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Latter-Day Saint Fathers of Children With Special Needs: A Phenomenological Study

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LATTER-DAY SAINT FATHERS OF CHILDREN WITH SPECIAL NEEDS:
A PHENOMENOLOGICAL STUDY

by

Michael M. Olson

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of

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GRADUATE COMMITTEE APPROVAL

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ABSTRACT

LATTER-DAY SAINT FATHERS OF CHILDREN WITH SPECIAL NEEDS:
A PHENOMENOLOGICAL STUDY

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Department of Family Sciences
Master of Science

This research, presents a qualitative study of six Latter-day Saint fathers of children with special needs. In-depth interviews were used to examine the demands and resources fathers draw upon in meeting the needs of their child(ren), the application of the conceptual ethic of fathering as generative work and crisis/stress theory, as well as an analysis of how fathers incorporated their religious beliefs, faith, and practices into fathering their special needs children. Narrative accounts are used to illustrate the results. These results are then applied to an integrated conceptual framework and clinical applications are made.
ACKNOWLEDGMENTS

I am truly grateful for the support and strength given me by my wonderful wife, Camille. I would also like give special thanks to David Dollahite for his insight, mentoring, and helpful comments throughout the research process as well as the support and helpful comments of my committee. I express special thanks to Loren Marks for his invaluable assistance in the interviewing and coding of this research. I also express my gratitude for Karen Hahne, director of the program “Kids on the Move,” for her assistance in helping coordinate this research. And finally, I am grateful for the wonderful fathers and their touching life narratives, who participated in this study.
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Introduction

The past three decades have seen an increased involvement of many fathers in their children’s daily lives (May, 1997) but have also seen a dramatic increase in fatherlessness (Blankenhorn, 1995; Popenoe, 1996), and fathering as a research topic has blossomed in the last few decades (Biller, 1993; Lamb & Laumann-Billings, 1997; Snarey, 1993). Unfortunately, relatively little substantive research has been published regarding fathers of children with special needs (i.e., any type of chronic illness and any form of physical/physiological, emotional, or psychological/mental challenge). This is especially true when compared with the body of research studying mothers of children with special needs or parents of children who develop without special needs (Blacher, 1984; Bristol & Gallagher, 1986; Brotherson & Dollahite, 1997; Lamb & Laumann-Billings, 1997; Lamb & Meyer, 1991; May, 1997; Pederson, Rubenstein, & Yarrow, 1979). In fact, Lamb & Laumann-Billings (1997) conclude that fathers of children with special needs have been conspicuously ignored in the research. As a result of this lack of extended research on fathers with developmentally or physically disabled children, what little information does exist is limited in both scope and applicability (Hornby, 1994; Lamb & Laumann-Billings, 1997).

This study takes as its focus the father and uses a qualitative research design, employing methods of in-depth interviewing and analysis of narrative texts with special needs children ranging from two to sixteen years old. This research uses a “non-deficit” paradigm based on fathers’ capabilities and
strengths (Hawkins and Dollahite, 1997).

Review of literature

Based on a review of the literature, seven main themes on fathers of children with special needs were identified: (1) diagnosis and initial response, (2) economic concerns, (3) the burdens and blessings fathering a special needs child, (4) uniqueness of father’s experience, (5) father-child interaction and influence, (6) faith and fathering, and (7) marital and family relationships.

Diagnosis and initial response. Diagnosis of a child’s disability has been seen as a critical juncture for parents, and this experience is almost universally regarded as negative and troubling (May, 1991; Stoneman & Brody, 1982, August). Fathers’ stress may be exacerbated when physicians or support systems personnel fail to recognize and include the fathers’ interest and concern (May, 1991). Although the initial response of parents to learning of a child’s disability or other need can be very stressful, some research suggests that most parents and families adapt fairly well to the stressors and demands of the situation (Lamb & Meyer, 1991).

Economic concerns. Fathers are concerned about the future, especially increased financial demands (Lamb & Laumann-Billings, 1997). Rodrigue, Morgan, & Geffken (1992) found that, although fathers with developmentally delayed children reported more financial worries and disruption in family life, on all other measures of adjustment used in the study they were closely comparable to fathers of developmentally normal children.
Burdens and Blessings. While there are clearly negative aspects in raising a child with special needs, usually there are positive ones, as well. However, a disproportionate amount of the research literature has focused on and reported the negative reactions and experiences of fathers in response to the challenge of a special needs child.

Some published studies on fathers of children with special needs have reported serious negative effects on the father’s psychological functioning, including depression and personality difficulties (Cummings, 1976; Margalit, Leyser, & Avraham, 1989). However, other studies have found that some fathers do not have serious negative responses (Brotherson & Dollahite, 1997; Gallagher, Cross, & Scharfman, 1981). These studies seem to suggest that while many fathers experience negative effects, others experience effects that are more similar to fathers without special needs children. Brotherson and Dollahite (1997) and Dollahite et al. (1998) have found that many fathers of children with special needs report personal and spiritual growth.

Uniqueness of fathers’ experiences. Until fairly recently, most scholars have reported the effects of children with disabilities on their parents based on research conducted with the mother rather than the father. A review of more than 85 studies on parents dealing with a child’s disability showed fathers were rarely assessed (Blacher, 1984). Thus, for years, mothers’ and fathers’ experiences were considered indistinguishable, ignoring potential uniqueness of each parents’ experiences with a special needs child. Recently, studies have found important
differences between the experiences of mothers and fathers (Bailey, Blasco, & Simeonsson, 1992; Beckman 1991, Frey, Fewell & Vadas, 1989; Goldberg, Marcovich, MacGregor, & Lojkasek, 1986).

**Father/child interaction and influence.** Fathering a special needs child may involve increased challenges in bonding with and effectively and sensitively interacting with the child (Turbiville, 1994). This may be particularly true when the child is a boy because fathers tend to have higher expectations for their sons that may make the father’s adjustment more difficult (Grossman, 1972; Frey, Greenberg, & Fewell, 1989; Lamb & Laumann-Billings, 1997). Recent research (Brotherson, 1995; Brotherson & Dollahite, 1997; Dollahite, et al., 1998) found, however, that many fathers respond creatively in connecting with, caring for, and playing with their children who have special needs. Although studies exploring the influence fathers have on their special needs child are relatively few, increasing efforts have begun to provide a more coherent picture of fathers in such circumstances (see Brotherson & Dollahite, 1997; May, 1991, 1997; for more in-depth discussion of findings on father involvement).

**Faith and Fathering.** Research specifically addressing religion/faith and fathers of special needs children is only beginning to emerge. Scholars have also found that parents who practice religion before the birth of a special needs child find that levels of engagement of other coping resources are likewise stable after the birth of such children (Rutledge, Levin, Larson, & Lyons, 1995). Finally, a review of the literature on religion/faith and fathering was conducted. Other
scholars (Bennett, Deluca, & Allen, 1995; Dollahite et al., 1998; Dollahite, Slife, & Hawkins, 1998) have found that prayer, church attendance, and specific religious beliefs can provide resources to help parents feel a sense of strength and hope.

**Marital and family relationships.** The father is an important part of the family and marital system (Biller, 1993; Lamb & Laumann-Billings, 1997; Snarey, 1993). Fathers also have a significant impact on their children with special needs (Lamb & Laumann-Billings, 1997). A father's inability to cope with having a special needs child may affect the family and the marriage negatively (Bristol, 1984, October; Lamb & Laumann-Billings, 1997). However, such a challenge can also strengthen the marriage and bring families closer together (Bristol, 1984, October; Darling & Darling, 1982; Krause-Ehart, 1981, April; Lamb & Meyer, 1991). That is, increased paternal involvement responding to the challenges of having a special needs child may enhance the well-being of the family and have a positive effect on the marital relationship (Lamb & Laumann-Billings, 1997). Many families report that in addition to the expected stress they bring, disabled children affect family life positively, including new values and personal growth for the father (Dollahite et al., 1998; Lamb & Laumann-Billings, 1997, p. 183; Palkovitz & Palm, 1998).

**Summary.** In short, the literature on fathers and special needs children shows that: (1) fathers are an important part of family and marital systems and can have a significant impact on their child with special needs; (2) much of what
we know about fathers of special needs children has come from maternal reporting of paternal involvement and behavior; (3) a disproportionate amount of the research has focused on negative rather than positive aspects of fathering a special needs child; (4) some research suggests that religious practices, beliefs, and religious communities can be resources for meeting challenging circumstances; (5) fathers often respond creatively in caring for their special needs children and want to be involved in their children’s special programs; and (6) fathers and children reciprocally influence each other.

**Conceptual Sensitivity**

The Generative Fathering perspective (Dollahite & Hawkins, 1998) and the Resource Management Model of Crisis/Stress (Dollahite, 1991) served as the initial conceptual frameworks to encourage conceptual sensitivity to the data.

**Generative fathering.** Dollahite, Hawkins, and Brotherson (1997) proposed a conceptual ethic of fathering as “generative work” which drew from the developmental conceptual work of Erik Erikson (1950, 1982) and John Snarey (1993). The Generative Fathering perspective (Dollahite et al., 1997; Dollahite & Hawkins, 1998) is based on the idea that universal human challenges create needs in the next generation that fathers should and can work to meet and that both fathers and children benefit and grow as a result. This framework conceptualizes fathering as generative work, or what the authors term *fatherwork*. This approach assumes a non-deficit (Hawkins & Dollahite, 1997), capabilities-based perspective of fathers rooted in the proposed ethical obligation for fathers
to work to meet the needs of the next generation.

**Resource management model of crisis/stress.** The Resource Management Model of Crisis/Stress proposed by Dollahite (1991) integrated both resource management and family stress theories. For this research, the main ideas taken from this perspective include the importance of how people define stressful situations and how people work to balance demands and resources as they adapt to stressors.

**Integration of Conceptual Frameworks**

Figure 1 illustrates the three main elements of this project, including empirical, theoretical, and applied conceptual methods. Part I shows that the Generative Fathering perspective and the Stress/Crisis Management model provided the theoretical frameworks. In integrating these two frameworks, it can be proposed that fathers use effective cognitive, affective, and behavioral resource management to bring about generative meanings and behaviors that may enable them to meet the needs of their children. Part II shows that qualitative phenomenological research was the empirical method used. Part III of the figure shows professional and clinical applications/implications which stem from this research.

**Research Objectives**

The literature shows that fathers are affected by their special needs child. The generative fathering perspective (Dollahite and Hawkins, 1998) assumes fathers want to be involved in the lives and endeavors of their child(ren). Thus,
Figure 1. Research Methods

I. Theoretical
   Inductive
   Deductive

II. Empirical
   Quantitative
   Qualitative
   Non-Narrative
   Narrative

III. Application
   Non-Narrative

Narrative
Phenomenology: Emancipatory
(Change Society)

Generative Fathering
ABCD-XYZ Model of Crisis and Stress

NARRATIVE

Implications for Generative Narrative Therapy with Families of a Special Needs Child
the focus of this study is an in-depth view of the father’s perception of the father-child relationship.

This study has four objectives: (1) to identify and analyze themes or patterns of experience that fathers have in common with each other; (2) to explore how fathers make meaning in relation to the challenges of having a child with special needs; (3) to investigate fathers’ experiences as they relate to the empirical literature and conceptual frameworks discussed earlier; and finally, (4) to provide a more coherent, non-deficit, picture of fathering in such circumstances.

Methods

Procedures

A letter explaining the nature of the study and the objectives of the research was sent to a group of 50 Latter-day Saint (LDS, Mormon) fathers involved in an early intervention program for children with special needs. Fathers were asked to participate in a study of fathers of special needs children. Each potential participant had the opportunity to respond, have any questions answered, and prepare for the interview by reading materials sent to them describing the type of questions to be asked. Entry into the project was negotiated with the study participants, as well as information concerning interview duration and frequency, objectives of the research, use of interview content, and ethical considerations. The father was permitted to set the time and location of the interview.
Of the 50 fathers contacted via letter, the response rate was 12 at the time this research was initiated. Interviews were conducted with 6 of the fathers, at which point it was felt that theoretical saturation had occurred (i.e., no new or relevant data was being collected). For their participation, fathers received a copy of the audio recording of the interview, a hard copy of the transcribed transcript, and a 3.5" formatted diskette with the transcribed interview.

The role of the researcher and the research design process were explained to each father upon initial contact for participation in the study. Fathers were informed of their right not to answer any of the questions asked during the interview and to terminate the interview at any time for any reason. Each of the fathers who decided to participate in the study read a statement of purpose and signed an informed consent form (see Appendix A).

Sample

Table 1 provides an introduction and description of each of the interviewees and each child with special needs. Each of the fathers were active members of the Church of Jesus Christ of Latter-day Saints (LDS or Mormon), which teaches that fathers should give highest priority to their work as husbands and fathers (Hawkins, Dollahite, & Rhoades, 1993). Dollahite et al. (1998) demonstrated that a unique aspect of fathering for Latter-day Saints is that the church has a lay priesthood in which most fathers are also elders or high priests in the Church. Church teachings and practices are designed to strengthen families, and for most Mormon men, the most important Mormon religious obligations,
covenants, and involvements are family centered. Latter-day Saints tend to infuse much of daily living, and particularly challenges to stressors, with religious meaning (Dollahite et al., 1998). Each of the fathers are white, middle socio-economic-status (SES), ranging in age from mid-thirties to late-forties. All names were changed unless otherwise requested.

TABLE 1 Respondents and Their Special Needs Children

<table>
<thead>
<tr>
<th>Name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Todd</td>
<td>Todd works at the university. He is the father of Andrew, age 7. Andrew was born with shortened forearms, scoliosis, and missing fingers.</td>
</tr>
<tr>
<td>Eric</td>
<td>Eric works as a university administrator. His sixteen-year-old son, Benjamin, suffers from a malady of the heart called truncus arteriosis.</td>
</tr>
<tr>
<td>Lance</td>
<td>Lance works out of his home so he can be more available for his child with special needs. Lance is the father of his six-year-old son, Joshua, who has Down Syndrome.</td>
</tr>
<tr>
<td>David</td>
<td>David works in computer/information systems. David is the father of a two-year-old special needs boy (developmental delays), named Tyler. Tyler was adopted and of a different racial background than David.</td>
</tr>
<tr>
<td>Matt</td>
<td>Matt works out of his home. Matt is the father of a seven-year-old autistic girl named Jennifer, and an eleven-year-old boy, named John, with Tourette’s Syndrome.</td>
</tr>
<tr>
<td>Ryan</td>
<td>Ryan is the father of a three-year-old son, Luke, who has Down Syndrome.</td>
</tr>
</tbody>
</table>

Interview Development

The first step in the development of the interview schedule was to use a review of current research to formulate key themes and issues. Questions were then developed and refined to address the strengths and weaknesses of the current research. Literature on stress, coping, and faith/religion and fathering were also considered in the formulation of the instrument questions.
The interview was revised many times as part of a process of consultation with other professionals and fathers of children with special needs. Finally, pilot interviews with two fathers of special needs children were conducted to elicit additional feedback for revision and adaptation of the interview schedule.

Construct validity (connecting the theory to the questions) was maintained through the researcher's familiarity with the concepts of the generative fathering, special needs, stress/crisis management, and religion and fathering literatures. Contextual validity (thoroughness of the information) was encouraged through in-depth questioning in the interview, and interpretive validity (connection of the account to "lived experience") through seeking personal narratives that reflected actual experience.

**Research Design**

According to Morse (1994), if research is aimed at eliciting the essence of personal experience, the approach should be phenomenological. The method used in this study is a phenomenological analysis of audio taped interviews of personal experiences elicited through in-depth interviewing. Because of the nature of phenomenological research, the number of respondents was small (Bergum, 1991; Giorgi, 1970, 1975; Morse, 1994; and van Manen, 1990). The type of results yielded by this type of research were in-depth reflective descriptions of what the experience of being a father of special needs children or child is like. For a more in-depth discussion of the phenomenological approach, see (Bergum, 1991; Giorgi, 1970, 1975; and van Manen, 1990).
Because of the nature of the study, the research must take into account certain methodological issues that stem from the interview technique. These issues are reflexivity, reactivity, credibility, transferability, dependability, and confirmability.

Reflexivity concerns the recognition that the researcher acts from a subjective, interpretive position in the research process (Hammersley & Atkinson, 1983; Riessman & Lieblich, 1993). The role of the researcher in this study was not to separate (objectively) from the stories and participants but rather to be intimately involved in collecting and seeking to understand the narrative accounts given by respondent fathers.

 Reactivity involves knowing that research participants may react differently when they are under research conditions, rather than in a more natural, realistic position (Cozby, Worden, & Kee, 1989). The researcher attempted to minimize reactivity by interviewing fathers in their own homes or offices and by inviting them to relate how their experiences are meaningful to them rather than to the researcher. Individual interpretation is inseparable from narrative presentation of life events (Widdershoven, 1993). Efforts to interpret fathers’ narrative experiences were subjective, and the research strove for “believability, not certitude, for enlargement of understanding rather than control” (Stivers, 1993, p. 424).

Credibility refers to the “fit” between the constructed reality of the respondent and the reconstructions attributed to them by the researcher. The
techniques used in this study to establish credibility were “peer debriefing” and “progressive subjectivity” (described below), using constant peer review during analysis. In-depth interviewing techniques were used to establish transferability in this study through “thick description,” or providing as complete a data base as possible. The method for establishing dependability and confirmability (i.e., to “track” changes in design and to make these changes “trackable” and to make data traceable to their original sources) in this study, was to emphasize careful, thorough documentation, and to make these documents available for scholarly inspection. The data in this study is available on audiotape, transcribed accounts on hard-copy, and disk.

Analysis

For the purposes of this study, narratives are defined as stories with common properties about a specific past event (Labov, 1972). In Sarbin’s (1986a) words, narrative is “a way of organizing episodes, actions, and accounts of actions; it is an achievement that brings together mundane facts and fantastic creations; time and place are incorporated. The narrative allows for the inclusion of actors’ reasons for their acts, as well as the causes of happening” (p. 9). The purpose is not to determine cause-and-effect relationships, to predict and control, or assign objective truth to events; it is, however, meant to make sense of “human desires, goals, and social conduct . . . which are often ambiguous, and resistant to paradigmatic efforts to understand them” (McAdams, 1993, p. 29).
Coding. Each of the interviews were coded independently by the author and another graduate student who has been involved in the research from its inception (Loren D. Marks). Following the transcription of the interviews, the author and the other graduate student met 3 times a week for several hours at a time for a month to compare and contrast and discuss the coding procedures and memos and to establish criteria for including or excluding categories. The criteria established at this level of coding for the inclusion of a category were (1) it was generally consistent with fathers’ lived experiences and (2) it was telling the “story” of the fathers interviewed. The criteria of whether the account was narrative in content, and whether the account was descriptive of father’s stories was used for deciding which narratives, categories, and themes would be included in the final write up of this study.

A qualitative software program called QSR- N.U.D.I.S.T. ™ (Non-Numeric-Unstructured-Data-Index-Searching & Theorizing) was used to code, sort, collapse, and analyze the interviews. These data were analyzed and explored to identify major categories and properties using open coding (Strauss & Corbin, 1990, p. 61) and thematic analysis techniques so as to form a description of the general structure of the research topic (Tesch, 1990), which also relates closely to qualitative research categorized by Tesch (1990) as that which aims at “discerning of patterns” in the data.

Originally, these data were divided into 27 categories and 61 subcategories, based on N.U.D.I.S.T.™ analysis. These were refined into eleven
general categories. Five of these categories were selected for inclusion in this study based on their descriptions or storying of respondents' experiences. From five categories and themes the researchers formulated a composite summary “narrative account” or “story” which included the essential elements of each of the six fathers’ combined experiences. This composite “narrative account” was then mailed to each of the interviewees for their review and response. Each had the opportunity to evaluate the narrative summary and indicate its accuracy in relation to their own lived/storied experience. A scale was included for fathers to use to rate the account, 0 = not at all descriptive of my experience, 3 = somewhat descriptive, and 5 = very descriptive of my experience (and all values in-between).

Within the thematic analysis, we identified the specific demands that were most difficult and resources that were most meaningful for fathers. We then examined the data for both commonality and descriptiveness of experience among fathers and how they related to the guiding conceptual frameworks of the study. This approach coincides with Josselson and Lieblich’s assertion that

story cannot stand alone but must be linked to some theoretical context or previous knowledge. Movement to the conceptual level necessitates insight and parsimony, where a different level of interpretation allows us to see things or organize data or to generalize from this story or stories to other people or other aspects of experience (1993, p. xii).

Results

The results are presented here are in narrative form and arranged by category and theme. The categories and sub-categories are: Diagnosis and Initial
Response; Demands and Constraints (physical demands, medical and educational demands, and religious communities); Father Involvement -- Complementary Care; Resources (marital support, religious beliefs, religious communities, practices, and ordinances); and Child’s Effect on Father. Some of the narratives included in this section deal with more than one theme, these were classified as to the most salient point of the account. Narratives were edited to shorten length but maintain the essence of the stories told by the fathers, (i.e., extraneous wording was deleted).

**Diagnosis and Initial Response**

Diagnosis was a critical juncture for these fathers. In response to a question about initial feelings upon learning of their child’s special need, some fathers related feelings of uncertainty and questioning, while others expressed an immediate feeling of love and acceptance for the child. All reported that, in time, they adapted well to the situation.

**Lance**

We discovered the diagnosis five minutes after he was born. “Down Syndrome” is what the doctor said. All the things my mom had told me came flooding back through my mind. [Once] she said, “these little mongoloid kids have super human strength and they only live to puberty and it’s really too bad.” That was the first thing that came through my mind, all the outdated information we had ever been in touch with, came flooding back. We were quite frightened, we were living in California at the time and our family was in Utah and Michigan. We felt real isolated [pause] and scared.
Eric

My initial thoughts, after the terror? [Eric laughs] I guess there was an interesting series of emotions. We found out something was wrong the day after Benjamin was born and they told us we needed to take him to Primary Children’s [Hospital]. We knew something was wrong with his heart but we didn’t quite understand the extent of it. I have to confess that at first, I honestly found myself wondering, “Do I want to get too close to this?,” that passed really quickly. I remember that I just kind of thought, “Man, they’re talking about this child dying.” And I had that moment when I just kind of thought, “Do I really want to?,” but all you have to do is hold a child and it’s over.

Todd

Before Andrew was born, I was alone in my bedroom kneeling beside my bed praying on a different topic [and] I got a strong impression related to our future child, I wasn’t praying about Andrew, I didn’t know him, he was just half term. I got a really strong spiritual impression that there was something very wonderful about this child. It was something that I experienced that was very clear to me. That happened a second time when I was praying some weeks later. I brought it up to my wife, and to my surprise, she independently experienced the same thing twice during her personal prayer. We were kind of surprised in a positive way and didn’t know quite what this all meant, but we felt we had a premonition that there was something wonderful about this child.

When Andrew was born we were videotaping the birth in a discreet way. As soon as he started to come out the doctor said, “ooh,” he paused and fumbled a bit and said, “well, there’s something going on with his hands, we have something here.” I think Angie was a little nervous, I was. When the doctor brought him up we could see that he had shortened forearms and was missing some fingers. They wrapped him up in set him on Angie’s tummy. I was instantly concerned about how Andrew might interpret that someday. It was very important that he know how much he is loved. I don’t remember exactly what I said but I made sure that we kept video taping, expressing our complete love and acceptance of this neat little soul.

For most, the diagnosis comes early on, many times at birth, but for others it is a process of searching and learning of what special needs exists for the child.
Matt tells how he came to learn of his daughter’s autism:

I wasn’t involved enough in this particular aspect of my daughter’s life, certainly not to my wife’s satisfaction. She said “you need to know things that I know and be more involved with this child and what’s going on with her. I would like you to read the first ten pages of this book.” So I sat down at about 10:30 p.m. intending to read the first 10 pages and be done. I read the first 150 pages that night. I couldn’t stop reading because basically what was in that book was my daughter’s life. Her speech, her problems, were just unfolding in this book. I realized after I got done that she was autistic, and really, it hit me like a ton of bricks, and I just, I broke down and just bawled.

Demands and Constraints

When asked what some of the greatest challenges, demands, and constraints are facing them as a father of a special needs child, fathers told stories which included themes of (a) physical constraints/demands, (b) medical and educational systems, and (c) religious communities.

Physical constraints and demands. Fathers related accounts where there were multiple demands and constraints facing them. Many of these demands were related to the physical challenges facing these fathers including time and schedule constraints. Matt’s narrative is illustrative of how time serving in the Church, time at work, and time trying to be a good father inter-face:

When Jennifer was two years old I was in a BYU bishopric [demanding church duty]. I was spending Sundays and occasionally a week night at BYU. Two years after we had Jennifer we had our fourth child. My wife Laura was spending a lot of time with the baby when Jennifer was approaching two. Autism manifests itself in a way that autistic children need a routine. Everything needs to be mechanized; when something is introduced into their routine that is not normal, often times they’ll just go into hysterics. I was putting her to bed every night. That was enormously time consuming to me. I had my business, I was in a BYU bishopric, spending a lot of time there. Each evening I was needing to put this child
to bed plus trying to be a father to my other three children and a husband to my wife as well as deal with other things I was dealing with at that point. It was very, very difficult.

**Medical and education systems.** When fathers were asked what their experience had been with health care, special education, and other support systems, fathers gave the following types of responses:

**Eric**

Let me separate this. In terms of physicians and nurses, I have seen some of the most saintly people I know. In terms of the business side of health care it’s been awful, horrific. You have to fight that side of the system or you’ll get eaten alive. There are so many inaccuracies in record keeping and financial ramifications. My wife saves us probably fifteen to twenty thousand dollars a year by just catching errors in processing of bills.

Education has probably been more of a frustration than the business side of health care. We have created in our public education a kind of machine, and if the child doesn’t fit the machine, the machine doesn’t work. Benjamin has always been in some kind of special education class. He’s been in and out of school. This last fall was the first time where we kind of looked forward and said, “There’s really not much else that can happen health care wise, no more surgeries. So we thought, “Let’s put him in mainstream.” He really wanted it. It was just an absolute disaster because he had missed so much; the machine had a pace to it and within probably six weeks he was emotionally just destroyed. He has always wanted to just be normal and all of the sudden it just hit him in the face, he’s not normal, in the sense of educational preparation. The machine just couldn’t adapt to him. We found one individual, Mr. Witherspoon out at Timpanogos H. S., who’s been marvelous. He’s bucked the system and created a space for Benjamin where he’s doing quite well now.

The following excerpt illustrates how one father struggled getting the medical help he needed for his little boy:

**Lance**

Children with Down Syndrome have much higher probability of getting leukemia. Josh was having some of the general leukemia symptoms, so
we went to a regular physician who had been pretty good to us, but I guess that day he just didn’t feel like indulging a parent. He said, “okay, I know you’ve got the statistics, he’s 16 times more likely to get leukemia, but the chances normally are this much in a thousand,” he just tried to put it off. We went to a different doctor who loves Josh to pieces. He just took care of it.

With Down Syndrome, Josh’s sinus cavities, esophagus, and trachea, are really small. Josh had tonsillitis when he was three, his tonsils got so big that they actually cut off his air and he passed out. One physician said, “we don’t give three year olds tonsillectomies.” We went to another doctor who went and consulted with someone else and returned and said, “just last week there was a child with Down Syndrome that had tonsils that swelled shut, and he died. Of course, let’s take Josh’s tonsils out.” It did take some effort on our part to find a doctor that’s willing to learn and stay on top of something special.

Religious communities. A majority of the fathers primarily related positive experiences with regard to their religious communities. However, when asked about ways in which religion or religious beliefs may have been demanding, a few fathers related negative experiences, explaining how at times their religious communities constituted an additional demand.

Ryan

Concerns of church leaders are at times legitimate, but in this specific case the nursery leader never talked to us to find out what Luke’s status was. She had been acting off of hearsay. She basically said “I don’t want to be bothered with it. I have too much to do. He shouldn’t be here.” We brought the bishop up to speed on everything, now it seems that there isn’t a problem on the surface, but it is still there.

For LDS people, having a “calling” or a responsibility in the “ward” (congregation of about 500 people) is very important and some church leaders are hesitant to give parents with special needs children callings so as to not add to
their burdens. Integrating children with special needs into the ward can also be demanding. The following illustrates how one father struggled with some of these issues:

**Lance**

Our real challenges unfortunately have been integrating Josh into the ward. I guess it has caused some contention now and then. The Primary handbook is very specific, it’s very appropriate to have a special aid that is Josh’s buddy through Primary. That’s important for two reasons: one is, we feel that Josh didn’t just come for us, and certainly part of my personal mission is to share Josh’s spirit and gifts with other people, and two, I feel that someone from the ward helping Josh during church is something that the ward can do to minister to our needs a little bit is to give us a break during Primary. I wrote a letter to the bishop of the ward to express our perspective. This process has been very frustrating, it is hard that he won’t find the resources to help, they’re certainly available. It bugs me and I’ve never been bugged by a bishop before. Feeling agitated then spills out into other things. The bishop has not given my wife a calling. The bottom line is, Josh is going to be here for the duration and that doesn’t mean that the Lord has no need of us elsewhere. I visited with him probably four times before he gave her a calling as the fourth alternate assistant librarian. So if the regular old ladies serving get sick, then she gets called in to do it. The bottom line is she still doesn’t have a calling. It’s been frustrating for her and she’s questioned her worth and her worthiness, . . . it’s been tough.

**Father Involvement—Complementary Care**

As fathers balanced the resources and demands facing them, each father chose to connect with and meet the needs of their child(ren). This is illustrated by a category of narratives labeled “Father Involvement—Complementary Care.” Within this category, several themes emerged: medical—educational/special program involvement and intimate involvement (e.g., communicating openly, touching, playing/singing). The term complementary care is meant to convey
fathers’ feeling that they were able to complement the care of their spouse and visa versa. Though in a few cases fathers were able to be uniquely involved, it was more common for fathers to report that as a couple they worked as together to meet the needs of their child based on each others’ strengths, weaknesses, and preferences.

Ryan, whose son has Down Syndrome, in response to a question about his involvement and contribution as a father, said:

Whenever I come home, if Luke has been having a bad day I pick him up and take care of him. He doesn’t always calm down, but I am the one that deals with it whenever I am home. We kind of joke about it but he’s my kid. I stay up all night rocking him when he can’t sleep. When he’s screaming having his night terrors, I just know him, I can just take care of him. I come home and he’ll be screaming, I can pick him up and make him a sandwich and help him eat it and he’ll calm down. Everybody knows he’s my kid and I take care of him.”

Some fathers, like Lance, also influence their child’s life indirectly through involvement in special programs, legislative processes, and channeling their efforts and time towards other children and families facing similar special needs and challenges.

The Kids-On-The-Move (early intervention program) folks asked me if I’d work with the legislative coalition for people with disabilities. I worked on the early intervention committee for about a year. One thing that we have done that’s has had probably the biggest impact on the whole family is Lana and I got trained to be parent support folks for the hospital. We asked the people at the hospital, “What about families that have a child with a disability?” We thought, let’s see if we can do something to help them have a better birth experience than we did. It has taken about four years to get someone in charge of the program at the hospital, but now we get called when a child is born with a disability. Now we go in and visit with folks or on the phone or at the hospital, or have them come over here and see Josh, to see that he’s a cute little boy.
Fathers also related several experiences where they felt they were able to be uniquely involved in their child’s life. This is consistent with literature (Bailey, et al., 1992; Beckman 1991, Frey, et al., 1989; Goldberg, et al., 1986) which has found that fathers’ experiences are often unique from mothers’ experiences.

**Todd**

There were times when the pain was very bad on Andrew. It was really hard for him physically and emotionally and the pain was really something. When I took him back to have his catheter removed there was a mishap when I was taking him out of the car. The cord from his catheter to the bag that would collect his urine accidentally caught on a little knob under the passenger’s seat. When I lifted him out it ripped the catheter out of his body, right where he’d just had this really delicate surgery. I was talking to Angie about the situation and she said, “I’m glad that you were there, I don’t know if I could have handled that.” I was thrilled to be able to be his dad and to be there for him. It was great to be there for him and to fill a role and be steady, calm, and strong, when it was necessary. Not in a sexist manner, but Angie has a harder time with that stuff. It was a time where I felt like I was able to give him emotional strength.”

**Lance**

Sometimes he’ll just be crying hopelessly. I have been pretty good at finding ways of breaking him out of these crying spells. It is different all the time. For example, right before you came he had to go to the bathroom and he didn’t want to come in and go. Eventually I had to kinda drag him in here just crying. He just stood there by the toilet, just crying and crying, instead of just going back out and play. I tried to talk to him and it just wasn’t working so I decided to kneel down with him and just hug him. Just that contact broke it and then he just somehow connected and said “okay,” and he went to the bathroom and went out and play. Sometimes I’ve had to be more creative to get his attention. I never know what it will be at any given moment.
Matt

When Jennifer was young she used to tantrum a lot, expressing her frustration and anger very physically. I used to pick her up and hold her close in an attempt to settle her down. Eventually I could wrap my arms around her and sit in a chair or something, partly to restrain her and partly to communicate to her the enormous love and caring I had for her. I am not sure if holding her is what calmed her, but it did. Laura couldn’t do the same thing that I could do, maybe because of my size, but I always felt from a very young age, that we had a bit of a bond. And I still feel like it exists today. I feel every bit as involved as Laura is in her life. I make sure that I am there for her, that I am reading and singing to her at night. I am in her life. Maybe too much, I am not sure. She probably has me wrapped around her finger. I love my girls. I love my boys too, but I really love my girls.”

We asked in what ways fathers responded initially to and how they now approach their child and what affect that might of had on other family members.

Fathers recounted their experiences with frequent references to a special “bond” or “connection” they had with their special needs child, another form of involvement.

Matt

I look into her eyes. Autistic people in general never look at you, they will always look down. Early on Jennifer didn’t make eye contact, but later on in life she started to make eye contact. For me, looking into her eyes is like looking into her soul. I see a lot, I read a lot, I sense a lot. This might be the primary method of communication between me and this little girl, by looking through her eyes. Sometimes I will just sit down with her in a chair, she will sit on my lap, and I will just look into her eyes. I feel like I am gazing into eternity, it is enormously joyful for me to do that.

A majority of the narrative accounts refer to the bond these fathers felt for their child during the earlier years of the child’s life. The following account is unique in that it illustrates the bond a father and son had during mid-
adolescence, at a time when the end of the child’s life was immanent.

**Eric**

It was confirmed by doctors that Benjamin’s heart was shot. He was on IV’s at home, kind of forcing the heart to pump. He was losing weight rapidly, the doctors gave him 1-3 months to live. I was really open with him, he handled it incredibly well. We spent a lot of time together, talking through the Plan of Salvation (LDS theology). We spent 10-20 hours a week just talking. It was a great experience, I wouldn’t trade it for anything. At the same time, he was failing noticeably. He weighed about 70 pounds, he was 14 years old. It got to where I had to carry him upstairs, he was on oxygen. He couldn’t bathe by himself. He was too weak. He hated baths and loved showers so I would prop him up in the shower. I could tell when we first started having to do this that he was kind of embarrassed. It was hard for me at first, I knew he was embarrassed. Those became really choice times [long pause, eyes fill with tears]. Sorry [pause], he was so submissive, in every way. He was so at peace with what was happening.

When Benjamin had his fifth open heart surgery, he really had a hard time keeping his heart beating. They had to remove the pacemaker to pace him. They had this wire coming down through his neck and it kind of delicately hooks into the heart muscle. If you move your neck like this [moves his head from side to side] it actually dislodges. Benjamin just wouldn’t settle down to keep his neck still and so they were essentially going to have to put him back on the ventilator, which is an awful experience, Benjamin hates it. It was about midnight when they called me, they said, “Benjamin is going to have to settle down or we’re going to have to put him out.” I said, “You can’t do that, it would just destroy him emotionally.” So, I jumped in the car and rushed up there. I asked, “What do I have to do to prevent you from intubating him again?” They said, “He has got to hold his head still.” So, I held his head, I held his head all night [chokes up]. It was one of the hardest things because he was just groaning. He would go in and out of sleep. It was a long night but it was a great experience.

Lamb & Laumann-Billings (1997) assert that increased paternal involvement responding to the challenges of having a special needs child is likely to enhance the well-being of the family and have a positive effect on the marital
relationship. When asked how he thought he influenced the family, Eric said:

I can give you one example I think shaped everyone’s interaction with Benjamin. At the time he was being transported up to the hospital, my wife’s family was having a family reunion that evening. They were aware that he had been moved up there and they had all of our children during the day. After meeting with Doctor Orzman that evening, we understood what Benjamin’s condition was. We went back to Lynn’s parents house in Salt Lake. It was just Lynn and I when we walked in, everyone else was gone. After walking in I felt this profound sense of gratitude. For some reason, I just felt grateful, so we knelt down and had a prayer. The first thing that I said is how grateful we are for Benjamin. That’s kind of persisted through out his whole life. We’re just grateful. We shared that experience with Lynn’s whole family when everyone came home. They all gathered together to understand. We had a little family council to try and explain what was going on. I repeated to them how grateful I was for Benjamin. I think that has influenced everything about our interaction with Benjamin. It’s a blessing to have him.

Resources

In addition to the demands and challenges fathers discussed, they told about resources they drew upon. Within the category of resources, themes included (a) the importance of marital support, (b) religious beliefs, and (c) religious practices, ordinances, and communities.

Marital support. When asked what things had been the most meaningful in helping them to be the kind of fathers they wanted to be, fathers reported marital support as one of their greatest resources. The following excerpts show how this support became salient not only in meeting the needs of their children, but also in meeting their spouse’s needs.

Eric

All of the sudden Benjamin collapses in church and is back in the hospital. Back in the hospital again. I just said, “Why, hasn’t he suffered
enough?” I was so tired of watching Benjamin suffer and there was not a thing I could do about it. What do I do? Take him home? [Laughs in frustration], like that would really help. I had this emotion, I remember walking around the hospital with my wife and just sitting down and starting to sob. That’s when she taught me a great lesson that “Heavenly Father loves him more than you do and He’s not going to do anything that Benjamin can’t handle so what’s your problem?” She’s really candid about those things. That was a great moment. There’s been lots of moments like that.

Matt

My wife has been the single greatest support that I have had. My marriage and our relationship as a couple to God is the most treasured thing that I have in my heart. She has never wavered. In the spring of 1994, around the time of John’s diagnosis with Tourette’s Syndrome, there was an enormous amount of turmoil. One day she got an invitation from a family member to go to Arizona for the weekend, she asked me if I would take a couple of days off of work and watch the kids so that she could go. I said yes although I was also in a lot of turmoil. I probably had a panic attack as she was driving off. She had to get away. These experiences though gut wrenching, have really drawn us together, more than anything else in our married life.

Ryan

I can take care of Luke and deal with that. My wife can fight her way through the medical stuff and keep that in place where I don’t know, between work and being the father and trying to meet those needs, [pause] she picks up where I don’t. It works fairly well.

Religious beliefs. Many of the fathers related that their religious beliefs became valuable in helping them to meet the challenges of fathering a child with special needs. When asked the question “what two or three things had been most meaningful for them in helping them to be the father they want to be” fathers gave such responses as the following:
Lance

Josh is a child of God, just like all of my other kids. Knowing that he’s an extra special child of God, [reflects], it’s been real helpful. I feel honored, to have him in our family. That’s probably the thing that makes it easiest to deal with everything else.

I know I’m in the presence of a great spirit, one of the very valiant and true spirits. Not to take away from gratitude I feel for the other children, but It’s like I don’t know whether to feel like I couldn’t have made it back to Father [God] without him, or just really grateful that I’ve got that extra help.

Todd

One time Andrew and I were alone in the kitchen and he looked up at me and said “you know dad, if I were born again, I would like to have hands like Kathleen, and like Benjamin.” I didn’t say anything for just a moment, and then he said, “but, I guess this is just the challenge that Heavenly Father has given me for this life.” And, he, paused again, and he said, “So it’s okay.” It wasn’t a mournful “okay,” it was more a, “this is alright” okay, almost with a little spunk. I think that his belief grows out of our faith.

These narrative accounts reflect the LDS belief that life is part of an ongoing “eternal” plan with its origins as literal spiritual offspring of God or Heavenly Father. This belief embodies the idea that death is not the end, but a new beginning as families and marriages, can continue beyond the grave as an “eternal family” in the presence of God. Respondents in this study expressed repeatedly the belief that their child is a child of God and a loving gift from God to “bless” their families and marriages.

Religious communities, religious practices, and ordinances. Several fathers commented on support they received from church members and leaders.
Religious communities as a theme falls into both the “resources” as well as the “demands” categories for fathers of children with special needs. The former will be addressed here, and the latter will be addressed in the following section.

When asked whether their religious community or congregation helped them to meet their child’s needs, fathers gave the following types of responses:

**Eric**

We had one of the best home teachers in the world in Chicago, John Shane. The day after Benjamin’s transplant John came to the hospital at 12:30 a.m. to help us give Benjamin a blessing. That morning at 8:00 he came and picked up the two littlest boys and took them for the day. We didn’t have to worry about those two. That’s one of a hundred instances where our religious community has been helpful.

**David**

There was certainly a lot of community support just by virtue of bringing a child, especially an ethnic child into our home. The religious community acted appropriately in being very excited for us. Something that didn’t happen, but could have, was any kind of negative feelings about his ethnicity, it just didn’t happen. Actually, it was just the opposite. They made comments like, “what a good looking kid he is” and expressed their excitement that he was in our family and in the neighborhood.

**Ryan**

I love to play sports. One of our church friends said that she would watch our kids at the game so I could go play and help out. While I was playing I took an elbow. So her husband took me over to the hospital and she stayed with the kids. They just kept everything in control while my son Luke was in ICU and I was in getting 22 stitches. They stayed until I was finished and then brought me back home. They didn’t even hesitate, It was just “here we go.”

**Todd**

We were relatively new members in our ward congregation and our bishop had learned of Andrew’s upcoming surgery. The bishop got up in
church, [laughs with emotion], and let the ward know that we have a good little guy in our ward who needs our prayers and faith right now, and needs our fasting and effort to request a blessing on his behalf. The ward just responded! Many church members told us of their fasting and prayer and their hope and wishes that he'd have a successful surgery, expressing their love and support for Andrew and for our family.

The LDS religious community is a community that operates on principles of cooperation. A lay-leadership provides a majority of members the opportunity to be involved in providing services for the local congregation. Each member may serve as a home or visiting teacher who regularly visits each LDS home. The ward provides worship services, friends, economic assistance, and a support group that can be relied upon to provide the assistance any family might need.

Another source of help for these fathers came from “priesthood blessings.” When babies are just a few weeks old, they are usually given a priesthood blessing for the special purpose of conferring a name by which the baby will be known and bestowing promises based on spiritual impressions regarding the baby’s future life. Fathers holding this priesthood have the authority to give a priesthood blessing by the laying on of hands on the head of the one receiving the blessing in times of need or on special occasions to members of his family. The following narratives are illustrative of how the priesthood, or the exercise of the priesthood became a resource for these fathers.

Lance

When I gave Joshua a name and a blessing, it felt as though a prince had come into our house. It was then when I imagined what it might be like
on judgement day, when this special elect child stands there in the glory he’s earned. I never want to have done anything to offend him. I want to have done everything possible to be a good father and to help him be the best person he can be.

**Ryan**

When Luke was two he was extremely sick and I gave him a father’s blessing, it was the best experience I have ever had. I knew at that time he was a perfect child, I have never forgotten that feeling. I recall wondering why I was chosen to have a perfect person in my house and hoping to live up to whatever was expected of me. Priesthood blessings have always amazed me. I still have Luke’s baby blessing; in it I blessed him with the strength to overcome the challenges and endure the challenges he’d have. The blessing never mentioned a mission or a temple marriage, just about having the strength to endure challenges and being a valiant spirit. It is the neatest thing I have ever done. It is the neatest thing I can ever do.

**Todd**

Andrew’s surgery was the first one of the day, about 5 a.m.. Upon arrival at the hospital I picked a dark corner of the parking lot and gave Andrew a priesthood blessing in the back seat of the car, where he was laying down. As I gave him the priesthood blessing, I felt a very palpable and powerful feeling of the Holy Spirit, that Andrew would be blessed, that this 24 hr. surgery would be successful. Although it had not happened yet it was a foregone conclusion that he would be blessed. Just before the surgery began the doctor got a new idea he’d never had before. He sent his chief assistant surgeon out to see if it would be okay with me if they tried a different procedure. As soon as he said that, I knew it was a good thing. I said, “yes, please proceed that way.” They did, and it shortened the surgery to just 12 hours. It was so successful.

These fathers’ stories are illustrative not only of how priesthood blessings help to meet the needs of their child but how they can also be helpful to the father in gaining personal faith and perspective.

**Child’s Effect on Father**

Finally, each of the fathers experienced certain outcomes or effects
through fathering their child. These fathers described increased empathy, patience, tenderness, humility, submissiveness, as well as understanding more clearly the purpose of fathering in the context of a divine “eternal plan.” They felt they had put life in perspective and become more sensitive to others with special needs. The responses in this particular category tended to be more descriptive in nature rather than the more structured narrative or story form.

Lance

I’m more thoughtful and patient, not that I’m perfect on all occasions, but I’m certainly more tender with the children in general.

Ryan

I’m not even near what I used to be. It was nothing for me to punch someone in a basketball game. I was a hot head. I was out of control. I was pretty obnoxious and ornery, and now I’m just mellow, don’t get excited. Things are in their proper perspective now. I don’t get excited over things that used to upset me. They’re just not important.

David

I’m a lot more conscientious about how I look at people. I recognize now that he is not going to follow the path that I took intellectually, Tyler isn’t going to be a scholar. I have become much more sensitive to his worth as a person outside of his scholastic ability and that has impacted the way I look at people in general, how I judge people. That there’s worth outside of their grade point average, and education. He’s got some great talents, some great gifts.

Todd

I’ve become more sensitive, more thoughtful, more empathic, you know as far as growing and changing and adapting.
Eric

Another significant thing that I’ve learned is that Benjamin, as a person and as a situation, has served to kind of jerk me back to what’s really important. Early on in my career when I came to BYU, I got involved in a big research study with IBM. I was working with their (CIO), one of the most senior I.T. people in the world. We were planning on going to dinner that evening. Well, for some reason I thought I’d drop by my office and check my voice mail. The first message was from my wife, she said, “Benjamin has run away from home.” My heart just sank. He was on this medication that he had to have two times a day. He couldn’t go out roughing it for a few days. So all of a sudden that was all that was important. I told Dave and all of ‘em, “Sorry, I can’t go to dinner.” I just rushed home and my wife showed me this little note he had left on his bed. I just started driving around the area, for some reason I just happened to turn in to Fred Meyer and there was Benjamin’s bike sitting out front. So I parked the car and literally ran up and down the aisles until I found him. He had a bottle of Sprite and a bag of Doritos. He was headed for California and [he had] stocked up on food. When he saw me, I could see this moment of panic in his face and I just knelt down and hugged him and we got out to the car and drove around for a little bit. I just sat there thinking and I said, “Benjamin, what’s going on?” And he said, “Dad, I don’t know you. You’re never home.” You know, at that moment, I was a bishop, I had a wonderful wife, I had wonderful children, I was getting research awards, I mean my every measure I was on top of the world, and in one instant he put it all into focus.

Eric further related how since this experience with Benjamin, he frequently “checks in” with his children to see how he is doing as a father. He mentioned that there have been several times when his children have taken the opportunity to bring him back into focus and put things in perspective.

Summary Narrative

A summary narrative was created to try to capture the essence of these six fathers’ experiences. The narrative was sent to each father for a response with a numeric evaluation. A few chose to include written feedback or comments. Five
of the six fathers rated the narrative a “5,” (indicating a very high degree of congruence between the summary narrative and fathers’ lived experiences) and one father a “3.5”. Feedback from one father was noted and the summary narrative changed slightly to reflect his comments. The inter-rater checks and the member checks/verification by respondents were two additional criteria of credibility that were used to check the “fit” between the constructed reality of the respondent and the reconstructions or interpretations attributed to them by the researcher. The summary narrative reads as follows:

Upon diagnosis or learning of their child’s special need LDS fathers experienced a range of thoughts and emotions. These ranged from uncertainty and questioning to a feeling of instant love and acceptance for the child. Following this initial response, fathers’ experiences seemed to revolve around their religious beliefs, practices, and resources and an experiencing of certain challenges and demands. Some of the most salient resources for these fathers were marital support, reliance on religious beliefs, religious practices, ordinances, and communities. Some of the most difficult challenges and demands experienced by these fathers’ included physical constraints, medical and educational demands, and challenges with religious communities. As these fathers made meaning based on the resources and demands facing them, each chose to strive to connect with and care for his child. Fathers’ efforts to connect and care for their children are illustrated by their stories of father involvement and care. Fathers choose to be involved in many ways, some of these included; medical and educational involvement and intimate involvement (e.g., communicating openly, physical affection, playing and singing with child, etc.). Finally, each of the fathers reported feeling as though they had undergone a change as a result of their experience fathering their children. Some of these reported changes included increased empathy, patience, tenderness, humility, submissiveness, understanding more clearly the purpose of fathering in context of an eternal plan, life put in perspective, and becoming more sensitive to others with special needs.
Discussion

This section contains a conceptual model that illustrates the major findings of this research and a discussion of the implications for professional practice and future research in this area.

Generative Narrative Process Framework

These findings are consistent with research which indicates that disabled children have a positive effect on family life and that such a challenge can strengthen the marriage and bring families closer together (Darling & Darling, 1982; Dollahite, et al., 1998; Krause-Ehart, 1981, April; Lamb & Laumann-Billings, 1997; Palkovitz, 1998).

Concepts from the Generative Fathering and Crisis/Stress Resource Management theories have been combined with the data from this study to form a model called The Generative Narrative Process Framework (GNPF, see figure 2). The GNPF illustrates the process that these fathers went through and is another (more traditional) way of summarizing the findings (in addition to the summary narrative presented earlier). The GNPF seems to have some validity, relating closely to many areas of these fathers lived experiences. This framework includes four phases:

Phase I: Conditions/Challenges

Consistent with extant scholarship, the diagnosis of their child’s disability was a critical juncture for fathers. The fathers in this study reported feeling a serious of mixed emotions; feelings of fear, despair, disappointment, isolation,
Figure 2.Generative Narrative Process Framework
and most reported later feeling an outpouring of love and acceptance for their child.

Phase I includes the “A” factor or the stressor (special needs child). Dollahite (1991) stated “the initial phase begins when a potentially challenging circumstance enters the individual or family system.” The “A” factor is the challenge that is presented eliciting or “calling forth” a response.

Phase II: Meaning Construction Narrative

Fathers in this study made meaning through a combination of resources, such as: religious beliefs, religious practices, drawing upon the strength of their marital relationship, relying on religious communities, and considering demands such as: physical constraints, medical and educational professionals, and religious communities and leaders.

The second phase of the GNPF includes the revised concepts from the “B,” “C,” and “D” factors from the Dollahite (1991) model. This phase involves how a father may perceive his situation, or construct meaning by comparing the resources (e.g., marital relationship, own personal strengths, religious beliefs, religious communities) with the demands (e.g., physical demands, lack of information, meeting needs of other children, medical and educational systems). The comparison of both the resources and the demands (“B” and “D” factors) of the situation may contribute to how a father defines, or makes meaning of the situation, or (“C” factor).
Demands/Challenges of the Situation ("D" Factor). The challenges and demands facing the fathers in this study included, (a) dependency upon others, especially medical professionals and others who specialize in the treatment of the child’s special need; (b) scarcity of some resources (e.g., money, time, energy, information); (c) a potential for higher levels of stress/tension (i.e., managing stress from both home and work, lack of information, trouble working with health insurance companies, increased demands to nurture marital and other father-child relationships, physical demands of child); (d) isolation/aloneness resulting from a lack of support networks (i.e., unsupportive or indifferent members of their religious community, distance of extended family). None of the fathers interviewed in this study reported or manifested any of the negative effects previously reported in the research. On the contrary, they tended to respond to and care for the needs of their children, and many reported much personal and spiritual growth.

Coping Resources and Capabilities ("B" Factor). Having a special needs child potentially enhances the resources for generative fathering (e.g., provides a context to draw upon internal resources/strengths and resources external to the family system in meeting the needs of the child) as well as increasing the potential demands of the situation (e.g., financial demands, decreased stability, and strain on time and energy).

Findings in pattern/thematic analysis indicate that marital support, religious beliefs, and religious practices were useful resources for helping these
fathers meet the needs of their child(ren) with special needs.

Definition of the Situation ("C" Factor). It was primarily through the medium of a story/narrative, and the interpretations they placed on these stories, that fathers' expressed the meaning ("C" factor) or sense of coherence derived from both internal and external environments and the comparative interplay of the demands/challenges and resources/opportunities available to them. Through the consideration of both the coping resources available to them and the demands of having a child with special needs, these fathers storied their experience in such a way that led them to feel confident about meeting the needs of their children.

Phase III: Work/Action (Involvement)

Fathers worked for the benefit of their special needs children in a variety of ways. Fathers became involved by storytelling, communicating openly about the disability, interviewing medical professionals and doing medical research on behalf of child, singing at night to child, playing/wrestling, teaching child about his/her special need, showing affection verbally and physically, spending individual time, and becoming involved educationally as well as with other programs. Each of these behaviors conceptually fall within the generative work component, or the "Y" factor of the framework.

If the father chose to define the situation in a "generative way," (i.e., a hopeful, positive, faithful way), the intended result was generative work or involvement ("Y" factor) to meet the needs of the child. In contrast, if the father had constructed negative meaning regarding his situation, there was potentially
either a lack of involvement or a resulting nongenerative behavior. As expected, several of these fathers related experiences when they handled stressful situations in a nongenerative manner. This seemed to be due largely to a lack of information regarding the child’s special need. This was especially true in cases where the child’s special need was not readily detectable. While these “nongenerative narratives” existed, they were so isolated, they didn’t constitute a separate category to be included in the description of fathers’ experiences from the study.

Fathers reported that their experiences are unique and distinct from their wives’ experiences. Their primary emphasis was on how their involvement complemented their wives’ involvement in meeting the needs of their child. Each of the fathers suggested there were both strengths and limitations in each partner, and most reported that the ways they were involved was based primarily on each other’s strengths.

Phase IV: Generative and Nongenerative Outcomes (“Z” factor)

Outcomes were not systematically assessed, although the narratives have provided suggestive information regarding such outcomes. Fathers who became involved in the lives of their special needs child talked about ways that they had changed as a result, becoming more patient, empathic, sensitive to others needs, gaining new perspective, etc.

Fathers’ narrative accounts were rich with descriptions of how their lives have been positively affected as a result of being involved in their children’s
lives. Fathers’ stories conveyed experiences of continual growth and change as they became more aware of their own prejudice, put life in perspective, became more submissive and humble, relied more on their religious communities and faith, and became more thoughtful, patient, tender, and empathic.

The arrows on the framework suggest that this process is not linear; rather it is a process of fathers’ repeated construction and reconstruction of meaning, adapting and readapting of behavior and thinking, and continually changing outcomes. The changes fathers’ experienced are related to the ongoing telling and retelling of narratives, potentially influencing the demands and resources present in the fathers’ construction of meaning.

Conceptual work is needed to make this framework more inclusive of the depth and breadth of these fathers experiences. It is presented here only as tentative effort at conceptual illustration of the process of father’s experiences.

Application

Many different types of professionals (e.g., family life educators, special education teachers, medical doctors and nurses, mental health professionals) interact with families with special needs children. This section will address implications from this research for such professionals generally as well as make some specific suggestions for clinicians.

General Implications

The following suggestions stem from this research, and are meant for professionals interacting with such families, these are: (1) strengthen/support the
marital unit; (2) encourage parenting based on complementarity; and (3) focus on the value and strength of religious beliefs, practices, and communities.

**Marital Relationship.** Findings from this study are consistent with theory and research which have shown that strengthening the marital relationship can positively effect the father–child relationship (Doherty et al., 1998). The fathers interviewed in this study reported that their marital relationship was a helpful resource in meeting the challenges of a special needs child. This suggests that a strong marriage can provide a valuable coping resource which may contribute to the father making meaning based on his strengths and capabilities, consistent with the “B” and “C” factors of the GNPF. Professionals should be mindful of the value of the marital relationship as a resource when intervening with and educating such families.

**Relational Complementarity.** Complementarity suggests that mothers and fathers become involved in their children’s lives based on each parent’s strengths rather than on traditional gender or social norms. In a few cases, fathers related experiences where only they were able to meet a need of their child; these were primarily related to challenges where the fathers’ physical strength was necessary to meet the demands of a child. A majority of the fathers reported that their involvement in their children’s lives was based on each spouse’s strengths, complementing each other’s capabilities. This system of complementarity not only worked well for meeting the needs of their children, but was a potential source for strengthening the marital and family relationships. Departure from
stereotypical male/female roles with a focus on what strengths spouses have may prove beneficial for supporting, intervening with, and educating such families.

**Religious resources.** This research confirmed other research that religious beliefs, practices, and communities can provide much needed support in stressful situations (Pargament, 1997). Professionals can use this knowledge to help families consider the potential value of religious beliefs, practices, and communities in meeting the needs of a child with special needs. Professionals working with such families must consider individual needs and the context of their challenges to determine which practices may or may not be helpful.

**Clinical Implications**

Although families with special needs children do not constitute a large part of the clinical population, there are definite implications of this research for clinical practice. The results of this research are consistent with clinical theory and practice that pathologizing or labeling clients is neither appropriate or helpful.

An effective method of treatment of families relies heavily upon intervention at the family level. Families facing challenges with a special needs child may find already existing patterns of problematic relating exacerbated. Many families learn to adapt, but still others may find it difficult to meet the challenges inherent in parenting a child with special needs; in such circumstances, marital and family therapy may prove beneficial.
Dienhart & Dollahite (1997) have integrated concepts from generative fathering and narrative therapy to suggest that through the identification or creation of alternative generative narrative accounts, fathers may create new meanings, bringing desirable possibilities that are more helpful, satisfying, and open-ended in their attempts to generatively father a special needs child. These authors also suggest that listening to fathers’ stories provides an opportunity to draw out their contributions to the children’s lives and point out their resourcefulness in meeting the challenges of parenting.

The following clinical suggestions stem from this research: generative fathering, solution-focused therapy (de Shazer, 1984, 1989), and narrative therapy (White, 1989) concepts and are meant to apply to a more clinical population. (1) Fathers have control over the way they make/construct meaning surrounding the child’s special need; (2) the therapist must engage in a collaborative and empowering therapeutic relationship to challenge a father’s deficit and/or pathologizing descriptions of himself and/or others; (3) therapy must focus on the strengths and capabilities fathers have and explore times when the challenges and constraints facing the father did not dominate the self-narrative (story the father tells himself and others about his experience); and (4) movement towards more “generative” behavior depends in part on the fathers’ “re-storying,” his experience (i.e., creating a narrative which emphasizes the fathers’ past, present, and future influence over the course of their lives and challenges).
Limitations and future research

There are several limitations of this research. The micro-focus on the fathers’ experiences in the family was a limitation. The exclusive focus on the father in such circumstances was deemed necessary based on the scant literature. However, future research should assess multiple perspectives (e.g., mother, siblings, children, grandparents) to create a more holistic picture of the work of fathers in such families. Second, the sample used in this study was highly religious and comprised of men who were probably more likely to be involved in their children’s lives than the general population of fathers of special needs children. Although the method used in this research did not necessitate a comparison group, future research could include a sample of fathers of a lower SES, different ethnic background, and from different religions in order to contrast and compare experiences. Third, although the interview was designed to explore the challenges and demands of fathers’ experience, more attention could have been given to the stressors, difficult adjustments, and pain that such families experience. The questions lacked in soliciting narratives when fathers were not being involved in their children’s lives or were involved in ways that were not as generative or helpful for their children. Future research should investigate when the father felt he wasn’t being the type of father he wanted to be. Future research may benefit by grounded theory techniques which examine process over time and contextual factors of experience. Because fathers’ reactions to a special needs child are mixed, future research, including “studies of factors relating to
successful adaptation by fathers” (Bristol & Gallagher, 1986), is needed to understand this relationship.

Though connections made here are preliminary and conceptual in nature, the implications for future research and development of clinical theory are apparent. There is a continuous need for more research focused on fathers in families from a non-deficit (Doherty, 1991), capabilities, and strengths paradigm.
Appendix A

Statement of Purpose

The following information is for the interviewer and to explain the purpose of the project to the fathers.

I am interviewing fathers for a project conducted by Dr. David Dollahite of Brigham Young University in Provo, Utah.

The purpose of this project is to gather experiences, ideas, and suggestions from fathers who have a child or children with a special need. This can help us to (a) explore how father’s stories of their experiences with a special needs child can help other fathers facing similar challenges, (b) learn ways in which fathers are able to connect with and care for their children, and (c) explore how fathers are able to draw upon resources (i.e., faith, religious beliefs and practices, family, communities, special programs for children with special needs, etc.) to connect with and find special meaning in fathering their child.

The interviews will be audio-taped and transcribed. Rather than paying you for your participation, copies of the audio tape of the interview and a written transcript will be provided to you along with a disk copy of the transcribed interview. From past experience, participants greatly appreciate having a copy on disk of their interview since they can then make this part of their family history.

I would like to explain some things about your participation in the project and then ask you to sign what we call an “Informed Consent Form” which indicates that you understand the purpose of the project, the ways this information may be used, and the ways we will protect your privacy.

Interviewer then reads the information in the informed consent form, has the father sign and date it, and then signs where it says “witness.”
Informed Consent Form

I acknowledge that I have had the purposes of this project explained to me and I hereby give my consent to be interviewed for this research project.

I understand that the research project I am involved in is collecting narrative accounts (stories) from fathers to be used to better understand fathering with children with special needs and to help promote good fathering.

I understand that my privacy will be protected by the researchers in the following ways: (a) my name and the name of my family member will never be used when the experiences I share are discussed in written publication based on this research (unless I specifically and in writing request that my name and child’s name be used), (b) I can request that any story I tell be deleted from the written transcript of the interview.

I understand that I am free to decline to answer any question I do not wish to answer and that at any time I wish I can end the interview.

I understand that I will be given an audio tape and written transcript and a disk of the transcribed interview as a form of compensation for my participation in this project.

_______________________________  ______________________________
Signed  Witness

______________________________
Date
INTERVIEW SCHEDULE

Fathering a child with special needs:

To begin, I'm going to ask you a few questions that pertain to your fathering your child with a special need. There are eleven questions with three parts to each. First, I will ask a general question. Next, I will ask for a specific experience from your life, and lastly I will ask you a question related to what meaning that experience might hold in your life today or how you are different because of your experience.

What is the name and the age of your child with a special need? (Insert the child’s name where appropriate throughout the interview)

Child’s Name______________________________
AGE____

Probe for a specific experience and ask meaning/interpretive question for each:

1. What were some of the initial feelings and thoughts you had when your learned of ___________ special need?

2. What 2 or 3 things have been the most meaningful to you in helping you to be the father you want to be for ________________?

3. What are some of the things that you have done well in your family to meet ___________’s needs?

4. What might be some of the greatest challenges you have faced in being a father of a child with special needs?

5. What has been your experience with the health care system, special education programs, support systems, and the communities in which you participate?

6. Are there specific people you have learned the most from in meeting ___________’s needs?
Some research shows that fathers of children with special needs have unique experiences that are different from mothers or from other fathers.

7. In general, what are some of the experiences you have had unique to being a father of a special needs child?

8. Can you relate a story when only you were able to meet a need for your child when no one else could?

9. Are there ways in which how you responded initially to ____________ or now approach him/her affect other family members in how they first responded to and now approach him/her?

10. Are there ways in which you believe that fathering a special needs child has changed you in significant ways?

11. What advise or suggestions would you make to another father who has a child with a special need?

**Faith in Fathering**

The last part of our interview we will be asking you some questions about your religious beliefs, faith, and practices as they relate to your fathering your child with special needs. As before each question will have three parts, a general question, a question for a specific experience, and an interpretation question or what meaning that experience holds for you in your life today.

12. Do your spiritual/religious beliefs influence the way you father your children (special needs or otherwise). If yes, how so?

13. What are some of your deepest and strongest spiritual beliefs (relating to your fatherhood, to your children, to your family)?

14. Is there a religious practice or ritual, or tradition (ordinance, ceremony, personal habit, worship, etc.) which holds special meaning for you as a father?

15. Are there any religious beliefs, practices, traditions, or rituals that have been burdensome or less than helpful to you as a father of a special needs child?

16. Has your religious community/congregation helped you to meet your children’s needs? In what ways?

17. Can you recall a time when you began to understand you had a special
role/calling/responsibility in the life of your child?

18. Looking back, is there one experience which especially helped you to commit to be the best father you could be?

19. Can you share with us a sacred or spiritual experience you have had with your child?

20. [For LDS fathers] In what ways is the temple and the idea of eternal families meaningful and/or helpful to you as a father?
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