaker and Curt is a dentist.

I initially met Gina at a "Sharing" meeting. She was warm, down-to-earth, sensitive, soothing, gushing with warmth, and very genuine. Gina conveys her thoughts and feelings through her heart and soul. She possesses the utmost care for all human kind and gives unconditionally.

Gina began the interview and Curt joined in shortly after his appointment. They were like two ships passing in the night. Plus the scheduling for this hectic couple was quite difficult but worth the wait.

We met in their home, even amongst the home renovations the atmosphere was still a serene and omniscient one. The family portrait was displayed with pride over the fireplace. David, her son said goodnight and really did not want to go to bed. This was a very healthy, happy, and hectic household as children filtered in or woke up for a drink of water.

It was a highly emotional evening with tissues flying here and there. Tears welled up in both the mother and researcher's eyes as deep and genuine feelings, stories, personal incidences, and experiences were told. No stone was unturned and all was very revealing. Gina spoke passionately focusing on her sons' strengths and achievements, her initial lack of experience in the area of Down syndrome, and her constant battle of reform.
Curt's perspective was more technical and direct in terms of terminology. His feelings were strong and adamant when discussing the education system. He conveyed the need for more self-respect and partnership as a solution to the current education system.

**The Thori Family #12**

Kathleen and Carl Thori have five children. Two children are fraternal twins. Clay a son 13 a twin, and two sons a twin 13, another son 15, and two adopted daughters; 22 and 21.

Kathleen and Carl have high school diplomas. Kathleen also completed Junior College and holds a Bachelors degree. Kathleen is a public assistant and Carl is a mechanic. Both moved here from the state of Alaska in 1981.

Clay was diagnosed at birth with Trisomy 21 by his physician. Clay attends special classes in a public school. All the other children attend different public schools in the area.

My initial contact was by telephone. We meet some years later at a ‘Sharing’ meeting. The Thoris' live in Phoenix, Arizona. The interview was informal, casual, and very informative. We convened in the living room. I sat on the floor surrounded by the entire family. Even Clay joined us and said a few words. Carl's relax nature conveyed his thoughts on numerous issues. Carl is a real character, very frank, candid and put on no pretense of what he feels and how life truly is. He was very colorful in his choice of words and possesses an outstanding sense of humor.

Kathleen was also direct, sincere, and strongly voiced her stories and daily occurrences with a blend of emotions conveyed in such words as frustrated, independent, hard work, achievement, intimidation, achievement, and respect.

**The Contreras Family #13**

Anita and Clemente have four children. A daughter Melissa age 16, another daughter, 12 and two sons ages 23 and 18. Melissa was diagnosed with Trisomy 21 four weeks after
birth by her doctor. Melissa had tubes in her ears and at least 10 surgeries for her hearing. 
Melissa and her siblings attend public schools in the regular class setting. Melissa is not 
attending her neighboring high school like that of her brothers. They did not have a 
adequate program to provide for her needs. Her parents were able to get her a transfer to 
another school in another district.

Anita and Clemente both have high school diplomas. Clemente also attended Junior 
College. Anita is a homemaker and Clemente works for the postal services.

I initially met Anita at a "Sharing" meeting. I was impressed with her pose, grace, and 
her natural knack for talking with people. She possesses a certain calm and warmth of a 
very genuine nurturing being. For Anita and Clemente both attended to matters of the heart, 
were not afraid to express their rainbow of feelings and truly provided the researcher with a 
fuller perspective of their experiences.

Anita’s devotion and advocacy ranged from being a school board member, still till this 
day President of “Sharing”, a mother, a confidante, wife, friend, colleague, ear to bend, 
and head to rest on. Clemente is a real genuine person and there was quite an interchange of 
conversation back and forth between him and his wife on the subject of their daughter.

Both shared equally and freely. The dialogue was reflective and corrective in actual 
events and times. The conversation was on a continuum...a dual interaction.

The interview took place in their Phoenix home. We sat around the kitchen table while 
their daughters were in the other room watching television. The smell of freshly baked 
cookies filled the room as we proceeded forward to territory once covered 16 years ago.

The Miller Family #14

Evelyn and Evans Miller have five children. Two of the children are from Evans 
previous marriage. Both have a daughter Brenda age 32, two daughters from a previous 
marriage 36, 42 and two sons ages 50 and 33.
Brenda was diagnosed with Trisomy 21 a few days after birth by a doctor. Brenda and her siblings attended public schools. Evelyn and Evans both have high school degrees. Evans also has a bachelors degree. Evelyn is a wife and homemaker while Evans is a Hotel manager. Both moved around the states a lot due to Evan's job.

I first met Evelyn and Evans at a “Sharing” meeting where their daughter was the keynote speaker. I was so mesmerized by this young woman’s poise and story that I introduced myself to her and her parents. We bonded, talked freely of life-long learning pursuits and the possibility of Brenda learning to drive. As of this moment this investigator is proud to report that Brenda does have a drivers license.

Evelyn and Evans are both articulate, caring and open minded about life. They are true pillars of strength, courage, and wisdom. This investigator met at their home in North Scottsdale, Arizona. We sat around the kitchen table and the conversation just took off from there.

They had massive amounts of documentation; from doctor reports, to therapy to school progress reports to thank you letters from children. Brendas life was shared along with the memories that they so vividly captured with utmost description on her birth. Each event and every moment in time to the present brought back the same gut wrenching emotions of jubilation, terror, frustration, disbelief and the daily trials and tribulations they encountered along the way.

The Duffy Family #15

Betty and Patrick have 5 adult children; Irene a daughter, age 40, three sons; ages 47, 43, and 37 and one daughter 45. Irene was diagnosed at birth with Trisomy 21 then referred to as ‘Mongolism.’ Mrs. Duffy, however found out about this diagnosis after she went home from the hospital with her husband.

All of her children attended Catholic schools in the state of New York (parents had to pay for this education versus the public which is free). Irene attended special education
classes in a self-contained room in the public schools at age 7. She remained in the same school and classroom until she was 18. Early intervention was not heard of at this time. Irene is currently not working or attending classes. She resides at the home of her parents.

Both parents graduated from high school. Betty is a housewife and Patrick is now retired. Betty's job was a housewife throughout her life.

My initial contact was by telephone with Mrs. Duffy. Mrs. Duffy was extremely interested in this study and anxious to tell her story. Without hesitation she began to share her experiences and concerns about her adult daughter (i.e. moving from New York to Arizona, possible adult classes, finding peers for her daughter, etc.)

The interview was held at their home in North Phoenix. They lived in a spacious one level desert landscaped home. Mr. Duffy was doing wood work prior to the interview. Irene joined in while Betty sat in her rocker. Patrick came in and sat near his daughter.

Betty did a majority of the talking. She was very frank, expressive, emotional at times, and reflective about her life experiences from birth to the present. Patrick expressed his thoughts and feelings throughout the interview. Patrick was a critical listener and assisted with additional items left out. At times Betty and Patrick conversed with each other while taking this remarkable journey back in time.

Given the age and time that had passed by it was difficult for one to recall specific names and details of school events. However this did not stop this couple married 49 years from expressing their views.
The birth of a child for most families is a time for rejoicing and jubilation. It is a time for gathering loved ones in celebration of life. However when families are confronted usually by their pediatrician first with an unusual unknown diagnosis and assigned a medical label other than “normal”, “healthy” or “congratulations” such a celebration comes to a complete halt. Such medical labels as “abnormal”, "mongoloid", “Mongoloid idiot”, “mentally retarded”, "trainable" and now “Down syndrome” stated alone or isolated in text followed by “I do not know” or with an outcome of “institutionalization” can be offensive. In addition these labels placed an insurmountable amount of preconceived notions about the future of their newborns. Parental feelings and emotions only escalated causing additional worry, stress, and confusion about the unknown. Even though the issue of emotions is covered under a separate theme of adjustment, this theme will overlap with the proceeding one. The intermingling of this theme lends itself to how adjustment has taken place. It is easier for some and not so for others. It all begins with the birth. At the bare minimum parents expect some concrete suggestions or answers. However this was not a common practice and generally advice for several families thirty to forty years ago.

The doctors were not very encouraging...they dragged it out. There seemed to be some "Mental retardation". She is "Mongoloid." The doctor continued...we know little about them and their age span is about 14 years. He continued to say...I would like you to leave her in the hospital and I will put her in an institution. The doctor continued to say that a pediatrician will come in to see you tomorrow. He is more knowledgeable. Well he never showed up and that is the last we saw of my doctor too.

Eve and Evan Miller

They called her Mongoloid. I thought that was the worst thing in the world. They did not know what it was. I was told by one doctor that it was the loneliest thing in the world. Even when I brought her home I had three other children, the family doctor who would come and give shots to my children said "Don't ask me, I only know one other case." When I asked where this child is he replied "in an institution."

Duffy Family
It should be noted that these families did not succumb to the advice and pressures bestowed upon them by their physicians and by society. The quality of parenting for many of the older participants had no direct effect upon their parenting skills or upon their child’s life. They still provided the best possible for their child as they did for all of their children. Any noticeable and documented differences in the raising of a child with Down syndrome at that time were more due to the lack of options, the lack of knowledge or information on the subject, and the lack of opportunities available at that time.

More recently over the last thirteen years with mixed tones in their voices Kathy and Carl expected an ethic of care and quality of life for their twins.

One doctor, the head doctor at the time when he found out said about our son(twin) He said” he has Down syndrome. Our society is not ready for any more people with handicaps. If he needs heart surgery I recommend that you not give it to him and just let him die and to take him off of his food.”

Thori Family

As recent as seven years Llana giving birth filled with emotion also combated a sense of confusion, worry, and wonderment for one of her nursing staff:

I was in labor all night. He arrived in the morning. It was quite strange. There was a lady who stayed with you (like a birth mother) in the hospital. It was like a special professional like a nurse. She was with me most of the night. We developed a kind of friendship over this night. I find it very strange that she did not say the blessing in Hebrew when my son was born. I thought she was angry with me. I did not know or was told.

It was not the reaction I expected. She put him on my tummy and did not say any good words.

Llana Uzily

Families seek care from their physician and other health care workers that are well informed, resourceful and empathetic. Numerous developments have occurred over the last 10-20 years to make high quality care a reasonable expectation for children and young adults with Down syndrome. Yet with only a two exceptions (one out of country) 13 out of 15 families talked in great length and detail about their delayed or unsure diagnosis, the
negative manner in which it was handled and conveyed and the impact it had upon their family.

Delayed diagnosis ran the gamut from the next day to 4 weeks later. Several parents captured their experiences of this process.

We had her four weeks before...we thought we thought we had a typical child. They said I think your child was mongoloid. The doctor who delivered her did not tell me. The nurses in the hospital did not give me a clue. Now thinking back for my daughter, no one said anything. They did not have me sign her birth papers as I did the other children. Our family doctor told us to take her home and bring her back. We will see if she gains some weight. He did not even deliver her. He did not say it was definite He was looking for separation of the toes, the simian crease. Well my other kids had that too! He said, well your other kids might have had Down syndrome.

Contreras Family

No one told us until 10 days later. Due to an early birth the doctors were more concerned about her surviving. Her features were questionable. They looked at her and yeah or maybe no. They were not sure.

Lyrae Thomas

We were communicating with a neonatologist. He was in Intensive Care for 10 days after birth. The pediatrician did call us the night before and said they had examined him and did not feel he had Down syndrome. So it was pretty iffy until we found out. We did not know till four or five days later.

Mack Family

The most mentioned issue regarding the medical profession was their lack of sensitivity, timing (telling a parent while still giving birth, telling one parent first), understanding, or lack of compassion for the families involved.

Such riveting stories begin with the Thori Family. Kathy articulates with anger and frustration as she relates her story prior to birth and at the time of delivery of her twins.

When I was four months pregnant I was big. I got big real fast and I was worried and ask the doctors if I was just carrying one kid. The doctors said don't worry your first kid was nine pounds two ounces. So after a lot of stress four weeks before I delivered them they finally gave me an ultrasound and I was told I had twins. In the delivery room Clay came out first and Ricky had to be pulled out by his feet. It was a teaching hospital so I figured everyone was interested in multiple births. The doctors said the heart beat of Clay is a little irregular and suspected something. I was trying to deliver Ricky and still pushing and they came over put Clay on my stomach, and told me he has Down syndrome. Then they asked me if I
knew what it was. I thought I was still pushing Ricky out and I thought he was going to fall on the ground.

Kathy Thori

Another parent like others was accused of doing something wrong.

When she was born one medical person said the reason she was like that is because I was doing drugs.

Kelly Cook

Many fathers voiced dissatisfaction about how the news was conveyed and how they were told separately.

While Bev was recovering the doctor came out and said to me that “I have some good news and some bad news. The good news is that both babies are very healthy, responded very well and the bad news is that we have a 95% chance that Morgan has Down syndrome.”

Ben McClaren

He called me in first. He did not know anything. It was not confirmed medically. The doctor did this through a blood test about a month later.

Evan Miller

This most private father voiced his thoughts about this experience.

He told me first. I found out from the neonatologist. They told me the problems. They threw out the reasons that he had all these medical complications because he had Down syndrome (voiced dropped). Right after they brought her down on a bed to the nursery. All these people were standing around. This social worker gave her some books. This was poor timing. They should have known us and waited a couple of hours before telling us. We needed to be by ourselves first.

Curt Campbell

A strong majority of the families' discussed that the medical profession was not listening or being intune to their needs, concerns, or having a strong general knowledge regarding their child as being diagnosed with Down syndrome. These professionals did not consider the parents inner feelings with regards to “there is something wrong with my child” or “spoke in terms we did not understand”, or showed “us outdated encyclopedia books” of what “these children” looked like.
Three out of fifteen parents knew and sensed there was something wrong with their child. Two parents knew prior to birth and one after birth. However these concerns do not meet immediately.

As one mother so poignantly tells her most intriguing story with warmth, humor, frustration, anger and relief:

_I knew when I was carrying. To be very honest...I think it was God talking to me. We had waited 8 years to have children. I did not take any fertility drugs. I was high risk. I gave birth back East and not here in Arizona. They (the doctors) were very unfamiliar with Down syndrome. They had me go every two weeks. They knew it was a boy and a girl after 4 weeks. I would say check Julias neck fold for thickness, check the circumference of her thighs verses her legs and all those measurements came up negative. I asked them to check for her heart all came up negative. They were born premature. It was a regular birth. They were strong. First thing I asked when Bobby was born was did Lulla have Down syndrome. The whole operating room stopped and looked...replied" she is under a lot of stress."_

“Our daughter is fine.” Next we went to the recovery room, the kids were screaming and doing great. Then I said “does Julia have Down syndrome.” Thinking they were going to tell me any minute. I got the pat on the shoulder and a reply that” she is just fine. You are under a lot of stress.” I requested a blood test. The doctors replied “it was a waste of money and our time.” This was in Boston, the medical Mecca of the world or of the USA where my children were born.

_Come the next day when it was time to go home, I would not sign the discharge papers until my daughters blood was taken. In walked 8 physicians (this was also a teaching hospital) who stated that “your daughter is normal. We have checked her out, examined her, she does not have it.” I replied that “I am not going to sign...I know she has it.” I did not sign, they stayed in the intensive care unit for 7 days and one week later they came back to tell me that after they had taken blood the results showed she had Down syndrome. Of course with tons of apologies._

_Paula Stella_

While another expressed similar concerns and cries out her dissatisfaction when not receiving a thorough diagnosis of the situation. The Campbell’s story was not uncommon:

_I never felt the same with David as I did with my other children. He was my fifth child. I feel it was Gods way of gently preparing me because during the whole pregnancy I sensed there was something wrong._

_During the delivery, my doctor was on lunch and turned him over only one hand, because he thought he might have Down syndrome. Nothing was on that hand and he left. Nurses can’t tell you what is wrong...there was nothing wrong with my baby and they gave me something to calm me down. I knew something was wrong._

_Gina Campbell_
Yet another mother enraged and intune to her babies needs recalls her incident of a medical professional as being insensitive to her needs.

When I was nursing her...something about her relaxed nature of her body struck me. It hit me like a ton of bricks...she has Down syndrome. When the pediatrician came in he said" looks good, good muscle tone, (which is a joke).” So I asked “when would something like Down syndrome show up?” He retorted nervously and in avoidance... “Down syndrome, Down syndrome...why would you say something like that.” “There is something about her body” I replied. “Well you do look for that crease, but” he said “I have that too...it does not mean that. She is just fine.” I said “ah phew...we are going to be laughing about this later, talking to her child...that you were such a funny looking baby.”

The next day, he came in early in the morning and now that he could look at her in the light of day he said “it would be a good idea to have a blood test.” Well the nurses said something too... “the nurses” I raised my voice and was angered. “I said something to you!” I was angered that he did not take the time to listen to my concerns.

Kathy Kennedy

Two highly educated parents one with a masters in engineering and another with a bachelors degree reflect upon the issue of knowledge and intelligence and how this information about their daughter was conveyed in a most unprofessional demeanor.

When you are in a Health Medical Organization (HMO) you do not know who your doctor was going to be . Ours just happened to be a pediatrician who was also studying to be an attorney. He was in his last week of practice as a pediatrician. He must have been thrilled with us. He tried very hard to talk about it and to explain to us “what loving children these are and how easily they are to be trained.” Meaning trainable. I wanted to look at him and just say are we talking about a person or a golden retriever. I feel a lot of pediatricians and a lot of the medical community are still very dated in their approach and explaining to parents about Down syndrome. He just kind of well pat her on the head and she will be real happy all the time. In retrospect...just go away. I just wanted them to talk to me like a medical doctor about her medical problems. I never felt that I got that.

Eliz Hughes

While two other doctors explanation was just as belittling:

When my son was born there were no tests. We did not know. When I was going home, he (the doctor) told me don’t leave I need to talk to you. He said give me 15 minutes and he came back. He came back with these books and had them open to these pages. He said your son is born with Down syndrome. We did testing to make sure. So he told us about the testing, blood work, showed us pictures of genes. He used big words and "I told him you have to speak to us in plain English because we are Indians and we don’t know these big words.”
My son was born in Phoenix not in an Indian Hospital. Our doctor was a white man.

Tricia Enos

For another (currently single) mother, six years ago recalls:

He tossed this book across the table written in 1965. He said that this is your daughters future. Of course in it were kids in institutions, and picture of these kids. It was a bad deal. He told us that your kid will never marry, or learn to walk or talk or go driving. He said you can take her home and nurture her.

Lyrae Thomas

Even a social worker did a special “hand off” of material to one mother as she conveyed this story:

When my daughter was in the Intensive care unit a social worker came up to me and whisper... “does she”... ”Yes I boasted she has Down syndrome.” “Do you know about it”...then she passes out under their clip board this book. Well she starts passing it as some secret hand-off. I thought to myself here I am standing in the hospital ICU where people in this room surely know at least fifty more things about my daughters life than I do and she is pretending to hide this!

Kathy Kennedy

There are some pediatricians another mother concludes...well I am more knowledgeable than most. “Give me a break, this is a little child, a little boy, with a classic case of Down syndrome.” As one parent begins to tell a story about her friend.

I have a friend who lectures to pediatricians. My friend has a child with a rare birth defect. They often talk about the quality of life for these families with a child who is handicapped. In fact, the current manual OB, there is a paragraph that states your job is to deliver only healthy normal babies in this world. When a doctor asked me about this of course being the mother tiger I am...with sadness I said “you don’t know what you are missing. Yes, if you asked me if I wanted a retarded child I would have said are you nuts?” But not knowing the growth I would have obtained.

Gina Campbell

Many of the families also expressed that their doctors gave them insufficient medical advise with responses like “I do not know”, or “I don’t know what to do in these situations” were not thorough and were not considerate to the pressures upon the parents of other life threatening medical complications.
Forty years ago Patrick expressed throughout his years of wisdom that:

They did not know what it was. One doctor said one thing and another something else. One doctor said it was lack of oxygen to the brain. You did not know who to believe. There were few cases and no direction. There were no specialists. No where to go.

Patrick Duffy

Twelve years ago as two parents reflect on their experiences:

My doctor did come to my room the next day. He said, I am heartbroken. I know what you are going through. He is a real sweet man but I said "No you do not know what I am going trough." My doctor found out later. He said you have a real sick little boy...with endacolititis, poysythemia, plus Down syndrome what do you want me to do? Do you want me to save his life? Later I wrote him and thanked him for saving our boys life. He wrote back and said I never know what to do in those cases. I do not know if the parent wants me to let the child live or not because it may be a burden.

Gina Campbell

We brought her home and she was somewhat jaundiced. The doctors said don't worry just take her out in the sun. If she looks yellow in the house take her outside. Two days later I went back to the hospital and they put her in the Intensive Care Unit and into double photo therapy. Her bilirubin levels were extremely high. It angered me that children with Down syndrome have a tendency to run extremely high billing levels. I believe it was his duty, knowing that to tell me to bring her back in 24 hours to be checked.

Later on ...it was the day I brought her back that pediatrician said he wanted me to stop by his office on my way home. Luckily Ramone met me there. The doctor did not even say bring your husband. We got the carotypes back...the doctor hesitated and stammered and he finally said." She has Down syndrome." He was so uncomfortable he said "this is what she will look like." He held up an encyclopedia picture. We proceeded to grope our way home. You should not let people drive in this situation.

Kathy and Ramone Kennedy

Only four years ago one mother recalls her reaction and the insensitive nature or matter of fact of the diagnosis.

Wow the pregnancy went great. It was a natural child birth while my others were C-sections. When he was born he was not breathing so they had to resuscitate him. Then they took him away. Later the pediatrician comes in and says well we have a few problems. Doctor continues... "he has an intestinal blockage and needs to have corrective surgery.

He has two holes in his heart. And oh like by the way now the doctor is laughing and chucking ...he also has Down syndrome."

Maria Conrad
Happily, some parents have experienced the “other side” a more “optimistic side of the coin”. Several professionals provided a more positive attitude and philosophy about children with Down syndrome. One parents most heartwarming and sensitive story, while in Israel recaps how her doctor providrd a “special touch” for her and her child.

The doctors here are all so busy and not very friendly. I waited for him and I thought of the worst things. Then he came in very special. He (the doctor) held Oren wrapped in a blanket. He was wrapped in a cute way. Like a baby from a picture. Gently he said your son is okay, but he has a genetic problems. I did not know that there were so many. He let me hold him. You don’t know what you think in these moments. I just held him. He was so cute. I do not know what is Down syndrome but we will learn it together.

I was treated special. The hospital tried to locate my husband who was on business in the USA. They tried to call him for me.

They gave me a room by myself which is not the ordinary. Every hour or two someone came in and asked if I wanted to talk, or see some books or if I wanted anything.

Llana Uzily

I think another parent expressed that the medical profession is an individual problem.

Our pediatrician who was not around at the time feels that children with Down syndrome are no different than any other child. It is critical that they are all different and are all going to reach different plateaus. To generalize because of a spare chromosome is ludicrous.

Eliz Hughes

One father articulated even though he was not happy with how the words came out at the time, looks back now and adds:

Even though our doctors were not real cold in their approach they were somewhat sensitive. How sensitive can you be? I do not know how easy it is for anyone to say that your child has Down syndrome.

Ben McClaren

Theme Two
Adjustment Issues

As explained by families it is painful beyond belief to be told that your new born child has Down syndrome. Instead of feeling that special sense of joy, all those months of
waiting, your world now is “turned upside down.” For the baby you were expecting never arrived.

The initial responses ranged from those of “shock” to that of an intensive crisis. One parent did feel relief while others did not. The venting of such responses intermixed with evocative words were used by families to describe their experiences. Such emotions at the time parents were told took the form of shock, numbness, isolation, grief, helplessness, powerlessness, rage, anger, disbelief, denial, fear, sorrow, disappointment, sadness, self-blame and guilt.

Every family discussed their emotions at time of birth as:

*Even though I cried...we were in shock I was relieved that I knew. For I did know.*

Paula Stella

*It is like being slapped in the face. It hurt real hard at first, but once the sting goes away and it takes a long time for the sting to go away. You begin to realize what a blessing...just like your other children.*

Eliz Hughes

*I cried, screamed and cried and denied it. We wanted to have four children and I said do not ask me to have another child. I did not believe a thing. I could not see that he had Down syndrome. Now I look back and see his new born picture...it is like a slap in the face.*

Maria Conrad

*His dad took it real hard. He said he would grow out of it. I told him that it will be with him the rest of his life. After that he never talked about it for a whole month.*

Tricia Enos

*Looking back at that time it just seems like a blur. There were so many health issues that we were trying to get through: he had two holes in his heart, he was on life support, was not breathing. It was a shock, once it settled in we just needed to get him health and out of the hospital. That was the primary concern. Then we kind of absorbed all the implications of having a child with Down syndrome.*

The Mack Family

*When I was told I just collapsed on the floor. "I went around still on medication unaware...."*

Betty Duffy
Even going to the geneticist I was not comfortable with anything they had to say. I just wanted them to tell me that it was not true. My emotions were ready to explode. I was in denial.

Anita Contreras

He started to cry and buried his head and balled. He was really shook. I was numb. After he was delivered I thought do I name this retarded child after a dear man (my grandfather). But then again who if anyone would have loved him more.

Gina Campbell

These emotions ran the gamut and were highly individualized to the diagnosis. The intensity of the responses and manifestations of reactions varied widely among and between families. This depended upon the stage of life of the child or young adult, the time in history (one year ago verses forty years) the personality and individual make-up of the parents, parental aspirations and expectations, self-esteem and feelings about how their son or daughter with down syndrome was addressed.

As one mother (Anita Contreras) raising a teenager daughter explains:

... “as a child you feel there are so many fears and worries and then what next or ... then it gets better and you are more accepting. Life goes on like normal. It is not over here. For now it is like the beginning. Now I feel those same feelings and have those same thoughts as she gets older.”

Another reflected upon “why me” or a little self-pity ridden with guilt as to why she had a retarded child.

It was how could I have had a retarded kid. Both Mike and I were fairly smart people, did not do drugs, etc. I had all these guilt feelings as to what caused this and we never did anything that we should not have done.

Lyrae Thomas

Past experiences or prior contact, knowledge or images of children with Down syndrome played a role as to impact upon the parent and their initial reaction to having a child with Down syndrome.
When I was told my child was "mongoloid"...well the only one I knew was five years old and he could not do anything. All he could do was sit on a rocking horse (toy) and rock. He had a blank stare in his eyes. He died when he was seven...I shed a few tears.

Eve Miller

You are happy to have a child. You go along and then they tell you she has something you have never heard of.

Clemente Contreras

I was familiar with the magazine articles but not familiar with it for real. I knew generally, but not sufficient to have a child.

Kathy Kennedy

They had run some tests and we had to wait through the weekend to find out the results. We were nervous and scared. We panic when something is wrong. So we were a nervous wreck...finally he sits us down and his bedside manner was horrible. I hate this doctor, even to this day. He is a geneticist and his wife was our pediatrician. He said I have some bad new. Well my husband (at the time) knew. He was raised with a girl with Down syndrome who was severe. She was raised by older parents...and his immediate thoughts was that our daughter was going to be like this girl. He literally just passed out, fell on the floor, turned real white and had tears in his eyes and got all choked up.

Lyrae Thomas

All interviews were colored with emotions and the language of emotions. Parents cried and laughed and grew angry and frustrated within minutes of each emotion. Sometimes changes in topic occurred or were stopped short and other times long pauses of silence followed those more emotional moments.

Emotional issues were not separate or distinct but rather overlapped and intertwined with numerous concerns. Even those who were apparently more comfortable with their emotional level, appeared to have traveled a long way. It was a most tiresome journey and often trying for some and for others a constant reminder or coming to grips with the road they finally chose.

Many parents went through their own personal grieving process. Some did not even know at the time. One mother relays her news:

One pediatrician sat me down and said...there is something you need to know. You are going to go through a grieving process...do you understand. I'd said no and started to cry. You are going to cry...he walked me through what it was like. I felt
better. I had to be brave and walked around the corner of the nursing station to my room. Then I burst out into tears.

*Gina Campbell*

While other parents had a complete opposite response and believed that mourning was a horrible thing to do.

*I get angry when parents go through a mourning period. They are mourning a healthy child. How about a live one!*

*Bev McClearen*

Many fathers told their own personal plights of how they addressed their feelings and emotions. One father explained his rare circumstance and how he handled his emotions.

*I was out of the country at the time (in the USA instead of Israel) and I received a phone call from my wife. I did not question it at the time. Then she told me he had Down syndrome. The next 30 hours were strange...I was on a waiting list to get home. On the other hand I had lots of calm hours to myself. This helped me a lot. I am the opposite of my wife. I do not get out my feelings directly. I am more logical. Here I was thinking people are raising all types of kids...more and more thinking brought me to Israel with a full mature and complete decision of what was happening.*

*Shafrir Uzily*

While two other fathers captured a past experience in their life and reflected upon this image as it related to his newborns life.

*I remember as an athlete playing games to raise money for those kids...it did not make me feel sorry and really did not affect us. I recalled having to separate my wife from the doctors. She was under a lot of stress. As she said “When you all realize that I am right we will all be a little more happier.” When the tests came back I took it hard. I did not want to believe. I went home and did not want to talk to anyone. Then a few days later this man shows up at our door. He said he was Dr. Cooley. He said he had a daughter with Down syndrome and wanted to talk to us. I just closed the door in his face and got my wife to handle it.*

*Jim Stella*

*At the time of our sons birth I had no prior experience with Down syndrome except in Junior high school. I was a counselor for children with Down syndrome. So I was not apprehensive from that aspect. When we found out, it let the air out of our sails. Here we were extremely excited about twins. Then we did go into a bit of depression.*

*Ben McLaren*

Others talked about personal loss or death mixed with guilt:
It is almost like loosing someone through death. I never knew how Clemente felt because he was so strong for me. I was a basket case. I was lost for the first year of her life. I regret that because I was not able to take the joy for having her as my first daughter.

Anita Contreras

Another mother fell silent as her voice quivered to explain her riveting experience.

I was barely nineteen and my husband was a jerk. I seriously considering giving her up for adoption but I could not just leave her at the hospital. I talked to the social workers a long time. I had a name picked out. I did not know it was going to be a girl but I knew.

I had a hard time naming her after my mother. I thought I might save the name for my next baby.

Kelly Cook

Stress came up in 13 out of fifteen interviews. Stress took various forms from handling it on my own, constant worry, to" destroying the ground you walk on" to simply overwhelming, to monetary issues.

Two single parents looking forward to the future life with their child conveys a compelling, individual and daily concern.

I worry about her so much. You do not have the liberty to let someone else take her for a while. Even though she is the light of my life she is tough. Even when her father and I were together I did no have that. He was in denial and I still think he is. He is one of those people who feels very strongly and says he understands and accepts her for who she is. Even though he tried to make it look like he accepted it I know he can't. That broke my heart because I needed the help.

Lyrae Thomas

When she was first born and once I had decided to keep it. The decision had been made and you deal with it. There have been stressful points. There are things I have to do that normal parents do not.. I have to go to meetings (Individual Educational Implementation Plans-IEP), sign up for these programs and I can not leave her alone. I have a sitter for her, I have to come home right from work, and She does not take well to my boyfriends.

Kelly Cook

With lowered voice, anger, and seriousness one parent relays back to her first pregnancy:
Of course it caused complete and emotional upheaval. It did destroy the whole ground you walk on. My first pregnancy I worried every single day. I thought about what physical deformities will she have, will she have all her toes, etc. It crossed my mind. However when my first daughter was born such a perfect specimen when it came time for my second pregnancy I did not think about it.

Kathy Kennedy

Fathers were not excluded from the initial stress of the situation.

It was more stressful for his dad. He wanted him to be like him when he got older and said that it would be harder to do things. His dad is in construction and wanted his older brother and him to do that.

Tricia Enos

I remembered us both being real tired and yakking at one another and our tempers were short. It did cause underlining stress.

Ben McClaren

However it was not uncommon for mothers to carry all the weight on their shoulders regarding her child.

She took on all the stress for everybody. She carried it on her shoulders. Lots of it...I went to sleep thinking of it, waking up with it, constantly thinking and even when doing my everyday things thinking...retarded. It was there in my mind. It was not Melissa but the disability. It was the fears of not knowing.

Contreras Family

While at the same time several mothers looked upon their husbands as pillars of strength so that the stress became evenly weighed.

I never knew how Clement felt because he was being so strong for me.

Anita Contreras

No my husband is strong. When we found out he just accepted Levi right away. He followed after him. For me it took two weeks to even say it is okay to love him. Before I was afraid of getting too attached. My husband was there when I needed him.

Maria Conrad

Financial stress became another underlining factor regarding the burden upon the family unit. As two families relate their individual experiences:
The idea of having twins was a shock enough. Carl was 38, we lived in a house big enough for three people, we did not have much money, then having a child with Down syndrome on top of this caused a lot of strain.

Kathy Thori

For the Hughes stress is a bit of an issue for Tom. He replies that “for me the therapies cost twice as much as a mortgage (house) payment.” Elizabeth adds that:

“It is not fair that the insurance companies and health and human resources agencies get cut rates and if you are private paying you pay quadruple. Why doesn’t everyone have to pay the same rate. So that was stressful. It was very stressful when I looked at him and said well we are going to have to have another baby now (she laughed).”

Throughout all interviews, a tremendous amount of emotion was evident in the relation to school issues. Even though schools, teachers and the education system are presented as a separate theme the emotional side of this aspect deemed worthy of mention in this section as well.

All families conveyed feelings of tremendous frustration and anger when discussing the education of their child or young adult. Twelve out of 15 currently (several were not attending school yet) regard the education system as inadequate, a battle grounds, and a lack of mutual respect. Both fathers and mothers took equal and strong views in this area.

Mothers views went from rage to anger to frustration all within a matter of a few seconds. Some asked if we had a few years to explain this inner frustration of not having adequate provisions to continually locating provisions and placement for their child, from watching and questioning the educators every move, and to finally having to do their own investigation and special homework assignments.

For one family it was a difficult time (forty years ago) to explain to someone in this day and age that nothing was offered or provided.

She had no education. They had a doll house, blocks, and things like that. She spent nine to ten years in one room.

Betty Duffy

140
While others more recently believe strongly and with conviction that:

*I think parents are forcing the education system to provide and educate her. I do not think the education system is capable of doing any long term. The parents continual overbarring involvement show that the education system can not be trusted. The intent is to truly educated all children with handicap kids. The goal of our district is to accomplish the bare minimum and what is cost effective.*

Kathy Kennedy

*It was a constant looking over their shoulders (meaning educators). Because they understood but did not have it in place. They did not practise it. They could say this and that and get away with it. I found them falling back on what they should have been doing with my child’s education. So it was not a consistent program for my daughter and it took away from her education.*

Anita Contreras

*They are not ready for children with Down syndrome to be in the regular education in general. Because they think that the regular education kids are going to be ignored. The teachers are so afraid...they have no education about special needs kids. They have not had to be educated about special needs kids because you have special educators. Well with the changes...there will have to be some co-teaching and that will be hard. It is like changing your whole philosophy in education.*

Stella Family

A hot and debated topic for parents is the issue of the IEP or Individual Educational Program. It is just “lip service” given to show the importance of the parents’ role. It is alarming to see as indicated by a strong majority of these families the limited amount of time the parents take in actually deciding what, when, or how their child will be taught. Many IEP conferences are predetermined with already documented placement, related services, goals and future plans.

One parent related a very humorous story in relation to the parents presence and participation at these conferences.

*It was in the morning and both parents arrived to be placed at this round table with an entourage of professionals spanning the services that their child was receiving. The school psychologists lead this session and all read their reports on what their child’s future. Upon completion of this lengthy meeting and the mass amounts of paper work that prevailed the parents were asked for their input. The mother got up with all the documents in hand and ripped them in half. She then replied, we need sometime to think about these reports and will then respond by having our own in a few days. The parents walked out.*

Kathy Kennedy
While another mother on a more serious side noted that:

*I think the hardest part of the educational process is that I have to go to bat every single day at every meeting. There has not been an IEP meeting where my head did not throb, where I did not cry...and say this is my son. Yes I see he is mentally retarded but I see so much more. It has made me an old woman...but it is worth the battle and I would do it again.*

*Gina Campbell*

Compliance and the law, Due process (tribunals) and the actual provision for the most an environment that best suits the needs of all children had no boundaries with this mother.

*Our home district (on the Indian reservation) wanted Brian to come back to school. I did not want him too. The superintendent told me if you are going to send him there you must pay for his transportation. I did not know, about that so I called Pilot Parents (support group). They told me that they could not do that. So they sent me the information and I called him back and said I can see you now. I did my homework. I went to visit and took Brian with me. I stayed five hours and I asked them for information. I said that the home district did not have one on one, or a feeding program for my son. Well, the superintendent said he could not pay for this. I replied "you are not paying for it out of your pocket, the school is." He was trying to find a way for me to pay for it. So I said, "Do you want to look at my papers here...my laws and my rights?" That superintended looked at me like...oh I will get back with you. He did and I got him out of the home district into a special school.*

*Tricia Enos*

In addition there are numerous barriers that might account for a discrepancy between society’s values and that of parent participation in this decision making process. These might range from the school’s allotment of time and paper, and attitude, but this does not explain how they are not within the intent of the law.

Fathers voiced similar and yet stronger views as often felt the adversary in respect to their child’s education.

*The schools have laws to govern and are supposed to provide but they wont provide unless you make them. As long as you don’t say anything they want. They will try to keep you in the dark about everything you have the right to. Until you investigate and even then after you show them, teach them, they will do it only to appease you. You have to keep them on task.*

*Clemente Contreras*
The problem is their attitude. We are the experts and they do not know everything either. It would be better if attitudes of the educators were better and provided a softer approach...like a give and take. Instead they come in with an attitude that they are right and we do not want to mess with you. Hey who are you people!

I went to college for nine years and so what. I would have gone for three months. I do not want you to be impressed with me. So I don't expect you to come across with this attitude that you know it all. I don't believe anyone does. They just get under your skin that way and the put you on the defensive.

_Curt Campbell_

The importance of emotional support is in school achievement. If you want children to grow up in an affectionate environment they have to interact with their peers. Their peers in turn act as models from which to learn how to express feelings, emotions, and thoughts.

Inclusion which will be discussed in full length as an overall theme, or integration of child with Down syndrome into the educational classroom setting is a very high powered emotional and trialsome journey to take.

As one parent explains:

_On a more personal note my daughter is now integrated into the regular school program. She befriended an obese child who himself had been ridiculed and had no friends. In turn, this obese child assisted my daughter by not only being her friend but also providing her with more motivation to come to class after playtime was over._

_Kathy Kennedy_

Regardless of the arena; home, school, or within the neighborhood many mothers had to overcome feelings and attitudes imparted upon them in public (society).

All of these families have expressed an experience of ridicule or insensitivity or plain ignorance placed upon them by society. Some have experienced a sense of isolation, powerlessness, and of being afraid to be the only one:

_I would look at the street up and down to find a child with Down syndrome. I felt alone. If someone would have come and told me that I would not have had anything to worry about...we did not know what was going to happen._

_Duffy Family_

_My worse moment was taking Brenda to the store(choked up and lowered her voice). People would just stare and her and look me over. Just watching their
expressions...some would laugh. Some would hit each other and whisper like she was a little freak. At that time the doctors said there was one born out of every 10,000. Now 10 years later it is 600 or 700.

Evelyn Miller

When I walk through the grocery store I can tell the people that know and those that don't know about Down syndrome. I use to be like those people too. You look the other way or you don't want to be confronted with an issue that is uncomfortable. This is because of ignorance. It is simply like that.

Lyrae Thomas

Subsequently we were in a movie theater. I went out to the lobby and someone asked if she was a "Mongoloid." There are some moments depending upon the party asking that I would have taken it offensively. But you have to give people credit for asking. It is scary to ask someone. If I ever wrote a book it would be called...They either stare or they smile. That is the reaction you get in public. No one really frowns at them.

They stare like they are trying to decide because they are not really sure. I had someone ask me if she had a little bit of Down syndrome. “Yes I replied and I was just a little bit pregnant when I had her!”

Hughes Family

One lady I met in the grocery store who was delivering before me asked about my child. She said what did you get and I told her. She said how exciting and she held firm onto the cart. I thought I would have to get emergency for her. You have to treat all the people you tell. You somehow digest it or take it and then everyone gets it.

Llana Uzily

This in turn has subsequently added stress and “burden” upon the family unit. However no matter what the experience 15 out of 15 families convey a strong sense of family strength and bonding.

At times they formed a strong enough bond to retreat within themselves. They learned to live and accept the disability and protect the child and meet the needs within the family structure. These families' parenting skills did not suffer or falter due to the fact that they had a child with Down syndrome. For there are a combination of factors (variables) that incorporate any families lifestyle. These may include (as previously mentioned) the age of the of the parent, rank of the child within the family structure, siblings, additional roles, or
society at large. However, no one single factor can be pinpointed as having a direct reflection upon raising a child or young adult with Down syndrome.

Not one family viewed their child as negative. All parents viewed their child as just that a child or in some cases a person first. The time to adjust again was dependent upon each individual family member individually and collectively.
CHAPTER VIII
Theme Three
Family Issues

The parents are not the only ones caught up on this "emotional rollercoaster" or in some cases traveling to an unknown world. For extended family and siblings also experience repercussions from having a member with Down syndrome in their family.

Every family reflected upon how these reactions, interactions, adjustments with family members, grandparents, brother, sister were influenced by not only the child's presence, but the mere discussion of the child.

Talking to their parents or addressing the issue in an open manner was not only difficult for some families but also was not immediately done. Several couples related this in the following quotes:

*My mother did not know about it until she was four years old. It affected my father at the beginning. He would just sit out and look at our garden. Our neighbors did not even know. It was just Patrick and I.*

*The Duffy Family*

This was difficult. I did not want to tell anybody (in a lower voice). I felt as if I let everyone down. My brothers have beautiful and wonderful kids. This was my husband's first baby girl and grand baby. We kept it to ourselves and we did not tell anyone for quite a while. Sydney was in the hospital for 30 days so we had time to think. Mike sat down with his folks and they started to cry. It was pretty emotional. My father-in-law at the time, did not pick her up or love her until she was two years old. That hurt. He just did not know how to deal with it.

*Thomas Family*

On a lighter side, but still difficult at the time one family (the Kennedy family) relates a story on how they told their friends when they first came to the house to see the baby.

*I guess initially nobody said anything. You know you call people. We have this wonderful and beautiful little girl. She is still wonderful and all of a sudden just not perfect. I just could not say anything. I could not tell people she had Down syndrome. It was like stabbing me in the heart with a knife. Same thing, same affect.*

*However all these people are now coming to visit. It was impossible for me to tell anyone. So as (mother laughs and father smiles) Ramone runs out of the house as people are about to come into the house and says in one full sweep...*
"Baby is fine, Kathy is fine, baby has Down syndrome and we are happy." Now as the mother continues... "we are having catatonic people walking in the door."

Even though the initial reaction was delayed or encompassed with "shock" by many extended family members, a strong majority of families did convey favoring or supportive experiences.

All of my family was very supportive as they are to this day. For us it is just one more family member and we just go forward.

Hughes Family

My mother was okay with it. My brothers and sisters were understanding.

Enos Family

We have a very strong family network. Even though Seans relatives live in Alaska, far from us they have been great. A majority of my family live in Phoenix. They have been great also.

Mack Family

Some grandparents and great grandparents were old or tired. Such news and attitudes held by their own parents can be devastating to these families who are at a vulnerable state and just merely struggling to cope. Even when the families tried to or attempted to offer information and clarification on Down syndrome, it was still difficult or nearly impossible to accept. As quoted from several families:

My grandmother showed real pity. Poor me this and poor me that.

Maria Conrad.

My mothers reaction was...why is God punishing you that way. She still struggles. It is not the mother who has the hard times but all those who interact with her child.

Gina Campbell

When I called my family none of them called back to check on how she was doing. I am the type of person who if something is going on with my family I would say what can I do? How can I help? I update myself on how things are going all the time. On both sides of the family I did not feel they did this. No one ever took the time to ask what it was. Not even my mother. They were more concerned about me than the baby. Even now when I share some of her accomplishments with them
they say “oh really...” They are not involved with the excitement as with our other kids.

Contreras Family

A lack of understanding or misunderstanding followed by ignorance fear, or just not knowing was not exclusive to parents and their families.

The hardest comment for me was from my cousin. She was trying to comfort my mother by saying that Gina always loved children and now Gina will have one the rest of her life. I did not want to hear this. I did not want to think David would be five the next fifty years.

Gina Campbell

My mother was very negative. She always is. She still tries to make a big deal out of it. Her age and generation attribute to this attitude. They grew up with the old way of thinking that differentiates them from the rest. She still thinks we have an inter-racial marriage...oh come on! (Referring to Maria as being Cuban).

Brian Conrad

My brother and sister-in-law who was pregnant a few months later thought she could catch it or something. Intellectually she knew she could not but there was that fear of “My God what if I have that thing...” Everyone processes and accepts things differently.

Mack Family

They could be a little more supportive. I feel our relatives just do not know how to treat her. They do not know how to react or how to talk to her...They do not feel they could go up to her and say hi how are you feeling? Just like they would talk to our other kids. There is no in-between just either one or the other.

Clemente Contreras

My brother is around but not consistently. Another brother lives in Globe, AZ and resents my mother for spending so much time with Megan. Thus his kids resent me. I have not done anything to him. My mother seems to think that it is because she does so much for me and Megan he feels that way. It is just me...I need the help. They are married. They have that support where I do not.

Kelly Cook

Depending upon their past experiences, knowledge of or connotations behind this “medical label”, strength, spiritual and or religious beliefs some extended members experienced difficulty dealing with having a grandchild or relative in the family with Down syndrome.
I have a brother that did not call us for 10 months to even acknowledge that Conner was born. People feel very uncomfortable about it. People avoid me because they do not know what to say. There are others who are comfortable with dealing with it and say they can not imagine what it is like. However they are there when you need them or just want to talk.

Mack Family

When my mother found out she went to the library. She never said anything except that they are “mentally retarded.” We came home and I could not speak to her for days. Oh my God she had waited for me to have children all these years and now I have a child and I do not know what it means. She had read all those books written in the 1950’s and 40’s. Her response was... “she will be fine. She will be with you forever and she will always be your child. We will be fine with the problem.”

I know she was being as supportive as this knowledge left her to be. I told her... “I don’t want her to be with me all the time. I want her to have a normal life, get married, drive a car, and have a job. No this is not going to be her life. We did a lot of self-searching and when we did not find it...it was done. We treated her the same.

The Hughes Family

On a more refreshing note:

Even my 93 year old grandma “Nana” when told about Julia said... “I don’t know what this Down syndrome is but she is going to grow out of it. She will be just fine. I will pray. I called her this morning and told her about how she was talking, riding a bike and out of special education classes. She replied... “I knew she would grow out of it.” She has been the most on target. No, she is not going to grow out of it but characteristically she is really so unlike other children.

Paula Stella

The religious celebration for this family did not come without a story.

The day he was born was a special day. His beginning was very hard. After eight days there was a special operation. This was an event. The whole day I did not know what to tell people. So I prayed and I don’t pray. I was not sure if I could keep it to myself. If people would come ahead of time ...but no one came because everyone was so busy the planning of this celebration. I did not know how to say to Shafrirs mother and father and mine. You can not do it like... “oh hello and I have a statement to the family.” I first told Shafrirs mother. I pulled her aside and told her that this boy has a problem. She was sad. I asked her to tell her husband. Then I told my mother and in her way she was very naive. She did not know about Down syndrome. I told her the little that I knew about genetics, mental retardation a special look. She was sad. Then I told my father and he heard about it. Later he opened all the encyclopedias. It was not optimistic information because the books he had were...said they did not live long and talked about institutionalization. I then asked him to tell anyone related to us or he felt like. I said that we were not going to hide it and they were doing me a great favor if they transferred the information.

Uzily Family

149
For the most part the number one factor for parents and family members was their own personal time or time to adjust. For siblings it was the excitement of having a new brother or a sister. Nothing more or less. If the siblings were too young they just grew up with knowing they had a brother or sister. If they were older when questions would arise that is when parents would explain. The explanation some parents would say would come from your “gut” not from a book, written word or suggested and sometimes told comment from another professional.

The treatment and handling of any issue relating to their siblings acceptance did not change with time. It remained the same for all families interviewed over a span of forty years.

We told the rest of the children not to treat her any different...she is like you. They really never hit one another. But she did get punished like everyone else. Her brothers and sisters did spoil her with a tremendous amount of love.

There was a pause and Betty brought back a black and white family portrait of the family when they were little. She continues... “They had a ball. I think it was better than having five normal children. She was a balance wheel for them. She taught them an awful lot. She taught them patience, to love, to cry and then they (her siblings) turned around and taught her. She taught them also how to handle other handicap children. They would not let anybody touch her.

Even today the attitudes of our children have not changed. Our oldest son who listened to our concerns about placing in a group home made this comment. “Why would you do that. Well, mother if you ever did that I would go to court and take her right out.

The Duffy Family

It was hard at the beginning for we lived in the hospital. He was in intensive care. They just wanted to see their baby brother. At first they did not really understand. They just loved him. His older brother wanted to take him to school (public) for show and tell when he was six months. A teacher asked if anyone in the class knew what Down syndrome was. One girl raised her hand and said that those are special kids that eat lunch together. I got mad but it was my son who said “he is no different he is like everyone else and we treat him like that.”

Conrad Family

We never sat down and put a label on it. We brought him home as their brother. We did not feel comfortable about telling them. We would address questions as they came up. We thought it was just healthier not to stick a label on his head when he came home. We wanted them to treat him like their little brother. Last week I took
Patrick to therapy with me and Conner. His brother thought we were going to Conner’s exercise class. And sometimes his other brother Ryan calls Conner’s therapy his P.E. (physical education) class.

The Mack Family

Another family gave their collective perspective.

We told them right away. There was no problem at all. We told them what Down syndrome was and that he was going to be slower. His sister Mary and him are real close.

Kathy Thori

I was much tougher on him than anyone else. Mother and I are not going to be around forever. He had to be the best he can be. There is no reason he should have to live with his brothers and sisters if he is capable of living on his own. At times I felt embarrassed when he clung to me.

Carl Thori

I don't remember a special reaction to Clay when he was first born. As I grew up he was interesting. We had typical brother and sister quarrels and we still do today.

Thori Sibling

For another family who had declared no message to the nation or world at the time but conveys her most teachable moment for all her children.

We consulted one another and we were wondering what to tell them and when. They were waiting nine months. Since our children were 5 and 7 we did not want to cancel their celebration of this new born. We brought him home and we celebrated. We let them hold and congratulate him. In the evening of the day we called them into our room we remembered a moment. It is amazing how things go in life...we were doing many hikes and it was spring. In Jerusalem there are many flowers in the mountains.

Our children know all their names. One day it was not long before Oren was born they found one of the flowers. It was real strange. All the leaves were up and one was falling down. Something like a mistake of nature. They said “oh look at the strange flower.” Then we discussed how sometimes in nature there are mistakes. Sometimes things are not going quite the regular way as they always do. It was just an innocent discussion on what they saw. I did not start to tell them of this at that moment. But when we started to tell them about their brother we told them about the strange flower. With your brother nature did a little bit of a mistake. He won’t grow and develop like a regular kid. He will be slower. I did not know much more than I told them.

Uzily Family

For this parent another natural moment only perceived through the eyes of a child.
They were 27 months apart. We were on television a lot, at events and talked about Down syndrome and what her future would be. We always talked on the phone because I am a pilot parent. Not talking in front of the children. However, I do remember my eldest daughter...saying one day how did you feel when you found out.” I wanted to be honest with her. I did not have the time to formulate any answer. I wanted to use language she understood. But if I knew now what I have known then I would not have had to say anything different. She then said answering her own question... “You must have thought you were the luckiest mother in the whole world.” All I could think of was “yeah that is me.” I think even if you ask her friends at school what is Down syndrome? I don’t think it would matter to them. For that is who she has always been.

Kathy Kennedy

No one is immune to change, but a majority of the siblings seem to adjust surprisingly well. Each sibling depending upon their age and understanding will adjust to their brother or sister at their own individual pace. Some times initially that they became sad, felt a sense of guilt, found it difficult to accept, became overprotective or overachieved while others so often very proud.

My daughter was very emotional. I did not know if she understood. She just became very sad and she looked at him.

Her brother who is very mathematical and technical (like his father) replied “he will develop slower?” We told him that his brother will not be capable of being one maybe one half year baby. Well he replied” I will work with him and I will work with him so hard that he will have just one day of delay.”

Uzily Family

Nicholas felt guilty at first. He use to make fun of kids with Down syndrome. So he took it quite hard. Now he loves them very much and is real close.

Bev McClaren

Some siblings take on extra roles of parent, teacher and friend.

Tim was seven. Rueben grew up with her. Tim was very intelligent. He picked up on everything. He did exercises with her and talked to her. He took the role of a parent. He did everything and understood her. He never really told us what he thought of her.

Contreras Family

Jim was sixteen years old at the time. He was more like the father than Evans was. Evans was busy with his business. Jim would come home and he would dig in. He did not have a social life. He feed her, changed her diapers, rocked her and sang
to her. I would not have made it without him. He was a tremendous support.

Miller Family

Bobby is her best teacher. Bobby was her only teacher for the first two weeks. Me being her mother, I could help and teach but she could model Bobby. They told me do not even try to potry train her until she is five years old. So I did not. At two and one-half Bobby had enough of diapers and decided to go to the bathroom. Julia went with him. It was like she was saying to herself what are you doing? So at two and three-quarters she self potty trained. I never made a big issue of it.

Paula Stella

Nicholas now is his best friend. He will play with him on the floor. He is not too old and tired like us. All our children love him. They are like other parents. They do not take on all the shared responsibilities of raising him, but play an equal part in Morgan’s affections.

McClaren Family

My girls the oldest one is overprotective of her brothers and sisters. I guess she is mean and short tempered like the father (laughed). She will tell him no and not to do things. She gets mad when others make him cry. When she sees him doing something wrong like taking off his diapers when he knows they are wet she will yell for me.

Tricia Enos

It is worthy to note that the role the sibling takes on may be due to the order of birth and age of the sibling (see table 5) within the family unit. These roles many cause further concern for some parents.

As one father voiced his concerns regarding how it would effect or what impact his daughter with Down syndrome would have on their son:

I have no doubt that my son is 50% responsible for the achievement my daughter has made today. Not being generous only straight forward I do not know what affect that will have upon him for the rest of his life. I do not know if it will put so much pressure on him to be too compassionate or to what his level of understanding will be at such an early age. Or how that would shape some of his thinking about women. Or shape his thinking about children in general or people. I do not know the outcome.

Jim Stella

The experience of having a sibling with Down syndrome on the other hand can have a very interesting, subtle and implicit message that children who don’t may not be in tuned to. One mother voiced such an outcome of her older siblings to be:
I will be able to match my kids empathy, patience, humor, love and compassion with anyone.

They have learned these gifts of the heart that you can not get in any classroom from their brother. I have even had friends see my children interact with David and say "I do not think mine would have been so good."

Gina Campbell

My children get excited when they see someone else with Down syndrome. It has helped them realize that all people should be treated the same.

Brian Conrad

Out of 13 families that had siblings one brought up issues of the sibling having a problem and the direct effect upon him. The Miller family comments that:

Bret has a fear of his sister (only one year apart) and the family situation. When he was three he had his two step sister live with him. Susan was 6 carrying a bottle and a blanket and Lynn was twelve and always fighting at the time.

Bret also was teased at school, high strung and very sensitive. He never said anything and this gave him an inferiority complex. We found out years later that he thought we were all 'retarded.'

Miller Family

Theme Four
Social Issues

The family unit in this day and age can possess additional strains with its activities of daily living, general child care and domestic work. Within this unit a child with Down syndrome brings in new rewards, additional challenges, stresses, happiness and disappointments as do its siblings. With each child or member of the family unit a parent or relative have certain dreams, expectations and ambitions for what they want their child to be. If however, their child does not measure up to your expectations you then have to start from scratch.

For all families, especially for those who had their children, now adults some 30-40 years ago that is what they did. Knowledge from the doctors as mentioned in theme one
(Chapter VII) was “I don’t know” or “The only case I do know of is in an institution.” For others it was a chore to just get the facts, it was hit or miss or word of mouth, reading endless outdated literature. And for some it was a continual search of finding or being in the presence of another family with a child or young adult like theirs.

The most commonly mentioned area was the amount of time, energy, and perseverance required on the part of the families to provide an insurmountable amount of services for their child’s needs. The time these services began and the types of services provided depended upon the following factors:

1). The dissemination of information regarding programs for their children. Or in some case location of current information.

2). Utilization of personal and professional support services.

3). Location, availability and continual update of these services.

4). Flexibility of the parents (whether both parents worked, flexibility of their personal schedule and siblings schedule).

5). Financial status and feasibility of these services.

Word of mouth appeared to be the most effective method of dissemination of information regarding programs, services, counseling.

One parent with a great sense of humor commented that:

*It is interesting once you have a child with Down syndrome they seem to be coming out of the wood work. Everyone seems to have a story like being pregnant...everyone knows someone who has a relative. It is amazing how did you all keep it so quiet if nobody knew this?*

*Eliz Hughes*

Other parents found out through their nurses, geneticist, social workers, or those in the medical profession who had a child with Down syndrome.

One parent received immediate information from a nurse and acted upon it.

*She told me about the Emily Anderson Center. This was a consumer health library for parents It had information about support groups and agencies. They had a lot of resource but it was a matter of picking and choosing what fits in to how you are. They had recommended that we come home and take books out and talk to our two*
and four year old. We did not feel comfortable with this. So we kind of took the information that was available absorbed it and then molded it to fit our needs and to the way we were.

Mack Family

While another parent was not ready to act about her immediate information.

The information was available to me as soon as I wanted it. In the first days I just wanted to get home and be with him and breast feed him as my son. Then I would start thinking about Down syndrome. Now I am striving for all information I can get but then I just did not want to hear about Down syndrome. It was not denial. I knew Down syndrome. A social worker brought me a book. She said a mother with a child with Down syndrome would come to the hospital and would talk to you. I can not explain...I just did not want it. They honored my wishes.

Liana Uzily

This parents information was personally delivered by a parent and doctor with a daughter who has Down syndrome.

Dr. Cooley a good friend of mine now...at the time drove from Dartmouth, New Hampshire to Manchester and knocked on our front door. He said “do you have a couple of hours.” Our kids were still in the hospital at the time that he decided to visit. At the end of two hours Jim got to see and experience another professional male (a role model or pilot parent) who has a daughter like him with Down syndrome. Dr. Cooley has a daughter and she is okay. It does not destroy your life, your life savings are not thrown out the window.

He had helped me to think that when she is so many months old you do this test and watch for this. He had been good in that sense. He is really my support. I have learned a lot from him.

The Stella Family

It is then not surprising that a strong majority of families chose as their best resource for information that of other parents. They participated and utilized various personal and professional support groups (i.e. Sharing, Pilot Parents, Church Guilds) as well as international conferences.

Fifteen out of fifteen have participated in various support groups throughout their child’s lifetime. Some more active than others but all commenting favorably on the benefits. For many fathers attending a conference was more beneficial than a picture or a written word.
For me attending a National Down Syndrome conference was like diving into the ocean. You can see pictures and read about it but, it is different when you go there. There are people talking about it and you are surrounded with it for ten hours a day. You come up to speed real fast.

Tom Hughes

Pictures and words do not mean anything to me. I need to see it in the physical sense. I need to see a young child, his or her actions, moves and what he or she can do. I need to see how the child interacts with his family.

Jim Stella

For the mothers conferences were helpful, overwhelming, and eye opening.

The conferences were very helpful overall. There you saw the full spectrum of nationalities, potentials, and young adults in college. A huge majority were in college and considering what they were born into at that time it was pretty phenomenal.

Eliz Hughes

Mothers also found the support of another mother and the time to ‘share’ an essential part of their growth and development and as well as for the child. It was a unique type of therapy for both mother and child.

I think “Sharing” evolved after a year. We all met in therapy. We started questioning why don’t we have get togethers at each others house and share information. Nancy instigated it. She had different contacts. We decided to share. To share our experiences and to provide comfort.

I remember sitting at a different restaurant and having a pop and just talking and reminiscing. We would always talk when doing therapy.

I can see Danny in his army crawl and Wendy with her daughter ...I can see it just like yesterday. We would sometimes go out for a hamburger afterwards and we just started talking...about how we feel. Or this is what we did. Other than that we had no other support.

Anita Contreras

Another mother comments on the past and now:

For me “Sharing” is the greatest. The first time they had a meeting Vanessa was a month old. I remember...afterwards all the kids came in after the meeting was over. I had her in my arms. I was standing simply horrified and started to cry. Anita and Nancy just like a flock of angels came up to me and said “it is not that bad everything will be all right.” They just came flying over. I did not even know them then. It was just so funny now.
As Vanessa got older...I now see "Sharing" playing a bigger role. The older your children get the larger the role is. The older your child gets the larger the gap gets the more difficult the social interactions become. "Sharing" does provide you with availability of more options. It is a vehicle to provide information. However, many of us do become involved in other things and we just can’t keep up that level of intensity. You then decide to move on and lead your life the way it is. You get to know your child. Your child is healthy after all. It is not the end of the world. There are lots of reasons for moving on...”

Kathy Kennedy

As for many parents with younger children the support serves other means.

Last thing I wanted to do was to talk about intimate things about my daughter to a stranger. So I called a Parent support groups "Sharing" This group just about feel out of their chair. They said no one calls us we usually call the parent. I just needed to know if there was something I should be doing to maximize my daughters future.

It was helpful in the first year and one half and then I think you get on with your life. The bottom line is that Kinney is no different than her sister Claire. I do not want to self perpetuate this exclusivity. It is nice in the beginning to listen, for we all have our axes to grind. Everyone wants to change the world but all you can do is fight your own battle. Hopefully the ripples of your little battle will make it good. It is good to share.

Eliz Hughes

There really is not a strong support group in the Phoenix area. I went to one in the East Valley. I thought it was beneficial and nice to meet people. I have missed out on that...life gets so busy. I did get to a point four or five months ago that I had a strong need to have someone to call and vent or tell my frustrations too. I think it would be real helpful to speak to a parent who has a child close to the age of my ten month year old.

Nancy Mack

Each daily schedule ran down a different road, some with bends and curves, others with hills and winding roads and some with complete stops. No matter what road these families decided to finally take they did end up in the same place...that of providing the best possible for their child. Each road provided a different glimpse of the additional undertakings that these families encountered. All of the mothers rearranged their schedules and careers in order to provide these schedules:

I worked my schedule so that the therapies for my daughter are in the morning. She gets speech, OT (occupational therapy), PT (Physical therapy) through government funding and day care at Easter Seals (early intervention). Taking her to therapy required extra time and it is in Phoenix not Tempe where we currently live.
In the afternoons she is in home care. She is with 10 other children from age six weeks to three. She also has to see her cardiologist. For my husband he just has to watch them when they are home and help put them to bed.

Hughes Family

It takes a lot out of you. I can see how both parents are needed to manage it. I can't image any baby-sitters to take him to therapy. When Levi was little he was going to therapy (OT, PT) three times a week for one half hour session. I can’t imagine someone else packing up their children and Levi and taking them. It is a real pain in the rear...it is real hard. For an average day I would have an early interventionist come and work with him at the house for one hour once a week. Then three days a week I would pack the kids up and take them all with me. They would have to wait one half hour. I thank God that things have calmed down now. Now the only therapy we have out of the house is speech. He gets personal living skills, music therapy at home from Division of Developmental Disabilities.

Conrad Family

He started at four weeks with an PT and OT. We were in a small town at the time. We moved to Gilbert and we had him in Easter Seal and private speech.

He had early intervention which was hard for me. I also had to take him an hour two or three times for his heart and other medical appointments.

Campbell Family

I was not working at the time. You can’t. I took her to Arizona State University program twice a week along with Easter Seals. Not many jobs would let you take off that much time. For me my motivation was to attack things with energy. This is my coping mechanism. So of course everything I found I did. I did not want to think that if there was something I could have done that would have had a significant influence that I did not try. So I spent a lot of time reading, looking into alternative therapies, from vitamin to electra magnetic, early stimulation, patterning and a ton of stuff. I tried every single thing that was noninvasive and that did not have a potential to harm her.

Kathy Kennedy

My daily schedule changes. I go to PT at the Foundation for the Blind, go to speech twice a week, rush around, but it is now a part of my life. I do not see it as work. It is just something I have to do. If I had a third child who was playing soccer it is just another part of my schedule.

Paula Stella

All families agreed strongly and supported early intervention or infant stimulation as it was called for numerous reasons. Many mothers relay touching and provoking experiences about their early intervention programs and their therapists.

Early intervention is the way to go. I believe now it was more for me than Melissa. You have to identify the development of the child and be offered the different types
of therapies. I use to get upset because I would get lazy or have a bad day. Or not doing the therapy as long and I felt more guilt. I told a therapist this one time. She said it could be Melissa that did not want to do the therapy. She continued If you did not get it done maybe it was necessary to continue at a different time or maybe she just was not developmentally ready. Melissa started early intervention at two months.

Anita Contreras

They tried common experience scooting on the floor. I was thrilled. The therapist said he should do this meaning to crawl. It was almost like a joke. A new mother who was there at the time rushed up to me and said... “I feel so bad my child is scooting and your boy is doing so well. What can I do? I said “I did not do a thing, it came in due time. Sometimes therapists would put a guilt trip on you. Sometimes they need to look at the whole picture of the parent and what they have to deal with (i.e. a large family, making dinner, outside activities) verses just this little guy.

Gina Campbell

Early intervention is recommended for all. It is a help to the child. It does depend upon the individual therapist. Some parents are unfairly marked and told they are uncooperative for not spending enough hours at home doing infant exercises. When dealing with parents who are in an emotionally difficult period of time, or on an emotional roller coaster it takes a period to time. This is overlooked.

There are days where I wake up and say I can do this. I have a plan. I have an agenda. But there are others I just wanted to go back to bed. It always depended on what Vanessa's day would be.

Kathy Kennedy

Time, energy, finances, and the fragmentation of services have been described as anything less than satisfactory. This quest for help and services has been an evolving process. First seeking out the pediatrician, neurologist and some geneticists. Then finding out when to start, how all is going to be funded, or insured by the families insurance company, the ‘well visits’ or prevention services, any extra medical conditions like heart, muscle tone, hearing, respiratory and immune systems. A variety of descriptions of therapies are also called upon for each family to participate in such as PT, OT, speech, and infant stimulation. Continuation of speech therapy is an overriding issue with all parents, in all age groups, as well as needed continually in the education system.

This state is far behind. It lacks tremendously. I pay for preschool for Bobby and that is my choice. I also do the same for Julia. We have been lucky that we did not need all of the equipment to rent.
I do object to paying for speech for two years until I got them to say oh you are right. She should have speech therapy. Now the state is looking at all children with Down syndrome ages 3-5 because they are doing so well that they feel they do not need long term care. So for people like myself, who are self-employed, if she goes off long term care she has no insurance. So look at me...yeah I can pay for it but one car accident and we are bankrupted.

I do not mind paying for the doctor visits. She is very healthy. More healthy than a normal child with allergies. She has no heart problems, had tubes twice, no hearing loss, and has glasses. She has never been in the hospital nearly six years and they do not want to give her insurance. It does not make sense.

You have to be medically needy to qualify. The state basically told us that since she walks she does not need PT. She says some words so maybe speech. I fought hard for her to have speech twice a week. She can pick up a Cheerio so she does not need OT. That is pretty much how they determine medical need!

Respite is a service (baby-sitting). This service is to provide someone to come into my home and allow me to time to do various chores or just give me free time. I have not found anyone who can meet my needs. So if I don't use it that is a black mark against me.

Paula Stella

We were given the run-around. In regards to respite you are given twenty hours a month. We interviewed fifty and only one showed up. This person had no shoes on and had been living in her car! This is the mentality you have to deal with. We finally got one we could leave him with and was reliable. She was a nursing student. Both the twins love her.

The case workers from DDD (Developmental Disabilities Division) are behind in their reviews and have never seen him. We have had at least 50 case managers and only know this through letters.

You get other services depending on your child's health. We go to meetings and doctors and we have to wait. We travel far from Mesa to Phoenix for his upper respiratory services. I finally complained and then they lightened up. I don't understand why we can't go to the local doctor down the street. I can't imagine if my child had a life threatening situation going on.

McClaren Family

It was real hard for him to get into any long-term care because they told me he was not sick enough. I reapplied and I contacted another parent. They told me to try again. He did finally get it but by the time he did I thought it was too late. He was too far back.

I did get respite care. It helped me do errands. It was hard finding a provider. Most providers lived in Casa Grande far from the reservation. If I did not know them how could I pick them. Also they did not want to come to the Indian reservation. Maybe they were afraid that they would get lost!

Tricia Enos
It is frustrating in Arizona. Parents are left in the dust. They would call and get on a waiting list. Social workers would call and I would say I am fine. I always felt as if they wanted to judge me as if I was not a good mother. I had strong feelings about welfare. I did not need this.

Gina Campbell

I had a case worker from ages (1-5) who did not do anything. I was in Globe Arizona at the time. When I moved down here I did it all myself up until last November. I got DDD (Developmental Disabilities Division) services for respite care and prepaid medical. From ages 6-11 I got her ears checked, took her to the doctor for hearing tests, paid for baby-sitters, took her everywhere until I received services from DDD. What a difference it has made. I have medical insurance that saves me $80.00 a month, day care is $125.00 a month. For a single mother it saved me $200.00 a month.

I have a personal living skills person set up to come by but he has never gotten back to me.

Kelly Cook

Even for services in another country provisions for services are a catch 22:

Now this is quite new. Every child with Down syndrome gets one half allowance from the national security. This was done after many years of parent pressure. With Down syndrome there is a kind of catch. You work with kids so that they can have high performance and if you stop working with these kids they won’t advance anymore. They test him when he was two. He was quite advance so why do you need the allowance? You explain that you need this to continue with all his therapies in order for him to progress. So you need to push all over the years.

Liana Uzily

Demographic characteristics, the mothers flexibility on the job, martial status, income, and the parents utilization of personal and professional support were significant factors in the daily lives of these families.

Another area within the day to day issues, compounded by emotional concerns and adjustments was the marriage. Several of the families were well aware of the stress they may have been placed under, however out of 15 no one faulted their marriage as being weak or under any serious concern. On the contrary there were numerous testimonies of additional strength within the family and marriage.

Well we are celebrating our 49th anniversary this year so I guess it did not hurt us. At the time our marriage was safe.

Duffy Family
If we did not have a strong marriage we would have split up. It was rough on me. I could not accept it. I was ashamed of myself because I could not accept it. It was tough.

Carl Thori

One single parent conveyed that there were other underlining problems in their marriage and it was not directly reflected upon their child having Down syndrome.

My ex-husband was there at birth. He took off to South Dakota to look for a job. He did not find one and left again. He has three other children and does not pay attention to them either.

Kelly Cook

While another who is single but in partnership explained:

He helps support us financially. He is there when the kids come home and the children show him their work. We are trying to make it through ten years before we get married. Then we can do it right and have the kind of wedding we want.

Tricia Enos

Another underlying area within the day to day issues of these families was religion. This area was directly voiced by eight families and indirectly conveyed by seven. Fifteen out of twenty-seven participants were of the Catholic affiliation. It is again worthy of mention that out of the total base of overall participants (N=54) both the Catholic affiliation as well as other denominations were equally represented. Since religion for a majority of the participants was more of the families' "way of life" and inherent within each individuals' personal preference (some parents represented two different religious affiliations), it did not represent a major issue or theme specifically relating to raising a child with Down syndrome. It is however, important to mention as an underlying issue within the daily lives of the family unit.

Even though a strong majority of the participants in this study represented the Catholic affiliation (15 out of 27), religion was not voiced as "the major factor" when raising a child with Down syndrome.
What Catholic families did believe and practised carried through for all of their children. From the point of view of many of the Catholic families parents conveyed that:

When raising any child religion is important. However, religion is not a major factor when raising our son with Down syndrome any differently than our other children. It is more of a moral factor than anything else. Our Christine beliefs just happen to be part of our philosophy of life.

The Mack Family

Religion is an underlining factor, but it goes beyond Catholicism...it is a belief in Christianity which includes all denominations. It is the basic structure of our faith and belief. We have seen other children as a witness to our daughter being part of her Bible study class. When she could not talk, children in her Bible class still recognized that she should still be accepted.

The Stella Family

Yet for another family they summarize their view with a few statistics:

We believe religion is an issue. On the surface it does have a lot to do with the integrity of the marriage. However, on the other hand one must take into consideration and look more carefully at other factors within the Catholic religion. These factors would be: The percentage of divorces among Catholics regardless of the Church's position. The percentage of Catholics who got birth control regardless of the Church's position. The percentage of Catholics who call themselves Catholic but are not practicing nor attend services.

The Kennedy Family

For one mother being Catholic was associated with a positive characteristic of her own mother:

I was raised by my mother who is a strong Irish Catholic. As I grew up I admired her independence and courage. So I chose these characteristics and made them a part of my life. I saw these as a good part of my upbringing and I wanted to pass them on to my children.

As far as making a difference in the life of my child with Down syndrome...I think it is one-hundred percent up to each individual. I raised my first two children as Catholics and now they won't even go near a Church!

Bev McClaren
For those families of other religious affiliations their comments were quite similar:

Religion has no bearing on raising a child. Religion can cut both ways for and against you. It can be positive and at times be discriminating. Religion is not a sole factor when raising a child with Down syndrome. It is more of a human factor.

The Hughes Family

Religion is a non-factor. We chose to be married and maintain our beliefs before Levi was born.

The Conrad Family

Religion is a non-factor in regards to raising a child with Down syndrome. It is more of an ethical and moral issue.

Lyrae Thomas

Yet for a mother who converted from one religious affiliation to another her perspective was quite different:

If I believed like my father who is an atheist, I would have felt defeated before I started. As for my mother she still sees God as punishing me. For now, I see religion as making a difference. Now, I do not feel so hopeless. For we believe that David is here as our teacher. He is here because "I" need these life experiences that he brings. Religion is a way of life...22 years of my life. For now I see David as the greatest blessing where before I converted I would have truly struggled.

Gina Campbell

Basically families saw religion as important but not a major or only factor when raising their child with Down syndrome. Religion was a personal preference. It was either passed down from generation to generation or part of what their parents currently believed and or practised. Or it was what appeared to be familiar or comfortable. For some it was seen through positive role models or traits within their faith or through the faith of others.
All of these families were solid families. A strong majority of these families had Christian ethics which would predispose them to acceptance and the nurturing of all of their children. However, when talking to these families the least of their problems was solely religion or just their son or daughter with Down syndrome. For these families had "so much on their plates" that at times they were more consumed and overwhelmed with simply life in general.
Interwoven throughout every interview were the experiences concerning educators, teacher training, schools, and program availability. All parents presented this as the area of greatest concern. Each conversation was laced with exhilarated emotion, tones of frustration and anger. Voices changed quite frequently in tone, occasionally fluttering while body language became excessive.

Everyone had an opinion and where one parent began another ended. Sometimes it was a simultaneous combustion. All channels were open and the wave lengths were jammed.

Parents conveyed more negative responses than positive ones. Parents showed dissatisfaction in the following areas:

1. Categorizing and labeling their child or young adult as a group. Henceforth lowering their expectations and placing unrealistic limitations on them.

2. Not providing enough opportunities or not providing adequate programs in the area of curriculum and socialization to meet their children and or young adults needs. Speech was an area that 15 out of 15 parents voiced their concern for more time, more service and more techniques.

3. Not conducting themselves on a professional level of performance or showing "mutual respect" (i.e. IEP conferences, mediation, legal interactions).

The second area was of the greatest concern to all parents interviewed. For all parents at one time or another did not have a choice at the time of placing their child in a private (religious or charter) school. As one parent reflects and represents many parents decision to send their child to a public school:

This is part of the time consumption, there is so much to think about, to reframe, in terms of goals and objectives. I grew up in a parochial school, I would have sent my kids more likely or not. You seem to follow the established patterns set before you.

Well Vanessa went to a regular preschool and a developmental the other days. After that there was no choice to make. The choice was made when she was born. When
I took her to her PT in Tempe I overheard a mother arguing with St. Francis about putting in a ramp for the last two years for her kid. This is absolutely crazy. I am not going to fight with the school. And the truth of it is little did I know I could have fought until the cows came home...a ramp was nothing!

For us it was important that all our kids be together. Our criteria has always been if she did not have Down syndrome what would we do. Well that is the road we should follow. Not look for some special path she would take on her own. Any persons strength lies in the family that surrounds them and their supports. The fact that she had no place in private school basically took her siblings out of the private school too!

Kennedy Family

Professional performance regarding who is responsible (i.e. special education teacher, training, IEP conferences, compliance within the law), behaviors of impatience and condescension, were continually stated and voiced in all interviews. The terms "partnership" or "collaborative team" were not utilized on the part of the professionals.

Insistence upon included them in the regular class setting (full inclusion) or the most appropriate one for their individual needs presented many heated and intense debates. Parents as mentioned in the meta-themes also took on an additional role of advocator and monitor.

A lot of the time it was their (educators) and her first time. She was kind of a pioneer. It was tough on her too.

The schools have laws to govern and are suppose to provide. However they will not provide unless you make them provide. As long as you do not say anything they stop. They will try to keep you in the dark about everything you have the right to.

I think also that public schools tend not to always think special educators are the ones who should be responsible. When Melissa was out in the regular class out in the playground when got sick. So instead of taking care of her needs then they went to seek the special education teacher. They were the ones who should have handled it. I think the regular education teachers are like this because they don't have the practice (or training), are not aware, and do not buy into the concept of inclusion and or see accept the child as an individual. They have to work together in partnership and be a collaborative team. A lot of the time this is not the case. It really hampers the program and the child.

Contreras Family

It has always been a battle. One day when David went to kindergarten he dressed himself. He put his pants on backwards but I was proud just the same. The teacher said in front of other professionals to me." Oh I see why you put his pants on backwards. You do not want him to play with himself. This way he couldn't put
his hands in his pockets. I was so horrified...no he is only five. I was frustrated too. He dressed himself I thought. I was proud of him. You have some nerve.

Gina Campbell

We have tried everything for him. He had mainstreaming classes to now self-contained. He has had only two teachers worth their paychecks.

In elementary school it was okay because he had one class and one teacher. At the middle school (junior high) they were not ready for my son because he had Down syndrome. Even other students who did not have Down syndrome but were in wheel chairs (physically challenged) were not accepted. The school was not willing to adjust to them all. He had a paraprofessional to help him with his classwork. The teachers were not following through and he became bored, distracted and started acting out (inappropriate behaviors). I fought to keep him in and the school kicked him out. They illegally suspended him for 10 days. By then I was too tired to fight and I just started a new job. There was no point of putting him somewhere where people do not like him or accept him.

Even if we fought and would have won...what would we have won? He would have been given the same treatment if not maybe not more.

Thori Family

Even changes in disposition were not uncommon in regards to their child’s education:

I was very young and nice back then. I am not nice now not because of my age but because I had to fight and speak for her rights. My other kids went to private Catholic schools. They did not have any programs for her so I called the public schools in my neighborhood about classes for her. He said “where are your other children going to school?” I was honest and I told him. Then he replied “tell your story to them.”

Betty Duffy

One father relates his job as a professional, as a dentist, with that of an educator.

With my job I tried to explain to this lady what was going to happen to her tooth. After I tried to explain the options she went to my partner and said I want you to do it. I don’t think he knows what he is talking about. I was trying to explain the steps, but the exact scenario that I told her turned out to be exactly what happened. Then she came back to me. She had gained confidence in my six years later. I guess she just wanted to be told. That was the bottom line. She did not want to get informed and be part of that decision. Maybe teachers get trained that way too.

However, we would rather be informed as parents and be part of that decision. The teachers tell you the way it is going and how it is going to be. Then they want you to sign the papers. We have because of this always been on the defensive. We are just not able to work together as a team.

Curt Campbell

169
Terminology and diagnosis was often a major deterrent in communication and attitude. Even though parents understood the terms, accepted them, the terms seemed to take the form of what was wrong with, what problems they had or what they couldn't do. Such limitations and low expectations provided additional stress as well as the medical diagnosis. Such indignation on the part of the educators often turned parents into fits of rage, frustration, and defensive confrontation.

*When your typical child is born you see all the potential in the world. You can dream...anything is possible. When you get a child with a diagnosed disability everyone tells you all the things that do not happen.*

**Kennedy Family**

At the time we were in Texas and Brenda was in the third grade special education. They did not have anything else to offer her. The special education headquarters decided to use Brenda even though she tested out of the educable area and put her in with the trainable. They did not tell us. They wanted to use her as a model for the other kids. This is what they did. They said they wanted to work with her on a one-to-one basis versus with the whole class. It sounded good to us. At the time these trainable and educable did not mean anything to us. They wanted as we found out later to bring the other children up to her level of ability. This would then draw her down to their level and she would have no other place to go. After finding this out we took her out of that class. She went back to her class and was embarrassed. After that we moved to Ohio. For Brenda, I don't think has known any limitations. No limitations were set for her.

**Miller Family**

I wanted him to go to another program. I did not like the teacher. I never had an official IEP meeting. We went to this meeting at a huge table with the special education director. I brought my speech teacher, a friend and also a school board member who had a child of her own with Downs syndrome. There were all these people there it was horrible. I was not prepared for what happened. The director racked me over the coals. The teacher commented to another who happened to be my friend...the reason she is acting this way is that she has not gotten over the guilt of having a retarded child. She is trying to pretend he is normal. I was infuriated. I know he is retarded. I live with him everyday. I know he is not normal this is not news to me. Number one I am suppose to feel guilty...well absolutely not. I went to talk to the superintendent of schools. I thought I would have to back up my position of why I wanted him included. He was with me all the way. He called the director in with a ten minute warning.

*He told me come back on Monday and we can talk. The director was not happy but I was grateful for that change.*

**Gina Campbell**
The climate of success, freedom of choice, opportunities, discovery, making individual progress, self-motivation, expanded interest, individual capabilities and responsibilities as a "included" part of the world were issues that continual came to mind throughout these interviews. Therefore the norm seemed somewhat not or when standards of learning were not being challenged it was not uncommon for problems to erupt.

She had no education. She had no opportunities. She spend all her years in one room at one public school for eighteen years. Then they wanted to train her to take public transportation but it was so late. We thought it was terrible. Then we got her in an special school, a trading program. However no skills were taught. They keep saying "we are going to teach her how to use the washing machine, and take care of herself, but this came every six months." It was a lot of paper work but no results.

Duffy Family

On the reservation he did not get enough education. I want him to learn a lot. Here he will not learn anything. We just do not have the help here. The teacher on the reservation said I can do this and that. She said I can teach him sign language in two weeks. I replied "no you can't. You can not teach him anything in two weeks." That is when I changed schools and I found a special school that would offer him more services. The program now is more organized.

Tricia Enos

In academics throughout her schooling the teachers identified the level she was at each year. They did not take the responsibility of really developing and making sure that the program was pushing her or meeting her needs. They did not continue to develop or challenge her throughout school from second to 8th grade. I took a year off to look at all high school programs. I meet with staff, observed and got to know the faculty. Others did no have inclusion and the ones that did had a very different definition than mine.

I wanted her to be with her peers. The only way to be typical is to be right with her peers. It was a more difficult journey.

I did find a staff after my research, that not only bought into this concept but were committed. By law this district is suppose to have inclusion.

Contreras Family

For one mother whose daughter was ignored replies:

One reason I pulled her out of special education classes is that she was being taught by an aide. Not even by a special education teacher.

They are not ready for children with Down syndrome to be in the regular classes. They still think that the regular kids are going to be ignored. The teachers are also afraid..they do not have the education about special needs kids because you have
special educators. Now as you have to move that transition form special education self contained to regular education you need to do some co-teaching. That is hard. It is like changing your whole philosophy of education.

Paula Stella

For a few parents the education system and a few teachers did stand out in their mind that did make a difference for the success and future of their child.

Megan reads real well, can write her name, and sounds out words. She is a real bright kid and her teacher is doing well with her.

Kelly Cook

We are getting more than we thought we would get. We came from Israel and there is nothing established. You invent things or do it by yourself.

Llana Uzily

Thank God for this one teacher... after a few months she talked to us and told us to get Brenda out of this trainable class. She told us we were set up and that this class is going to hold Brenda back.

Miller Family

Speech was an overwhelming concern for all parents at all ages and stages of their child's life.

Speech was a problem. She had a tongue thrust. She had speech but it was not enough. She went on to community college to take classes in speech, voice and diction.

Eve Miller

His biggest delay is in his speech. He goes once a week for an hour. He understands a lot. My major concern is how he will be able to react with other children as far as talking and communicating with them. He is a real social kid. The kids usually get scared because he can not talk a lot.

Maria Conrad

I am concerned about her speech. I took her to a private evaluation and they told me that at this age it was not going to get a whole lot better. She does not talk in complete sentences and uses one or two word phrases. I understand everything she is saying yet the general public does not.

Kelly Cook
I fought for getting him to have 20 minutes of speech a day. It is a constant battle. They wormed their way around it. It just does not happen. What is written up in the IEP and what takes place are two different things.

Gina Campbell

Her biggest delay is her speech. There will be a day where I will say Julia enough! We waited four years for her to say one word. Like a month ago I just said Julia stop talking and we both laughed.

Paula Stella

With all seriousness intentions blending with a dry humor one father sums it all up by saying:

The big issue and it could be a road block is her speech. I got through school and I did not say many words. I did not start talking till I was in my thirties...so I had to go to speech classes when I was in school. She could get tremendous speech therapy more often.

Tom Hughes

The opportunity to be involved in various subject and curriculum areas were also voiced as the children are presently progressing through school by many parents. For parents with infants and non school aged children these were only projections and very often ones they could not think about at this time.

She is working on computers now. She also qualified as visually impaired 20.80 acuity with corrected vision. I would like her reading skills to improve. In terms of math as long as she can use the calculator...it is foolish to beat the dead horse on this math stuff. What ever independent skills she learns will not depend upon math. She will need to make change, and do more practical applications.

During High School I would like her to get into a science, and social studies class. She needs to have a sense of what her country is what a voter is and her obligation as one. She needs to have the general orientation to citizenship.

Kathy Kennedy

I see him learning to use a computer and learning to survive everyday life.

Kathy Thori

Hopefully the program she is in we (the parents) developed in high school will have her ready for placement in a job. Not just slinging hamburgers. We are looking six years in High School. We are working with her on academics and then vocational training that could lead her to a job.

Campbell Family
Other areas not necessary of academics were also voiced by several parents:

*Education needs to give as much emphasis to socializing as they do to academics. I have no doubt that Julia will be able to read and write when she graduates. But I hope she learns what it means to be a friend. No one can teach that but you can foster those little friendships all through school. This issue you can’t ignore.*

*Paula Stella*

*At first it was hard. She loves to play with Barbie dolls. She did this before she started school. This was her own playtime and talking to herself. At school she did not know what to do with all these other people. She would go to a corner and play with a toy. It has taken up to this year (she is six) to begin to interact with the other kids.*

*Lyrae Thomas*

**Beyond School**

Generally speaking; children with Down syndrome will grow up to function with a great deal of independence. However, such a discussion as related in the section on mega-themes was apparently more realistic for the parents with older adults than those with infants and young children.

As reiterated throughout all interviews we just take “one day at a time.” Eleven out of 15 families were able to only project into their child’s future. Many comments were stated in the form of “I want”, “I hope”, “I wish,” or “I would like” or “I see.” The “I” was still representative of both parents thoughts unless indicated. For like any of their other children parents wanted or hoped they will get a job, live independently, go to college, be happy, be challenged, have friends, get married, drive a car, and be a successful and productive citizens.

These future projections did not come without feelings of worry, frustration, excitement, and fear. All predictions for the younger children were in more general than specific terms.

*I want Morgan to be motivated and well rounded young person. He will be grounded enough to handle anything.*

*He is an individual. The whole issue of mainstreaming or “inclusion” is too difficult to see right now.*

*McClaren Family*
I hope to see her in a group home facility where she can take care of herself. I see her employed. I try not to think of marriage. I am concerned about death. If something should happen to me I know my parents would take care of her. I do not want her real father to take care of her. He would not do it with the quality I do. I would want another baby just for that reason if I could afford it.

Kelly Cook

I see him driving (not until he is thirty). I see him with a girlfriend but I am not sure on marriage.

Thori Family

I see her talking, into sports, ballet, learning about CPR, thinking of college, or what she wants to be when she grows up. When we asked her what she wanted to be she said “a mommy”. That is wonderful we replied. Then she also said a “doctor” not a “nurse”.

Stella Family

I see her getting married. If the right person would come along yes I think she could handle it.

Miller Family

I see her being a teaching assistant in a school from kindergarten to three. She likes to read to kids, is responsible, and enjoys children. I think as her mother I see her being with me until I am gone. I don’t see her having any children.

Anita Contreras

I see her going to school, making my sister eat crow (laugh). My sister is not enlightened as to how far Kinney can go. Then she will do all the rest.

Eliz Hughes
CHAPTER X
Theme Six
Parental Experience and Needs

Throughout these interviews and ongoing research families do change over time. Families have different needs for their younger children than the older ones. Families have different needs at different times. When the child is of school age the family may seek a smooth transition from home to school. Of course when any child enters school and when he or she leaves there are times when vulnerability creeps in. For families with children or young adults with Down syndrome, transitions may become more difficult, because changes are delayed and may be hard to come by. Families therefore might establish routines to keep stress more manageable.

In any case the stress, strain, and the commitment of the family for their child with Down syndrome does not reflect the child itself. It is an extended stress produced by a larger unit called society.

Many parents expressed this view of themselves and others after the birth of their child with Down syndrome.

One father on a soft and inner moment notes that:

_ I was guilty before we had Levi. I did not know how to talk to people with disabilities. I probably talked down to them. I thought if they had a mental disability that they were just not all there. But now I know better._

_Brian Conrad_

_Of all the silly things that people said when she was born...that really made sense to me now. It really hit home with me that it is a shared responsibility._

_Kathy Kennedy_

Virtually every participant voiced suggestions or recommendations of what parents need in order to most effectively and comfortably attend to the experience of raising a child with Down syndrome.
While this area was addressed at numerous points throughout the interview many parents again come back to this point. They often spoke with great conviction and purpose as they are in the midst of this experience. Parents focused recommendations were mostly directed to the educators, medical profession, professionals and society at large. Parents wanted information gathering. Parents wanted a mutual understanding and respect whereby the parents and the professional worked together. Strongly voiced (pleading in tone) one mother further clarifies that “It is dealing with the lack of normalization in school, workplace and society as a whole that cause this extended stress.”

Parent involvement and needs as a unit may be working less effectively because the wrong perspective is being used. For it is the family who is needing the assistance and not the system delivering this service. Many parents throughout the interview related their individual needs as a single mother, as a two parent working family, and as a homemaker of seven children.

What is needed said the majority of parents is to take into consideration the “diversity of families”, their daily and unique schedules as well as their emotions and feelings. As Kathy Kennedy’s eloquent view is representative of most families conveys:

For you always project with small children, You can project into eternity. Today ’s a good day things are going right and everything is moving along. Yet when you have a bad day you wonder how am I going to do this! It is that learning to take each step or each day at a time. It is such a simple and set thing. Yet it is very difficult to do. When you are so focused on what your child can do, you loose all sight of just appreciating your child for who they are and what they can do.

The needs and focus for all families interviewed were again directed to the education arena. The majority of the families wanted education to be positive experience. Families wanted educators to have higher expectations (by not emphasizing the label) and fewer limitations. They wanted their children to be provided with the best just as for all their other children.
Any child regardless if they are delayed or not need to be pushed toward a good education. More so than ever. We will not deny our child anything. As voiced by many:

*He is going to college. He may be 87 but he is going. There is nothing wrong with that. He has to be educated and not stifled.*  
*McClaren Family*

*Schools are far behind in their approach. It is not an integral part of their way of thinking. They the teachers need to get past the label and see them as people.*  
*Evans Miller*

*Have high expectations...teachers think if they can only count to five that is good. The kids are all counting to 20 in kindergarten. I would say get a life and make her count to 20.*  
*Paula Stella*

As one parent reflects on her needs and experiences and the road she will hike.  
*All you can do is the best you can. You give them direction, good values and deal with a little different perception. If we were all as upbeat as that what a nice world we would be. I think expectations have been so shorten for so long that how do they know what they can do? It is going to be a real interesting hike. In a way it is kind of nice that I do not have to walk the same trail twice. I am getting to take two trails.*  
*Eliz Hughes*

As for the medical profession as explained in theme one even when parents knew that something was not right they found very little validation in their experiences.

*The thing is that people rely on them and that they should have all the answers. When they come across something that is so unfamiliar to them (for they have so many syndromes) simply saying I don’t know is difficult for us to understand. Maybe it is because they have this aura about them that over hundreds of years they knew everything, could save lives or could chance things. What is important is to find the information and understand the emotions that go along with it.*  
*Lyrae Thomas*

*Give each and every one of these children a chance and let them show you what they can do. They could teach you (those doctors) and awful lot.*  
*The Duffy Family*
Doctors need more positive attitudes. Why should a doctor look upon them any different...they are babies. Only within them lies more love than 15,000 people.

Evans Miller

Information comes in many forms and through a variety of sources. Availing themselves through the different avenues was a long a arduous task. However the outcomes, individually speaking, provided growth intellectually, emotionally, and socially.

I have learned that materials, articles and monographs did nothing. There are so many antiquated terminology still being published in the 60's. There has been some improvement but the best stuff comes out of associations (support) and conferences.

Kathy Kennedy

I read these books and I became depressed. I read that they would not develop or develop things differently. I needed to read to be aware of all things. So I read and read and I cried and cried.

Bev McClaren

I will never forget meeting Emily Kingsley. I had my daughter on my chest she was only ten weeks old. Emily asked me her age and I told her. She asked well how do you find all this...I said on Friday it was overwhelming and then I just started to cry. She confronted me and said "now it is not so bad." Then she began to cry. I said I was sorry and continued to say what did I say to...She answered you reminded me of when my son Jason was born. Wait a minute...are you telling me that when Kinney is 17 I will still be balling like a baby. Yes she said regardless and I said I guess you are right. That was the most interesting and helpful lesson. Even when you go away form it you are reminded of it.

Eliz Hughes

Parent support groups were also described as a valuable source and means of parents support. Even though all parents joined in at one time and benefiting the reasons for staying actively involved or just knowing the support was there varied.

For us our support came when five of us rented and raised funds to use a building (store front) for us to have meetings in. This was the only way all children with handicaps had some recreation together. The people were so good. The kids had a great time. We just wanted something for our handicap children. The other children did on their own. It was started by five mothers. It was a nice feeling. Later it became always the same people involved and we turned it over the GUILD for exceptional children. The building is still standing today.

Duffy Family
One mother goes back to her own personal beginnings of support and her needs now:

You see mothers all the time and you sit around and talk. After a while I did not even care if Vanessa did her stuff (therapy). It was just so good to see everyone. It is so good to see the other kids and their parents. In those days services were based on family need. I was participating in early intervention and a parent advisory group.

Part of why people (parents) feel less and less needy in terms of support groups is their use. If you are looking for support group to emotionally void you up...that ends. You get your emotions under control and that happens when you get to know your child for your child. Then you do not see just the disability. You have up days and down days but neither one of them is the last day.

Kathy Kennedy

For one mother she felt that she was being drawn down verses being raised up:

I felt as if I was being drawn down more than being helped. It was like a support group for mother who could not handle it or did not know how to love their child.

Paula Stella

For another mother time was an issue:

You do not have the time and you just get on with your life. That is why we are not so active.

Hughes Family

The comfort of having a Pilot parent, a friend, or someone to talk to that has walked in your shoes was shared by all families. The need to continue to ‘share’ and in turn become your own Pilot parent played itself out as the circle of families, and the support and updated knowledge of their child grew.

For me it was Dr. Cooley. He is my real support. I have learned a lot from him.

Paula Stella

For me I wish I could have had one person at the beginning who could have called on a regular basis. Although we feel pretty comfortable and I did have a few contacts that one person would have been helpful.

Mack Family

I remember meeting my first pilot parent. She asked if she could come see me and I did not want her too. So finally she talked me into going and seeing her child’s school. She asked me if I could tell which one was her son. I looked at all the
blonde kids. Then he came up to me and said this must be Mrs. Campbell. He smiled and I said are you allowed to smile? Now at this time my son was only 4 months. I thought it was against the rules. You go through this craziness where nothing will ever be the same. That is why I do my Support group and I am a Pilot parent. You just have to reach out like this mother did and give to another.

Gina Campbell

Parents were often aware that for many professionals the knowledge and experience of raising a child with Down syndrome was beyond their level of expertise. However, what was most disturbing was when professionals did not admit to this or listen to parents as they pursued special avenues for information and sharing which were so much like their own.

I enjoy personal testimonials. Some intellectual and emotional. I enjoy them all because your own feelings run the gamut. I thought of writing my thoughts and feelings down of how people would look at me, some could be so crass and how they did not think it would affect me. No one would believe that I lived in such a place! However, it was nothing unusual. All I wanted is what I want for my other daughter and son. I do not want anything out of the ordinary. You would think I was a czar of the education system. This is such a revelational idea to people. This is not an original one.

As someone once said to me “it is not original, it is not different, it is just something that you would do for someone else.”

Kathy Kennedy

Theme Seven
Advice to New Parents

All things that are true regarding the role of any family are true regarding that of parents with children with Down syndrome. All parents made endless suggestions and recommendations for new parents with children with Down syndrome. They all spoke with great conviction and purpose due to their ‘lived’ experiences. The most overwhelming response as discussed in the meta theme to follow was to see their child as a child first. Optimistically many parents advice to new parents included that:

They love just as good as other babies.

Bev McClaren
Enjoy your baby because he or she is a baby first.

Paula Stella

Treat you child as a child. Take care of them like any other baby.

Kelly Cook

Look at each day as a challenge and you are going to learn something new everyday. My daughter is the light of my life. I know it is going to hurt and be emotional. It is however, the most wonderful thing.

Lyrae Thomas

In reference to materials and information one parent spoke:

Throw away and disregard anything that anyone had told you that is negative. You can't compare these children. They are individual. Don't be discouraged. Keep on going.

Maria Conrad

On a more subtle note two mothers advised from a different angle:

It is going to "suck" for the first two and 1/2 years but then everything is going to get better. Don't indulge in your self pity. Put it aside and focus on your child's future. Take the time for your grievance. Don't let pity for your misdirected dreams get in the path.

Know that it is okay. It is good to feel the way you do, spin that emotion and get it out. Don't spend so much energy that you neglect your job...of moving forward with your child.

Eliz Hughes

Foremost it is a crummy thing. I do not think that you talk to anyone and say hey this is great. It is not...it sucks. But the reality is that it is your child. You do not want people to be around who give you the candy coating. The reality is that it is going to be shitty for a while but as long as you are able to vent to someone...you will get through it and accept it.

The Mack Family

The tables turned for this mother whose parental advise went to a doctor:

I told him who was curiously looking at my daughter. Yes she has Down syndrome. On my defensive I said "why?" He said he just had a child with Down syndrome. So I told him you are going to have a wonderful life and great time. Do not worry about it. So get yourself a couple of support groups. I gave him this information. I went to see him six months later and asked how are things? He
replied fine and I told him “do have other children because they are going to have a ball.”

Betty Duffy

In retrospect what helped the mother as she relates it to others is when a friend consoled her by saying it was okay if you feel sad and your heart was breaking.

She asked me if I read the Grinch that stole Christmas. I said Yes...well she continued in that story the Grinches heart had to break so it could grow bigger and hold more love. That is what is happening to you. I balled and said yes...but it helped. For you have to work it out on your own...you are disappointed but you get past that. He is just a kid and treat him like everyone else. At that point you do not see any differences. It is a gradual period of time.

Gina Campbell

Theme Eight
Advice To Society

Society finds it difficult to cope with differences. For all of these families interviewed this had been expressed in subtle covert and unconscious ways. Whether through segregation or non inclusion to just a plain stare, to lack of knowledge or fear.

Thus the role of the family can only be viewed and understood in a sociopsychological text. Here as with all families interviewed there is a continual reciprocal effect of family-child, and family-culture-child. The only difference for these families are the attitudes, pressures, and requirements placed upon them due to having a child who society deems as different.

So in a strong majority of cases these families have taken on another role as mediator between society and their child. Families have taken upon themselves to give advice through doing but also raise the current level of consciousness about their child or young adult.

As one parent laughs she begins by saying...not to be afraid when you see someone different.
People in the grocery store who look at him differently I tell them "oh you are interested in my son:" "Would you like to meet him?" Get to know him as a person. He is not an object to stare at. He has Down syndrome and he is not contagious.

_Thori Family_

We simply talk to people. We hope even though this experience that it can make an impact upon other people. So that they would in turn go out and make an even stronger impact upon society at large. We hope by talking to others that it would be easier on other kids in the future. So even though we get overwhelmed at times we take this positive attitude with us.

_Morgan loves us more than any other child. No one has taught him that!

_McClaren Family_

To treat them equal. Not just say it but do it.

If someone says something incorrectly do not take it offensively, just straighten them out in a nice tone or manner.

You can change society by saying "hey he is a kid let him be a kid."

_Brian Conrad_

I do it everyday by going out into the world with her. Not being shy about saying "yes I have a daughter with Down syndrome." Or by saying she can do this or by proximity. I do not think you can cram change down peoples throats. It is a gradual process. I think twenty years from now they may chuckle at our conversations and this interview we are having. Or even five years from now...

_Eliz Hughes_

I think lack of knowledge engenders the fear. That is why I do Disability awareness workshops in my school district. The kids have an opportunity to experience disabilities. The only thing that makes you understand is knowing someone well enough that you don't see the disability.

For we do not treat her any differently. When people see that we treat her like any other "normal" kid it helps. That is part of teaching others.

_I think that the educators get the most out of it. The kids catch on right away.

_Kennedy Family_

One young woman with Down syndrome has become her own spokesperson and or public relation agent as her mother explains:
Brenda, her awareness...like some of the letters she has received from children make me cry. For Brenda speaks to normal classes about Down syndrome. Now, these children are not afraid. They had fear. They said a lot of the fear was from lack of knowledge.

Eve Miller

A most heartwarming view shared by one father as an ode to educators and society in general summarizes the feelings of all:

Blessed are you who take the time to listen to difficult speech. For you help me to know that If I persevere I can be understood.

Blessed are you who never bid me to hurry up or take my task and do it for me for often I need time rather than help.

Blessed are you who stand beside me as I enter new and untried ventures for my failures will be outweighed by the times I surprise myself and you.

Blessed are you who ask for my help for my great need is to be needed.

Blessed are you who understand that it is difficult for me to put my thoughts into words.

Blessed are you with a smile will encourage me once more.

Blessed are you who never remind me that I ask the same question twice.

Blessed are you who respect me and love me just as I am and not as you wish me.

Catholic Standard Washington DC. 1/22/81

All the parents in this study shared a great deal of themselves and their families as they recounted their trials and tribulations. Their offerings of what parents need and expect from others was purposeful and yet at times pleading. Many clearly wanted to share with parents and families with children with Down syndrome something that may or may not have been given to them.
Summary

The Eight thematic (content areas) provided 15 families; 15 mothers and 12 fathers a vehicle to express their thoughts and feelings when raising their child with Down syndrome. Even though each family and family member was treated as an individual yet within the range of each unit 3 commonalities were shared by all as significant.

The initial approach made by the medical profession and supporting services touched each and every member. This in turn had a rippling affect upon the extended family members, siblings, and friends. The quality of ongoing issues, difficult interactions with professionals and unpredictable futures still prevail.

These families continue to travel down many a paths, their perseverance and at times determination of getting to that road was noteworthy. In addition, the universal themes (to follow) further contribute to the understanding of this phenomenon and expand upon the implications for the medical, social, educational, and societal members of our immediate world.
CHAPTER XI
Universal Themes

Meta Themes

Every family spontaneously presented the experience, a chronology, of raising their child from birth to adulthood. The review of their personal history was unique to the period of time it occurred. While each family shared the experiences they encountered along the way often times experiences, common ones reoccurred. Their struggles and triumphs frequently had the same flavor. The journey taken may have been different but their final destinations were the same.

Three meta themes emerged which were consistently woven throughout all fifteen interviews. These themes were like spring boards between situations which spanned the past to the present. While related in a variety of ways these themes can be captured by the terms: 1). Living One day at a Time, 2). See the person first...treated the same in his or her "included " world, and 3). Advocacy...being their voice.

Meta Theme #1
One Day at A Time

Having a child does not make you a parent. To be an outstanding parent requires skills, knowledge, sensitivity, and wisdom. The key is the growth process which lies in the opportunity which the family affords children a safe and secure environment. Sometimes parents had to guide people to "buy into" other opportunities that were not available at the time. Provision for all these families came in many different forms of therapies, treatments, schooling, social and recreational interactions, activities and time.

However very often spoken it depends upon their child whether she was "having a good day." Or he was ready to go onto the next step. So often parents found themselves not projecting into the future as often and just taking one day at a time. One family relates that:
When our other children were born we did not think about them going to school. Our major concern at the time was his health. We give him every chance at success. However we can not think past where he is now.

Mack Family

For one father:

The best for me is to set goals. You can not plan. You have to take one step at a time. Once she is finished with one goal you move onto the next. Like crawling, walking, or working on her muscle tone.

Sometimes it is so frustrating ..for you wait and wait for her to achieve something and then it just happens. We have missed it because of anticipation and being over anxious.

Jim Stella

While another father conveys:

We have to learn from day to day. We have to learn that it is okay. This is my son and he is the one who has to deal with it. My life is not changed other than having him as a child. When he first leaned how to crawl and sit up we were thrilled. Even though he is behind the "normal" child it was great. He understands completely in three languages, English, Spanish, and sign language. He does not speak, but that does not stop us from getting him speech.

Brian Conrad

Yet for another father:

One thing with him, is that the further out you see the more you worry. Unlike a regular kid. I do not know where she will even be in ten years but five years I could pretty much say. With Oren we are creating the path as we go. We take the decision to either next year or maybe a maximum two years. That is the longest horizon we are looking at.

Shafrir Uzily

His wife adds that:

I do not have the time to think about jobs, careers, marriage. It is just a waste of time and energy because I do not know now. I will know when the time comes. Then I will think about it and know my opinion.

Llana Uzily

With such daily demands comes a relentless amount of patience and at times parents address the difficulties of the situation.
I just can not plan or fathom the future. He amazes me each day and each year. He kind of grows up just without me realizing it.

Gina Campbell

I on the other hand keep waiting. I am having a hard time as I did before because I am waiting for it to get better and easier. In regards to the amount of work and effort to keep him for hurting himself. I want him to be able to do more things and be trusted more.

I would like him to get up and wonder around the house and hope everything will be okay the next morning. The first nine years we never let him out of our sight.

Curt Campbell

All these families have been involved on a daily basis with their immediate issues, at their own pace, even when life takes them down an unknown path. Yet they manage to weather the experience and continue to live day by day and not worry about what might come. Stella summed this up so well:

I use to think of all those things and Dr. Cooley told me don't worry about it. You have a good ten years to think about those things. I think I will have the answers to those questions when I get to that stage in life.

I remember Jim saying to me when she was a baby in the hospital... “What will we do when she asks us if she could have a baby?” I am like... “what?” He says “What am I going to tell her?” Well probably that is her choice. She has a 50% change of having a baby with Down syndrome and a 50% of having a normal child. By then Jim we will have the tools to tell her the right things.

Paula Stella

Meta-Theme #2

Person First...To be "Included" and Treated Like Everyone Else

More often than not the diagnosis of Down syndrome was a passport to an institution or a back room. Sadly, these children then lived up to the dreadful images remembered from old biology textbook. These old stereotypes may be laying to rest but the generalizations or categorizing that goes along with them still exist today.
Seeing the individual child first was a consistent thread woven throughout every aspect of the interviews. Moreover, the issue of person verses disability was evidence everywhere; between parents and their child, between siblings, teachers and school personnel, other professionals as well as society at large.

Their children, their presence, served as proof of simply that a child first. However, these families seemed greatly affected by the message delivered along with the termed words.

As mentioned in previous sections, coming to terms with a label or given a “medical diagnosis” was particularly difficult early on. All families discussed situations between themselves and others along with their past images and experiences. It was over time that the adjustment period in turn furthered their ability to share and communicate their thoughts and needs.

When asked about their personal definition of Down syndrome and how they intellectualized this term the majority of the results reflected their child first. The range of responses ran the gamut for both fathers and mothers from no formal definition to one which used nonatursive language such as a “little slower,” “having some extra genetic material,” or as” my son or my daughter.” While other families used humor mixed with genetic or the technical definition to describe their child.

*We call her the girl with something extra. We figure if she ever gets a flat chromosome she has a spare. She is prepared for a flat. For she is just different. This is neither good or bad. Some things are better and some things are not so good.*

*Hughes Family*

*Still other families explained:*

*He is just like any other child just a little slower.*

*Thori Family*

*My daughter has our genetic material with a little bit of extra chromosome. She is a little bit of extra material. She is very normal. Although I do not know how you would describe normal in today’s society....*

*Paula Stella*
If you ask me what is Oren I would give you a different answer than Down syndrome. My answer in general is more disconnected and not so much with feelings.

Sharfir Uzily

I never thought of my child as a disabled person. I saw him as a child first.

Tricia Enos

One parent explains this experience by the following:

If you are riding on a bus with a guy in a wheel chair and you start talking about baseball cards, you forget that he is a person in a wheel chair. The next time you see him do you want to know how that person's wheel chair works or what team he is for?

Kathy Kennedy

While another mother sums it all up by saying:

You do not look and see a spare chromosome. Tom is a real smart man and that will play a lot in it. If she has her fathers brains and she is “mildly retarded” she will be like me or the general population. If she has my brains and is “mildly retarded” well then we need to teach her a few things. She has individual skills. I expect the same from her as from her sister. So we are not going 75 miles an hour instead we are going 55. We are still going to get there.

Eliz Hughes

No matter how it is defined either by the medical or educational sectors it is basically a non important factor at any stage. What is important and remiss by the professionals and society as conveyed throughout each interview is seeing the individual person first. This theme of “person first” as part of their world and treated like everyone else was difficult at the onset. However, these families continue to work relentlessly and effortlessly to convey that we are all “people first.” We all can make a difference for we are all part of this world.

Meta Theme #3
Advocacy...Your Child’s Voice

It is most important for all parents to become strong advocates for their children. For many families this was a very difficult task to take and at times the only means to take.
Many parents were quiet, shy, and very soft spoken years ago. However, now as many articulated... “watch out, I am a lot older, and a little wiser.”

It is a bit overwhelming initially for all parents. However all parents are experts of their child. Parents have done this through continual observation and records on their child’s growth. They have in the area of speech understood the non-verbal clues of their child, learned sign language and in some cases are teaching sign language to others. They have always let their child’s needs and abilities guide them. Professionals on the other hand are not the parents, their knowledge of the child is shaped by limited observation and printed material. They deal in generalities.

I tell the education system to open their eyes. You can not expect every child to be in a typical classroom. I think each parent has the choice to make. I think they have to offer the opportunities. I want educators to treat my kids as kids. If you (the educator) have a question about Down syndrome just ask me. I am willing to talk to you. It is not contagious, none of the other kids will get it. I want him to get the same opportunity.

Maria Conrad

For once the child is in school, parents can not stop by being an advocate. They have to become an even stronger one. I marched down to the State Capitol many times, to get bills passed.

Kathy Thori

I lobbied in the State Legislature. I drove in every day to lobby and put my family on the back burner for a while. That is why we moved out here. So our life would not be so hectic. Once a baby like this has touched your life... you can not just sit back.

Gina Campbell

When it came to school meetings, half of the families expressed strategies before going to the meetings, while several fathers expressed how they do not like to go because it was too frustrating or they just do not know what to say. One mother even commented on how aggravated she was such treatment:

It does not matter how prepared I am or how serious I am taken. It’s a coffee club. When I walk in the door with Ramone, well he does not have to say a word. All of a sudden we are conducting business. The entire demure changes. When you go by yourself you just can’t carry that same weight.

Kathy Kennedy
It has been a very bumpy road, a lonely road and one that is in need of constant repair. It has been painful and depressing working with the negative ideas in print, and facing the attitudes in print that will surface in people. For one young couple:

*It is tough reading literature that we have not gone through. We do keep abreast of what is new out there. We are being made aware of new technology and research.*

*Mack Family*

Public Advocacy is suppose to be the final stage. However all but two parents are not in agreement of receiving the most appropriate services for their child. Several mothers comment on their sense of urgency and what they have learned in the process:

*If only educators could read and understand. I have yet to find the words to impart upon them this sense of urgency I feel in terms of my daughter's education. I assure you I have not...for they would be working right now getting a program together.*

*I can not believe that they do not feel an obligation to provide information to the parents. If there were not any Federal laws mandating this I could understand.*

*Kathy Kennedy*

*People will not recognize Down syndrome unless they are personally involved in it. Other than that they will not find out. Just like my family. If we did not have a child with Down syndrome they would be on their marry way...and we did and they are. People (society) thinks it is okay. There is a problem but we have people to deal with it.*

*Like in the schools we have such a diversified population and many problems that go along with it. So the schools are getting businesses involved. This should be the same for those with disabilities. It will serve them better to get them working instead of having them as dependents.*

*Anita Contreras*

An opportunity to share their experiences through the current interview was also a significant experience of communication for all families involved. Several parents disclosed things to their partners that had not been expressed before and many parents stated that this gave them an opportunity to share among themselves their own perspective of the experience. These families were highly engaged and several have requested transcripts of the other participants.
Their words were the source of true communication to each other and others. The following are a few quotes of what each couple shared about their experiences as participants in this study:

The experience has let me learn more about how he feels. He is always so closed book about it. It was very interesting. I know that this is his girl. She has said daddy at a year and one half. She just started to say mommy (mother). So can we allow her to say mommy on tape!

Eliz Hughes

This experience made me see how lucky we are. Even though our children can not always tell us all that they feel and all that they are...I know someday there is more in that little heart and mind and I will learn to appreciate it.

Gina Campbell

By reflecting on my life and that of my child, I am now given more reason to continue sign language, communication and business classes. For my goal someday is to start a non-profit school/training center. I want to provide more parents with more reliable and knowledgeable resources for their kids.

Lyrae Thomas

Conclusion

We listen, we speak, we take one day at a time, and we see that our children remind us of all the magic, mystery and laughter in everyday life. For this way of thinking has served as a tool to use toward growth and development within the family as well as within the larger context (i.e. professionals and society). These families have shared a viable experience of how important you are as a person, that your voice should be heard and not to worry too far into the future.

Indeed these families have provided a wealth of information, a rich resource, a bountiful dialogue with the intent to listen, to construct criticism and to evaluate. These will be useful tools for other families as well as for many professionals who also share in this experience.

The following Chapter XII will address how such a relationship can happen based upon what the current study has revealed. It is clearly time to address the issues at hand.
As these families have expressed there is a profound effect upon the family when raising a child with Down syndrome. There is no forewarning and it often follows an unpredictable course. This final quote is an analogy describing and putting closure on life in the world seen by a family of a child with Down syndrome.

Life is like a prism. If you like the certain facets of the prism what a pity for those who do not recognize them. For the more facets of the prism that you polish and clean up the more light that comes into your world. Her sister just by her existence will be a more sensitive and caring person in this world. Her cousins, aunts and uncles have been given a gift. You will never be the same again.

The Hughes Family
CHAPTER XII
Discussion

Staying on the "Up" side of Down syndrome means many things like lots of love; patience; kindness; encouragement; being proud of us; helping us to be independent; giving us a chance to succeed or even sometimes allowing us to experience failure. Always believe in us a little longer to do what we are trying to do...Don't ever try to set limits on what we are able to do because I can guarantee you will guess wrong and that we will surprise you with our accomplishments. (Forts, A. 1995).

Introduction

This exploratory study into the phenomenon of what life is like for families when raising a child or young adult with Down syndrome has revealed a wealth of rich and compelling data. It was not a goal of this study to develop a profile of the family with Down syndrome. It was not a goal to make comparisons between families for each is unique in representation of that unit. However within this study many significant shared themes did emerge. The method and design of this exploratory study was such that the family unit was interviewed together through an open and supportive forum in which to explore various aspects of their lives. In doing so, these parents willingly shared their thoughts, feelings and perceptions. In turn they gave voice to what up till now had not been respectably provided or reported in the literature. The themes which emerged from the data were: Diagnosis and adjustment issues, Family and social issues, Educational issues and beyond, Parental experiences, needs and advice for new parents and to society. These themes highlighted the areas in which families with children and young adults with Down syndrome are significantly affected. The results of this exploratory phenomenological/heurist study clearly describes the complex ramifications and alterations in family life as forementioned. Having reported these results, this chapter will address the meaning behind this study. This chapter will focus on four main areas: 1). How this study relates to the Review of literature and what the findings represent for this population; 2). Implications for
all professionals within the context of the home, school, and community environments; 3). Future Implications for research; and 4). Critique of methodology and final conclusions.

**Current Findings in Relation to the Review of Literature**

The results of this exploratory study were quite consistent with the findings in the literature which specifically focused on the area of Down syndrome. The children in this study like those reported in the most recent and popular literature, are simply that...children first. They are their own person no matter what the “diagnostic” label connotes. They have a right to self-actualization as any other child or young adult. They develop and learn academically, socially, and emotionally at their own rate. They have the same need to love, to learn, to share, to grow and to experience the world as everyone else. Canning and Pueschel (1990) further define a child or young adult with Down syndrome to be first and foremost a human being with all of humanity’s inherent strengths and weaknesses.

When reviewing the literature about the many and varied difficulties of this “label”, it is striking how the family experience as told by the parents, portrays it to describe the child only in his or her own experiences. Such euphemisms and attached labels characterize and convey a very strong and negative image. In turn, the “label” in either medical or technical form does not reflect upon the family-wide issues as revealed in this study. The literature may address these issues as monadic or dyadic, but never quite captures what is going on within the dynamics of the family as a unit.

With respect to the comparative literature confusion and conflict abounds as seen throughout the terminology within the field of mental retardation. As we move away from institutions to the home, school, and community the demands and interpretations change. This reflects the American Medical Association on Mental Retardation (1993), revised definition as “no longer an absolute trait but a condition improving with the right and appropriate services.”
An interesting connection to the literature (Ludlow & Allen 1979; Pueschel 1988) pertaining to Down syndrome then carried over to the effectiveness of such services as early intervention/infant stimulation. The parents' description of their feelings and that of their new-born were dependent upon each child's daily response, reaction or even readiness to such services (therapies) at that point in time. Some sensed a powerlessness and at times an over anxiousness when working toward the enhancement of their new-borns development. However, as stated throughout the literature in the area of Down syndrome, well designed studies are needed in the future to identify the amount of variables and their interactions occurring at one time. Such variables could range as reflected in this study, from medical to organizational (daily life decisions, routines) to personal living style, time for adjustment and the interactions and attitudes imposed by their communities. Such studies, as addressed in the literature on Down syndrome also relate a need to understand within the social environment as it contributes to the development, growth, and successful adaptation of each child (Sontag & Schacht 1994).

These parental feelings in this study, were also similar to those sensed in the practice of public education. For progress of children with Down syndrome depends upon the type of early intervention and education available. Only one family out of fifteen in this study did not have such available educational services. While another family did but started this intervention late due to availability.

A Private or religious school system for school aged children, was only addressed from the stand point of providing no adequate programs for children with Down syndrome or "no options for placement in that system" versus placement in a public (state) school system. Since the Review of Literature did not specifically address the benefits of placing a child with Down syndrome in a Private or religious system, it is difficult to extrapolate or to make any meaningful discrepancies between the two. Yet, according to the findings of this study, one could speculate that the Public (state) school programs for a strong
majority, were not meeting the individual needs of these children. In turn this has had a significant effect upon the family unit.

As explained by parents, they did not designate most teachers and educators in the public system to be inherently good or bad people. Parent's considered the main problem to be the teacher's initial training and lack of specialized education. Teacher's typically were trained in regular education versus that of having additional or specific training with special needs children.

The limitations placed by the Public (state) school systems were described under the "rubric" of mental retardation. A majority of the time the "syndrome" was viewed first negating the individual and the complexity, and changing nature that such an individual encompasses.

In addition services in general were often fragmented and financially ridden with political underpinnings. This limited the future development of each child as an individual with special needs. Therapies in terms of occupational, physical and speech, and outside tutoring in the academic areas, were not provided on an individual need or ongoing basis. As reported by a majority of the families' of this current study, even the Public (state) schools chose to educate the child as an "outsider" or separate member of his or her school environment. The Public education system in turn did not insure the integration of all its' students under one system as equal and or "included". The IEP (Individual Educational Plans) conferences were held once or twice a year epitomizing the time given to develop a program which was often pre-determined between school and the family. Clearly, Public (state) schools as public institutions are geared toward regular education which utilizes a more homogenous approach. In spite of the guidelines established in IDEA (Individuals Disabilities Educational Act and Public Law 94-142) as stated in the literature (Price & Goodman 1980), families also strongly commented in this study, as not being fully given a decision-making role. Family input as to what, when and how their son or daughter will be taught was limited or non-existent. A few families stated in this study, as well as in the
comparative literature (Goldstein, Strickland, Turnbull, & Curry 1980) that they did not know what was available and therefore maintained a passive role.

According to parents "inclusion" was a well advocated issue (universal theme) both in the formal and informal sense. This issue was of great concern for all parents interviewed. Inclusion is highly debated as stated in the literature with little or no research in the area of special education as it relates to children with Down syndrome. Most of the national debate within the comparative literature regarding general class placement in the Public (state) schools has remained theoretical and speculative. Inclusion, when looking at the effects upon the family when raising a child or young adult with Down syndrome, is difficult to draw clear similarities and differences due to the limited literature.

As reported in theme one, on the medical profession, in this current study and documented in the literature, treatment and the handling of the diagnosis is viewed as having a negative and emotional impact upon the family (Hooshyar 1986, Trainer 1995, 1991).

Doctors are still making slow recommendations. They are still telling parents to love the child but not to expect too much in his or her educational and developmental processes. As documented in this current study and in the literature on Down syndrome pediatricians are not spending enough time with parents to guide and learn about their infants development, its' implications, and its' effect upon the family and the future of the child. For physicians as stated in the comparative literature, have perceived individuals with mental retardation by a strict medical model. At times they were not thought of having to deal with the acutely ill. Therefore treatment and diagnosis became uncomfortable.

Theme two on the adjustment issues are also very complex and filtered in and out of every theme. Trainer (1995), description of adjustment stages was quite accurate. According to her schema the adjustment begins at the time of diagnosis with pivotal points emerging as the child develops. However these adjustment stages for all families in this current study, were not sequential nor concluded after the child is seen first then the
disability. These stages not suggested by Trainer, run a lifetime, a continuum through all areas of the development of a child in relation to school, community interactions, and adulthood.

Schools and the education system at large, in this current study seem to ignite the most significant adjustment crisis for families emotions ran high. Other professionals were tied in generating stages of adjustment for both the parent and the child.

Frequently the data, as reported in the literature on Down syndrome, has been lumped together on the issues of adjustment. Therefore, data about families with Down syndrome contributed unwarranted conclusions and statements about one kind of family to another.

The results of this current study did not support the popular notion of mothers as “disabled” or ineffective in their mothering. In fact, given time to gain ample understanding of their child along with personal support, these mothers represented a highly competent and articulate group. In addition, mothers in this study did not see their child negatively, nor foresee a pessimistic future for their child.

Worry, fear at times, frustration and concern would be appropriate feelings to describe how parents perceived the future of their child. For as the current study indicates (universal theme) all parents chose to take each day at a time and made their decisions accordingly. Therefore, what the future holds for each child can only be dealt with as a prediction, a generality, and not an established fact.

None of the mothers generalized their child with Down syndrome as being anything less than a child (Singer 1995). While the comparative literature portrays mothers as being overprotective or overinvolved, the actions of the mothers represented in this study seemed to be based upon an assessment of realistic goals and needs of the child within the family unit. These were the same actions and decisions demonstrated by all but two families (one child family) in this study. As further documented by parents in this current study, the more outlandish behaviors (i.e. screaming matches with the medical profession, storming out of IEP conferences, etc.) are all viewed within the context of each situation. Often
parental response were due to the lack of adequate information, causing a sense of powerlessness, and at times frustration and stress with disconcerting individuals and the systems outside of the family unit.

The current study viewed the mothers as being more powerful advocates and decision-makers than in any of the existing literature. For some mothers, their reactions to their situation emerged from anger and a sense of vulnerability of the experience of having a not so called “perfect” child. For society has classically sanctioned that mothers are to nurture their “perfect” and “normal” children. However when a child is not “perfect” or “abnormal” the mothers assume the blame and the burden. Mothers, henceforth are more, as reported in the comparative and current literature, apt to manifest signs of depression more so than fathers. Fathers do experience similar feelings, but emotional issues pertinent to mothers are what is reported in the current and comparative literature.

This study in contrast was drawn from interviews of parents representing a wide spectrum of the family unit. The families varied in stated, ethnic background, religion, income, and demographics (as cited in Tables 3-10). In contrast a majority of the studies both current and comparative, were reported from the mothers perspective only. Moreover, studies on this topic have been primarily from the perspective of the clinicians and authors. Such studies have not been written to focus on the fathers perspective in the area of Down syndrome.

In this study, mothers were not the only ones, solely to carry on the “emotional load” as well as the day-to-day demands. In contrast to the limited theoretical based current and comparative literature on fathers, this study reflects fathers sensitivity, adaptability at time of the diagnosis, frustration and emotional overtones throughout their child’s development. For fathers in this study, beyond the mother-child dyad take on a more “shared responsibility” (Russell 1980).

As documented in this current study; fathers expressed emotional and sensitive sides to their experience. Nonetheless, the majority of the “emotional work “ was either assigned
to the mother or intuitively carried out by the mother. In contrast, the role or the more active part of the relationship compared to the feeling part were frequently negotiated but not consciously addressed. These more sex-assigned roles seem to be overused and may over time place far too much emotional burden on the mothers.

The emotional issues for the fathers which emerged from the current study brought to light the need to look more closely at the father’s experience. This has been a consistent recommendation in the comparative literature and has not been looked at any great length in the literature about families with children with Down syndrome. Of course, viewing the family experience solely from one side or the other presents a rather fragmented and lopsided view. It is far better to capture the “total” family units feelings and thoughts to not only bring out the differences but also highlight the similarities not previously acknowledged. Fathers are all too often excluded and mothers over-ascribed as the caregivers and regulators of the family.

Fifteen families demonstrated an enormous range of emotions particularly the mothers experience. Such emotions did not hamper or alter their child or the functioning of their family. Further exploration of these women’s and men’s experiences would be of value in understanding the mother and father experience, the family as a unit, and the interrelationship within the family.

The most common phrases stated in the popular literature has been; "set no limitations," "be an active voice/advocate", "treat them like everyone else", and "take one day at a time." These were well worn out phrases, utilized by fifteen of the families in this study as well. The popular literature, generally coincides with the experiences expressed by these families when compared to the clinical or empirically based studies. The more clinically-based literature does not represent the quality of the daily demands or real-life experiences. In addition, the literature ignores and separates the child from his or her context within the family unit. Moreover, professionals seem to concentrate quite intensely on the parents’ vulnerability and often overlook their individual strengths and intuitive knowledge of their
child. The popular and current literature, while more times than not, written from a families' perspective, does not integrate the context of the family into the experience. The results of this study, clearly suggest how the family unit when raising a child or young adult with Down syndrome, individually and collectively is affected.

There are many striking similarities developed between the findings of this study and that of the comparative literature with children with mental disabilities. First, is the fact that it can not be taken as a given that having a child with Down syndrome will have a deleterious effect upon the family. In reference to parents who have children with mental disabilities, Paul (Ed.1981) further expresses that parents must learn their new role in this world as well as about themselves. This new role as he points out is a correlation between adaptation, attitude, and behaviors of the individual within the family. The parents in this study also indicated that their role is expressed as a combined “interaction” and a “shared” one between the entire family unit and its members. For parents function in a “double bind.” Like the parents of this study, they are not only involved in the integration of their ways and understanding to their other children, but also deal with an array of feelings and interactions with their “specific child.”

Much of the feelings and language conveyed by parents in this study echoed the words of parents or authors of the literature about families with children with mental disabilities. As the comparative literature also reports, marriages are affected, for “better or for worse”, as are sibling relationships and development in general. Where this study differed from the comparative literature was in reference to “pathological” representation connoted to mothers and their “uninvolved” fathers (Cummings 1976). The current study revealed “healthy” and enabling mothers and supportive and “involved” fathers performing as an effective team. Fathers and mothers did not coincide with the commonly held view that mothers carry more of the “burden” than fathers. Fathers were often not given an opportunity to express their view, not available due to career, and often looked at by society as having a role of the pragmatist and or strategists of the family. Even though some mothers more openly
combined their emotional energy with practical viewpoints, a majority of this thinking was equally representative by both genders.

As documented in the comparative literature and in contrast to the few studies (Buscaglia 1983, Featherstone 1981), the belief that having a child with a mental disability would cause more marital discord or divorce, in this study reflected the opposite view. These studies (as cited in the literature) were in general terms and highlighted the level of disability (severe verses mild) as having a greater impact upon the marriage. These studies were not specific as to whether having a child with Down syndrome caused a higher divorce rate and or had a negative impact upon the family unit. In reference to this current study all families were in tact, solid and provided a strong foundation for their child with Down syndrome as well as for all their children. Out of the fifteen families interviewed all marriages were not shattered or less of a unit due to the fact that they had a child with Down syndrome. In the case of a divorce (two single mothers related) the child was not the cause or underlining grounds for that divorce.

The families in this study were bonded and strong, educated, and making ends meet. Yet, life was confronted in many ways to all and only compromised for a few due to the presence of a child with Down syndrome upon society at large.

Recent studies along with those in this study have brought to light that there are no adverse negative outcomes in relation to a lower self-esteem or conflicts upon sibling relationships. In contrast, with the current literature, often sibling relationships are defined from the mothers perspective, this study conveyed both perspectives along with a few sibling statements. In all families except one, siblings demonstrated more sensitivity and a conscious awareness toward individuals with disabilities. This study also conveyed that siblings did take on various roles; parent, advocate, friend, or just brother or sister. A few of the siblings (older siblings) as indicated in this study, provided more caregiving roles. However, for the majority, the siblings just grew up with their brother and sister with Down syndrome. More direct assessment is needed as indicated in the current literature for
little has been documented in the popular literature as the direct effects of children with Down syndrome as well as their siblings. As indicated on Table 5, the rank of the child with Down syndrome among his siblings may prevail other variables toward the functioning of the family unit. More direct assessment is needed in this area.

Extended family and friends as reported in the comparative literature along with this study are needed to maintain important functional links and emotional support. This study has shown that a majority of the extended family members (with few exceptions) and friends have been a positive influence upon their child and family unit. The reactions varied as in comparison to the comparative literature, due to time, age, understanding, stigma, and adjustment (Gabel & Kotsh 1981, Crutcher 1988). The research in the area of Down syndrome has been limited and future investigations as to the roles in the development and validation of parents' identities are needed.

Theme four, reported in this current study, on social issues recognized these families have additional demands placed on their time, patience, endurance and finances. The logistics entailed not only meeting the needs of their child with Down syndrome but also the family in general. Few people outside of this experience seem to fully acknowledge or comprehend what is often required or involved in their average day. The additional demands and inherent constraints, in regards to general childcare, domestic work, and finances created a strain for the majority of these families.

With the added planning and organization required for day-to-day scheduling of medical appointments, therapies (i.e. speech, OT, PT, early stimulation/interventions) school and school related activities, outside activities such as sports and recreation, tutoring, school meetings and functions, etc. life for these families could be considered to an onlooker to be quite overwhelming. The daily needs both obtainable as forementioned (i.e. scheduling of therapies, interventions, medical appointments) and at times non obtainable (i.e. rest, socialization) as raised in the current literature, were supported by this study (Drower & Hansen 1991, 1993). In all fifteen families no matter the availability of
general services, treatments, massive phone calls, paper work, shuttling back and forth, locating information, attending support groups, to rearranging their work schedule the final outcome was the same. This perspective views the family as a consumer of services and argues for “enabling” or “empowering” families to gain access to resources and direct usage of these resources. For as documented in this current study, these families placed the context of their child within the family unit. Therefore, the service/educator providers’ efforts should be more focused on supporting this view of the child and their family within the larger ecological system in which they live and learn (Bronfenbrenner 1979). These families like others wanted to provide the best of possible worlds for their child along with maintaining a balance in their lives.

This study exposed numerous “troublesome” areas for these families. Even through, from what parents conveyed, the findings imply a sense of stress and strain somewhat similar to that in the comparative literature on mental retardation. Stress manifests itself in varying degrees to the disability (Holroyd & McArthur 1976) along with the stress of finances and the amount and availability of services needed for that child. However, what is not explicitly conveyed in the current literature, but is in the comparative literature (Barsh 1968) as in this study is that stress and strain are not caused directly by the child but only by the demands placed upon the family by society at large.

Just as the literature points out that there exist biases, stigma, and prejudices around the disabled and their families, this also was the experience for a majority of parents who have children with Down syndrome. Pearl Buck (1950) in her book “The Child who Never Grew”, reflects upon how her daughter born severely mentally retarded lived in China and was not recognized as a disability. The Chinese, at that time accepted the disabled as simply a fact of life. They cared for them as they would any other child. It was not until she was brought back to Western culture that she began to see the stigmatization and prejudice toward the disabled.
In our culture as expressed by all families in this study, such attitudes and prejudice still prevail. In addition, when the disability is readily apparent or noticeable as suggested by Buck there is a greater chance of discrediting the individual and the experience and only seeing the "disability." Discrimination has taken on a new degree and possibly a new reform movement in terms of being segregated from the general population due to the fact that you have a "disability."

Significant among the daily issues is the nature of support and support networks. Perhaps greater than any of the findings between the comparative literature and this study was the vital and highly individual relevance to support groups and networks.

Pearson and Sterberg (1986), and Trute and Hauch (1988) have attributed positive mechanisms for coping and developing family inner strength to be best described through the "sharing" process. Bronfenbrenner (1990) also contends that this support must be extended to come from the broader community content, to include neighbors, friends, co-workers, and others within the families' community. The findings of this current study strongly support the need for various support and reliable alliances. These as stated in this current study took on the form of family members, "pilot parents" or "parent partnerships", international conferences, Down syndrome associations at the local, state and national levels, as well as updated written information. This study, in contrast to the current literature, did show a significant fluctuation of involvement in various support networks over a period of time. This was due to numerous reasons; family time scheme, need for resources, adjustment, need and daily life activities.

Olshansky's (1962) concept of "chronic sorrow" was not evident in any of the families. What was evident was the families long-term process of adjustment. There was not a specific time where adjustment as cited in Wilker et al (1981) occurred. For it was a periodic phenomenal process (experience). This process, as reported in this study, occurs at various points and times throughout the development of the child with Down syndrome.
In theme number five, on the educational concerns and beyond, parents expressed a surge of feelings ranging from frustration, to a sense of urgency of the proper placement of their child in an appropriate program. Attitudes, improper actions, and the lack of mutual-respect were continually voiced concerns of these families regarding the educational profession. Such difficulties with teachers, principals (head masters), psychologists, case workers, etc. perhaps are triggered by the uncertainties of the medical or technical definitions and the categorization and stigma of “Down syndrome” under the rubric of mental retardation. The limitations verses expectations, as cited in this current study, has been in turn communicated endlessly to all families by these professionals. Communication and awareness of the family circumstance were underlining concerns for all families in this study. Professionals as stated in this study, need to exercise more discretion by individualizing interventions to meet both the families’ and children’s needs. The professionals need to be more flexible, go beyond the traditional jurisdiction of their agency or facility and cut across professional boundaries to work with all families. Thus, as a “team” they can then in turn work together to meet the needs of each family unit.

For teachers, their best resource, as for any student is the family experience. Rather than simply viewing the diagnosis teachers should focus on each student’s given ability. As one proud father responded to his golf partners while participating in a fund raising tournament for group homes for the disabled, unaware at first that his daughter has Down syndrome: “Do you see your daughter living here?” “No” he replied to their dismay... “I see her running the place!”

No one expects children with Down syndrome to function or be at the exact same “normal” academic level as his or her peers, but what is important as expressed by all families in this study, is to provide them with the same educational opportunities for learning as everyone else.
Implications for Professionals Within the Context of the Home, School, and Community.

The following recommendations and implications for “eclectic” care emerged from this study as presented by the participants. The investigator's current thinking has been enlightened through this “shared” experience. For the investigator has come to a better understanding and has gained new meaning behind the direct experience of raising a child or young adult with Down syndrome.

The aimless accounts of these families did reveal that raising a child or young adult with Down syndrome has a profound effect upon the daily functioning of the family unit, adjustments, and perceptions of the family and its members. What families had to express offered a realistic and practical view into the real life and adjustment issues and their relationship with the professionals and service providers.

While there was not one universal effect of the experience, several shared themes, as stated in Chapter VI through XI and reiterated in this chapter. All of these have implications for the professionals who work with families and their children with Down syndrome. Through the elucidation of these themes, families revealed needs which they have experienced (and in many cases still are) as well as the growth and developmental effects related to raising a child with Down syndrome in the family unit.

Numerous statements and experiences were described concerning the uncomfortable and intimidating encounters with such professionals as physicians, social workers, nurses, educators, psychologists and community members. A frequent issue was professionals lack of empathy and understanding of the parents’ concerns, pressures and expectations for their children. For a majority of the parents, interactions with professionals have become “battle grounds” which has taken on recurring rounds and heightened levels.

A few parents, in this study did, however, experience some positive encounters with professionals and mentioned satisfaction and gratefulness toward a particular individual.
Some parents prefaced their comments as being lucky or fortunate to find such qualified staff. This indeed should be the norm and not the exception.

In nearly all these families stories appeared to reflect how they have remained the provider instead of being provided for. Parents, already experiencing the “shock” of an uncertain diagnosis found themselves in an unknown and powerless position in relation to the medical profession. Their experiences were negative and unsatisfying. Combined with their own words, parents expressed their experiences with a sense of urgency, an intensity, and in a frustrated manner that pleaded for attention to their issues at hand. These families further conveyed more careful and mindful individual attention and intervention needs to be addressed by the professionals. Addressing implications for the professionals rather than concentrating on only the clinical implications is highly noteworthy with this population for two reasons. First, often times the key “decision makers” involved with the child with Down syndrome and their families are represented from an educational spectrum at an IEP (Individual Education Plan) conference. Some include teachers, psychologists, special education directors, curriculum specialists, etc. These people generally speaking possess the most powerful positions as well as the parents toward the implementation and facilitation of the future programs for their child. Henceforth, this is an audience needing to be targeted toward the complexities of the issues these families face. According to the families in this current study the education system has not been in tune to their child’s individual needs, their child’s current ability levels, or has not “bought into” the idea that their child should be educated along with everyone else.

The second reason for highlighting a broader base of implications and interventions is to move away from viewing this population within a strict clinical model which has frequently been represented since the beginning of time.

In general, all things that are true regarding the role of any family are true of families with children with Down syndrome. Basically the role of a stable family is to offer a solid
training ground for children to learn to be human, to love, to build upon their unique personality and to relate with and to our changing society.

However, the amount of stress this experience will carry varies over time in relation to societal influences and the support and services available to them. Professionals particularly from the medical or psychological profession have added this undue stress due to their training in a clinical world. The clinical view tends to define or categorize children and families very narrowly in terms of the disability or "medical/technical" label.

The literature up until now, pertaining to the child with Down syndrome and their families diagnosis is already far too uncomfortable and biased toward children who are not "normal." It behooves professionals who work with these families and who in turn depend upon their expertise to see these children as individuals and take a broader and more "eclectic" and "holistic" view.

The implications for professionals who typically work with children and their families may be working from the wrong perspective. First and foremost, it is important to recognize the meaning behind the family experience and being available, to provide service and to assist the families with their diversity of needs. This kind of provision may entail a more objective acknowledgment of possible options and opportunities for that family.

Secondly, clinicians and educators need to make certain that their interventions do not upset the delicate balance of the family unit. They should be certain that what they ask and the manner of what is being said is both important and efficient toward the interests and the needs of the child and the family members.

Thirdly clinicians and educators should recognize the responsibilities of the family unit and support them in establishing priorities to their values and day to day needs. They should begin to focus on positive contributions that a child with Down syndrome makes upon the family needs.

Finally clinicians and educators need to be more supportive of families as they move through the life cycle. They should recognize all facets of the individual child and prepare
each child to the best of his or her ability with the same expectations as for other children, to become fully functioning and successful members of society.

As these parents mentioned, advocacy was of paramount importance in getting their voices and that of their child heard. Professionals need to be more aware of not talking down to parents and the precise language they use which will communicate best what is intended. Consideration for cultural beliefs and customs should also be accounted for. Throughout this study parent's actions and languages became more specific to daily needs and general to future goals, their manner of expression (non-verbal) and movements also provided meaning beyond words.

Several parents both equally engaged (father and mother) shared stories of volatile episodes, involving the educational planning conferences of their child. Confrontational behaviors or outbursts occurred due to confrontational behaviors or outbursts occurred due to the educator's attitude as seen as the “sole” authority of the child's progress and development. Frustrations arose on the part of the parents for not having their needs listened to, nor being “included” in their child’s school progress.

This experience requires not only a more holistic or “eclectic” view of the experience but a more cooperative one. For the responsibility then lies on the professional, being a more critical listener to the context of what the parents are saying and then actively participating in the final outcome. Without knowing the “world” from the families perspective or even asking, problem solving and feedback may only warrant further confrontation.

Whether working with the family or an individual (father, mother, extended member) professionals should structure their interventions as a collaborative partnership. Therefore each and every encounter should entail an individual approach to information in concrete and appropriate terms within the families understanding of the experience. What can emerge from a conscious effort of the parents and professionals being equally involved will be of benefit in the long run. These should henceforth encompass the following:
1) The right to helpful, relevant and specific informational exchanges between parents and professionals.

2) The right to acknowledging parents as a viable resource toward placement or services for the child.

3) The right for a vested team effort endeavor, a productive relationship between parents and professionals toward the success of the child.

Clearly, not all professionals and parents will be able to establish such a collaborative venture. However, it is the researcher's belief along with others that there needs to be further investigation into new models of collaboration with parents, the effectiveness of certain interventions, the role of advocacy and the training of parents on conference skills (Drower & Hansen 1993; Turnbull & Turnbull 1990).

Even within the Federal and State mandated laws, (in the USA), legislation alone cannot ensure such collaborative efforts. Efforts from all parties, whether they have a child with special needs or not are needed.

Information sharing, either through therapy or informal measures such as speaking to parent groups, conferences, "Sharing" networks school or church groups, and community programs are of great value. Along with the need for formal and informal support parents clearly wanted updated and relevant information.

Physicians are the ones often making the initial diagnosis and delivering this message to the family. It is here at this moment that the impact is initially felt and it then becomes imperative for such professionals to speak in a language that the parents understand. Even more crucial is the need to translate this "medical label" as to what it may mean in the child's and families' world. Physicians are in the position where they can assist the families with their adjustment period in a more effective and positive manner. They can take heed of their internal struggles and guide these families to the necessary resources or specialist if the situation prevails.
In some cases, by being served, families can then be assisted in accepting their new role as dependent and making effective as to what service they need or are ready for. While in other cases, families might be better served as being involved in an interdependent relationship with the professional.

Either way, it is when the child is diagnosed at this early stage that the professional and parents should begin to develop a partnership. Even though educators may not be able to stay involved with the family over time, psychologists, doctors and job coaches are in the unique position to establish a long-term relationship.

All parents interviewed, expressed a need for more concrete, current and up-to-date resources. Current resources in the forms of newsletters, resource centers at hospital sites, on-line networks, workshops and conferences might reduce the isolation and alter the unknowns. One family interviewed along with this study, whose daughter was diagnosed with rare chromosome analogy 9P plus parallels with the experiences and feelings of families with children with Down syndrome. Since there are "only 250 cases in the world", little information is available or known about the future of these children. So, as it was some fifty years ago that children with Down syndrome who may not have lived past 12 years in age had a bleak and untracked future. It is also interesting to note that in a recent study shared at a Parents-In-Partnership Conference in England during March of 1996, over one-thousand parents surveyed on the needs of the family with a child with a severe disability, all "virtually had one problem with the services, 1/2 had unmet needs related to their child’s learning and 1/2 has claimed that the professionals were not helpful." (Beresford 1995).

Service providers in the form of therapists (speech, occupational, physical) and early interventionists are a grave concern to parents in which more individual involvement, time, and techniques needed to be addressed. In many cases siblings play an indirect part as being there at many of the therapy sessions due to time restraints placed upon the parents of
finding professional care providers or adequate babysitting service (respite). Therefore therapists can also be helpful in providing parents with suggestions on sibling participation.

In addition, parents should be knowledgeable about sibling issues and mindful of how their involvement with a child with Down syndrome might be perceived by other children. In the literature and within specific accounts spoken by these families in this study, there was an urgent need for professionals and their families to keep abreast in their particular field as well as the changing area of Down syndrome.

Educators of today who were trained less than a decade ago are sorely outdated in their field just a decade later. Mainstream teachers (certified/regular educators) who typically have had one special needs course need to upgrade their knowledge. In a time where more children with Down syndrome are being provided with an education in the regular class setting, now is a most needed and vital time for educators to take continuing education courses. However, at the same time specialists and special educators should be imparting their current training and knowledge in a collaborative manner with that of the general educator. Educational institutions in the USA and throughout the world should offer an education which provides a dual major in both regular and special education. In-services and awareness workshops should also be an ongoing lifelong endeavor. Just as the medical profession needs to renew their certificates and knowledge within their field so should the educator.

Currently as well as over the past years the quality of education and teacher-training have been a major issue of public concern. What is clearly needed as expressed by several families is a need to prepare children with a variety of basic skills for competence in daily life and employment in the "market place." There is a further need for secondary school and colleges to develop and implement programs that would emphasize a plan toward a smooth transfer from school, to work, to adult life. All in all "every child or student needs special education." All children need individualized programs. As a child goes through school
teachers begin to learn about their character of who they are and this should follow them and avail them to every opportunity possible.

The unfortunate reality of providing all with a "special" education is the political and financial status of the education system within the state of Arizona as well as throughout the United States. This in turn adds to the families sense of frustration and disappointment.

However, through empowerment and advocacy of their children's rights, parents (family unit) as a group possess an additional key toward their child's future role in society. For nearly every parent in this study discussed how sharing their experiences and feelings can in turn make a difference in their lives as well as in the lives of others. Even though professionals are in the position to educate and support parents it was the parents who took on the pro-active advocate role of bringing these issues forward. They continued beyond the home to raise the consciousness of the general public toward the rightful "inclusion" of their children in their communities.

Taking a journey back through the history and movement of the field of mental retardation, parents have moved from the "twilight" to the "limelight". They have been known to be assertive and a powerful voice sometimes not readily heard or listened to. Yet this is an unfair burden and expectation to bestow upon any parent. Parents and the family unit need to be perceived as individual (units). They need not be categorized or pigeon holed, to fit into any one particular group, mold, or format. Parents of children with Down syndrome are not unlike other parents. For they are in no sense any more "ready" for the demands, change, and adjustments which confront them with the birth of a new born child. They are however, forced to take on new roles. They are forced to delve more deeply in a short time into their new role and its implications for their child. They are asked to then organize new information, assimilate and integrate it into their daily demands and added responsibilities. At the same time they are asked to understand the diagnosis, the medical and technical terminology and education jargon which relate to their child's future and well

217
being. They are continuously asked to cope with feelings and fears of uncertainty as they accept a new challenge toward providing a quality of life for their child.

There is, after all, no such thing as a ‘Down’ child. There may be ups and downs, trials and tribulations as with any youngster but the child still is simply ‘a child’. Along with the child comes a family with all of its extensions and interrelationships throughout the context of the home, school, and the community.

The family both nationally and internationally is now in a position to be a major force behind change. The family can now challenge established professional values both individually and through support groups. Thus an interactive, interdisciplinary, multi-leveled/"shared" and "committed" approach is needed to address the families needs. Success for the family unit therefore, depends on mobilizing a broad range of resources and services that directly produce a more positive outcome for both the child and the family. For it takes “a whole village (as stated in an African proverb) to raise a child.” Success for any child is truly a “shared responsibility.”

Implications For Future Research

As evidenced in the Review of Literature on mental retardation, there is a paucity of research which addresses the interactive relationship of the families and their child with Down syndrome within the context of the home, school, and community environment. The literature in the area of Down syndrome, similar to that on mental retardation, is flawed and more limited in scope due to theoretical and prescriptive studies. The literature focuses solely on the mother’s perspective and lumps the area of Down syndrome under the extensive field of mental retardation.

While the examination of behaviors or experiences of individuals or dyads are important, to truly assess the effects of the family-styles, more research is needed within the realm of the family-context. In other words, instead of viewing the family norms as “givens” they should be seen as agreements worked out through family interaction. Both
qualitative and quantitative approaches are needed to complement one another and to offer a fuller perspective in greater depth and magnitude toward the understanding of this experience.

Chains of the family influence that extend across generations should be looked at through longitudinal and cross-sectional designs. Such designs are needed to capture values and cultural commitment that focus on both the traditional and non-conventional parents invested family interest and lifestyle. Such designs should further consider how these families have negotiated the meaning in their family circumstances with one another, their culture and sustained it over time. The results may need a "simultaneous translation" (as in the United Nations) to make sure the experience is understood and translated in terms of the individual.

Studies in which families are followed from the time of diagnosis through early stimulation, school, work and adolescence would add substantially to the lack of knowledge and information about individuals with Down syndrome. Such studies would not only provide a blueprint for development but allow families and professional support services to glean from a more comprehensive and positive outlook on the variations within each child.

Similarly, studies are also needed in a variety of variables; parent, child, siblings, social and extended systems. Such research might reveal important sources of support that may not be evident when families are coming to terms with their new born child.

For families with children and young adults with Down syndrome, the educational system requires careful analysis and more detailed understanding in the areas of academic performance (from elementary through higher education), class placement, and integration/inclusion. To this end more studies representing a collaborative partnership including the experiences of parents, psychologists, educators, specialist and community members would only enrich the world by bringing forth neglected aspects of every child's education.
Studies are needed, and of interest, of the academic and cognitive development of twins, both fraternal and identical. Out of fifteen families in this study three gave birth to fraternal twins. The findings on the developmental process of the child with Down syndrome due to the relationship of his or her twin sibling would provide a new resource for families, educators, as well as society.

Studies are needed in the area of the medical and health care programs in relation to describing the effects and diversified interactions of these professionals with the families. Research is also deemed necessary in the education and development of measures to improve the actions and behaviors of professionals dealing with families who have children with Down syndrome.

Studies that move away from the "pathological" oriented perspective and focus on the societal pressures, problem areas and professional roadblocks would be more useful to families than those to date. Studies encompassing individual coping strategies, networking systems and interactions are also needed.

Further research, specifically looking at parent issues is the sibling experience. Up to this point this perspective has strictly been (as in the Review of literature) seen from a clinicians or mothers view. Focusing on the sibling experience in both directions would be extremely informative. As previously mentioned studies in the area of rank or placement of the child within the family context are also needed to access direct or indirect effect on the siblings.

As a majority of the research on mental retardation and in the area of Down syndrome has indicated, father's perspectives are still somewhat void and more adequate recruitment and documentation is needed. This current yet small exploratory study revealed a reliable sample of father's experiences. How fathers make meaning and the role they play needs to be looked at in further detail. Equally important is studying the mother's current view and experiences as mediators and advocates in light of the past view of being a "superwoman" or carrying the "burden".
Finally, studies are needed within the area of Down syndrome "reform." Studies on the interactive process of the family and the child ought to yield a fuller understanding of their roles, design and implementation of programs as well as empower those involved to change. However, what is vitally needed is for society to re-examine its role and its new frontiers by finally waking up from its amnesia to recognize the connections of its pursuits toward the education and livelihood of all its citizens.

Critique of the Method

The purpose of this study was to explore and learn from parents their perspective when raising a child or young adult with Down syndrome. This was accomplished utilizing a phenomenological/heuristic approach which incorporated a validity check to ensure accuracy and clarification. This method allowed the investigator to capture a wide spectrum of experiences reported by fifteen families. The rich and vital data collected addresses the meaningfulness and accountability of this method. These findings further imply the capacity of qualitative methods to delineate the dynamics of the participation process and to gain sensitive information related to the diversity of the family and its complex structure. It is important to reiterate that the forementioned, is crucial if professionals are to relinquish stereotypical notions about families whose structure does not resemble mainstream or generalized ideals.

The investigator chose to conduct interviews with families of diversified socioeconomic, political, religious, cultural, and educational backgrounds, and status, both in the traditional (two-parent) and non-conventional (single) family, in order to reflect a more divergent participant perspective.

The depth and scope of what families shared may actually have been due to a common bond and personal interest on the part of the investigator. 'Sharing' and articulating their experiences was natural, therapeutic, and informative. Children and families are inextricably intertwined and therefore many siblings and the children with Down syndrome
were present at a majority of these interviews. What seemed most vital was providing a universal perspective as voiced through these diversified participants.

Due to the inherent nature of the method this sample is small. Qualitative research has not had a long history in the educational research arena. By educational research standards such a sample would not be a representative one. However, the goal of this method was to describe the meaning or "meaning-making" experience and embody and reconstruct out of the narrative these real-life experiences. Certain aspects of the sampling process suggest that the study maybe focusing on families who share certain characteristics. The parents from which this sample was taken was in itself a special population. However, it is not the purpose of this study to generalize or compare, but rather to offer an understanding of the process.

The criterion for participation were somewhat limited due to the fact that all participants were affiliated at the time with support groups. All families included in the sample as previously mentioned were diversified in scope. All families except one resided in many urban towns and cities. A broader cross section encompassing rural, outlying towns in the state would have proved to be more informative.

Concerns specific to single parent, reconstructed families, families with adopted children, single (but in partnership) and minorities were included on a small scale basis in this study.

It should be noted that prior to selection of the twenty-seven participants out of fifty-four, the content analysis was conducted and the universal themes established so as not to allow any bias of selection reflect in the final results. This selection was solely based on providing the reader with a wide range of ages and well articulated experiences of the development of a child with Down syndrome from birth to adulthood.

A strong majority of participants were of the Catholic affiliation (15 out of 27). This may have limited the study by not including a larger cross-section of religious affiliations.
However other religious affiliations may have chosen abortion or adoption for a child with Down syndrome and would therefore not be a part of this represented group.

Further studies conducted solely on the impact and breakdown of religious affiliations within the family unit would be worthy of future investigation. Even pinpointing variables such as whether a family is practicing, or living the religion, is converted, or passing the religion down by name only would be of further interest. Out of the families that were not Catholic only one family would have chosen abortion, while the others viewed this issue as a non-choice.

The design of the interview appeared to be satisfactory and elicited an insurmountable amount of responses, thoughts and feelings. The open-ended non structured dialogue allowed all participants to speak freely and to choose their own path or direction. The probe questions also added a sufficient structure to help bring parents back on focus.

The presence of the tape recorder did provide some intimidation for a few families. For these families at the beginning were more aware of this tool then the conversation or dialogue. Some compelling stories and provocative experiences were also conveyed as after thoughts when the interview was no longer being recorded. At those times depending on the sensitive nature, extensive notes were taken or the recorder was turned on given light to the importance of what the parent were addressing.

The amount of interaction, conversation and coordination of interview times, traveling to distant locations (the state of Arizona is very spread out (refer to appendix I)) varied considerably with each family. The amount of time interviewing ranged from one and one half hours to three hours. Time was not an issue. For many parents found time a needed tool to reflect further, on the issues at hand, to inquire about the popular literature specific to areas of speech, reading, employment or just to have someone to listen to.

As previously stated, the fact that the investigator is more personally engaged in the area as an extended family member (Aunt), has met several of these participants at support groups, and is pursing an international degree in one specific area may have biased as well
as prompted more candid, intimate, and thought provoking experiences. In addition, although the investigators' role was to remain objective while valuing the participants' subjective reality, the amount of transcribing, analyzing, and synthesizing over 2,000 pages of transcriptions, at times became a most humbling and overwhelming task indeed.

Through the utilization of this method the investigator was able to cut the pie differently, so to speak, first by focusing on the congruence of the families' world and second by paying attention to the transition and daily adaptation phenomena within each unique family unit.

The accuracy and checking for the investigators understanding of the phenomena of these interviews was extremely helpful. An integral part was the second contact by mail and most times through documented telephone conversations. This additional time provided greater depth, additional sharing and clarity to every interview.

Concluding Statement

It has been a long journey where the investigator started by climbing up many hills and dales and ended up on top of a mountain. For the investigator has not only been allowed the privilege and honor of being invited into the lives of her participants but also given birth to and grown along with a remarkable number of children and young adults. The investigator was also able to witness and experience their individual potential as she relearned how to crawl, walk, run, interact, read, talk, and even drive for the very first time.

The diversity of the participants in this study and their endless decisions based on real life experiences, surprises along the way have been shared and accounted for to this investigator.

These participants have taught this investigator many new meanings behind the words 'patience', 'humor', 'respect', 'adaptability', 'understanding' and 'effective communication.' They have allowed this exploratory research to be the "vehicle" toward
bringing to light issues and concerns of significant value for researchers, medical and health care professionals, educators, and society at large to affirm respect and actively support each unique family unit.

Their relationships, detailed stories, daily encounters, and continual dialogue about their sons and daughters have been personal and span a lifetime. It is this investigators hope that this “life saving” research will continue to contribute to the very limited body of knowledge about the family experience when raising a child or young adult with Down syndrome.

It is a further aspiration that this research will provide families, educators, professionals and researchers, with a further understanding of its value and the impact it has through a long-term awareness. Applying what has been learned with a solid base of information will hopefully be useful and practical for children with Down syndrome and their families along with the system with which they co-exist.

For this investigator the challenge has just begun. For we will have only met this challenge when all educational facilities are special and all teachers are special. Only when all of our citizens are more concerned with the inner worth of all humankind and when each one of us assumes responsibility for making tomorrow a better place to live will this challenge then be achieved (Buscaglia 1983, Stratford 1991).

It is this investigator’s final hope that this most humble beginning, this upward climb to the top, provide one step closer for all of us to begin to share equally and significantly in the joy of the human condition.
Bibliography


250


251


June 1995

Dear Parents,

I am a research doctoral student at Loughborough University of Technology, England and I am conducting a research project to explore perspectives and 'lived' experiences of families when raising a child and or young adult with Down syndrome.

My goal is to speak with parents who have children and young adults with Down syndrome, to gain valuable and rich information that will be gathered in order to give new meaning and insight toward the understanding of raising a child with Down syndrome, the effect upon the family members, the extended family, and the family as a whole. As an extended family member, proud Aunt of a nephew with Down syndrome my vested interest in this study takes on a more personal meaning. I am therefore, confident that this study will add to the limited literature in this area.

I am interested in speaking to parents who meet the following criteria:

1. They have raised their child with Down syndrome since birth.
2. The parents have an infant, school aged child, teenager or adult with Down syndrome.
3. Familiar with ‘Sharing’ Parent Support Network or other support groups.

To participate in this study, both parents or the primary caregiver will be asked to engage together in an interview with me lasting approximately 1 1/2 hours. A follow-up meeting will be scheduled for a later date, lasting 1 hour in duration. This interview will take place at your convenience at the earliest possible date. Interviews will be audio-taped. Confidentiality of the interviewees and their children’s identify will be guaranteed. Parent(s) will be asked to fill out a short questionnaire of demographic information and a brief description of the type of Down syndrome.

If you would like to participate in this study, please contact me at work 649-2225 during the day or at home 759-5912 in the evening. Please leave a message within 2 weeks of receiving this request. If I am unavailable to take your call I will return it promptly. I will be scheduling interviews in the month of June, July 6-10th, and then in September.

Thank you for your time, concern, and determination.

Respectfully,

Iris S. Drower
P.O. Box 2159
Mesa, AZ. 85214
APPENDIX B
CONSENT AGREEMENT FORM

I understand that I am being asked to participate in a doctoral research study which will explore the perspective and "lived experiences" of families when raising children/young adults with Down syndrome. The purpose of this study is to understand what life is like for families when raising children and young adults with Down syndrome.

I understand that in giving my consent to participate, I will be asked to complete a demographic questionnaire and to participate in an interview lasting approximately one and one-half (1 1/2) hours in duration. In the interview, I will be asked to discuss my perspective(s), feelings, experiences, and thoughts about raising a child/young adult with Down syndrome.

I will also take part in a follow-up session via mail, fax, and or telephone conversation in order to check the accuracy of our initial recording pertaining to each family members description/interview. You may at this time alter, add to or reclarify your description within 7 working days. Each description will then be mailed back (given a self-addressed envelope) to the investigator.

I understand that my identify will be disclosed only to the interviewer. All information will be treated confidentially. I will be assigned a fictitious name for all written records. I understand that material from the interview may be quoted or paraphrased in the final write-up of this study. No information which could identify me with that material will be used. I also understand that this information may be used as part of future research or publications by this interviewer.

I understand that I will not be paid for my participation in this study and that I may ask for a summary of the final results when this study is completed.

I understand that I am free to refuse to participate in this study and may withdraw from this study at any time.

I also understand that by participating in this study I will be contributing to an effort to increase the understanding of what it is truly like to raise a child or young adult with Down syndrome. Participation is also intended to enhance and expand the scope of knowledge and understanding for parents, educators, clinicians and society at large.

I have read this form and understand fully the terms of my participation in this research study. I have had the opportunity to discuss this project with the investigator and had the procedures satisfactorily explained to me. I understand that if questions arise during my participation they will be answered in detail to my satisfaction.

Given the above understandings, I agree to become a participant in this research study described above.

Date________________ Signature of Participant(s)__________________________
I have witnessed the reading of this consent form:

________________________________________________________________________

I have explained the procedures of this study to______________ and
have answered his/her questions to the best of my ability.

__________________________________________
Date

__________________________________________
Signature of Investigator
APPENDIX C
DEMOGRAPHIC QUESTIONNAIRE

Mother (M)  Father (F)

Name: First/Last __________________________________________

Last Name Used For Research: __________________________________________

Age: __________________________________________

Occupation: (M) __________________________________________
(F) __________________________________________

Educational Background
Put (F) for father and (M) for mother or (B) for both:
High School Junior College Technological School Bachelors Masters Ph.D. Other

Ethnic Background
Put (M) for mother and (F) for father or (B) for both.
Caucasian Black Asian Hispanic American Indian Other

Religious Background
Put (M) for mother and (F) for father or (B) for both.
Catholic Protestant Jewish Baptist Other

Combined Family Income
$0-$20,000 $20,001-$40,000 $40,001-$60,000

$60,001-$80,000 $80,001-$100,000 Over $100,000

Children
Names Sex Age

My children attend: public private home school

Primary language spoken in the household: English Spanish Other
Secondary language or languages: 

Chronological listing of places my child with Down syndrome was raised

<table>
<thead>
<tr>
<th>Location</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i.e. place of birth, moved to other states, countries, etc.)</td>
<td></td>
</tr>
</tbody>
</table>

Category of Down syndrome: Trisomy 21  Translocation  Mosaicism

Medical Complications: (i.e. heart, hearing, speech, etc.)

I first found out my child had Down syndrome:

<table>
<thead>
<tr>
<th>prior to birth</th>
<th>at birth</th>
<th>a few days after birth</th>
<th>weeks later</th>
<th>months later</th>
</tr>
</thead>
</table>

I found out my child had Down syndrome from the:

<table>
<thead>
<tr>
<th>doctor</th>
<th>nurse</th>
<th>educator</th>
<th>parent</th>
<th>other</th>
</tr>
</thead>
</table>

The primary caregiver(s) is: mother

<table>
<thead>
<tr>
<th>father</th>
<th>both</th>
<th>grandparent</th>
<th>other</th>
</tr>
</thead>
</table>

I am involved in the following with my child with Down syndrome:

<table>
<thead>
<tr>
<th>school activities</th>
<th>religious activities</th>
<th>recreational (i.e. scouts, clubs, groups, etc.)</th>
<th>parent support</th>
<th>other</th>
</tr>
</thead>
</table>

My child attends: regular classes  special classes  both  other
APPENDIX D
CONFIRMATION LETTER

Dear

Thank you for agreeing to participate in my research study. I am interested in learning about the families' perspective when raising a child or young adult with Down syndrome. During this interview (approximately 1 1/2 hours in length), I would like you to tell me in your own words what this experience has been like and how it may have affected your family. I am interested in your feelings, thoughts, and concerns when raising a child and/or young adult with Down syndrome in our society.

As we have discussed on the telephone, I have included a Demographic Questionnaire to be used as descriptive information to further enhance this study along with a Consent Agreement Form. Please read and complete these forms prior to our interview.

If you have any further questions, please feel free to contact me at your earliest.

I am looking forward to meeting with you on

__________________________________________________________________________

Thank you again for your participation.

Respectfully,

Iris S. Drower, Masters in Education
Doctoral Candidate
Loughborough University of Technology
Loughborough, Leicestershire
England
APPENDIX E
PROBE QUESTIONS

Name

Introduction Statement

I am interested in learning from your perspective the experiences you have and are currently going through when raising a child/young adult with Down syndrome. I would like you to tell me in your own words that the experience is like for you, how it has affected your family, both individually and collectively. I am interested in your feelings, thoughts, and concerns about raising a child with Down syndrome in modern day society.

I would like you to first define Down syndrome.

Probe Questions:
Reactions to the news?

Amount of information told to you? How was it told?

Where and how did you obtain the knowledge of Down syndrome in this area?

Did it cause you stress?

Has your marriage been affected by this experience?

Has your relationship with your child with Down syndrome or with your other children been affected?

Have sibling relationships been affected?

Family reaction, extended family members?

What impact does your son or daughter have upon his brothers and sisters?

How have their attitudes changed if any because of their brother, sisters, etc.?

Have social relationships been affected?
Dear Families:

Thank you for participating in "our" research project on the Families Perspective When Raising A Child or Young Adult with Down Syndrome.

Enclosed is a copy of "our" interview. Please note that this is the raw data, captured within your own words, thoughts, and euphemism.

I would appreciate it if you could read and comment, if necessary as to the accuracy of your stories and thoughts.

Again, if you feel you have something more to add to what has been said, feel free to call me and leave a message (649-2225) or fax me at 649-2111. If you wish to mail your comments I would appreciate them within a one week time frame.

Thank you again for providing the most valuable resource around...the parent's perspective.

The final results will be compiled upon your returned comments.

With Greatest Regards,

Iris S. Drower
PO Box 2159
Mesa, AZ 85214
The McClaren Family

Beverly and Benson McClaren have four children; three sons James, age 22, Nicholas, age 17 and Morgan age 3 and a daughter Meghan age 3. The eldest son attends University while the other children attend public education. Morgan and Meghan are fraternal twins. Morgan has Down syndrome, Trisomy 21. He is delayed in the area of speech. The primary language is English with sign language marked as other.

Both parents have completed high school education, while the mother has completed a bachelors degree and is working outside of the home toward her Masters degree. The mother use to work a night job and was home during the day while her husband worked a day job.

My initial contact was by telephone with Mrs. McClaren. Without any hesitation, she was delighted to participate and shared a deep interest in providing the best possible for her son. The interview was conducted at the McClaren's home. They live in a spacious one level home in the city of Mesa. Even though the interview started out as a serious venture, the setting (sitting around the kitchen table) lent itself to a very spontaneous, free-flowing, and open interview. Both parents equally participated. Benson expressed thoughts and feelings that were apparently new (or not remembered) by Beverly which provided for a more intriguing discussion.

Introductions to the family members were made, along with the three kittens. The twins especially Morgan sat in on the conversation while eating a snack and coloring in his book.

Definition of Down syndrome

Beverly expresses that it is developmentally delayed. "They say that it is a mild form of Mental retardation," (referring to medical and educational fields). He will always learn things in a delayed fashion. In time he will do everything everyone else will do only slower.

Benson: No formal definition. Morgan will be behind everyone else. Because he is a twin, we will utilize this to compare him to his sister to see where he is. Speech is one area that he is delayed.

Cognitive Development

Benson: Morgan is very quick. He knows a lot of sign language. He picks up on things very quickly.

Bev: He has done things before Megan. He pushed the push toys prior to her and then she did it.

Benson: Megan is very quick, so at times it has been unfair to Morgan. We have tried to place expectations upon him while making comparisons. Maybe this is not the right thing.
to do, but do it occasionally. Sometimes we become a little apprehensive if Morgan will ever reach the levels that Megan is at.

Bev: It does not seem to frustrate Morgan as it does us.

Bev: Morgan is Morgan. (Definition)

Benson: Morgan is his own person and he has to progress at his own rate. Morgan is mild as compared to other children with Down syndrome. We are very fortunate that he is very mild from that standpoint.

Bev: He is extremely healthy.

Benson: Minimal problems.

Bev: The only problem now this year is his speech. He can sit and watch a movie with the best of them, his concentration levels are way up there. It would be a normal boy girl twin situation, because the girls are usually smarter when they are younger than the boys at this time.

Reactions

Bev: We thought that it was pretty cool since they were both healthy. I did not know what it was or even saw a Down syndrome kid.

Ben: At the time no experience, only at Jr. High School I was a counselor with children with Down syndrome. So I was not apprehensive from that aspect. When we found out, it let the air out of our sails. Here we were extremely excited about twins. We did go into a bit of depression.

Bev: I asked, so what is Down syndrome? He told me...oh that is not too bad. I read books and I was depressed. The majority of the stuff I read Morgan did not have and I still became depressed. Ben said don't read it. I read and read because they do develop things differently and I needed to be aware of these things. I read and read, and cried and cried. Not so much for Morgan but for the others who have it so severely.

Doctors

Ben: Not real cold in approach, but while Bev was recovering, he came out and said I basically have some good news and some bad news. The good news is that both babies are very healthy, respond very well and the bad news is that we have a 95% chance of having Down syndrome (discussing good and bad among themselves regarding doctor). This was based on some tests at the time he was born. Bev didn't remember these words.

Ben: He had low muscle tone. Megan arched where as Morgan went over his hand. (He was in the delivery room when they were born.)

Bev: When Morgan came out he was placed on my stomach like a little marshmallow. Megan, I did not see her so I did not notice that there was anything wrong.
Ben: Doctor noticed facial features and simian crease in the hands.  
To confirm must conduct a blood test.  

Bev: He weighted 7 pounds and 1/2. Very healthy, had a hole in his heart.  

Ben : Doctor was sensitive about it. How sensitive can you be? I do not know how easy it is for anyone to say that your child has Down syndrome. I guess you just deal with it. It did deflate me.  

Bev: Did not realize that the doctor said "Good news and bad news."  
Not a good way of putting this.  

Bev: Was not tested genetically. Doctors told her that it was from me. I did have amino and found out then that I was having twins. Risk of miscarriage is 1 out of 25 risk of a genetic defect is 256. It is more common that younger women have a child with Down syndrome because of the numbers. More women younger are having more babies. My Gyno knew the most. He said " at 35 you drop your eggs and when you have twins you are dropping them at a higher rate." "Trisomy is an old egg". He was so compassionate. A specialist (65 years old) GYOB for high risk cases. Others have a lot to learn from him.  

**Stress / Telling Relatives**  

Ben: We were both very tired and yachting at one another, and tempers were short. Underlining stress.  

Bev: Only told her mother because she was there. Did not tell dad, sisters, mothers and fathers and or neighbors. Wanted to wait until we got the blood test back. My sisters and relatives were angry at us. We called parent support group within three hours. The support group was amazed at us for responding so quickly. Well, I lost a son when he was 14 months old and there is nothing to compare that too. I get angry when parents go through a mourning period. They mourn a healthy, new perfect child. How about a live one. However, many of these parents have children that are not as healthy as ours.  

Bev and Ben: we did not go through such medical complications as open heart surgery, intestinal and respiratory, hearing loss, etc.  

Bev: We went through hearing. He is so delayed. How can he go through a hearing test? He throws things at them. He does not comprehend what the tester is trying to do. He does not want to be held down as they do in the booth.  

Ben: Helped me is that I had the limited experience with Down syndrome. All good memories out of this experience. All positive thoughts for me. From that standpoint, this helped me get through that initial shock.  

Bev: This helped me knowing that Ben had this experience.  

Ben: All reacted in a positive way, except my sister. She is kind of quiet and did not say much. My family was not outspoken, but did not react in a negative way.  

Bev: Mad that we did not tell them right away.  
His family was real sweet.
Siblings Reactions

Bev: Nicholas an example, he was feeling guilty when I first took him home. "Have you made fun of a Down syndrome person. Yeah..." He did take it hard for a while, but loves him very much and has become real close." Nicholas is their best friend. He will play with them on the floor. He is not old and tired like us. They love all three of the older kids (siblings), it is like having three other parents. The siblings do not take on all the added responsibility of raising a child with Down syndrome, but play an equal part in Morgan's affection since he is not there 24 hours like us.

Bev: I read in those books about family negative reactions and if that would have happened to my family I would have ripped them to shreds.

Bev: Do not treat him any different than the other kids. He is a real clown.

Story....... We were all sitting up here and eating(in the kitchen) a family thing. Older kids were here, "MO" concentrates more at the table so we work with him at the table to talk. We were teaching him what does a dog say Bark Bark, what does a horse say and he sprays everybody(mother demonstrates). He would not do cat so we did cat and he went meow and we all clapped and screamed. It is as if he has an audience. And Megan his sister said he said it. Then Char says what did Char say.."Char, Char, Char." and he said "Char." And we all cried because he never said a persons name.

Bev: When ever I think about that I want to cry. And Megan is looking at us and saying to herself "you guys". I say bad words and you do not say anything.

Inclusion / Education/Early Intervention

Ben: We are just beginning to deal with this. He is in early intervention. He went to preschool for a few weeks. Not a mainstreaming thing now.

Bev: Morgan has had therapy since he was 11 days old; physical, OT, and PT. He goes to preschool in public school. He will not be offered anything more than Megan will get. If offered to go to a twin camp, or a Down syndrome camp etc where both could go, it would be OK. If he was offered specialized work/school by himself, no we would not offer him that. There is enough of us to teach Morgan. He had the same therapist for three years. She has never advised us to put him into a preschool nor to put him separate from Megan.

Ben: Too early to know where to place him. We will make that judgment as the time comes. Right now putting him into a mainstreamed program would be too stressful. We will make that judgment as the time comes.

Bev: We are not trying to hide this from ourselves about our child and his placement. We know he is delayed.

Bev: If Morgan works and he wants to do it he will. Morgan use to eat crayons and now he colors. It is a long hard haul for each of us to teach him how to color.
Down Syndrome Association

Bev: First meeting we went to there was no children there. One woman came up to me and said "I do not want my girl to come to these meetings to be associated with all these other Down syndrome children because I do not know if she has got it." What is she going to look in the mirror in two years and not know.

One woman told me that "Down syndrome children can not use straws. "Morgan used a straw in five months only because of that statement." He can drink a whole milkshake out of a straw now...that is a lie.

Daily Schedule

Bev: It is a full time job. Going back to school in special needs. I am learning art therapy. I want to learn to teach Morgan to be the best he can be. That is why I am going back to school to get my degree in special needs. Not to teach in public it is so that I know more about Morgan. So he will have the best he can have without us paying for it. We are going to teach Morgan to be the best he can be.

He excels with animals, art, music, books, etc.

He will play ball with dad.

Ben: That is one of the very few words he knows.

Ben: That is one of the reasons why she is not working.

Bev: Morgan loves to play ball and one of the few words he knows.

Religion

Bev:

My husband is Mormon and I was raised Catholic. I was raised by my mother a strong Irish Catholic. I admired her independence and chose to take that part of her life and add it to mine. I do not feel religion is a major factor when raising my twins. I raised my first two children as Catholics and now they will not even go near the Church. I have fourteen years of this experience and feel as long as I am doing good with my children that is all that counts. Even my doctor who was Jewish at the time recommended and performed an operation to tie my tubes so that I would not have any more babies. He did not believe in this but he did it anyway.

Services

Ben: Morgan has not required a lot. But if it does not exist it is difficult to get for those who do needed.

Bev: Given a big run-around. In regards to respite (Babysitting twenty hours a month) no one has ever seen Morgan, behind in reviews, case worker never seen him. We have had at least 50 case managers and never seen any of them. They just send us a letter. Respite (interviewed 50) and only one showed up. This was had no shoes on and had been living in her car! Did not seem reliable. This is about 20 hours a month, but I do not leave
him. Finally got one that is reliable. This one was a nursing student from the Mid West. Both twins loved her. Only 2 out of 50 I interviewed for respite. This is the mentality that you deal with. Developmental Disabilities Division is a year and one-half behind in his reviews. His case worker has never seen him. Depending on your child’s health you get different services. He has access due to his surgery.

Bev: CRS (upper respiratory services in Phoenix) did not treat you proper. This is used if you are on health plan called access. We go to meetings and doctors and we wait and have to go far. I finally complained and then they lightened up (local doctor down the street). I can not imagine if my child had a life threatening situation going on. For example: At head start program: One ladies’ child that we met had to have respiratory treatment every two hours in addition to a nurse (24 hours a day). Here she is caught up in the red tape. She has to coordinate so many departments that she can not allow one day to go by without knowing what is going on.

**Affecting You / Siblings**

Ben: My limited experience helped me. No bad memories, made some good friends. Positive thoughts for me and helped me get through the initial shock of my own son having Down syndrome. I know he is going to be a unique individual.

Bev: Her son 17, took it hard for a little while. He did make fun of kids with Down syndrome. Now Nicholas is his best friend for he is not 41 years old like his parents. The other kids love him very much. It is like having 3 other parents. The siblings do not take on the responsibility like we do but they do play with them a lot. Both: My son use to make fun about parents having children at their age, but it was none of his business. First few years a little rough, but he truly loves his brother to this day.

**Laws**

Bev: Arizona stinks as far as laws and legislation. Congress is getting better because they have Senators who have sons or daughters with Down syndrome and now kids with Down syndrome are living longer. It is becoming more common that they are keeping their children with Down syndrome whereas twenty years ago they did not.

Bev: Television show with Chris Burke put Down syndrome on the map. The heart specialist told us that when Morgan was first born...while asking what is this (referring to Down syndrome). OK you know that guy on Life Goes on, well that is how mild your son is.

Special Olympics not good for us. Made me depressed.

Ben: She saw a wide spectrum of Down syndrome. That disturbed her, to me I thought it was good for these kids to go out and compete. I did not expect anymore. To me it did not bother me. I thought it was terrific from the standpoint of competition.
Five years from Now

Ben: Morgan to be motivated and well rounded young person. He gets a lot of support from this family. We do not treat him any differently. I am apprehensive about how others may treat him. I hope he will be well grounded enough to handle it. He is his own individual. The whole issue with mainstreaming will be an issue for us but this is difficult for me to see right now. She sees the children with Down syndrome at Bashas (grocery chain).

Ben: It is a characteristic of some kids with Down syndrome to be very loving and friendly. That may be a drawback because he is very trusting.

Bev: See him talking.

Ben: I would not limit him because he is delayed. I would not try to hinder him. If he wanted to be independent, or move into homes with others, I would not object to that. I do not know how things are going to change in the future.

Both: We just put two kids behind the wheel and they are normal. It has to come from within Morgan. If he wants to and we know he can he will. We teach all our kids to drive and cook.

New Parent Info:

Bev: They love just as good as other babies.

Ben: I can sympathize with other parents who have children with Down syndrome with more serious problems. You cannot tell a parent that it is going to be easy. You have to give them love and support. And you have to include them in all your activities.

Bev: If I ever saw a Down syndrome child after Morgan was born, I would stop and talk to that parent or the family. It is fun. I see a lot of families at the zoo. Last time I talked to a man with a with Down syndrome who was with his uncle...he was so intelligent and that did me so much good than anyone else. He takes care of his grandparents...he did it all. Experiences: At Bashas I saw Paul and introduced him to Morgan and said "Paul look, Morgan has Down syndrome." Paul replied "sure enough." I promised myself to do this and that is how you become educated.

I took sign language in College for Morgan so that he can learn to talk with his peers. I am not sure that he will need to communicate with sign language when he is older but he still will meet children in his life that maybe deaf and he will need to be able to communicate with him. I only think it is fair.

Tell Educators:

Bev: More independent in their classroom. We want him to be taught more discipline techniques.
At first he was sad and afraid to go to school. The teacher does need to put her attention and time into my Morgan. We are selfish but that is how I am.

Ben: Too early to know.
Morgan is the only one in his class with Down syndrome. That is unique. He is one of the few who could not talk in his special needs class.

Bev: Need to review his case in speech. He needs to be exposed to all facets of education not just reading and speech, but the arts as well. Maybe even to have pet therapy.

Relays a story she saw on TV about a little boy who is now normal because of Dolphins. Dolphins talk him how to talk. Nothing could reach him (boy with Down syndrome). Took him to Florida for Dolphins therapy and now he is completely mainstreamed. Thinking of getting one for Morgan. Dad... hitting up the neighbors for a dog that could swim in a pool for Morgan instead.

Ben: It is all the matter of finding what really stimulates a child.

Attitudes of Society:

Bev: Since I am here most of the time... I don't get out much or have a life! In jest or seek out parents and kids with Down syndrome.

Ben: I work nights so the meetings are difficult to attend.

Both: Take him to the zoo, swimming, outside activities.

Added Experiences:

New experience with us. Any child regardless if they are delayed or not needs to be pushed toward education. More so now than ever. We will not deny him anything. He is going to college. He may be 87 but he is going (Dad laughs). There is nothing wrong with that. He has to be educated. He will stifle if not educated. If school is not what I think it should be it will change. I will push my opinion until they decide that it is right. Not enough time is spent with each child. If some are more severely handicap than others they spend more time with them.

Misc. Extra Thoughts:

Dolphin therapy is in San Diego with Sea World. On Public Broadcasting System there was a program about a 7 year old boy. There also was a the lady (nurse) who has 17 children with Down syndrome with a husband who is a doctor (cardiovascular) -- lives in Florida. Her Network would be interesting.

We belong to Down Syndrome Today, Down Syndrome Council from New York and Washington D.C. A valuable resource. They do a lot of counseling with young parents. There are still people running around out there that feel Down syndrome children should still be institutionalized.
Ben: We do this all the time by talking to people. Hope that it has an impact on other people so that they would go out and produce and have an impact upon society and the system. Hope any of this would be beneficial and would make life easier for the kids in the future. So we take a positive attitude.

Bev: Sometimes we get overwhelmed.

Morgan loves me more than any child. No one taught him that. I am curious about the demographics. Met two couples who had twins one with Down syndrome within a few blocks. The split of the cell is after they are already identical twins. Read this in the twins magazine.

Story: At a meeting there was a professor there and he found out that he was a carrier of Down Syndrome and replied: "I guess that is why I am not the president of the University."
APPENDIX H

MAP OF EAST CROYDON, ENGLAND (PILOT STUDY)

Dots indicate locations of interviews.
APPENDIX I

MAP OF PHOENIX, ARIZONA, USA

Dots indicate locations of interviews.
### APPENDIX J

**TERMS AND DEFINITIONS**

<table>
<thead>
<tr>
<th>British</th>
<th>American</th>
</tr>
</thead>
<tbody>
<tr>
<td>National system</td>
<td>Federal system</td>
</tr>
<tr>
<td>LEA (Local Educational Authority)</td>
<td>Board of Education within each area (school district)</td>
</tr>
<tr>
<td>Primary level</td>
<td>Elementary level</td>
</tr>
<tr>
<td>Junior or middle level</td>
<td>Junior High or middle school (12-15)</td>
</tr>
<tr>
<td>Upper level or six form</td>
<td>High School</td>
</tr>
<tr>
<td>Tertiary College</td>
<td>Community College or Vocational</td>
</tr>
<tr>
<td>Headmaster</td>
<td>Principal</td>
</tr>
<tr>
<td>Integration(^1)</td>
<td>Inclusion</td>
</tr>
<tr>
<td>Habilitation(^2)</td>
<td>Transition(^3)</td>
</tr>
</tbody>
</table>

\(^1\) Integration is a moral issue as inclusion. Here it revolves around the rights of individuals and society's willingness to acknowledge these rights in effective terms. These rights include the right to education, right to equality of opportunity and the right to participate in society (Hegarty, S. 1987) Special Needs In Ordinary School: Meeting Special Needs In Ordinary Schools, United Kingdom: Cassell Ed. Limited).

\(^2\) Habilitation is to make skilled people in the medical, social, psychological, and educational fields support/help the disabled in their development and daily life. It is to enhance their development based on the provisions of adequate resources and services.

\(^3\) Transition is part of career development known as a lifelong process from birth to adulthood. It affects an individuals development, the family, and that of the community.