PARENT RESPONSES TO THE BIRTH AND REARING OF A CHILD WITH DOWN SYNDROME: THE APPLICATION OF ENGEL'S 3-STAGE THEORETICAL MODEL OF GRIEVING

THESIS

Presented to the Graduate Council of the University of North Texas in Partial Fulfillment of the Requirements

For the Degree of

MASTER OF SCIENCE

By

Jenette L. Smith, B.A.
Denton, Texas
August, 1995
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Smith, Jenette L., *Parent responses to the birth and rearing of a child with Down syndrome: The application of Engel's 3-stage theoretical model of grieving.* Master of Science (Health Education), August, 1995, 89 pp., 14 tables, 2 illustrations, references, 36 titles.

The purpose of this study was twofold: 1) To analyze the similarities and differences between parent responses to the birth and rearing of a child with Down syndrome and; 2) To document the characteristics of grieving described in Engel's 3-stage model of grieving. A questionnaire was used to assess responses from randomly chosen parent members of the Dallas Down Syndrome Guild. Qualitative data analysis was conducted, using the methodology of triangulation.

Similarities were found among parent responses and Stages One and Two of the model of grieving; however, differences were found in Stage Three. Recommendations were based on questions answered by respondents regarding support services and interventions.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>LIST OF TABLES</td>
<td>v</td>
</tr>
<tr>
<td>LIST OF ILLUSTRATIONS</td>
<td>vi</td>
</tr>
<tr>
<td>FOREWORD</td>
<td>vii</td>
</tr>
<tr>
<td>Chapter</td>
<td></td>
</tr>
<tr>
<td>I. INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>Statement of the Problem, Need for the Study</td>
<td>4</td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>4</td>
</tr>
<tr>
<td>Significance of the Study</td>
<td>5</td>
</tr>
<tr>
<td>Assumptions</td>
<td>6</td>
</tr>
<tr>
<td>Limitations</td>
<td>6</td>
</tr>
<tr>
<td>Delimitations</td>
<td>7</td>
</tr>
<tr>
<td>Research Questions</td>
<td>7</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>7</td>
</tr>
<tr>
<td>II. REVIEW OF THE LITERATURE</td>
<td>10</td>
</tr>
<tr>
<td>III. RESEARCH METHODOLOGY</td>
<td>16</td>
</tr>
<tr>
<td>Design</td>
<td>16</td>
</tr>
<tr>
<td>Selection of Subjects</td>
<td>17</td>
</tr>
<tr>
<td>Instrumentation</td>
<td>18</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>21</td>
</tr>
<tr>
<td>IV. FINDINGS OF DATA ANALYSIS</td>
<td>24</td>
</tr>
<tr>
<td>V. SUMMARY, CONCLUSIONS AND RECOMMENDATIONS</td>
<td>56</td>
</tr>
<tr>
<td>APPENDICES</td>
<td>65</td>
</tr>
<tr>
<td>Table</td>
<td>Description</td>
</tr>
<tr>
<td>-------</td>
<td>------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1.</td>
<td>Descriptive Statistics of Respondents for Demographics</td>
</tr>
<tr>
<td>2.</td>
<td>Descriptive Statistics of Respondents - Initial Reaction to the Down Syndrome Diagnosis</td>
</tr>
<tr>
<td>3.</td>
<td>Stage One Likert Data</td>
</tr>
<tr>
<td>4.</td>
<td>Descriptive Statistics of Respondents - Counseling Services</td>
</tr>
<tr>
<td>5.</td>
<td>Descriptive Statistics of Respondents - Support Group</td>
</tr>
<tr>
<td>6.</td>
<td>Descriptive Statistics of Respondents - Stage Two Data</td>
</tr>
<tr>
<td>7.</td>
<td>Descriptive Statistics of Respondents - Stages One and Two Data</td>
</tr>
<tr>
<td>8.</td>
<td>Descriptive Statistics of Respondents - Stage Three Data</td>
</tr>
<tr>
<td>10.</td>
<td>Descriptive Statistics of Respondents - Rearing Issues, Other Children</td>
</tr>
<tr>
<td>11.</td>
<td>Descriptive Statistics of Respondents - Health Concerns</td>
</tr>
<tr>
<td>12.</td>
<td>Descriptive Statistics of Respondents - Future Concerns</td>
</tr>
<tr>
<td>13.</td>
<td>Descriptive Statistics of Respondents - Currently Used Support Services</td>
</tr>
<tr>
<td>14.</td>
<td>Descriptive Statistics of Respondents - Desired Support Services</td>
</tr>
</tbody>
</table>
## LIST OF ILLUSTRATIONS

<table>
<thead>
<tr>
<th>Illustration</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Mother and Father Age at Birth of Down Syndrome Child</td>
<td>27</td>
</tr>
<tr>
<td>2. Current Age of Down Syndrome Child/Adult</td>
<td>27</td>
</tr>
</tbody>
</table>
FOREWORD

On February 23, 1987, I began the tremulous journey into parenting a child with Down syndrome. When our physician first informed us that our precious newborn baby girl exhibited all of the distinguishing characteristics of Down syndrome, I was thrown with astounding suddenness into a darkness only another parent of a child with Down syndrome could fully comprehend and understand. Almost immediately, I requested books and information available on Down syndrome. While I found it extremely helpful to learn and understand the epidemiology of Down syndrome, the most helpful book I read was one in which parent comments and responses followed each chapter. I soon discovered that a truly genuine understanding of Down syndrome could not take place at a purely clinical level. This understanding could only take place through reading the reflections of other parents. Through those responses, I intimately entered the experiences of those struggling parents and I found myself there. I began to feel a camaraderie with those strangers, and found myself saying, "Yes, I understand. Yes, I felt that way." To glimpse into the very personal, emotional world of another parent, I soon developed a new perspective and attitude. I began an inward, soul searching exploration of Down syndrome quite unrelated to epidemiology.

It is my hope that this work will move other parents of Down syndrome children toward a quest for deeper understanding. It is my purpose to awaken in other parents their awareness of the deepest of meanings and emotions through their own reactions and responses to the birth and rearing of a child with Down syndrome. It is my dream that in honestly describing their personal experiences, albeit painful, fearful or frustrating, these parents can help themselves as well as others they have never met - just as they have helped me. Jenette Smith
WELCOME TO HOLLAND

By Emily Perl Kingsley

(The following essay was used upon written and oral permission from the author.)

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all 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 supposed 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, 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 Rembrandts.
But everyone you know is busy coming and going from Italy, and they're all bragging about what a 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."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things... about Holland."
CHAPTER 1

INTRODUCTION

The journey to parenthood is one of wonderment, expectancy, anticipation, and happiness. Parents await the birth of a baby with great joy and excitement. For many months, parents begin planning for their baby's arrival - reading books on child birthing and rearing, and dreaming of their child's future. Yet, this dream is severely altered when the baby is born with Down syndrome.

A baby born with Down syndrome has one extra chromosome in each of the millions of cells. Normally, there are 46, with Down syndrome there are 47. The extra chromosome appears on the number-21 chromosome, hence the naming Trisomy 21 (See Appendix 1). The majority of Down syndrome babies have Trisomy 21 (Cooley & Graham, 1991). With the exception of the number-21 chromosome, all of the other chromosomes are normal. Interestingly, the extra genetic material in the number-21 chromosome is normal, there is simply too much of it. Because there is extra genetic material, normal development does not occur, and mental retardation results (Kozma, 1986). The extra genetic material also causes unique medical problems, including congenital heart disease, hypotonia, delayed growth, developmental delays, and hearing and vision problems (Rubin & Crocker, 1989).

A Down syndrome birth creates an acute situation for all involved (Elkins & Brown, 1986). Zamerowski (1982) stated that parents of retarded children may experience an intense grief reaction. The initial news is devastating and painful beyond belief. Instead of elation and happiness, intense sadness, fear, grief, denial and loneliness set in. Pueschel, Murphy & O'Donnel (1979) stated that when a child with Down
syndrome is born, parents invariably suffer a profound emotional trauma. The birth of the child is no longer joyful, but is transformed into a catastrophe. Solnit & Stark (1961) suggested that parents of a handicapped child must actually mourn the "loss" of the normal child before the acceptance of the impaired child can occur. Brill (1993) wrote that some parents found the adjustment easier after they likened the diagnosis to a death in the family. Roos (1978) stated, "Because of our tendency to experience our children as extensions of ourselves, a defective child is likely to threaten our self esteem" (p. 18).

Many researchers have likened the grief response to parenting a handicapped child to that of death and dying. As stated earlier, the work of Solnit & Stark (1961) examined this comparison. The literature review has supported the view that some parents pass through a series of stages upon the birth and rearing of a handicapped child similar to mourning and death (Seligman, 1991). Perhaps, one of the most useful and descriptive stage models of grieving was developed by G. L. Engel in 1962. He made use of this model to describe death and dying, yet comparisons and applications have been made to parents grieving the birth of a handicapped child. The 3 stages in Engel's model are: 1) The Stage of Shock and Disbelief, 2) The Stage of Developing Awareness of the Loss, and 3) Restitution - the Work of Mourning (p. 274-279). Engel's model was highlighted by Farnham (1988) in grief work with mothers of retarded children. Farnham's study is explored in Chapter 2, as well as a detailed review of literature relevant to the Engel 3-stage model.

History of Down Syndrome. In order to better comprehend the grieving process of parents of a child with Down syndrome, it is first necessary to possess an understanding of the syndrome. In 1866, long before Down syndrome was linked to a genetic abnormality, John Langdon Down described it as a distinct set of physical and mental characteristics (Kozma, 1986). In this century, genetic scientists and researchers began to
understand the cause of Down syndrome. By the early 1930’s, researchers began to suspect that Down syndrome might be caused by a chromosomal abnormality (Kozma, 1986). In 1959, Jerome Lejune, a French cytogeneticist, discovered that cells grown from individuals with Down syndrome had an extra chromosome. The exact location of the extra chromosome was later discovered to be at the number-21 chromosome. These findings then led to the discovery of the other forms of Down syndrome, including Translocation and Mosaicism (Kozma, 1986). Because of this extra genetic material, normal development does not occur, and mental retardation results. The severity of mental retardation varies greatly, but most individuals fall within the mild to moderate range of mental retardation (See Appendix 2).

**Trends, Variations, Incidence and Prevalence.** Kozma (1986) reported, "Over 6 thousand babies with Down syndrome are born in the U.S. every year and thousands more in other countries. It is one of the most common birth defects" (p. 2). For every 800 to 1,000 births, one baby is born with Down syndrome. Down syndrome appears in every ethnic group, religion, and economic level (Brill, 1993). Gibson (1978) stated, "While incidence is probably decreasing, prevalence and visibility are increasing. Most parents no longer seek institutional care because support services for home care are improving and institutional bed space is shrinking as a matter of public policy" (p. 281).

**Etiological Agents of Down Syndrome.** The exact cause of Down syndrome has thus far eluded discovery. There are a number of theories of causation. Advanced maternal age is one established factor related to increasing odds of having a baby with Down syndrome, yet seventy-five percent of babies with Down syndrome are born to mothers under thirty-five years of age (Kozma, 1986) (See Appendix 3). Recent studies suggest that in nondisjunction, the father's sperm may be accountable in about twenty to thirty percent of babies with Down syndrome (Kozma, 1986). Other studies suggest that the age of the father may be as important as the age of the mother. Fathers over age thirty
may pose an even higher risk factor than mothers over age 30 (Duncan, 1988). Recent estimates suggest that between 20 and 30 percent of Down syndrome cases come from the father (Brill, 1993).

**Future Projections in Down Syndrome.** Gibson (1978) stated, "A final hope, absolute cure, is unlikely because the major structural and process disorders of DS are laid down embryologically and are developmentally prescribed, to a significant extent, from birth onward" (p. 1). Even so, Down syndrome research is on-going. Scientists, doctors, and researchers are continually exploring the causes, effects and treatment of Down syndrome. Genetic research is crucial in this study, and researchers are now isolating individual genes to study their functions (Kozma, 1986).

**Statement of the Problem**

This research was designed to study responses to the birth, rearing, and grieving process (as described in Engel's 3-stage model of grieving) as experienced by selected parents of a Down syndrome child.

**Need for the Study**

While studies have explored the birth and rearing of a child with Down syndrome based on medical and clinical data, relatively few have explored the grieving process experienced by those parents. Health care professionals rely extensively on stage model theories to understand the grieving process of parents of Down syndrome children; however, little research has been conducted to investigate the appropriateness of the application of these models to this population group. More research from a parent's perspective specifically regarding stage model theories is necessary.

**Purpose of the Study**

The purpose of this study was twofold: 1) To analyze the similarities and differences between parent responses to the birth and rearing of a child with Down
syndrome and; 2) To document the characteristics of grieving described in Engel's 3-stage model of grieving.

Significance of the Study

The Engel 3-stage model, or a variation of the model, is still widely used by health professionals to understand the grieving process experienced by the parents of children with Down syndrome. Previous studies have explored different aspects of this process, including clinical, medical and maternal responses; however, it was necessary to provide professional literature in a valid, qualitative format to analyze parent responses to the birth of a child with Down syndrome. Furthermore, it was imperative to determine the applicability of stage model theories to this process. Upon completion of a pilot study of parent responses conducted by the researcher in the spring of 1994, it was found that while Engel's stage model is useful in examining grief, there were significant differences found in the Restitution Stage of the model. Further study of both maternal and paternal responses specifically regarding stage model theories was necessary.

It is significant to allow parents a voice in discussing the grieving process. Parents' words have power. Parent responses provide an extremely useful way for scientists, researchers, and doctors to further understand Down syndrome and the grieving process. As stated earlier, there were significant differences found by the researcher between parent responses and the stated characteristics of grieving. It was necessary to discover if these findings were supported by a larger, more representative sample of subjects. Conducting a study on parent responses allowed a deeper understanding of the grieving process. A qualitative study allowed the exploration of subjective domain and answered questions such as, "How is it different?", "How is it similar?", and "Describe this process in your own words." In this way, stage theories of grieving can be better understood, and more importantly, parents can be better understood.
This is beneficial for parents, as well; it is a cathartic, healing process to discuss personal struggles, as well as to discover how other parents feel. It is comforting and reassuring for parents to learn that other people have had similar thoughts and feelings (Pueschel, 1990). Elkins & Brown (1986) described the necessity for communication as follows, "Parents need to hear from those who have been through the dark tunnel of a difficult birth and have come back to say 'come ahead' " (p. 423).

Examination and analysis of parent responses was also an excellent starting point for providing interventions for grief work based on their needs. In asking parents questions such as, "What support services would you like to have available in your community?", action research can take place, allowing the opportunity to provide for needs.

Assumptions

The study made the following assumptions:

1. Subjects cooperated and answered questions completely and honestly.

2. Subjects returned the questionnaire within the 2-week deadline suggested by the researcher.

3. Data gathered was appropriate for this study.

4. Subjects were a representative sample of the parents of children with Down syndrome in the Dallas area.

5. There was objectivity in analyzing data by using data raters trained simultaneously by the researcher.

Limitations

The study was limited as follows:

1. Honesty of questionnaire recipients was a limitation.

2. The study relied on self-reported data, which may have limited the internal validity.
Delimitations

The study was delimited as follows:

1. Participation was restricted to the members of the Dallas Down Syndrome Guild who are parents of people with Down syndrome. Professionals, physicians, grandparents, and other members were excluded because the nature of this study was to identify parent responses. The mailing labels of Down Syndrome Guild members were separated by association - parents, professionals, and other members. The parent labels were randomly chosen by the researcher.

Research Questions

The following research questions guided this study:

1. What are the parent reactions and responses upon the birth of a child with Down syndrome?

2. What are the parent reactions and responses regarding the rearing of a child with Down syndrome?

3. How similar/different are parent reactions and responses to the birth and rearing of a child with Down syndrome to the characteristics of grieving reactions stated in the three stages of Engel’s model?

4. Is the linear movement suggested in the Engel 3-stage model applicable to parents of Down syndrome children?

5. What are the differences/similarities in parent responses regarding rearing issues in a child with Down syndrome vs. an adult with Down syndrome?

6. What are the concerns of parents, and what are their desires regarding interventions?

Definition of Terms

Down syndrome - A common genetic disorder in which a person is born with forty-seven rather than forty-six chromosomes, resulting in developmental delays, mental retardation,
low muscle tone, and other effects (Stray-Gundersen, Ed., 1986, p. 187). Note: The correct way to write Down syndrome is with a capital "D" and a small "s". It will appear as capital "D" and capital "S" only in titles, or when the researcher is transcribing verbatim either from published works or from open-ended responses. Down's syndrome is also incorrect, and will only appear in verbatim transcription.

Genetics - The study of genes, chromosomes, and heredity (Stray-Gundersen, Ed., 1986, p. 188).

Handicapped - Refers to people who have some sort of disability, including physical disabilities, mental retardation, sensory impairments, behavioral disorders, learning disabilities and multiple handicaps (Stray-Gundersen, Ed., 1986, p. 188).

Karyotype - A picture of human chromosomes. These can reveal the presence of extra genetic material (Stray-Gundersen, Ed., 1986, p. 189).

Mental Retardation - Below normal mental function. Children who are mentally retarded learn more slowly than other children, but "mental retardation" itself does not indicate the child's level of dysfunction (Stray-Gundersen, Ed., 1986, p. 189).

Mosaicism - A rare type of Down syndrome in which a faulty cell division occurs in one of the early cell divisions after fertilization. The result is that some but not all of the baby's cells contain extra genetic material (Stray-Gundersen, Ed., 1986, p. 189).

Nondisjunction Trisomy 21 - The most common type of Down syndrome, caused by the failure of chromosomes to separate during meiotic cell division in the egg (female) or the sperm (male) (Stray-Gundersen, Ed., 1986, p. 190).

Translocation Trisomy 21 - A rare form of Down syndrome caused when a part of the number-21 chromosome breaks off during cell division and attaches itself to another chromosome (Stray-Gundersen, Ed., 1986, p. 192).

Trisomy - The presence of extra genetic material in the cells; three rather than two chromosomes in the cells (Stray-Gundersen, Ed., 1986, p. 192).
Summary

The purpose of this study was to conduct qualitative research in a retrospective format to analyze differences and similarities between parent responses to the birth and rearing of people with Down syndrome and the characteristics of reactions stated in the grief and mourning 3-stage model of G.L. Engel. While this model is enormously useful in understanding the dynamics of parent grief reactions, it was important to note significant variations and deviations from the model in order to fully understand the grieving process. The literature review of Chapter 2 further explores this notion.
CHAPTER II

REVIEW OF THE LITERATURE

Exploring parent responses to the birth and rearing of a child with Down syndrome can be a significant component in the grieving process. Elkins & Brown (1986) stated, "In the present era of noninstitutionalization for persons with Down syndrome, understanding the unique psychodynamics in such cases is necessary for establishing a supportive environment for the newborn infant" (p. 420). Pueschel (1990) believed that parents of Down syndrome children are a valuable resource in understanding grief.

Studies have shown that some parents pass through a series of stages upon the birth and rearing of a child with a handicap. Opihory & Peters (1982) employed a stages model in understanding grief in parents giving birth to a disabled child. According to Laborde & Seligman (1991), the stages are shock/denial, anger, bargaining, depression, and acceptance (p. 357). Solnit & Stark (1961) have described maternal reactions to the birth of a handicapped child to be similar to the death of a loved one. There is a mourning of the loss of the idealized, perfect infant. Perhaps the most descriptive and useful model of grieving the death of a loved one came from Engel's 3-stage theoretical model (1962). Farnham (1988) has written about the grieving process of mothers of retarded children, and made use of Engel's 3 stages to discuss the similarities of grieving the loss of a loved one and grieving the loss of the idealized child. Farnham provided interventions for these mothers based upon the theoretical framework of the grief process described by Engel. It is important to note, however, that while it is useful to employ stage models to the grieving of parents bearing handicapped children, it is also necessary to note exceptions and differences. Olshansky (1966) argued that the death of a dream child is not equivalent
to the death of a real child because the sorrow continues. He described this concept as "chronic sorrow" (Olshansky, 1962). Elkins & Brown (1986) described this concept as follows, "The sadness felt at the birth of a handicapped child is significantly different from the sadness felt at a perinatal death" (p. 423). Elkins & Brown continued, "Parents are saddened by both the loss of the idealized child and the presence of the very real impaired child. This chronic sorrow can steadily erode the parents fragile self-esteem as they face constant developmental delays in their child with Down syndrome. Physicians must understand that the parents need the opportunity to express sorrowful feelings over an extended period of time" (p. 423). Hodapp, Dykens, Evans, & Merighi (1992) concurred with Olshansky's findings. They examined emotional reactions in mothers of children with Down syndrome (N=25) and children with motor impairments (N=20) cross-sectionally. They described the responses of mothers to their children with handicaps as a process of recurrent mourning, as mothers repeatedly reacted with grief to the discrepancies between what might have been and what is.

It is necessary to discuss the 3 stages described by Engel because the focus of this study was to analyze the similarities and differences between these stages and parent responses. Engel's 3-stage model is described below, with a discussion of the characteristics of each phase.

G.L. Engel: Stage One - The Stage of Shock and Disbelief:

Stage One is characterized by feelings of denial, shock and disbelief. Farnham (1988) stated, "In this stage, persons do not allow themselves to think about the loss and may try in some fashion to carry on ordinary tasks. Some may overtly accept the loss intellectually, but deny its painful emotional impact. Denial is the most important psychological mechanism and is more likely to occur if the loss is unexpected" (p. 75). Brill (1993) stated that utter shock is a common first reaction to the diagnosis of Down syndrome. Brill continued, "Denial takes over. After all, Down syndrome is something
that happens only to other families" (p. 19). Pueschel (1990) believed that parents informed of the diagnosis of Down syndrome describe sensations of overwhelming shock and disbelief, and feel as though their world is coming to an end. Simons (1985) stated, "The initial reaction is usually shock and panic. 'I can't handle this! What will I do?!!' They are terrified - afraid that they will not be able to cope with the situation; afraid of the future - both theirs and their child's - which they assume will be terrible" (p. 5).

G.L. Engel: Stage Two - The Stage of Developing Awareness of the Loss:

Stage Two is characterized by feelings of sadness, anxiety, guilt, and aggression. Farnham (1988) stated, "Persons now experience acute sadness which may be mixed with anxiety. There is aggression which may be felt as anger toward persons or circumstances held to be responsible for the loss - doctor, nurse, hospital, or other family member. Feelings of guilt also predominate. Finally, crying serves as a catharsis in relieving the tension caused by intense emotions" (p. 75). Brill (1993) concluded that as the shock lessens, an unbelievable sadness develops. "Gradually, the sorrow turns into anger. 'Why me?' you ask repeatedly. You may be embarrassed when you go out. You become jealous of parents who have healthy babies. You become angry when they don't appreciate how lucky they are" (p. 19). Simons (1985) described parents at this stage this way, "At the same time they feel angry - at the doctor who told them for being insensitive, for not preventing the handicap, for not making it go away; at each other for not solving the problem; at the unfairness of the situation, and at the child himself for having disappointed them so badly" (p. 7).

G.L. Engel: Stage Three - Restitution - the Work of Mourning:

Stage Three is characterized by feelings of loss, sadness and responsibility. Farnham (1988) stated, "In the beginning of the third stage, the mourners may be preoccupied with general thoughts of the loss as well as with specific feelings of responsibility for it. Memories of the loss must be brought up, thought over, and talked
about. This process is slow, painful, and sad. Gradually, however, preoccupation with the loss and with sadness abates and interest in other objects increases.” This stage is said to eventually terminate, as feelings of pleasure and enjoyment in life are experienced.

This is the only stage in Engel's 3-Stage theoretical model of grieving that bears significant differences in the literature review. It has been shown that this stage does not end or "terminate"; rather, it is something that must be worked through continually throughout life. Hodapp et al., (1992) pointed out that parents whose children are mentally retarded have deeper concerns as their children get older, as social services are less often used. Parents are never completely allowed to relinquish the parenting role, even when their children become adults. For these reasons, a simple, three-stage model of mourning is not adequate in describing reactions and emotions. Murphy (Pueschel, 1990) writes, "Their feelings of sadness and loss may never disappear completely, but many people describe some beneficial effects of such an experience" (p. 12).

While stage models can be enormously useful in understanding the grieving process of parents with handicapped children, it is necessary to point out the disadvantages, as well. Featherstone (1980) stated, "Those who write about parent's response to a child's disability often speak about stages of adjustment: denial, rejection, and finally the promised land of acceptance" (p. 232). Featherstone continued, "I agree that many families follow similar paths when they move beyond despair, but I am uncomfortable with most stage theories. They carry too heavy a freight of straight-line progress; they also suggest an implausible final harmony" (p. 232). The danger in theoretical models lies in their very nature - that grieving is very linear and predictable. A simple stage model fails to capture the diversity of each family and their reactions and emotions (Featherstone, 1980).

Comparing parent reactions upon the birth and rearing of a handicapped child to grief from death and dying in all stages may also be inaccurate. As discussed earlier,
Solnit & Stark (1961) found that parents of disabled children may have an even more difficult time adjusting than those who have lost a child, because of the limited time and emotional space for mourning the normal child they have lost. Featherstone (1980) stated, "First of all, disability is never as clear-cut as death. Grief usually mingles with confusion and uncertainty. Parents of a Down's syndrome child may be told little beyond the label and have no idea what degree of retardation to expect. As they learn more, either through their own research or through professional consultation, the picture changes. And as the child grows, he or she changes too - often invalidating earlier professional predictions. Not knowing what fate to mourn, the parent faces a thousand alternative scenarios" (p. 233).

Parents and professionals must be cautioned against believing in the finality of grieving. Parents need the opportunity to express sorrow and grief, even over an extended period of time (Elkins & Brown, 1986). Monsen (1986) discussed the multiple tasks parents of handicapped children face, including the loss of the normal child, as well as the on-going care of the disabled child. Lavelle & Keogh (1980) stated, "It seems fair to conclude that the process of adaptation to a handicapped child is a complex one, in which considerable individual variability must be anticipated" (p. 4). It is important to discover, through parent responses, whether or not these stages are accurate.

A Review of Qualitative Research Literature

This study was conducted qualitatively because of the nature of the research - a holistic inquiry into the lives of parents of persons with Down syndrome. The researcher will be asking subjects to describe their experiences, retrospectively and in their own words - all characteristics of qualitative research (Rubinson & Neutens, 1987). As stated earlier, parents' words have power, and a qualitative study was necessary to explore these responses. Quantitative research could, indeed, be conducted on the subject of grieving and parenting a handicapped child, but a strictly numerical analysis would not obtain the
"heart and soul" of parent responses - this must be conducted in a qualitative, descriptive format. Rubinson & Neutens (1987) described qualitative methods as describing multiple realities. Bogdan & Biklin (1982) have developed a table of comparisons between qualitative and quantitative data. Key concepts associated with qualitative data, according to Bogdan and Biklin, are: the reviewing of documents, observation, description, and developing understanding. Kirk & Miller (1984) used the terms "naturalistic", "ethnographic", and "participatory" to describe qualitative research. Quotations are also often used in qualitative data (Rubinson & Neutens, 1987). Forchuk & Roberts (1993) stated, "Rather than numerical data, qualitative research generates narrative that reflects on the whole rather than the parts" (p. 50). The spirit of qualitative work involves open-ended, exploratory work (Sandelowski, 1993). Patton (1990) stated that the use of open-ended responses allows deep understanding of the points of view of other people. It provides an understanding of the world as seen by the respondents. Patton continued, "Direct quotations are a basic source of raw data in qualitative inquiry, revealing respondents' depth of emotion, the ways they have organized their world, their thoughts about what is happening, their experiences, and their basic perceptions" (p. 24). Kirk & Miller (1986) described qualitative research in terms of a 4-phase affair: 1) Invention-Research Design, 2) Discovery - Data Collection, 3) Interpretation - Data Analysis, and 4) Explanation - Documentation (p. 60).

It was the purpose of this study to obtain and represent a "fuller knowing" in order to advance knowledge regarding grieving, and this could only be achieved using qualitative methodology. Issues of reliability and validity of this qualitative study are addressed in Chapter III, Methodology.
CHAPTER III

RESEARCH METHODOLOGY

The purpose of this descriptive, exploratory study was to analyze the similarities and differences between parent responses to the birth and rearing of a child with Down syndrome and the characteristics of grieving described in G.L. Engel's 3-stage model of grieving.

Design

It was necessary to conduct this study qualitatively because of the nature of the research - a holistic inquiry into the lives of parents of persons with Down syndrome. The researcher asked subjects to describe their experiences, retrospectively and in their own words - all characteristics of qualitative research (Rubinson & Neutens, 1987). As stated earlier, parents' words have enormous power, and a qualitative methodology using a questionnaire format was necessary to explore these responses. Miles & Huberman (1984) stated, "Words, especially when they are organized into incidents or stories, have a concrete, vivid, meaningful flavor that often proves far more convincing to a reader - another researcher, a policymaker, a practitioner - than pages of numbers" (p. 15). This study's purpose was to ascertain the "whys" of issues, not merely the numbers or even the association of variables.

Patton (1990) reported that the task of the qualitative researcher is to provide a framework within which people can respond in such a way as to accurately represent their points of view and their experiences. Although questionnaires represent an elementary form of qualitative data collection, open-ended responses allow the opportunity for depth and detail of feelings - the fruit of qualitative methodology (p. 24). There are, indeed,
limitations to data collected using questionnaires. These are, according to Patton, limitations related to the writing skills of respondents, the impossibility of extending or probing responses, and the effort required of the respondent (p. 24). Nevertheless, a questionnaire design format was the most suitable design format for this study for several reasons: 1) This was a confidential study. Respondents did not identify themselves or their children. 2) The study was voluntary. With the use of a questionnaire, respondents could freely choose whether or not to participate without repercussions. 3) Open-ended responses were the "heart and soul" of this study. Even responses received that were seriously flawed grammatically were useful.

The qualitative design method of triangulation was used in this study. Patton (1990) stated that triangulation - the combination of methodologies in the study of the same phenomena - can strengthen a qualitative study. This study involved two basic types of triangulation: 1) investigator triangulation, and 2) methodological triangulation. Regarding investigator triangulation, the researcher employed three additional individuals to aid in data analysis in order to eliminate researcher bias. Regarding methodological triangulation, the researcher used open-ended, qualitative methods as well as quantitative methods. Patton (1990) stated that because qualitative and quantitative methods each have strengths and weaknesses, they constitute alternative, but not mutually exclusive approaches for research. Patton continued, "Both qualitative and quantitative data can be collected in the same study (p. 14). Further discussion of these methods is provided under data analysis and instrumentation, respectively.

Selection of Subjects

Approval for this study was granted by the Institutional Review Board, and a copy of the letter of approval appears in Appendix 5. Subjects for this qualitative study were randomly selected members of the Dallas Down Syndrome Guild who are parents of persons with Down syndrome. Approximately 250 subjects were randomly selected from
a list of 466 parent members of the Dallas Down Syndrome Guild and participation was voluntary and anonymous. The researcher mailed the cover letter/questionnaire. All fees were incurred by the researcher.

The Dallas Down Syndrome Guild was selected by the researcher for participation because of the large number of members, as well as the differing ages of persons with Down syndrome. Data collection for this study needed to comprise all ages of persons with Down syndrome, from infancy to adulthood. Demographic data was charted and analyzed, using measures of central tendency, mean, median and mode, and percentage calculations.

**Dallas Down Syndrome Guild:** Permission from the Dallas Down Syndrome Guild was granted. The permission letter, as well as the letter requesting formal permission from the Board of Directors of the Dallas Down Syndrome Guild appears in Appendix 5. Ethical considerations such as confidentiality and voluntary participation were addressed in the cover letter (Forchuk, Roberts, 1993). Respondents were informed in the cover letter that the study was confidential and voluntary, and that permission for the study was granted by the Dallas Down Syndrome Guild as well as the Institutional Review Board - Protection of Human Subjects. The cover letter written to accompany the questionnaire appears in Appendix 4.

**Instrumentation**

A pilot study was conducted in the spring of 1994 by the researcher to ascertain appropriate research questions relevant to the questionnaire which was used to gather data in this study. The content validity was established by pre-testing the questionnaire in the pilot study. The questionnaire was changed and updated based on subject responses and the review of relevant literature. The pilot study proved to be enormously helpful in development of the researcher-designed questionnaire; however, its findings were limited due to the fact that data collection was confined to parents whose children were of school
The current instrument was tested to ascertain its face validity. The data collected from those subjects was used by the researcher to create a data analysis coding sheet. A detailed description of this coding sheet appears in the Data Analysis section of this chapter.

The researcher administered the cover letter/questionnaire through the mail using randomly chosen mailing labels of parent members of the Dallas Down Syndrome Guild. Mailing labels of members of the Dallas Down Syndrome Guild were separated according to association (parent member, professional member, other members) The researcher randomly chose 250 out of 466 parent member labels. Subjects were asked to complete the questionnaire honestly, voluntarily and anonymously. The questionnaire took approximately 15 to 30 minutes to complete. Subject participants were asked to return the questionnaire through the mail, within a two-week time frame, to the researcher in a self-addressed, stamped envelope provided by the researcher.

In order to strengthen this study design, the qualitative method of triangulation was employed in the questionnaire. Patton (1990) stated that triangulation - the combination of methodologies in the study of the same phenomena - can mean using both qualitative and quantitative approaches. The questionnaire comprised questions designed to gather both qualitative, open-ended data as well as quantitative data. The questionnaire was written as follows: The first section addressed demographic data, such as gender, age, education level, and county of residence. This data was analyzed and charted. The next section of the questionnaire was titled "Section One", and addressed questions related to Stage One of Engel's 3-stage grieving model. Questions in this section were asked qualitatively as well as quantitatively. For example, question one asked respondents to check off all feelings that apply (quantitative) as well as to describe these feelings in their own words (qualitative). Likert-type scaling questions were also included, such as: "The person who gave you the news was: Physician, Nurse, Spouse, Other Relative, Clergy
Person, Other", and "The person who informed you that your child was born with Down syndrome was: Informative: Strongly Agree, Agree, Uncertain, Disagree, Strongly Disagree." Using this format allowed the researcher to obtain both quantitative data (80% of all respondents answered "yes", their initial reaction was one of shock, denial and disbelief) as well as obtaining the "heart and soul" of qualitative research using the descriptive, open-ended responses.

Section Two of the questionnaire addressed questions related to Stage Two of Engel's 3-stage grieving model. Respondents were, once again, asked quantitative as well as qualitative questions.

Section Three of the questionnaire addressed questions related to Stage Three of Engel's 3-stage grieving model. Respondents were asked questions such as, "Do you feel as though the sadness regarding the birth and rearing of your child with Down syndrome has ended? Yes____, No____. If yes, why? If no, why not?" Again, this provided both quantitative and qualitative data.

Each section of the questionnaire also comprised questions which could be useful for action research. For example, respondents were given a forum to voice their needs for possible interventions by answering such questions as, "If you could change anything about how you first learned your child had Down syndrome, you would...", and "Did you participate in any support group designed for parents of Down syndrome? Yes _____ No____, If you could change anything about the support group, you would..." This could well be important information for action research regarding possible services and programs, as well as being useful in revising existing programs and services. The complete cover letter/questionnaire appears in Appendix 4.
Data Analysis

Data analysis for this qualitative study was completed by the researcher using the qualitative research method of investigator triangulation. Patton (1990) stated that the use of different researchers or evaluators can strengthen the design of the study. The researcher employed three individuals who are separated from the study to aid in data analysis. Because the use of quotations and open-ended responses can be vulnerable to researcher bias, these individuals analyzed data collected to control for researcher bias (Glendinning, 1983). Sandelowski (1993) stated, "Researchers may make serious analytic errors in attempting to find temporal, informational, or intentional consistency among stories" (p. 5-6).

Issues of reliability and validity of this qualitative study must be addressed. Kirk & Miller (1986) stated that for reliability to be calculated in a qualitative study, it is incumbent on the researcher to document his/her procedure. The reader must know exactly how the qualitative researcher prepares for the endeavor, and how the data is collected and analyzed (p. 72). This study specifically addressed procedure, data collection, and data analysis. Kirk & Miller (1986) discussed objectivity in addressing the issues of reliability and validity. They stated that objectivity can be obtained in two ways: 1) The experience is reported in such a way that it is accessible to others. When reporting an experiment, every effort is made to describe the way the experiment was carried out in case someone else would like to do the same thing, and 2) The results of the experiment are reported in terms of theoretically meaningful variables (p. 13). Kirk & Miller (1986) described issues of reliability and validity in qualitative research in this way: Reliability is the extent to which a measurement procedure yields the same answer however and whenever it is carried out. Validity is the extent to which it gives the correct answer (p. 19). They continued, "Reliability is the degree to which the finding is independent of accidental circumstances of the research, and validity is the degree to which the finding is
interpreted in a correct way" (p. 20). Kirk & Miller (1986) reported that most errors in
the validity of a qualitative project do not fall within the typical Type one and Type two
errors of quantitative research. Type three errors frequently occur - asking the wrong
question. Kirk & Miller (1986) stated, "Asking the wrong question actually is the source
of most validity errors. Devices to guard against asking the wrong question are critically
important to the researcher" (p. 30). The questionnaire in this study was tested in a pilot
study in 1994 to obtain information regarding proper questioning. The questions have
since been re-written and re-tested on another small pilot-study sample. Patton (1990)
stated, "Qualitative analysis does not have the parsimonious statistical significance tests of
quantitative analysis" (p. 431). The researcher, therefore, provided an in-depth
description of the procedures for data analysis, and descriptions of the procedure can be
found under Instrumentation, Design and Selection of Subjects of this chapter.

Instructions for Data Analysis: As stated earlier, data analysis for this study was
conducted by the researcher with the aid of three individuals who are separated from the
study. The researcher instructed the raters, but did not actually analyze any of the data
collected in order to eliminate researcher bias. Following were the steps involved in data
analysis for this study: 1) The researcher provided complete copies of the research
proposal to the raters so that they could familiarize themselves with the purpose and
significance of the study. This took place during the two-week period when the
respondents were completing the questionnaires. 2) After all data had been collected, the
researcher met with the raters to provide the instructions for coding the data onto the Data
Analysis Coding Form. This form appears in its entirety in Appendix 6. Raters then
transcribed data directly from the questionnaires received onto the coding form. One rater
read the questionnaires and the others transcribed the data. The questionnaire was broken
down into 4 sections: Demographic data, Section One, Section Two, and Section Three.
Under demographic data, raters read and transcribed information onto the coding form
regarding gender, age, education level and county of residence. Mean, median, mode and percentage calculations were made as instructed on the coding form. For example, the first section of demographics addressed gender. Raters were asked to count the actual number of females and males completing questionnaires, then computed percentages. Current age was the next section where raters listed current ages directly from the questionnaires, then described mean, median and mode. The data analysis coding form gave explicit instructions for each and every item contained in the questionnaire.

The next section of the questionnaire addressed questions regarding Stage One of the grieving theory. Raters took frequency counts of the actual number of responses directly from the questionnaires (43- Denial, 85- Shock, etc.) then computed percentages. The open-ended, qualitative data collected from the questionnaires was randomly chosen by the raters for inclusion in the Findings of Data Analysis section. The raters randomly chose 10 questionnaires. The use of open-ended responses and descriptive data is essential to qualitative research, and was included in the reporting of findings (Patton 1990). To minimize researcher bias, the researcher had no input whatsoever as to which open-ended responses were used in data analysis. The final Master File of data contains analyzed demographic data, quantitative, and qualitative data used in the discussion of results and recommendations.

Appendix 6 contains the data analysis coding sheet which was used in data analysis. This coding sheet contained step-by-step instructions used by the raters in data analysis.
CHAPTER IV

FINDINGS OF DATA ANALYSIS

The purpose of this study was two-fold: 1) To analyze the similarities and differences between parent responses to the birth and rearing of a child with Down syndrome and; 2) To document the characteristics of grieving described in Engel's 3-stage model of grieving. The results of the data analysis are presented according to the sections of the questionnaire. The first section presents descriptive data on the demographics of the questionnaire respondents. The second section presents data regarding Stage One of grieving theory. The third section presents data regarding Stage Two of grieving theory. The fourth section presents data regarding Stage Three of grieving theory. All questionnaires containing at least 80% of completed data were used in the study. Only 1 questionnaire did not meet the 80% completion requirement, allowing 70 questionnaires for data analysis.

In interpreting the findings of the data, it is necessary to discuss the possible sources of bias and limitations of the data. First of all, out of 70 questionnaires, only 6 were completed by males. Research on male responses to the birth and rearing of Down syndrome children is severely limited in the literature review. It was the hope of the researcher to obtain more data on male responses; however, 6 completed questionnaires from the male population is inadequate data to base conclusions on male responses. Secondly, only members of the Down Syndrome Guild were included in the study. Although the questionnaires were sent randomly to 250 members out of 466 members, parents of Down syndrome children who were not members of the Guild were not included. Parents who belong to a support group such as the Guild may respond to
questions differently than those who do not belong to a support group. Third, the data received is self-reported data. This may limit the validity of the data.

Out of the 250 questionnaires sent, 70 were properly completed and returned to the researcher within the 2 week time frame, representing a 28% return rate. (As of May 2, 1995, 15 additional questionnaires were received, 3 male, 12 female. These were not used in data analysis). Table 1, Demographic Data follows:

Table 1

Descriptive Statistics of Respondents for Demographics

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6</td>
<td>8.6</td>
</tr>
<tr>
<td>Female</td>
<td>64</td>
<td>91.4</td>
</tr>
</tbody>
</table>

N = 70

Current Age of Respondents

N = 69

Range 20 to 93, Mean = 41.25,
Median = 37, Mode = 37

Mother's Age at Time of Birth of Child with Down syndrome

N = 69

Range 19 to 45, Mean = 31.48,
Median = 32, Mode = 33 (See Illustration 1)

Father's Age at Time of Birth of Child with Down syndrome

N = 66

Range 19 to 48, Mean = 33.18,
Median = 33, Mode = 33 (See Illustration 1)

Education Level

N = 69

Grammar School 0.0
High School 8.7
Some College 37.7
College Degree 37.7
Graduate Education 15.9

(Table continues)
<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>County of Residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N = 68</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denton County</td>
<td>12</td>
<td>17.6</td>
</tr>
<tr>
<td>Dallas County</td>
<td>46</td>
<td>67.6</td>
</tr>
<tr>
<td>Collin County</td>
<td>10</td>
<td>14.7</td>
</tr>
<tr>
<td>Current Age of Child/Adult with Down syndrome</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N=70</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range 0 to 50, Mean = 9.21,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median = 7, Mode = 1 (See Illustration 2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex of Down syndrome child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N = 69</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>33</td>
<td>47.8</td>
</tr>
<tr>
<td>Female</td>
<td>36</td>
<td>52.2</td>
</tr>
<tr>
<td>Sex of other children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N = 112</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>66</td>
<td>58.9</td>
</tr>
<tr>
<td>Female</td>
<td>45</td>
<td>40.2</td>
</tr>
<tr>
<td>N/A</td>
<td>1</td>
<td>0.9</td>
</tr>
<tr>
<td>Current Age of other children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N = 112</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range 0 to 60, Mean = 15.21</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median 12, Mode 6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Illustrations 1 and 2 follow, describing current age data:
ILLUSTRATION 1

Mother and Father Age at Birth of Down Syndrome Child

ILLUSTRATION 2

Current Age of Down Syndrome Child/Adult
As evident in Table 1, it was unfortunate to receive only 6 male responses to the questionnaires. It would have been interesting to compare the results of the data received from the female population to the data received from the male population; however, only 6 male responses severely limits comparison or analysis based on gender. The age range of respondents was age 20 to age 93, representing a good cross section of the entire parent population. The researcher was interested in the mean age of both the mother and the father at the time of birth of the child with Down syndrome. As stated in the review of the literature, advanced maternal age is one established factor related to increasing odds of having a baby with Down syndrome, yet seventy-five percent of babies with Down syndrome are born to mothers under thirty-five years of age (Kozma, 1986). This study found the mean age of mothers at the birth of their Down syndrome child to be 31.48. Out of 69 responses, only 16 were age 35 or older, representing 23.19% of this population. Of fathers, the review of the literature states that the age of the father may be as important as the age of the mother. Fathers over age 30 may pose an even higher risk factor than mothers over age 30 (Duncan, 1988). Out of 66 responses, the mean age of fathers at the time of birth of their child with Down syndrome was 33.18. Of those 66 responses, 52 are age 30 or older, representing 79% of this population. (The previous calculation for mothers was age 35 or older. Mothers age 30 older in this study represent 48 out of 69 responses, or 70%).

Regarding education level, it was interesting to find that 26 of 69 respondents had received some college education, and 26 had received a college degree, representing 75.36% of this population receiving higher education. 15.9% of this population had received graduate education.

County of residence: The majority of respondents came from Dallas county, 67.6%, with 17.6% from Denton county, followed by 14.7% from Collin county. Although the majority of respondents were from Dallas county, having data from Denton
and Collin counties will still be beneficial when evaluating programs, services, and interventions for families.

The current age of the child or adult with Down syndrome mean was 9.21, with a range from 0 to 50 years of age. Having a wide age range of persons with Down syndrome provided beneficial data for possible services, programs, and interventions. The study represented 47.8% of males with Down syndrome and 52.2% females with Down syndrome. The age range of other children in the study was 0 to 60, with the mean being 15.21, 58.9% male, 40.2% female.

Stage One Data

Stage One of the grieving theory is characterized by feelings of denial, shock and disbelief. Pueschel (1990) stated that parents describe sensations of overwhelming shock and disbelief, and feel as though their world is coming to an end. The questionnaire addressed questions regarding Stage One of grieving theory. Respondents were asked to describe their initial reaction to the news of the Down syndrome diagnosis. Respondents were asked to check denial, shock, disbelief and other, then to describe their initial reaction in their own words.

Table 2

Descriptive Statistics of Respondents - Initial Reaction to the Down Syndrome Diagnosis

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N = 67</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>34</td>
<td>50.7</td>
</tr>
<tr>
<td>No</td>
<td>33</td>
<td>49.3</td>
</tr>
<tr>
<td>Shock</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N = 67</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>55</td>
<td>82.1</td>
</tr>
<tr>
<td>No</td>
<td>12</td>
<td>17.9</td>
</tr>
</tbody>
</table>

(Table continues)
The data showed that regarding the initial responses to the Down syndrome diagnosis, a majority of respondents do grieve in the same way as stated in Stage One of grieving theory. Over 50% experienced denial, over 80% experienced shock, and nearly 65% experienced disbelief. Open-ended responses regarding initial responses were taken from 10 questionnaires randomly chosen by the raters. These 10 questionnaires provided all open-ended data for this study, thus, eliminating researcher bias. Of the 10 questionnaires used for open-ended data, all respondents were female, with the age range being 31 to 45, mean = 37.8. All open-ended responses used in the study were transcribed verbatim by the researcher, including typographical and grammatical errors.

Following are randomly chosen open-ended responses regarding initial responses:

"It was a surprise to all since the pregnancy was very uneventful with no problems, not even morning sickness."

"I could not believe this was happening. I was in shock and unprepared."

"I noticed that our daughter had Down Syndrome as soon as the doctor showed her to me. Our greater concern was that she was grunting and congested and kept turning blue."
"Unbelievable - Could not believe this was possible. Surprised and totally (sic) unexpected."

"When I was about 7 1/2 months pregnant I saw a segment on the TV show 60 minutes about a family who had a child with Down syndrome, how they had put him in an institution when he was just born and that he needed heart surgery to survive. The segment was about a foster couple trying to adopt him so they could have this surgery done and save his life. The family was in court saying that this child had no merit in today's society. I was out raged (sic) and very emotional while watching this. So when the pediatrician came in and said 'The baby has a problem' he was holding her in his arms and I looked down and saw her sweet round face and I said 'She is Down syndrome' (sic) He looked startled but said 'YES' I then asked appropriate questions about her health. Heart problem? Respiratory problems? The doctor thought I knew something about Down's. Which I really did not. I just was not surprised that my daughter had Down's. My family was shocked. My OB was shocked he just kept saying over and over that I was to (sic) young for this to happened (sic) to me. I was anxious to get home and start taking care of my first baby."

"I am a physician & could understand the objective signs easily, i.e. Simean (sic) creases, low set ears, wide eyes. I wanted to hand her back to the Dr. & exchange for another baby."

"I was fearful of the future & what our family & our baby may have to go through. (The minute she was born, I suspected it)"

"Thought there was a mistake and that Dr. didn't know what."

"I knew when she was born, at that very moment, but I pushed the thought from my mind - I hoped & prayed it wasn't true. When the pediatrician came in to examine her early the next morning I prayed God to let her be alright - I just didn't want a child with a handicap - it didn't fit my plan for my life."
"Did not know what Down Syndrome was. We did not get test results for 2 months so we were very anxious about the whole situation. Looked it up in an old encyclopedia...very old info & depressing!"

Table 3

Stage One Likert Data

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>The person who gave you the news was?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N = 69</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physician</td>
<td>62</td>
<td>89.9</td>
</tr>
<tr>
<td>Nurse</td>
<td>2</td>
<td>2.9</td>
</tr>
<tr>
<td>Spouse</td>
<td>2</td>
<td>2.9</td>
</tr>
<tr>
<td>Clergy</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Other: Midwife</td>
<td>1</td>
<td>1.5</td>
</tr>
<tr>
<td>Speech Teacher</td>
<td>1</td>
<td>1.5</td>
</tr>
</tbody>
</table>

The person who informed you of the diagnosis was:

Informative?
N = 70
Strongly Agree 15 21.4
Agree 26 37.1
Uncertain 13 18.6
Disagree 15 21.4
Strongly Disagree 1 1.4

Empathetic?
N = 64
Strongly Agree 16 25.0
Agree 15 23.4
Uncertain 10 15.6
Disagree 22 34.4
Strongly Disagree 1 1.6

You first learned of the Down syndrome Diagnosis:
N = 70
Before Birth 2 2.9

(Table continues)
<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immediately following birth</td>
<td>54</td>
<td>77.1</td>
</tr>
<tr>
<td>1-2 weeks following birth</td>
<td>2</td>
<td>2.9</td>
</tr>
<tr>
<td>2-4 weeks following birth</td>
<td>4</td>
<td>5.7</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>11.4</td>
</tr>
</tbody>
</table>

If you had known of your child's Down syndrome diagnosis before birth, would you have chosen to terminate the pregnancy?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Uncertain</th>
</tr>
</thead>
<tbody>
<tr>
<td>N = 70</td>
<td>7</td>
<td>45</td>
<td>18</td>
</tr>
</tbody>
</table>

Did your child experience other health problems at birth?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>N = 70</td>
<td>36</td>
<td>34</td>
</tr>
</tbody>
</table>

Of "Yes" responses:

<table>
<thead>
<tr>
<th>Health Problem</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory</td>
<td>16</td>
<td>44.4</td>
</tr>
<tr>
<td>Heart Defects</td>
<td>15</td>
<td>41.7</td>
</tr>
<tr>
<td>Intestinal</td>
<td>9</td>
<td>25.0</td>
</tr>
<tr>
<td>Other: Jaundice</td>
<td>3</td>
<td>8.3</td>
</tr>
<tr>
<td>Heart Valve</td>
<td>1</td>
<td>2.8</td>
</tr>
<tr>
<td>Leukemia</td>
<td>1</td>
<td>2.8</td>
</tr>
<tr>
<td>Feeding Problems</td>
<td>1</td>
<td>2.8</td>
</tr>
</tbody>
</table>

It was found in the review of the literature that there is a 40% prevalence rate for congenital heart disease among Down syndrome infants (Rubin & Crocker, 1989). This study found a majority of children born with health problems, (51.4%), and of that number, 41.7% were born with heart defects and 2.8% with heart valve problems. This signifies the need for EKG evaluation and pediatric cardiology consultation following the birth of a Down syndrome infant.

Following are randomly chosen open-ended responses regarding health:

"He was on a respirator and EKG should (sic) hole in heart."
"When born had a clapsed (sic) lung, which stablized (sic) by day 2. She was also 2 weeks early."

"Our daughter had PFE & PPHN (Persistant (sic) Fetal Circulation & Persistent Rel. Hypertension of the Newborn). She was ventilated and on many drugs. The 1st week - 10 days was very uncertain then she got better and came home @ 1 mos. of age. She was readmitted to ICU 7 days later in aniphylactic (sic) shock from here (sic) formula. Now she's fine & on special formula."

"Duodenal (sic) blockage, needed surgery to survive. Surgery was performed the evening of her birth."

"She began to have seizures when she was 18 months old."

"Slow weight gain. I had to use a supplemental feeding system with my breast feeding. (Huge pain in the butt!)"

"Diagnosed w/ Hirschprungs disease @ 9 mo."

"2 holes in her heart - a VSD & ASD requiring open-heart surgery at 11 mos."

"Found out she had heart defect at age 7."

If you could choose anything about how you first learned your child had Down syndrome, you would? Following are randomly chosen open-ended responses:

"Have had some privacy with doctor."

"When I was pregnant I asked my doctor twice about an amnio & twice I was talked out of it. As stated previously, I noticed it as soon as I saw her face; then I asked about her hands for everyone was whispering. Then she became sick & my thoughts went to other things."

"Have someone who had some sympathy and compassion give me the news. The neonatalist who told me was rude. They informed my husband then told me. I think we should have been told together."
"Tell my husband myself. He received a phone call from the hospital to come back to the hospital as soon as possible. He thought that something had happened to me or the baby (that the baby had died - she was early). He was just about in shock before he could get back to me, and he did not understand what Down syndrome was at all."

"The Dr. was perfect. She said: 'We've noticed some things about Alexis. She has wide eyes, low set ears, & Simean ?sp? (sic) creases.' I knew immediately what she was saying. She cried with us."

"like the Dr. to have shown a little more compassion. But now I look back on it, I don't know how she could have done it better."

"Would like to have known during pregnancy. Or, when notified after birth - to be notified in a way that was a positive view of Down children."

"Nothing except to have my husband there with me - he was at home with our boys & I had to call and tell him."

"Have someone who had such a child come & talk to me and let me see the child."

Table 4

**Descriptive Statistics of Respondents - Counseling Services**

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you participate in any counseling services available after the birth of your child? 70 Responses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>31</td>
<td>44.3</td>
</tr>
<tr>
<td>No</td>
<td>39</td>
<td>55.7</td>
</tr>
<tr>
<td>If yes, was it helpful? 31 Responses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>25</td>
<td>80.6</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
<td>9.7</td>
</tr>
<tr>
<td>N/A</td>
<td>3</td>
<td>9.7</td>
</tr>
</tbody>
</table>

(Table continues)
<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who provided the service?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31 responses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td>2</td>
<td>6.5</td>
</tr>
<tr>
<td>Hospital</td>
<td>7</td>
<td>22.6</td>
</tr>
<tr>
<td>ARC</td>
<td>3</td>
<td>9.7</td>
</tr>
<tr>
<td>Physician</td>
<td>2</td>
<td>6.5</td>
</tr>
<tr>
<td>Social Worker</td>
<td>2</td>
<td>6.5</td>
</tr>
<tr>
<td>Down Syndrome Guild</td>
<td>2</td>
<td>6.5</td>
</tr>
<tr>
<td>Clinic</td>
<td>2</td>
<td>6.5</td>
</tr>
<tr>
<td>College</td>
<td>1</td>
<td>3.2</td>
</tr>
<tr>
<td>Private School</td>
<td>1</td>
<td>3.2</td>
</tr>
<tr>
<td>DISD</td>
<td>1</td>
<td>3.2</td>
</tr>
<tr>
<td>Richardson Development Center</td>
<td>1</td>
<td>3.2</td>
</tr>
<tr>
<td>N/A</td>
<td>6</td>
<td>19.4</td>
</tr>
<tr>
<td>Child Study Center</td>
<td>1</td>
<td>3.2</td>
</tr>
</tbody>
</table>

Note: N/A represents non/interpretable data

Please describe in your own words: (Randomly chosen open-ended responses)

"These services were very helpful in the first several months of learning what to expect, etc."

"My husband had a very hard time with the neonatal intensive care experience. He spoke often with the social worker at the hospital. She also got us involved with the Guild who called often & answered many questions."

"I asked if other people with Down syndrome children could visit me in the hospital, and I said Yes (sic). It was very helpful to see pictures of other children, to see the pride in the parents faces when they were describing the accomplishments of their children. The doctors were no help. I had one ask me if I wanted to put her in an institution, and another doctor tell (sic) that she may never walk or talk or do most anything. The nurse told me that breast feeding was impossible. (I pumped my milk and fed her through a bottle and finally breast fed her at about 4 months) Later, when she was maybe a year maybe a little older I went to a Grieving seminar and it seemed to make a lot
of sense that some of the feelings I was having was grief. My father passed away 9 months after I had my daughter and I experienced some of the same emotions."

"My husband & I separated when she was 3 wks. old because of problems before her birth. I sought counseling about that plus the Down Syndrome."

"Enrolled child in ECI program @ 2 wks old." (Early Childhood Intervention)

"It was with a social worker & other moms at a school for Down syndrome children. I took her to this school 2 x week for 18 mos. for 3 hrs. 2 hrs. were with the teachers - 1 hr. with the group."

"ARC - Stages of Adjustment for Parents of Handicapped Children (same as grief process) We were in an infant stimulation program that helped at the private school."

If you could change anything about the way you were counseled, you would? (Randomly chosen open-ended responses)

"Due to her illness, I don't totally remember any counseling to answer this question fully."

"Nothing."

"It was really just a time to share concerns, hurts, questions, etc. We received lots of support from our families, friends, & church."

"ARC was excellent."

Table 5

Descriptive Statistics of Respondents - Support Group

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you participate in any support group designed for parents of Down syndrome?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>47</td>
<td>67.1</td>
</tr>
<tr>
<td>No</td>
<td>23</td>
<td>32.9</td>
</tr>
</tbody>
</table>

(Table continues)
<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>If yes, did you find the support group helpful?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>47 responses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>37</td>
<td>78.7</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
<td>12.8</td>
</tr>
<tr>
<td>N/A</td>
<td>4</td>
<td>8.5</td>
</tr>
<tr>
<td>What (if any) other coping methods do you find helpful?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>70 responses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Talking with spouse</td>
<td>54</td>
<td>77.1</td>
</tr>
<tr>
<td>Talking with other family members</td>
<td>50</td>
<td>71.4</td>
</tr>
<tr>
<td>Exercise</td>
<td>18</td>
<td>25.7</td>
</tr>
<tr>
<td>Stress management techniques</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Other: Prayer</td>
<td>13</td>
<td>18.6</td>
</tr>
<tr>
<td>Read</td>
<td>7</td>
<td>10.0</td>
</tr>
<tr>
<td>Cry</td>
<td>3</td>
<td>4.3</td>
</tr>
<tr>
<td>See older DS kids</td>
<td>2</td>
<td>2.9</td>
</tr>
<tr>
<td>Healthy diet</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Activity without child</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Activity with child</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Golf</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Log of activity</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Clean house</td>
<td>1</td>
<td>1.4</td>
</tr>
</tbody>
</table>

Randomly chosen open-ended responses:

"It is helpful to see and meet all the other children and see the differences. Plus, it was also very eye opening to meet a lot of parents younger than myself and my husband."

"They had lots of information; also it helped to have parents to talk to. They are the best ones with the information."

"It was educational, because at first I read and tried to educate myself as much as possible and there was other women in the group who needed to read up and understand just like I did. It also helped because you could discuss doctors and early intervention programs. We did not always agree, but we respected each other's opinions, just because a certain program worked for one did not mean it was right for us all. It also was very
helpful to talk to a mother who had just taught their child what you were starting to work on such as...rolling over, sitting up, crawling and walking. Later potty training! We had a common bond, but we were not necessarily in the same social group."

"getting more information & finding out we are not alone."

"it was an off & on thing as we moved to 3 different states after she was born. We are pretty busy & involved with lots of dif. activities so we didn't really feel a strong need for a support group."

If you could change anything about the support group, you would? Randomly chosen open-ended responses:

"have more support as your child ages."

"No (sic) the informal group that myself and a few other mothers started worked for me. When we tried to branch out and meet in a church later, it lost some of the things that had worked best for me, just sitting in each others home talking and sharing. Calling each other when we had been to the doctor, when we felt like they would never hold the bottle by their selves, (sic) or take that first step, just being a friend."

"I would have someone from the Guild initiate the conversation instead of waiting for me to call."

Stage Two Data

Stage Two of grieving theory is characterized by feelings of sadness, anxiety, guilt, and aggression. Brill (1993) concluded that as the shock lessens, an unbelievable sadness develops. Feelings of anger may also predominate.
Table 6

Descriptive Statistics of Respondents - Stage Two Data

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>After the reality of the Down syndrome diagnosis had &quot;sunk in&quot;, describe your feelings: (check all that apply); 69 responses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sadness</td>
<td>Yes</td>
<td>64</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>5</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Yes</td>
<td>51</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>18</td>
</tr>
<tr>
<td>Guilt</td>
<td>Yes</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>36</td>
</tr>
<tr>
<td>Aggression</td>
<td>Yes</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>56</td>
</tr>
<tr>
<td>Other:</td>
<td>Anger</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Self-Pity</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Loss</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Cry</td>
<td>1</td>
</tr>
</tbody>
</table>

The majority of this data suggested that the respondents in this study did grieve in the same way as stated in Stage Two of grieving theory. Of respondents, 92.8% experienced sadness, 73.9% of respondents experienced anxiety, and 47.8% experienced guilt; however, the majority of respondents did not experience aggression, only 18.8% said yes to this question.

Please explain in your own words: Randomly chosen open-ended responses:

"Sadness was: the loss of a dream. Guilt was: was it my fault."

"After reading literature given us by both the Guild and other professionals, I felt like everything had to be a lesson or she would get behind. I also was afraid she might sleep too long & become lazy. We did developmental activities of some sort 8 - 12 hrs. per day."
"As the mother I believe you always wonder if you did something to cause this. You are sad for the child you lost so you then go through the process to love and accept this child."

"I never felt guilty. My husband and I never blamed each other. But I felt overwhelming sadness when I took her to a store and someone stopped me and asked if she was Down syndrome. I did not think you could tell by looking. My husband was very anxious he kept trying to look deep into the future to see what would become of her. Would she get a job, live with us forever? Things like that. I was anxious that I could not have other children."

"I felt we had prepared the perfect room but were filling it with an imperfect baby. I wondered if my college marijuana use had contributed."

"I was really sad thinking about what could have been & very guilty as if I caused it or waited too long in having a baby."

"Felt sorry for my older son having to grow up with a Down brother."

"Mostly feeling the death of my dream of a daughter & all the expectations that went with that - sadness and wondering if her heart condition would be fatal & how we'd handle all the decisions & things needing to be done."

"I was very very depressed. Felt God was punishing me for something. Could not sleep. Had dreams about her dying. Didn't want grandparents to be burdened with this."

Table 7

Descriptive Statistics of Respondents - Stages One and Two Data

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you feel as though the feelings described in Stage One (Denial, Shock, Disbelief) ended when you began to feel sadness, anxiety, guilt, or aggression?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Variables</td>
<td>Frequency</td>
<td>Percentage</td>
</tr>
<tr>
<td>-----------</td>
<td>-----------</td>
<td>------------</td>
</tr>
<tr>
<td>Yes</td>
<td>45</td>
<td>65.2</td>
</tr>
<tr>
<td>No</td>
<td>19</td>
<td>27.5</td>
</tr>
<tr>
<td>N/A</td>
<td>5</td>
<td>7.2</td>
</tr>
</tbody>
</table>

N/A represents non/interpretable data.

If yes, explain: Randomly chosen open-ended responses:

"I think there was an overlap of feelings. Some of them still show up once in a while."

"It was the second stage of feelings, but never dwelled on any of these feelings for long. My ex-husband still suffers from them all."

"I wasn't only sad, I was angry, for we had done everything right during our pregnancy and there were crazy irresponsible people having babies who were just fine."

"I wasn't shocked anymore by what people said. I had proof positive in the chromosome studies. There was no doubt that she had Down syndrome, I just had to prove that this would not keep her from being a normal happy child. (Was that some denial left over. Yes of course)."

"I know there was no exchange process & was just so very sad."

"I felt from the beginning there was nothing to deny, it was just a fact that couldn't be changed. And after you realize this the shock is gone."

"I pretty much felt like it was reality, this was it & it was time to get on with life."

"When we received the test results at 2 months, Stage 2 began. We still had hope that it wasn't true before this...then reality set in."

If no, explain: Randomly chosen open-ended responses:
"They all continued for about 3 mo's after birth. Then we began to appreciate and enjoy the child so much that we rarely even think about any of the negative aspects (if any) about him."

"I think you go through these stages at certain times of your child's life. At times I am still shocked by some things, you are angry over things that happen."

Stage Three Data

Stage Three is characterized by feelings of loss, sadness and responsibility. However, this phase is said to "end", as feelings of loss and sadness lessen, and feelings of pleasure and enjoyment in life increase.

Table 8

Descriptive Statistics of Respondents - Stage Three Data

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel as though the sadness regarding the birth and rearing of your child with Down syndrome has ended?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>67 responses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sadness ended:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>38</td>
<td>56.7</td>
</tr>
<tr>
<td>No</td>
<td>26</td>
<td>38.8</td>
</tr>
<tr>
<td>N/A</td>
<td>3</td>
<td>4.5</td>
</tr>
<tr>
<td>Responsibility ended:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
<td>14.9</td>
</tr>
<tr>
<td>No</td>
<td>54</td>
<td>80.6</td>
</tr>
<tr>
<td>N/A</td>
<td>3</td>
<td>4.5</td>
</tr>
</tbody>
</table>

The data clearly showed that although a majority of respondents indicated that the sadness lessens, 56.7%, the responsibility for the child does not end, 80.6%. This is in direct conflict with studies that have shown that parents of handicapped children do pass through the stages consistently, and eventually, this stage ends.
Following are randomly chosen open-ended responses:

"The challenges facing us as a family and our son as an individual is a constant reminder of sadness of what will never be. The responsibility is strong to ensure his (sic) has a high quality of life."

"The responsibility of raising a child with or without Down's never ends. Responsible for her condition, never did."

"She is an extreme pleasure. She has progressed much further than ever imagined. She brings a new awareness into our lives. I believe she makes our whole family more aware and compassionate of other people."

"Do I feel as though the sadness regarding the birth and rearing of my child with Down syndrome has ended? No. Do I feel the responsibility has ended? No. If no, do I feel it will ever end? No."

"I've accepted what I have & just deal with it as best I can. I know I'm not responsible for her extra chromosome."

"I don't feel that responsibility ever ends until your child can take care of themselves."

"Sadness has ended - he is "the most wonderful baby in the history of the universe" (that's what we all say & think of him now). responsibility never ends - with any child."

"Not really, sometimes everything is fine & it's no big deal but sometimes (like right now) things are hard and my heart breaks all over again."

"The sadness has ended. But I feel I will always be responsible for her. She will not be able to live totally alone ... perhaps a group home."
Table 9

Descriptive Statistics of Respondents - Rearing Issues

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is raising your child with Down syndrome different from what you initially thought it would be?</td>
<td>65 responses</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>55</td>
<td>84.6</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>15.4</td>
</tr>
</tbody>
</table>

A majority of respondents did feel that the reality of raising their child was not what they initially thought it would be, 84.6%.

Of those who said "yes", following are randomly chosen open-ended responses:

"I thought we would never be happy - that people wouldn't accept her. But they have - most of them - and if they don't it's their loss because she is a delight. I have enjoyed her so much and my life has been better for having her."

"It is very rewarding."

"It is more like raising my other children & I thought it would be harder. She is still very young though."

"She is so much fun! She is very active & personable & very much closer to a normal child than I thought."

"Well, I was 'Super MOM' I took her to speech, occupational therapy, did everything the doctors said to, even made my own baby food. I was so careful about what she ate. I was so careful to make her independent. I really thought that if I treated her normally she would fit in the normal mold. You have to remember that this was my first child. You always have lofty goals for that first one! I remember when she was in the Kindergarten, she had started the year in the regular kindergarten around mid-year the school called a meeting and said she would be better served if she was with children like herself. This was back in the dark ages of self-contained classes. When my husband and I
toured the class, we both came out and said my child is not like that! But of course, she was in ways, and in ways she is just like any stubborn normal child."

"She was treated no different than our other child. Her behavior, manners, and attitude is wonderful. It has been easier to raise her till this age than I ever thought it would be."

"Everyone involves her, talks to her, and loves on her. People don't stare or feel sorry for her or us. She's treated like a cute little child."

"The doctors & therapists give you all options & can be overly done, since in the beginning you are not sure exactly what extent the retardation will be."

"Many medical problems. Challenges with education and future independent living."

If "no", why not? Randomly chosen open-ended responses: (Only one open-ended response from the 10 random questionnaires regarding "no"):

"I thought it would be challenging, difficult & richly blessed."

Table 10

Descriptive Statistics of Respondents - Rearing Issues, Other Children

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>For parents with other children: Is parenting different for your child with Down syndrome from your other children?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>69 responses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>36</td>
<td>52.2</td>
</tr>
<tr>
<td>No</td>
<td>17</td>
<td>24.6</td>
</tr>
<tr>
<td>N/A</td>
<td>16</td>
<td>23.2</td>
</tr>
</tbody>
</table>

Note: N/A data is non-interpretable data. Some respondents checked both "yes" and "no".

If yes, how: Randomly chosen open-ended responses:

"More patience, more attention."
"You gear your expectations to your child's abilities. Both children are treated equal."

"Yes, but all children are (sic) different. I have yet to hear a parent say my children were just alike. They always say they were as different as daylight and dark. My Down syndrome child is very strong willed. She will be in control of the situation. She is often in trouble at school. She knows the rules and she understands the rules she just waits until you turn your back to see if she can get away with something. She does not like crowds, therefore, any trip to the mall is torture for her. She prefers to stay home and watch TV. She is very comfortable in the "Adult" world and most of her friends are adults. She is very seldom invited over to friends from school. (She is the only girl in the class) I have to continually check on her to make sure her homework is done, that she is ready to go to school, to make sure that what is in her bag is what should be in her bag and not my bra or something as outlandish. That her underwear is on right, that her shoes are tied, to take a bath. Does this sound familiar? On the other hand my 11 year old dresses herself and has for years. I never have to ask her about her homework, or special assignments. If I ask her to be home by 4:00 you can set the clock by her. She is always ready to help out with her sister even though her sister does not want her to even be in the same room at times. They are at totally different ends of the spectrum. How can I judge?"

"It's been so hard to discipline her. She is more strong-willed than any of her brothers & it's hard to reason with her or find a method that seems to work well."

"It is different. You must repeat things more often. You must have more patience. You have to accept other people's reactions. But mostly, your expectations are different. You raise one to go a certain way and one to go another way."

If no, why not? Randomly chosen open-ended responses:

"Other than we are even more responsive to his needs."

"As a baby, she just acts like my other children did."
Table 11

Descriptive Statistics of Respondents - Health Concerns

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does your child currently experience health problems?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>67 responses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>32</td>
<td>47.8</td>
</tr>
<tr>
<td>No</td>
<td>35</td>
<td>52.2</td>
</tr>
<tr>
<td>If yes, check all that apply:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart Defects</td>
<td>Yes 8</td>
<td>25.0</td>
</tr>
<tr>
<td>Thyroid Problems</td>
<td>Yes 3</td>
<td>9.4</td>
</tr>
<tr>
<td>Intestinal Problems</td>
<td>Yes 6</td>
<td>18.8</td>
</tr>
<tr>
<td>Respiratory Problems</td>
<td>Yes 9</td>
<td>28.1</td>
</tr>
<tr>
<td>Leukemia</td>
<td>Yes 1</td>
<td>3.1</td>
</tr>
<tr>
<td>Vision Problems</td>
<td>Yes 18</td>
<td>56.3</td>
</tr>
<tr>
<td>Hearing Problems</td>
<td>Yes 12</td>
<td>37.5</td>
</tr>
<tr>
<td>Vertebra Instability</td>
<td>Yes 3</td>
<td>9.4</td>
</tr>
<tr>
<td>Weight Problems</td>
<td>Yes 8</td>
<td>25.0</td>
</tr>
<tr>
<td>Other: Hernia</td>
<td>Yes 1</td>
<td>3.1</td>
</tr>
<tr>
<td>Pacemaker</td>
<td>Yes 1</td>
<td>3.1</td>
</tr>
</tbody>
</table>

As stated earlier, there is a 40% prevalence rate of congenital heart disease among Down syndrome infants (Rubin & Crocker, 1989). The above question, however, asked respondents about current health problems; indicating that some heart defects had either been repaired by surgery or another explanation. This study's question regarding heart defects at birth rendered a 41.7% prevalence rate compared to the current state of health regarding heart defects at 25.0%.

The literature review also showed a 50 to 70% prevalence rate of hearing problems (Rubin & Crocker, 1989); this study measured 37.5%. Ocular problems according to Rubin & Crocker (1989) are as follows: refractive errors, 50% prevalence, Strabismus, 35% prevalence, and cataracts, 15% prevalence. This study's question regarding vision problems rendered a 56.3% rate. According to Rubin & Crocker (1989),
other health concerns are: hypotonia, 100% prevalence, delayed growth, 100% prevalence, developmental delays, 100% prevalence, thyroid disease (generally hypothyroidism, rarely hyperthyroidism), >15% prevalence rate, obesity, common prevalence rate, seizure disorder, 5-10% prevalence, emotional problems, common prevalence rate, premature senescence, increase with age. Also included are variable occurrences of: congenital gastrointestinal anomalies, Hirschsprung's disease, leukemia, hepatitis B carrier state, keratoconus, dry skin, hip dysplasia, diabetes, and mitral valve prolapse.

Table 12

Descriptive Statistics of Respondents - Future Concerns

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Childhood Programs</td>
<td>19</td>
<td>27.5</td>
</tr>
<tr>
<td>Education</td>
<td>46</td>
<td>66.7</td>
</tr>
<tr>
<td>Inclusion</td>
<td>40</td>
<td>58.0</td>
</tr>
<tr>
<td>Marriage</td>
<td>32</td>
<td>46.4</td>
</tr>
<tr>
<td>Employment</td>
<td>47</td>
<td>68.1</td>
</tr>
<tr>
<td>Community Integration</td>
<td>42</td>
<td>60.9</td>
</tr>
<tr>
<td>Neighborhood</td>
<td>26</td>
<td>37.7</td>
</tr>
<tr>
<td>Other: Friends</td>
<td>3</td>
<td>4.3</td>
</tr>
<tr>
<td>After Parent Death</td>
<td>2</td>
<td>2.9</td>
</tr>
<tr>
<td>Driving</td>
<td>1</td>
<td>1.4</td>
</tr>
</tbody>
</table>

Please describe your concerns in your own words: Randomly chosen open-ended responses:

"Be accepted in society. She could be an easy victim in today's society."

"My husband and I are both basically concerned about everything. We keep her very active. She's involved in an Early Child program through the school district plus OT"
and she goes to Gymboree. I worry about government changes hurting Inclusion and Education. As I stated previously, if I sit like this and think about (sic) too long, I worry about everything." (Note: OT probably stands for "Occupational Therapy")

"She is a wild child that will do whatever she puts her mind to, she is 13 and has a drivers education booklet because she is sure that she will be able to pass the test and drive the day she turns 16. She tells me that she is ready to move into her own apartment with a swimming pool and get a job at McDonald's, or maybe at the doctor's office, she is not sure. She is sure that she will be going to college to study to become a teacher and that it may take years for her to finish."

"I feel very positive about her future. Because she's so cute & personable I worry about future male relationships. I'm fortunate to be able to provide her with anything she may need that money can provide."

"What he will learn, where he will live"

"Of course, just like my other children, I want her to be except, (sic) treated fairly & have the best opportunities & to be able to function independently."

"In today's world, any parent is concerned over all the aspects listed above. You have to try & get yourself & child as prepared as possible."

"I want her to be happy, productive, safe. I want her to be loved. I just don't know how all these things will happen over the years."

"She is in a 1/2 day work program at school currently working at Mervyn's."
Table 13

Descriptive Statistics of Respondents - Currently Used Support Services

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please describe support services you currently use: (check all that apply): 69 responses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Association for Retarded Citizens programs</td>
<td>19</td>
<td>27.5</td>
</tr>
<tr>
<td>Down syndrome support group</td>
<td>39</td>
<td>56.5</td>
</tr>
<tr>
<td>Community programs</td>
<td>15</td>
<td>21.7</td>
</tr>
<tr>
<td>Private programs</td>
<td>5</td>
<td>7.2</td>
</tr>
<tr>
<td>Programs provided by school district</td>
<td>26</td>
<td>37.7</td>
</tr>
<tr>
<td>Other: Special Olympics</td>
<td>7</td>
<td>10.1</td>
</tr>
<tr>
<td>MHMR</td>
<td>3</td>
<td>4.3</td>
</tr>
<tr>
<td>Boy Scouts</td>
<td>2</td>
<td>2.9</td>
</tr>
<tr>
<td>Church</td>
<td>2</td>
<td>2.9</td>
</tr>
<tr>
<td>Psychologist</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Speech Therapy</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>Bowling</td>
<td>1</td>
<td>1.4</td>
</tr>
</tbody>
</table>

Please discuss the strengths and weaknesses of each of the programs you use:

Randomly chosen open-ended responses:

"Both great! Good parent support." (This respondent checked community programs and wrote in special olympics.)

"All these programs are good. The needs of the individual depends on the severity or deprivity (sic) of the family. We have been very lucky that even though I belong to all the special associations we haven't had to use any services they provide."

"Not enough hands on help from speech therapists & occupational therapists"

"School district programs are marginal to average"

"The DSG has been very exclusive. I offered my services as a parent & MD & did training, etc. & have not once been called by them to provide support. I find them snobbish & condescending."
"To tell you the truth I am not actively involved in any groups, when she was young I needed the support, but now we are busy living our lives. She is in Special Olympics and takes piano lessons. Sings in the church choir, and loves basketball. I can not tell you the weakness of either of these programs except maybe they don't grow with us. It seems to me that these teenage years we are out here on our own. They have Adult activies and activies (sic) for the little ones but nothing in between." (Note: the programs this respondent checked were Association for Retarded Citizens and Down syndrome support group).

"The support group is nice & it is there. I would probably be more active but I haven't as yet. The program through the school district (Project Kids) has been working out well; She's now also getting OT bimontly (sic)."

"All the programs we have been involved in are very helpful. She enjoys all the activities. I would like to see them more centrally located." (Note: the programs this respondent checked were Association for Retarded Citizens, Down syndrome support group, Programs provided by school district, and Special Olympics).

Table 14

Descriptive Statistics of Respondents - Desired Support Services

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respite care</td>
<td>15</td>
<td>21.7</td>
</tr>
<tr>
<td>Week-end day care</td>
<td>12</td>
<td>17.4</td>
</tr>
<tr>
<td>Babysitting cooperative</td>
<td>15</td>
<td>21.7</td>
</tr>
<tr>
<td>Child recreational programs</td>
<td>26</td>
<td>37.7</td>
</tr>
<tr>
<td>Adult recreational programs</td>
<td>13</td>
<td>18.8</td>
</tr>
<tr>
<td>Summer vacation programs</td>
<td>20</td>
<td>29.0</td>
</tr>
</tbody>
</table>

(Table continues)
<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inclusion support</td>
<td>23</td>
<td>33.3</td>
</tr>
<tr>
<td>School to employment transition</td>
<td>22</td>
<td>31.9</td>
</tr>
<tr>
<td>assistance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supported employment</td>
<td>21</td>
<td>30.4</td>
</tr>
<tr>
<td>Leisure time activities</td>
<td>23</td>
<td>33.3</td>
</tr>
<tr>
<td>Other: Clinics</td>
<td>1</td>
<td>1.4</td>
</tr>
</tbody>
</table>

Child Recreation Programs were the support services wanted by the majority of respondents, 37.7%, followed by Inclusion Support and Leisure Time Activities at 33.3%. School to Employment Transition Assistance and Supported Employment were also needed programs at 31.9% and 30.4% respectively.

Is there anything you would like to add? Randomly chosen open-ended responses:

"The birth of an (sic) handicapped child is traumatic. Over time you learn you can not solve all their life problems in one day. You take each day as it comes and make the best of it."

"Grief is a strange emotion. Some people grieve for years and some only grieve for a short while. I will always grieve for my child with Down syndrome. I grieve when the phone rings for my other child and she is invited to the movies. When she brings home a special project that she did all the work herself. When she brings home her schedule for next year's classes that she picked out. I will grieve when she gets asked out on a date. When she drives, when she goes away to college, and of course when she marries and has children. (that is whatever she chooses to do.) My Down syndrome child may have some of the same experiences but she will have to work 5 times as hard for them, and as any mother who has a child that things are difficult for, We grieve. Grief is not such a bad thing. Along with grief you become more compassionate, you become sensitive to other people's feelings, I know that I am more aware of people (sic) emotions now. When someone is suffering from grief in a multitude of different ways, be it a mother who is
struggling with a child that is terminally ill, on drugs, born with some kind of birth defect or whatever, I may not know exactly what they are feeling, but I have grieved just like they are now, and I can be a friend for them. I have learned never to say I understand what you are feeling, because I don't. I'm sorry isn't the thing to say when someone has just had a baby. But someone who has grieved who has truly grieved can always be a comfort to someone just beginning the process."

"She's a great kid & we truly love her. She has taught us much & we are grateful to have her."

Gallagher & Gallagher (1978) stated, "Still, in one sense, there is a modicum of truth in the phrase from the popular song, 'Without a Hurt, the Heart Is Hollow.' We can never meet another family with a handicapped child and not feel a surge of empathy and understanding that would never have been present without our own experiences" (p. 210).

**Summary of Data Analysis**

In summary, 250 questionnaires were randomly sent to parent members of the Down Syndrome Guild; and 70 questionnaires were completed and returned, representing a 28% rate of return. There were 6 male respondents and 64 female respondents, 8.57% male, 91.4% female. The mean age of respondents was 41.25, with the range being age 20 to age 93. The mean age of parents at the time of birth of the child with Down syndrome were 31.48 Mother and 33.18 Father. The majority of respondents had received some college, 37.7%, or a college degree, 37.7%. Dallas county was the residence for the majority of respondents, 67.6%, followed by 17.6% from Denton county and 14.7% from Collin county.

**Stage One Data:** The data showed that regarding initial responses to the Down syndrome diagnosis, a majority of respondents do grieve in the same way as stated in Stage One of grieving theory. Over 50% experienced denial, over 80% experienced shock, and nearly 65% experienced disbelief.
**Stage Two Data:** The majority of this data suggested that the respondents did grieve in the same way as stated in Stage Two of grieving theory. A total of 92.8% experienced sadness, 73.9% experienced anxiety, and 47.8% experienced guilt. Aggression was the only emotion characterized in grieving theory that was not widely reported among respondents; only 18.8% experienced aggression.

**Stage Three Data:** The data suggested that a majority of respondents expressed an end to the sadness regarding the birth and rearing of their child with Down syndrome, 56.7%; however, there was no widespread indication that there was an end to the responsibility regarding the birth and rearing of their child with Down syndrome. Only 14.9% of respondents felt that the responsibility had ended.
CHAPTER V

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Summary

The purpose of this study was two-fold: 1) To analyze the similarities and differences between parent responses to the birth and rearing of a child with Down syndrome and; 2) To document the characteristics of grieving described in Engel's 3-stage model of grieving.

The following research questions guided this study:

1. What are the parent reactions and responses upon the birth of a child with Down syndrome?

2. What are the parent reactions and responses regarding the rearing of a child with Down syndrome?

3. How similar/different are parent reactions and responses to the birth and rearing of a child with Down syndrome to the characteristics of grieving reactions stated in the three stages of Engel's model?

4. Is the linear movement suggested in the Engel 3-stage model applicable to parents of Down syndrome children?

5. What are the differences/similarities in parent responses regarding rearing issues in a child with Down syndrome vs. an adult with Down syndrome?

6. What are the concerns of parents, and what are their desires regarding interventions?

Data was obtained from 70 parents of children with Down syndrome having membership to the Dallas Down Syndrome Guild. A total of 250 questionnaires were sent
randomly from a parent mailing list of 466. Respondents were given a two-week period in which to complete the questionnaire and return to the researcher in the self-addressed, stamped envelope. There were 6 male respondents, 8.57%, and 64 female respondents, 91.4%. The mean age of respondents was 41.25, with the range being age 20 to age 93. The mean age of parents at the time of birth of the child with Down syndrome was 31.48 for the mother, and 33.18 for the father. The majority of respondents had received some college or a college degree, 37.7% and 37.7% respectively. Dallas county was the residence for the majority of respondents, 67.6%, followed by 17.6% from Denton county and 14.7% from Collin county.

In interpreting the findings of the data, it is important to point out the possible sources of bias and limitations of the data. These are as follows:

1) Out of 70 questionnaires, only 6 were completed by males, representing only 8.57% of the total study population.

2) Only parent members of the Dallas Down Syndrome Guild were included in this study. Parents of Down syndrome persons who do not belong to the Guild were not included. Parents belonging to a support group such as the Guild may respond to questions differently than those who do not belong to such a group.

3) The data used in analysis for this study was entirely self-reported data. This may limit the validity of the data.

Regarding Stage One of Engel's grieving theory, the data showed that regarding initial responses to the Down syndrome diagnosis, a majority of respondents do, indeed, grieve in the same way as stated in the theory. Over 50% experienced denial, over 80% experienced shock, and nearly 65% experienced disbelief.

Stage Two Data also suggested that the respondents experienced grief in the same way as stated in Engel's grieving theory. A total of 92.8% experienced sadness, 73.9% experienced anxiety, and 47.8 experienced guilt. Aggression was the only emotion
characterized in grieving theory that did not represent a majority of responses in this study, only 18.8% experienced aggression.

Stage Three Data suggested that although a majority of respondents expressed an end to the sadness regarding the birth of their child with Down syndrome, the responsibility did not end. A total of 56.7% of respondents stated that the sadness ended; however, only 14.9% of respondents stated that the responsibility had ended.

Conclusions

1. The parent reactions and responses of this study population regarding the birth of a child with Down syndrome were similar to the reactions characterized in Stage One of Engel's grieving theory. Over 50% experienced denial, over 80% experienced shock, and nearly 65% experienced disbelief. Open ended responses were extremely enlightening, and can be found in Chapter IV, Findings of Data Analysis.

2. The parent reactions and responses of this study population regarding the rearing of a child with Down syndrome were also similar to the reactions characterized in Stage Two of Engel's grieving theory. A total of 92.8% experienced sadness, 73.9% experienced anxiety, and 47.8% experienced guilt. Aggression was the only emotional characteristic of grieving theory that was not represented by a majority of respondents in this study. Only 18.8% experienced aggression.

3. The parent reactions and responses of this study population regarding Stage Three of Engel's grieving theory produced both similarities and differences. The data suggested that although a majority (56.7%) of respondents expressed an end to the sadness regarding the birth and rearing of their child with Down syndrome, only 14.9% of respondents felt that the responsibility had ended. Some respondents suggested that the responsibility of raising any child never ends; however, the majority of respondents suggested that raising a child with Down syndrome has very different implications and that
there would always be a certain degree of responsibility for their child or adult with Down syndrome.

4. Regarding the linear movement suggested in the Engel 3-stage model, when respondents were asked if the feelings described in Stage One ended as they began to feel the feelings described in Stage Two, 65.2% responded "yes" and 27.5% responded "no". Of those respondents answering "no", many said that the emotions in all three stages ebb and flow throughout the various stages of development of their child with Down syndrome.

5. Regarding the differences/similarities in parent responses of rearing issues in a child with Down syndrome and an adult with Down syndrome, the age range of Down syndrome persons in this study was 0 to 50, Mean = 9.21, Median = 7, Mode = 1. A total of 57 of those persons out of 70 were under age 18, and only 13 were age 18 or older, making conclusions based on child versus adult rearing issues difficult. However, of those respondents having adults with Down syndrome age 18 and older, following are some of their concerns:

"Programs are OK for children. For adults w/D.S., the prospects are not rosy." (Age of this respondent's child was 18)

"We were blessed with twins - 1 Down 1 "normal" so there was both shock, disbelief & also much joy." "The responsibility will always be there. Rearing a child w/DS is an ongoing journey but now with so many positive outcomes but will never be one of complete independence." (Age of this respondent's child was 18)

"Need more community support after completion of ISD. Transportation or lack of limits many possibilities. Need more supported employment & supported living." (Age of this respondent's child was 18)
"There seems to be less employment (sic) opportunities for people with Down Syndrome because of characteristics. Employers seem to feel they are also limited to what they can do." (Age of this respondent's adult was 22)

"I was told that I could put my daughter in an institution and go home from hospital and tell everyone she died. So I was not given any hope." (Age of this respondent's adult was 23)

"My Pediatrician told me. He acted as though I had committed a sin. He never came into my room at the hospital again." "Downs Syndrome group believes in mainstreaming & doesn't consider alternative choices. Mainstreaming is OK when child is young but at Junior High level it gets rough. Is mainstreaming worth it then?" (Age of this respondent's adult was 24)

"I don't see the type of residential opportunities in our area (Metroplex) that I would be happy with if my husband and I were no longer living. Private (non-medicaid supported) residential care is very expensive. There are no inclusion formal supports for adults." (Age of this respondent's adult was 26)

"I feel I will always be needed by him." "I kept him with me and his father till he was almost 50 yrs. old. He went to a home for Mentally Retarded adults. They have a work shop and he works during the day. The staff seems very good to him. He seems happy. He comes home often." (Age of this respondent's adult was 50)

6. Concerns of parents and their desires regarding interventions can be found in Tables 13 and 14.

Regarding concerns of parents, employment was the concern most often reported by parents, 68.1%, followed by education, community integration and inclusion. Regarding interventions and support services, child recreation programs were the support services wanted by the majority of respondents, 37.7%, followed by Inclusion Support and
Leisure Time Activities at 33.3% each. School to Employment Transition Assistance and Supported Employment were also needed programs at 31.9% and 30.4% respectively.

Recommendations

1. Stage One recommendations: When informing parents of the initial diagnosis of Down syndrome, professionals need to provide answers to questions in a knowledgeable, yet compassionate manner. This study found that while most respondents believed their source to be knowledgeable about Down syndrome, 58.5%, less than half of respondents strongly agreed or agreed that the person was empathetic. The majority of respondents were either uncertain, or felt that this person was not empathetic, 51.6%. With over half of respondents indicating that they were not satisfied with the manner in which their child's diagnosis was conveyed, more education and training regarding the grief process would be beneficial. How the news is conveyed by the physician can be crucial. The physician who is supportive and empathetic, while carefully addressing fears and questions, can help the family's adjustment immensely.

2. Stage Two Recommendations: Once again, health care professionals must be empathetic regarding the Down syndrome diagnosis, and must also remember that people do not necessarily grieve in a linear, pattern-like way. Adjustments for individual variances must be made.

3. Stage Three Recommendations: This study found that although the sadness of having a Down syndrome child lessens for the majority of respondents, the responsibility does not. Professionals must keep in mind that even the most accepting, best adjusted, positive parents do not necessarily "get over" these feelings (Simons, 1985). For some parents, there is no such thing as an "emotional promised land". The process of acceptance, understanding and adjustment for many parents is on-going. Parents must feel free to express their emotions over a period of time without fear of repercussions from health care professionals.
4. Health care professionals should proceed with caution when providing grief interventions based solely on stage model theory. This study has found that there are, indeed, differences in parent responses and stage model theory. Professionals must allow room for individual variation.

5. Counseling services should be made available to parents following the birth of a Down syndrome infant. This study found that of the 44.3% of respondents who received counseling after birth, 81% found it helpful. Support group involvement is also beneficial. Of 67% or parents belonging to a support group, 79% found the group helpful. Information regarding both counseling and support group services should be kept at the nurse's station in obstetrics/pediatrics in every hospital. At the very minimum, the telephone number of the Dallas Down Syndrome Guild (214-239-8771) and the telephone number of the National Down Syndrome Congress (800-232-NDSC) should be readily available. The researcher would also recommend keeping a telephone list of parents who would be willing to counsel new Down syndrome parents. This can be broken down by county or area, and the list can rotate so that each volunteer has an opportunity to provide counseling and information to new parents. (Appendix 7 contains a complete resource guide).

6. Parents must be informed about the importance of proper health care for their Down syndrome child. As discussed earlier, there is a prevalence in the Down syndrome population of heart defects, hearing problems, ocular problems, hypotonia, delayed growth, developmental delays, thyroid disease, obesity, seizure disorder, and premature senescence. In 1965, 50% of Down syndrome children were dead by the age of 5 due mostly to heart disease. Today, over 80% survive to age 30 or beyond (Cooley & Graham, 1991).

7. Community programs need to be implemented addressing the concerns of parents of Down syndrome persons. Among the greatest concerns of parents are
employment opportunities, education, community integration, and inclusion. Some communities have specifically addressed these issues with supported employment programs and broad-based community programs, but there is certainly room for improvement of existing programs, as well as the addition of programs. This study provided data on three different counties in the Dallas area, allowing for specific county-by-county implementation of intervention strategies.

8. Health care providers must proceed with caution when providing information to expectant parents regarding age and relative risk of a Down syndrome infant. As stated earlier, this study found the mean age of mothers and fathers in this population to be 31.48 and 33.18, respectively. Informing expectant parents that they are only at risk if they are over 35 is simply not accurate information. While the risk increases with advanced maternal and paternal age, studies have shown that a large majority of Down syndrome parents are under age 35. The researcher would recommend changing the age of possible chromosome analysis for mothers and fathers to age 30 and older, not age 35 and older. Only 23% of mothers and 36% of fathers in this study were age 35 and older; however, 70% of mothers and 79% of fathers were age 30 and older.

9. When asked the question regarding termination of the pregnancy of the Down syndrome baby, only 10% of this population indicated that they would have chosen termination. A total of 64.3% responded "no", and 25.7% responded uncertain. Cooley & Graham (1991) reported that for families unable or unready to incorporate a child with Down syndrome into their families, other alternatives have emerged. There is currently a waiting list of families who specifically wish to adopt a Down syndrome child.

10. More services, including support services should be made available to parents of older persons with Down syndrome. Many parents in this study with adults with Down syndrome expressed that there were a multitude of services for younger children, yet these
services decrease as the child ages. Transportation services need to be increased and improved, as well as transition, job training and supported employment opportunities.

11. Parents must be reminded that the prospects for their Down syndrome child's future are much brighter than they were even 10 years ago. Information that is obsolete must be replaced with more accurate findings.
APPENDIX 1

Karyotype of Chromosomes (Stray-Gundersen, Ed., 1986, p. 8)
APPENDIX 2

Range of Human Intelligence (Stray-Gundersen, Ed., p. 15)
Distribution of IQ in Population

Legend

- Severe
- Moderate
- Mild
APPENDIX 3

Likelihood of Having a Baby with Down Syndrome Based on Maternal Age

(Stray-Gundersen, Ed., 1986, p. 11).
### Likelihood of Having a Baby with Down Syndrome Based on Maternal Age

<table>
<thead>
<tr>
<th>Maternal Age</th>
<th>Frequency of Down Syndrome Among Births*</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 - 24</td>
<td>1/1450 (Average)</td>
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<tr>
<td>25 - 29</td>
<td>1/1347 (Average)</td>
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<tr>
<td>30</td>
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<td>1/826</td>
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<td>1/16</td>
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<tr>
<td>49</td>
<td>1/12</td>
</tr>
</tbody>
</table>

*This chart lists only the approximate frequency of babies with Down syndrome based on the mother's age. The figures are based on the average of the findings of four separate population surveys. (Hook & Lindsjo, 1978; Trimble & Baird, 1978)
APPENDIX 4

Cover Letter/Questionnaire
Dear Parents:

I am a graduate student at the University of North Texas conducting research for my Thesis entitled: PARENT RESPONSES TO THE BIRTH AND REARING OF A CHILD WITH DOWN SYNDROME: THE APPLICATION OF ENGEL'S 3-STAGE THEORETICAL MODEL OF GRIEVING. I am also the parent of a child with Down syndrome.

Studies in the past have stated that the grief and mourning process following the birth of a handicapped child is similar to the grief process involved in death and dying. Many studies have found that parents having a handicapped child actually pass through a series of "stages" of grief. These stages, stated briefly, are 1) shock and disbelief, 2) awareness of the loss and sadness, and 3) Reunion. I want to conduct thesis research to determine whether or not this is accurate for parents of persons with Down syndrome. Therefore, the purpose of this study is two-fold: 1) To identify parent responses to the birth and rearing of a child with Down syndrome through the use of the enclosed questionnaire, and 2) To analyze the differences and similarities of your responses in that of the 3 stages identified in grieving.

The enclosed questionnaire asks a variety of questions regarding your responses to the birth and rearing of your child with Down syndrome. I will be sending approximately 250 questionnaires in the Dallas area. I am asking you to look over the questionnaire and, if you choose to do so, to complete the questionnaire and send it back to me in the self-addressed, stamped envelope by April 21, 1995. Participation in this study is strictly VOLUNTARY and ANONYMOUS. If you choose to participate, PLEASE DO NOT WRITE YOUR NAME ON THE QUESTIONNAIRE. COMPLETION OF THE QUESTIONNAIRE IMPLIES CONSENT TO USE THE RESPONSES IN THIS THESIS PROJECT; HOWEVER, NO ONE WILL KNOW WHO YOU ARE OR WHO YOUR CHILD IS.

Without the help of people like yourself, qualitative research of this type could not be conducted. Understanding the parent responses to the birth and rearing of a child with Down syndrome is significant and important in the overall study of Down syndrome. I ask for your participation, and thank you sincerely for reading this correspondence.

THIS PROJECT HAS BEEN APPROVED BY THE UNIVERSITY OF NORTH TEXAS COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS (317-363-5949)

THE DOWN SYNDROME GUILD HAS APPROVED THIS PROJECT

Cordially,

[Signature]

Jeanette Smith

enclosure (questionnaire)
University of North Texas

Department of Kinesiology, Health Promotion, and Recreation

QUESTIONNAIRE

This questionnaire will be used for the purpose of Thesis research on Down syndrome by Janette Smith, University of North Texas. Thesis Title: PARENT RESPONSES TO THE BIRTH AND REARING OF A CHILD WITH DOWN SYNDROME: THE APPLICATION OF ENGEL'S 3-STAGE MODEL OF GRIEVING.

Please complete the following questionnaire anonymously and return to me by April 21, 1995 in the self-addressed, stamped envelope. Please feel free to attach additional pages for your responses. THANK YOU!!

You are: Male________ Female________
Your current age________
Age at the time of birth of child with Down syndrome: Mother________ Father________
Education Level: Grammar School________, High School________, Some College________, College Degree________, Graduate Education________
County you reside in________________________
Current age of child (or adult) with Down syndrome________ Sex________
Current age (s) of other children________________________ Sex________________________

Section One:

1. Stage One of the current grieving theory is characterized by feelings of denial, shock and disbelief.
Describe your INITIAL REACTION to the news of your child's Down syndrome diagnosis: (check all that apply)
Denial________ Yes________ No________
Shock________ Yes________ No________
Disbelief________ Yes________ No________
Other________________________

Please describe your INITIAL REACTION in your own words:

The person who gave you the news was:
Physician________ Nurse________ Spouse________ Other Relative________ Clergy Person________
Other________________________

The person who informed you that your child was born with Down syndrome was:
Informative? Strongly Agree________, Agree________, Uncertain________, Disagree________, Strongly Disagree________
Empathetic? Strongly Agree________, Agree________, Uncertain________, Disagree________, Strongly Disagree________

You first learned that your child had Down syndrome: Before Birth________, Immediately following birth________, 1 to 2 weeks following birth________, 2 to 4 weeks following birth________, Other________

P.O. Box 13857 • Denton, Texas 76203-6857
X17955-3634 • TDD 817/251-5799
If you had known of your child's Down syndrome diagnosis before birth, would you have chosen to terminate the pregnancy? Yes, No, Uncertain.

Did your child experience other health problems at birth? Yes, No.
If yes, (check all that apply): Respiratory Problems, Heart Defects, Intestinal Problems, Other. Please describe:

If you could change anything about how you first learned your child had Down syndrome, you would:

Did you participate in any counseling services available after the birth of your child? Yes, No.
If yes, did you find the counseling helpful? Yes, No.
Who provided the service? Please describe in your own words:

If you could change anything about the way you were counseled, you would:

Did you participate in any support group designed for parents of Down syndrome? Yes, No.
If yes, did you find belonging to a support group for parents helpful? Yes, No.
If no, why was it not helpful?

If you could change anything about the support group, you would:

What (if any) other coping methods do you find helpful? (check all that apply): Talking with spouse, Talking with other family members, Exercise.
Stress Management Techniques (deep breathing, meditation, yoga) ____. Other: ____________.

Section Two:

2. Stage Two of the grieving theory is characterized by feelings of sadness, anxiety, guilt, and aggression. After the reality of the Down syndrome diagnosis had "sunk in," describe your feelings: (check all that apply)

- Sadness  Yes  No
- Anxiety  Yes  No
- Guilt  Yes  No
- Aggression  Yes  No
- Other: ____________

Please explain in your own words:

Did you feel as though the feelings described in Stage One (Denial, Shock, Disbelief) ended when you began to feel sadness, anxiety, guilt, or aggression? Yes  No

If yes, explain:

If no, explain:

Section Three:

3. Stage Three of the grieving theory is characterized by feelings of loss, sadness, and responsibility. However, this phase is said to "end," as feelings of loss and sadness lessen, and feelings of pleasure and enjoyment in life increase. Do you feel as though the sadness regarding the birth and rearing of your child with Down syndrome has ended? Yes  No  Do you feel the responsibility has ended? Yes  No

If yes, why?

If no, do you feel it will ever end?

Is raising your child with Down syndrome different from what you initially thought it would be? Yes  No

If yes, how:

If no, why not?
For parents with other children:

Is parenting different for your child with Down syndrome from your other children? Yes__ No__
If yes, how:

If no, why not?

Does your child currently experience health problems? Yes__ No__
If yes, check all that apply: Heart Defects_____, Thyroid Problems_____, Intestinal Problems_____,
Respiratory Problems_____, Leukemia_____, Vision Problems_____, Hearing Problems_____,
Vertebra Instability_____, Weight Problems_____, Other__________________________

What are your concerns for your child’s future? (check all that apply depending on the age of child)
Early Childhood Programs_____, Education_____, Inclusion_____, Marriage_____,
Employment_____, Community Integration_____, Neighborhood_____,
Other__________________________

Please describe your concerns in your own words:

Please describe support services you currently use: (check all that apply)
Association for Retarded Citizens Programs_____ Down syndrome support group_____,
Community Programs_____ Private Programs_____, Programs provided by school district_____,
Other__________________________

Please discuss the strengths and weaknesses of each of the programs you use:

Please describe any support services you would LIKE to have available in your community: (check all that apply)
Respite Care_____, Week-end day care_____, Babysitting Cooperative_____, Child Recreational
Programs_____, Adult Recreational Programs_____, Summer Vacation Programs_____, Inclusion
Support_____, School to Employment Transition Assistance_____, Supported Employment_____,
Leisure Time Activities_____, Other__________________________

Is there anything you would like to add? Please feel free to attach additional pages. THANK YOU!!!
APPENDIX 5

Permission Letter Written to the Dallas Down Syndrome Guild

Approval Letter-Dallas Down Syndrome Guild

Approval Letter-Institutional Review Board
Ms. Minnie Blackwell  
The Down Syndrome Guild  
4315 Rickover  
Dallas, TX 75244  

RE: Thesis project involving the Down Syndrome Guild  

Hi Minnie!  

Thanks so much for the time you have spent with me discussing my Thesis project on Down syndrome. I am sending along a copy of the research cover letter/questionnaire that I would like to have sent to the members of the Dallas Down Syndrome Guild who are parents of persons with Down syndrome. I realize that this project will require approval from the Board of Directors of the Down Syndrome Guild.

I am tentatively scheduled to defend my Thesis Proposal (the first three chapters of the thesis!) during the week of February 6. Upon approval from the Thesis Committee as well as the Institutional Review Board of the University of North Texas, I will be prepared to send cover letter/questionnaires to members of the Dallas Down Syndrome Guild at my expense. I will also send self-addressed, stamped envelopes for the return of the questionnaires to me. Completion of the questionnaire is completely anonymous and voluntary. Any person wishing to view results from this project will be sent a summary of results. I anticipate completion of this project to be sometime in March or April.

I truly feel that this is a worthwhile study for parents of children with Down syndrome as well as for the professionals and researchers involved in the study of Down syndrome. I appreciate any assistance the Guild may provide, and I welcome any comments/suggestions you may have. Again, I thank you for your time!!

Sincerely,

Jenette L. Smith

jls  
enclosures

P.S. As I mentioned to you by telephone, I participated on the Board of Directors for the Midland Association for Retarded Citizens from 1989-1992 as well as serving on various committees, including Legal Committee, Guardianship, Fundraising, Education, and Advocacy. Please let me know how I can be of service to the Dallas Down Syndrome Guild. If you have any questions regarding my service in Midland, please contact Ray Unterbrink, Executive Director, MARC, 915-682-9771.
February 16, 1995

Institutional Review Board
University of North Texas
Administration Building
Room 310
Denton, Texas  76203

Dear Review Board Members,

The Down Syndrome Guild (DSG) has been contacted by Mrs. Jenette L. Smith requesting our cooperation in regard to her thesis project.

At the February 13, 1995 meeting, the members of the DSG Board approved Mrs. Smith's access to the mailing labels for our member families in the North Texas area. We understand that she will be sending these families a letter explaining her project and requesting their participation by completing and returning a questionnaire.

If you have any questions regarding this matter, please call me at the number listed above.

Sincerely,

Minnie Blackwell
Board Member

cc: Jenette Smith
February 24, 1995

Jenette Smith
KHPR
209J PEB

Dear Ms. Smith:

Your proposal entitled "Parent Responses to the Birth and Rearing of a Child with Down Syndrome: The Application of Engel's 3-Stage Theoretical Model of Grieving," has been approved by the IRB and is exempt from further review under 45 CFR 46.01.

If you have any questions, please contact me at (817) 565-3946.

Good luck on your project.

Sincerely,

Sandra Terrell, Chair
Institutional Review Board

ST/ut
APPENDIX 6

Data Analysis Coding Sheet, Rater Data Analysis Instruction Sheet
DATA ANALYSIS CODING FORM - INSTRUCTION SHEET

DATA FOR ANALYSIS WILL BE TRANSCRIBED DIRECTLY FROM THE QUESTIONNAIRES RECEIVED BY THE RESEARCHER. DATA ANALYSIS WILL BE CONDUCTED BY THREE INDIVIDUALS WHO ARE SEPARATED FROM THE STUDY, UNDER THE INSTRUCTION OF THE RESEARCHER, JENETTE SMITH. ONE RATER WILL READ THE QUESTIONNAIRES AND THE OTHERS WILL TRANSCRIBE THE DATA ONTO THIS CODING FORM. OPEN-ENDED RESPONSES WILL BE RANDOMLY CHOSEN BY THE RATERS TO APPEAR IN THE DISCUSSION OF FINDINGS. THIS WILL ELIMINATE RESEARCHER BIAS IN THE USE OF OPEN-ENDED RESPONSES.

DEMOGRAPHIC DATA OF QUESTIONNAIRE:

Male: (Count actual number, then %) __________ Female: __________

Current age: (List, then describe mean, median, mode)

Age at time of birth of child with Down syndrome:
Mother: (List, then describe mean, median, mode)

Father: (List, then describe mean, median, mode)

Education Level: (List # for each category, then %)
Grammar School

High School

Some College

College Degree

Graduate Education

County: (List, then describe by % represented in each county)
Current age of child or adult with Down syndrome: (List, %, describe mean, median, mode)

Sex of child with Down syndrome: (List, % Male, Female)

Current age(s) of other children: (List, %, describe mean, median, mode)

Sex - other children: (List, % Male, Female)

SECTION ONE OF QUESTIONNAIRE:

Question 1:
Count actual number, %
Denial Yes No
Shock Yes No
Disbelief Yes No
Other:
Initial Reactions, describe in Results section - Raters will choose responses from data randomly.

The person who gave you the news was: (List actual number, %)
Physician Nurse Spouse Other Relative Clergy
Person Other (List)

The person who informed you that your child was born with Down syndrome was:
Informative? (List actual number, %) Strongly Agree Agree
Uncertain Disagree Strongly Disagree

Empathetic? (List actual number, %)
Strongly Agree Agree Uncertain Disagree
Strongly Disagree

You first learned that your child had Down syndrome: (List actual #, %) Before Birth
Immediately following birth 1 to 2 weeks following birth 2 to 4 weeks following birth
Other

If you had known of your child's Down syndrome diagnosis before birth, would you have chosen to terminate the pregnancy? (List actual #, %) Yes No Uncertain

Did your child experience other health problems at birth? (List #, then %)
Yes No
List #, then %: Respiratory Problems Heart Defects
Intestinal Problems
Other

Describe: Raters will randomly choose open-ended responses:
If you could choose anything about how you first learned your child had Down syndrome, you would:
Raters will randomly choose open-ended responses:

Did you participate in any counseling services available after the birth of your child?
List #, then %: Yes __________, No __________
If yes, did you find the counseling helpful? List #, then %: Yes __________, No __________
Who Provided the Service: List:

Describe: Raters will randomly choose open-ended responses:

If you could change anything about the way you were counseled you would:
Raters will randomly choose open-ended responses:

Did you participate in any support group designed for parents of Down syndrome?
List #, then %: Yes __________, No __________
If yes, did you find the support group helpful? List #, then %: Yes __________, No __________
If yes, how was it helpful?
Raters will randomly choose open-ended responses

If no, why was it not helpful?
Raters will randomly choose open-ended responses

If you could change anything about the support group, you would:
Raters will randomly choose open-ended responses

What (if any) other coping methods do you find helpful? List #, then %:
Talking with spouse __________, Talking with other family members __________,
Exercise __________, Stress Management Techniques (deep breathing, meditation, yoga) __________,
Other: List:

SECTION TWO OF QUESTIONNAIRE

Question 2.
List #, then %:
Sadness Yes __________, No __________
Anxiety Yes __________, No __________
Guilt Yes __________, No __________
Aggression Yes __________, No __________
Other: List

Explain:
Raters will randomly choose Open-Ended Responses:
Did you feel as though the feelings described in Stage One ended when you began to feel sadness, anxiety, guilt, or aggression? List #, then %: Yes __________, No __________
If yes, explain:
Raters will randomly choose Open-Ended Responses:
If no, explain:
Raters will randomly choose Open-Ended Responses:

SECTION THREE OF QUESTIONNAIRE

Question 3.
Do you feel as though the sadness regarding the birth and rearing of your child with Down syndrome has ended? List #, then %: Yes __________, No __________ Responsibility? Yes__________, No__________
If yes, why:
Raters will randomly choose Open-Ended Responses:
If no, do you feel it will ever end?
Raters will randomly choose Open-Ended Responses:

Is raising your child with Down syndrome different from what you initially thought it would be?
List #, then %: Yes __________, No __________
If yes, how:
Raters will randomly choose Open-Ended Responses:
If no, why not:
Raters will randomly choose Open-Ended Responses:

Is parenting different for your child with Down syndrome from your other children? List #, then %:
Yes __________, No __________
If yes, how:
Raters will randomly choose Open-Ended Responses:
If no, why not:
Raters will randomly choose Open-Ended Responses:

Does your child currently experience health problems? List #, then %: Yes __________, No __________
Heart Defects __________, Thyroid Problems __________, Intestinal Problems __________,
Respiratory Problems __________, Leukemia __________, Vision Problems __________,
Hearing Problems __________, Vertebrae Instability __________, Weight Problems __________
Other:
What are your concerns for your child’s future? List #, then %:
Early Childhood Programs __________, Education __________, Inclusion __________,
Marriage __________, Employment __________, Community Integration __________,
Neighborhood __________
Other:
Describe concerns:
Raters will randomly choose Open-Ended Responses:
Please describe support services you currently use: List #, then %:
Association for Retarded Citizens Programs ________, Down syndrome support group ________
Community Programs ________, Private Programs ________, Programs provided by school district ________
Other: _______________________________________

Please discuss: 
Raters will randomly choose Open-Ended Responses:

Please describe any support services you would LIKE to have available in your community? List #, then %:
Respite Care ________, Week-end day care ________, Babysitting Cooperative ________
Child Recreational Programs ________, Adult Recreational Programs ________, Summer Vacation Programs ________, Inclusion Support ________, School to Employment Transition Assistance ________, Supported Employment ________, Leisure Time Activities ________
Other: _______________________________________

Is there anything you would like to add?
Raters will randomly choose Open-Ended Responses:
APPENDIX 7

Resource Guide
APPENDIX 7

RESOURCE GUIDE

Down Syndrome Guild of Dallas
P.O. Box 821174
Dallas, TX 75382-1174
(214) 239-8771, (214) 349-4586

Down Syndrome Clinic
1935 Motor Street, Fourth Floor
Dallas, TX 75235
(214) 688-8996 Appointments
(214) 640-2357 Questions regarding genetics

National Down Syndrome Congress
1605 Chantilly Drive, Suite 250
Atlanta, GA 30324
1-800-232-NDSC

National Down Syndrome Society
666 Broadway
New York, NY 10012
1-800-221-4602

The ARC - USA
500 E. Boulder
Arlington, TX 76010
(817) 261-6003

ARC - Dallas
2114 Anson Road
Dallas, TX 75235
(214) 634-9810

ARC - Texas
1600 W. 38th, Suite 200
Austin, TX 78731
1-800-252-9729

Advocacy, Inc.
1420 W. Mockingbird
Dallas, TX 75247
(214) 630-0916
REFERENCES


