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AN INQUIRY INTO THE LIFE EXPERIENCES
OF THREE SINGLE MOTHERS
OF CHILDREN WITH SPECIAL NEEDS

KRISTEN M. GOMEZ

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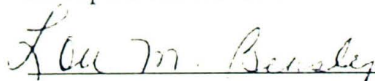
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A Thesis

Presented for the Master of Science

Degree

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Kristen M. Gomez

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DEDICATION

This thesis is dedicated to my husband

Brent Gomez

and my parents

Richard and Dorothy Bever

for their support and encouragement.

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ABSTRACT

This study explored the experience of three single mothers who had children with special needs. The special needs of these children varied depending on the nature of their developmental disabilities. Structured interview questions served as prompts to facilitate a discussion about the thoughts and experiences these single mothers had in regards to their adaptation and experiences with community programs. The interviews were transcribed and interpreted using comparative analysis of the transcriptions by three readers to find common themes. Themes that emerged were: focus on day to day challenges, family as a resource, child care needs, navigating the system, and advising a positive attitude. The findings offer insight into the vast challenges and adaptation experiences for single mothers who have children with special needs.

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CHAPTER 1

INTRODUCTION

Raising children is often referred to as the hardest job you will ever love. That job can be especially challenging if your child has special needs. Families who have children with a disability often face emotional and financial stress that can place strain on relationships and the family system as a whole. The situation can be further challenged when that family consists of a single parent who is taking on the increased responsibility.

Over the past three decades our society had made great advances towards providing much needed services to persons with developmental disabilities and their families in an effort to relieve some of the stress and increase the level of care available. Legislation passed in 1975, PL 94-142, titled the Education of All Handicapped Children Act, addressed the need for children with disabilities to be in the least restrictive environment, resulting in mainstreaming for children with disabilities. Mainstreaming allowed for children to stay in the regular classroom whenever possible, allowing them to interact and learn with their peers. The Individuals with Disabilities Education Act, PL 101-476 followed in 1990. This legislation added new categories of disabilities to the original legislation along with addressing needs such as rehabilitation counseling, social work services for children and adults with disabilities (Hardman, Drew, & Egan, 1999).

As legislation increased services for people with disabilities, so have early intervention services designed to address the needs of infants and preschool aged children with disabilities. Services in early intervention have currently geared towards utilization of community resources versus the former institutional settings. Early intervention services, designed for children age birth to three years old vary greatly from state to state

with different titles and differences in services provided. Overall, the early intervention services are designed around an Individualized Family Services Plan (IFSP). Each plan is designed to meet the needs of the child and the family as a whole. Typical interventions outlined in the IFSP are therapeutic services such as physical therapy, occupational therapy and service coordination needs such as assistance with transitioning a child to the preschool system. The plan is designed to meet the needs of not only the child with the disability but also the needs of the family, which can involve various community resources. There has been extensive research done looking at the effectiveness of early intervention programming. Predominantly, the research pertaining to children with disabilities and their families has been designed to look at the delivery styles of service, the assessment of children for enrollment into services, the involvement of parents and educators on program effectiveness, and the outcomes of service delivery (Hardman, Drew, & Egan, 1999).

The quality of services to people with disabilities is an important factor in providing both financial and emotional support for families. The needs of the family do not stop with community programs. The dynamics of a family are forever changed when they have a child with a disability. Early intervention programs are vital to the health of the child and therefore the health of the family, yet there are factors influencing the healthy adaptation of the family which remain to be addressed. Research has predominantly focused on the adaptation of two parent families, leaving many unanswered questions about the struggles that face single mothers. The needs of single mothers must first be understood in order to design quality services.

Introduction of an infant with a severe disability into a family brings new challenges. Just as the family is forever changed by birth of the child with a disability, the responses of that family forever affect the child (Crnic, Friedrich & Greenberg, 1983). The way a family changes and adapts to new challenges has a profound affect on the life of the child with a disability. Being cognizant of the ways in which single mothers adapt, change and the struggles they face along the way is imperative for our understanding of the services that these families need.

The focus of this study will be on the lived experiences of single mothers as they adapt to their life with a special needs child. This study will attempt to uncover information gathered from interviews with single mothers who have children with a severe developmental disability in order to construct themes in an attempt to reveal information about the adaptation process. It is hoped that the data collected from the interviews will enhance the understanding of the experiences and needs of these three families. This research is intended to give a voice to single mothers who have children with special needs.

Two-Parent Family Research

Literature regarding the adaptation process of families who have a child with a disability has been primarily focused on two parent families. Within this body of literature the mother is most often the focus. Due to the abundance of research on two-parent families having a child with a disability, this literature along with the literature on single mothers contributes to the focus of this research.

Kazak (1987) researched three families who had children with a disability or chronic illness and compared those families to families whose children had no known

disability or illness. The parents in these families were compared with respect to personal stress, marital satisfaction, and social network size and density. Kazak used measures designed to assess general mental health and marital satisfaction. The differences Kazak found were in the mothers' personal stress and marital satisfaction scores. Results indicated that mothers who had children with a disability or chronic illness were found to be at risk for psychological distress. Kazak concluded that further research was needed to understand the demands placed on mothers to identify what their experiences are when they are caring for a child with special needs (1987).

Children with special needs often require more time from their caregiver for day-to-day caretaking. Erickson and Upshur (1989) studied perceived caretaking responsibilities and perceived social support among mothers of infants with and without disabilities. The total sample included 202 families, 85 of which did not have a child with a disability, leaving 117 families who had children with disabilities. The two-parent families all had children who were 2 years of age or younger. The families who had a child with a disability were all participants drawn from an early intervention collaborative study. The assessments used were all self-report and measured parent perception of caretaking and social support. Results indicated that there were indeed differences between the two groups of families. Mothers of children with developmental delays and with Down Syndrome reported more caretaking difficulty when compared to mothers of nondisabled infants of comparable age. The mothers who had an infant with a motor impairment did not report more difficulty in caretaking but did report that their child required more time for caretaking needs than the mothers of nondisabled children. In addition, those mothers who had a child with Down Syndrome also reported an overall

increase in the time it took to attend to the caretaking of their child and a decrease in the time that they had to attend to their own needs (Erickson & Upshur, 1989). A similar study found that in two-parent families mothers reported more overall caretaking responsibility. In addition these mothers perceived more difficulties with their own personal health, role restriction and spousal support (Roach, Orsmond, & Barratt, 1999).

It is interesting to note that married mothers actually report higher stress levels than do single parents who have a child with a disability. At first this may seem contradictory. One might assume that single parents have a larger burden than do married parents. Research has pointed out that there is a strong need for intervention programs that reach out to fathers of children with a disability. Married mothers are facing an increase in stress not only due to the caretaking of the child, but also the struggle to involve the father. Intervention for families is crucial and can serve as the support that a family needs, yet the data points to a need for intervention to encompass the family as a whole so that the spouses can be of support to one another (Honig & Winger, 1997).

Honig and Winger's findings not only showed a higher stress level in married mothers, their results also indicated that mothers of infants ages birth to two years of age report a higher level of stress than do mothers of preschoolers who have disabilities. The participants in the study reported that early intervention assisted them greatly with their ability to realistically understand the long-term prognosis and course of life for their children with disabilities. Honig and Winger strongly recommend early intervention as the key to providing much needed support for families who have children with a wide range of disabilities, while also pointing to a need for improvement on reaching out to the fathers whenever possible so as to increase the supportive network of the family.

According to Honig and Winger, it is imperative that early interventionists recognize the diversity of the families present in our society today. It is all too easy to fall into the habit of designing services around a very old concept of family, where there are two parents of opposite sex in the household with mother as primary caretaker and father as the income provider. There is no argument that family life affects children on many levels and that family means different things to different people. When designing intervention, it is imperative to be sensitive to the fact that our ever-changing pluralistic society is made up of a variety of family configurations. This sensitivity is not only important as it conveys respect to families, but it also is an essential part of providing comprehensive quality services that will be a support to the family, which in turn benefits the child (Vincent & Salisbury, 1988).

Parental stress is a commonly researched topic in relation to families who have a child with a disability. Research looking into parental stress, family functioning, and social support provides great insight as to the experiences of a family with a disabled child. Research completed comparing families with nondisabled children to those families with disabled children has consistently found that stress levels are higher in families who have children with disabilities (Dyson, 1997; Innocenti, Huh, & Boyce, 1992; Kazak, 1987). When the dynamics of the relationship between stress, family functioning and perceived social support are examined, vital information is revealed. As an example, Dyson (1997) found that as fathers perceived greater social support and a positive family relationship, the mothers indicated a lower stress level. Dyson's work provides data that would support the need for intervention to focus on improving family resources as a way to relieve stress within the family unit.

Another source of stress that is commonly researched is the stress that results when a child with a disability ages out of one type of service. Early intervention services assist families until the child turns three at which time the school district is responsible for providing the appropriate support and therapeutic services. This transition phase is commonly a source of great stress for parents as they face new challenges with a new system of service providers (Beavers, Hampson, Hulgus, & Beavers, 1986). Innocenti, Huh and Boyce (1992) point out in their research that it is important to individualize intervention services so that the source of stress is recognized and addressed. Parents of children with disabilities have the same hopes and fears about their children as do other parents, yet they are working to get services for their children in a system that can often produce an additional source of stress. Understanding the source of stress in a family who has a child with a disability is crucial to providing the highest quality of services to that family.

There is a need to look at issues related to depression in relation to raising children with disabilities. Glidden and Floyd (1997) performed a longitudinal study looking at parents of children with disabilities and based on their measures of adaptation and stress levels, they found that there was a great variance between individuals, yet overall most parents had adapted well over time. An interesting point that Glidden and Floyd stressed was that they noticed in their assessment of stress that depressive symptoms can be recognized from some parent responses. While it was not their aim to be measuring depression separate from stress, they did recognize in their years of studying families that this was a recurrent concern that should be studied further. While interventionists may not always be qualified mental health practitioners, they are often

the people who see the families the most often and therefore they need to be trained to see when mood disorders in parents are in need of attention.

Gowen, Johnson-Martin, Goldman, and Appelbaum (1989) researched feelings of depression among mothers of disabled children in comparison to a group of mothers with nondisabled children of the same age. No significant difference was found between the two groups, despite the caregiving demands of parents who have children with disabilities. Mothers who had children with a disability reported that their sources of stress were marital problems, health problems of their child, inadequate resources and disciplining their disabled children. The results cannot be considered without also considering the sample, which was predominantly white, middle-class and well educated. Regardless of the amount of stress, there is stress in families who have children with disabilities and these sources of stress provide important information for intervention.

Intervention aims to assist families in coping and adapting. Frey, Greenberg and Fewell (1989) found that parent's belief systems, coping styles, and social networks were all related to the success of coping in families who had children with disabilities. While intervention is not intended to change a person's belief system, it is aimed at assisting families with accepting their new challenges, helping them to cope and assisting with utilization of resources.

A recent study looking at how two parent families of children with cerebral palsy coped emphasized the need for research to shift from looking at the negative aspects experienced by families of children with disabilities to looking at the positives of how these families adapt (Shu-Li, 2000). The key to understanding how intervention should progress from this point on is with the families themselves. Going to the families directly

and finding out what is beneficial to them as they adapt and what they have found to be unbeneficial may prove to be instrumental in bringing new information to light which can be significant in designing quality services.

The literature regarding two parent families of children with disabilities contributes valuable information that brings to light the variety of issues and concerns that families encounter. As with many groups of people, there are more similarities that bind us together than there are differences. In an effort to understand and address those differences among single mothers of children with disabilities, several empirically based studies using single mothers as the sample have been reviewed.

Single Parent Family Research

An area of great concern that arises in single parent families of children with disabilities is that they often experience a lack of community involvement due to the caretaking tasks involved in raising a child with a disability. It is this researchers experience that the void of involvement in social organizations can be a compounding stressor to a single mother who may already be experiencing low self esteem. Unfortunately, this researcher has seen all too often, mothers who blame themselves for their child's disability, resulting in a battle with a myriad of complex feelings. Low self esteem, lack of community involvement and support, low cognitive skills and dissatisfaction with life are not only difficult struggles for a single mother to face, they are also risk factors for child abuse.

Child abuse is a topic that is of great concern when designing intervention for families of disabled children. Caretaking demands, financial struggles and self-esteem struggles are all areas that can quickly become overwhelming for a single parent.

Research does not say that single parents of children with disabilities have a higher incidence of child abuse, rather they experience more of the risk factors associated with child abuse. Therefore, as emphasized earlier, there is a need for intervention services to include linking single mothers with community programs and supports. Respite from caretaking is also a vital component of intervention for single parents. Finding quality care for a child when they are outside their parents care is a challenge for any family, and it is often a dire challenge for single parents of children with disabilities. Children with disabilities often require special attention for medical or physical needs that typical care providers are uncomfortable with. Intervention that assists single parents find quality, reliable respite providers can be an invaluable asset to the family (Krikham, Schinke, Schilling, Meltzer, & Norelius, 1986; Wilker, Haack, & Intagliata 1984; Bristol, Reichie, & Thomas, 1987). Finding respite care that can be affordable, and still meet the needs of the child and parent can be difficult to obtain. Many community mental health agencies have become involved in the business of assisting families with this task. While the families are still individually responsible for the payment and supervision of the respite services, community mental health agencies will provide lists of approved providers and assist families in navigating through a system that is unfamiliar territory.

Research indicates that single parents of children with disabilities are predominantly female (Boyce, Miller, White & Godfrey, 1995). As noted earlier, there are more similarities between single parent families of children with disabilities and two parent families of children with disabilities. The differences start to appear when the socioeconomic factors are considered. The literature shows that single mothers of children with disabilities are often younger than married mothers and have less education

and lower incomes (Boyce, Miller, White & Godfrey, 1995; Hanson, Heims, Julian, & Sussman, 1995). Inadequate resources, low access to social support and economic pressure are consistently found to put single parents at risk for increased negative life events which in turn contribute to psychological distress (Simons, Beaman, Conger, & Chao, 1993).

When the socioeconomic factors are controlled there appear to be no differences in stress and adaptation of these families. While there may not be differences between the two groups, researchers indicate that the interplay between stress and adaptation needs to be further explored in single parent families in order to better facilitate coping. Positive adaptation of single parent families is just as likely as it is for two parent families. Assessing and building upon family strengths and competencies is the key to successful intervention (Boyce, Miller, White & Godfrey, 1995; Hanson, Heims, Julian, & Sussman, 1995; McCubbin, 1989).

Research by McCubbin (1989), indicated that single parent families of children with disabilities had some unique differences when it comes to flexibility of rules, power structure and role relationships. McCubbin's research indicated that single parent families of children with disabilities seem to have found flexibility as an invaluable asset to adaptation. Day to day routines were more flexible and adaptable to the unforeseeable disruptions and changes that often occur when there are a multitude of service providers that attend to the needs of a child with a disability. Decision making was also flexible and negotiable, allowing for a more team concept in the day to day running of the house.

Single parents of children with disabilities are rarely specified as being divorced or widowed in the available literature. Some unique concerns related to divorced single

parents have been noted (Wikler, Haack, & Intagliata, 1984). Divorced mothers of children with disabilities are experiencing post divorce distress that carries its own set of concerns that complicate the adaptation process. These mothers have the strains of meeting new challenges on both a practical and social level. While this group of mothers has not been shown to experience lower levels of long-term successful adaptation, there are nonetheless unique adaptation factors that they are experiencing. Financial stress is one of those factors. The newly single mother may not be accustomed to being the primary wage earner and may find herself in this position after a divorce (Wikler, Haack, & Intagliata, 1984).

Social isolation is another factor that can complicate the life of the newly divorced single parent. Along with the financial, emotional, and family structure changes, there can be dramatic changes in social relationships. During and after a divorce, relationships with friends and family members can alter and become uncomfortable or strained. Parents may have had great success finding a social support network while they were married, which unfortunately can change dramatically after a divorce. Social isolation is in no way unique to single parents who have gone through a divorce, rather it is a factor affecting two parent families as well, yet there are differences in what the single parent experiences which are important (Wikler, Haack, & Intagliata, 1984). Research also suggests that while parents of children with disabilities are no more likely to remain single than the general single parent population, there are unique concerns and challenges that a single parent of a child with a disability faces when considering marriage or remarriage. Many of these concerns center around the stigma attached to having a child with a disability (Cooke, Bradshaw, Lawton, & Brewer, 1986).

Persons with disabilities and their families may experience avoidance from friends, judgmental remarks, and social ostracism (Wikler, Haack, & Intagliata, 1984). These types of experiences are stressors that the single parent has to deal with often without adequate social support and in addition to the stigma attached to being divorced.

Divorced people are at a higher risk for psychological distress and physical illness than the married population (Wickler, Haack, & Intagliata, 1984). These risks pose unique challenges to designing intervention that benefits the divorced single mothers of children with disabilities. Intervention programs need to be aware of their professional responsibilities in referring families to professionals who can best assist family members who have psychological needs that warrant therapeutic intervention. As it stands now, early intervention services do include provisions for psychological services for children but they do not provide these services for parents (Wikler, Haack, Intagliata, 1984).

CHAPTER II

METHODS

Statement of Rationale

The literature on single parents of children with disabilities suggests that there is a strong need for further investigation into what single parents are doing to help themselves adapt. The need expressed was for investigation of the adaptation process that allows for the parents themselves to express what they are doing that is working for them and what is perhaps not working for them (Hanson, Heims, Julian, & Sussman, 1995; Kirkham, Schinke, Schilling, Meltzer, & Norelius, 1986; Boyce, Miller, White & Godfrey, 1995). According to Kvale (1996), the qualitative research interview is a mechanism through which the researcher can gain an understanding of the participants world. The interview method allows the participants to reveal their point of view about their experiences and what those experiences have meant to them. The qualitative research interview allows the participant to reveal their real lived experiences to the researcher. The interviewer is a traveler during the research process, walking through the world of the participant (Kvale, 1996).

Participants

The participants in the study were three single mothers who have children under age three with a developmental disability. Participants were chosen from this researcher's current client list from employment with an early intervention program. Participants were chosen based on their status as single mothers, and the fact that their children required a full team of therapists through early intervention. This team included a speech therapist, occupational therapist, physical therapist and a developmental

interventionist. Participants were also chosen based on this researcher's knowledge of their comfort level in talking to this researcher, based on the fact that all participants have been working with this researcher for over 12 months.

This researcher's relationship with the clients is one based on completion of the required paperwork for the state's early intervention program. The paperwork is completed by this researcher in order to keep services that are chosen and identified by the family and their team of service providers. This researcher has no authority to choose service providers for clients, nor the authority to enroll or discharge clients from the program. This researcher keeps in contact with clients to ensure that the contract, which is the individualized family service plan, between families and the service providers, such as a speech therapist, is being honored. This researcher has no authority to make changes in client's services and therefore these participants are not in jeopardy of service changes due to participation or lack of participation in this study. Participants were notified before the interview was conducted that their participation was voluntary and that the interview would be transcribed from audiotapes, by this researcher only. Participants were also notified that this researcher's faculty supervisor and graduate assistant would read written transcriptions for the purpose of conducting an analysis of the information gained.

Procedure

The procedural specifics of this qualitative interview design have emerged from information provided in several qualitative research guides (Creswell, 1998; Marshall & Rossman, 1989; McCracken, 1988; Kvale, 1996; Polit & Hungler, 1995). This researcher has worked with clients of all ages who have developmental disabilities and their families

for 10 years. Currently this researcher works as a service coordinator in early intervention. As an early intervention coordinator this researcher works with families who have children ages birth to three years old with developmental disabilities. All the children of the participants in this study had a developmental disability diagnoses that were known to put them at high risk for life long developmental delay. It is this researcher's experience that the mothers of children with severe diagnoses experienced a high degree of change and thus adaptation in their life. Quality of the data gathered would be contingent upon the depth of experience by the participant and their willingness to share their experience with the researcher (Hinojosa et al., 2001; Morse, 2000). The sample size was limited to allow for in depth information gathering therefore generalizability would be limited. The purpose of this qualitative interview was to obtain quality data by traveling through the experiences of the three single mothers from their point of view (Morse, 2000; Kvale, 1996).

Interview questions were formulated from a panel of early intervention professionals, (see appendix A). The professionals were asked what questions they perceived would be helpful in understanding the needs of single mothers with infants who have disabilities. These questions were then discussed with this researcher's faculty supervisor and subsequently refined to a series of prompts to facilitate information gathering. These prompts were then taken back to the initial group of professionals to ensure that the questions were prompting the types of information intended by this researcher. After this process was completed the final list of prompting questions was derived as appears in Appendix A.

The interviews took place in the homes of the participants. The interview questions served as prompts to facilitate discussion between the parent and this researcher. The goal was to retrieve information regarding how the parent perceived their world. As interviewer, this researcher was active in the interview, clarifying information as it was provided. Each interview lasted between 60 and 90 minutes. Participants first completed an informed consent form and then were asked to explain a little about themselves and their child with special needs. Each participant was asked all five of the questions and clarifying questions were asked as needed. Interviews were audio taped and transcribed with all identifying information removed. The researcher and two other readers consisting of a faculty supervisor and a graduate student were involved in analysis of the data. Each reader was given a copy of the three transcriptions to review independently. Each reviewer then gave feedback to this researcher and made comments on the transcriptions regarding themes and thoughts on particular interview statements. While each reviewer commented differently on the transcripts, all reviewers made comments on the themes explained in the results. Each reviewer made comments about consistent statements while one reviewer also made notes regarding any conflicting comments within the interviews. This researcher found that after all comments were reviewed the consistent themes were heavily agreed upon by each reviewer and therefore readily pulled from the data. This researcher carefully reviewed all transcripts and comments by readers repeatedly; themes that were consistently supported by the data were retained while themes that were not consistent were removed.

The process of analysis used by this researcher was a synthesis of different approaches outlined by Kvale (1996). The analysis approach used narrative structuring

along with meaning interpretation. Narrative structuring is where the data is reviewed and analyzed in an attempt to understand a coherent story from the interview. This approach allowed this researcher to develop potential meanings from the story that emerged from the participant's statements during the interview and as the transcripts were later reviewed. Meaning interpretation analysis was also used to assist in the analysis process. Meaning interpretation comes by taking statements of the participants and using them to create much broader themes and meanings (Kvale, 1996).

CHAPTER III

RESULTS

The following are the primary themes that this researcher saw as emerging through the analysis process. This section outlines the themes within the three interviews and comments made by participants that exemplify those themes. This researcher found that the participants themselves were able to make strong points that explain their experiences well.

Theme 1: Focus On Day To Day Challenges

When asked about the future, the participants consistently reported that they take things as they come. Each had goals for the future yet the demands placed on them had resulted in the philosophy that each day is important and thinking about each day as it comes was ultimately what occupied their thoughts and minds. Participants consistently expressed a positive attitude, commenting that they had many challenges to face daily, challenges which at times were overwhelming yet ultimately within their ability. Participants expressed that it was those day to day challenges that they consider to be a priority while the future remains in the back of their minds. It appeared that the thoughts of the future were overwhelming and anxiety provoking. Therefore, this focus on the day to day challenges was a coping strategy that emerged out of the experiences of these single mothers. The following comments from participants illustrate this theme.

Well we just take one day at a time and try not to focus on the negative. I mean, our basic needs are met. There are many things I wish we had. Times have been rough for me and [child's name] and we just get by with very little. I wish it were different, it's just going to take time before we can be more comfortable. We'll get there.

... see, I can't think about all the things that have gone wrong, just the things that are getting better. I take one day at a time because you never know if tomorrow will come for you. You know?

Hmm, my future. I guess I don't think about it as often as I should. It seems like just getting the day to day done is keeping me busy. I guess the future is a little scary for me. It's hard to make ends meet now and I stay real busy with work.

It has been an emotional roller coaster at times. At first I really worried about things. Now I know better. Things will work out, they always do. With [child's name], it just takes time. [child's name] will be just fine and we will be just fine together. I have my family around me and a job, things will get better with time. I have to stay positive.

Well, the most important thing is thinking about what [child's name] needs what [child's name] will be needing. Really I don't think about it. I just take one day at a time. I do what I can for [child's name] and [her older son]. I don't really think about tomorrow or even next week. I just take it one day at a time and do what I have to do to get through the day.

Ya, I've always been a day to day person. I believe in god and if you believe in god then you know that tomorrow is never promised to no one. If I worried about everything, I wouldn't be able to function, I just get through each day and hope there is a tomorrow. It's just extra strain to worry about things.

Theme 2: Family As A Resource

When asked about their experience as a single parent caretaker, two participants commonly referred to their reliance on others in their family to assist them. A third participant referred to family as a resource, yet a strained one due to the fact that her family had their own obligations that kept them from being able to assist as often as she needed it. There was a significant difference between the needs of the children whose families did assist frequently and the child whose family appeared to be less available for assisting with day to day care. In the case of the family that was reported to be less available, the child's needs were complicated involving breathing machines, suctioning, and a feeding tube.

The following comments from participants illustrate how family has been a resource to lean on for support, not only emotional and financial support but also support with child care.

Well like I said before, my parents have helped me a lot. I couldn't of done all that I have without them. They are the only ones I can trust to around [child's name]. I know that they know about his therapies and things. They understand our situation and can take care of him if I need them to.

Well, I don't really trust any one outside my family enough. I guess I just don't think that anyone could really understand what [child's name] needs and [child's name] is like. I mean, you know, he can be difficult at times. It just is too much for me to worry about. If he was with somebody who doesn't know him like family, I just think there might be problems. Since my family is usually available, or at least one of them is, then I just arrange my schedule so they can watch him.

She [child's maternal grandmother] will always be a very special part of [the child's] life. [child's name] has spent a lot of time with her and I know they will always be close. I guess it's just part of the life I have with her and the situation I'm in, being single and all. She has had to do ore that the traditional grandma stuff and I'm thankful for that. She and [child's name] are closer than just grandma and granddaughter.

. . . I wouldn't of been able to do a lot of things without having family around. I just hope to be more on my own in the future, get more on my own feet ya know.

We don't have a child care center equipped with things needed to take care of children like [child's name]. And another thing is it's hard to find people that you know and can trust to do things right. I mean my family is around to help, but they have to work too.

. . . my friends, they all love [child's name], they are always asking about [child's name]. If I don't have him with me, people are constantly asking about him Everybody loves him.

. . . I'm lucky I have family around, I don't know what I would do without them.

You need to open up to your family and let them help you out. I admit it's not easy, you want to do it on your own but you can't.

Theme 3: Child Care Needs

When participants were asked about their views on the support they receive and the unmet needs they still have, the issue of child care came up. It became clear that the participants had concerns in regards to financially meeting the cost of quality child care and finding quality child care that the participants could trust with the care of their special needs child. The following comments from participants illustrate this theme and the concerns.

Well, since I'm working, I get some assistance with child care...If I had to pay the child care bill and all my other bills, it would eat up my entire check. Day care is so expensive. I take [child's name] to a really nice day care, but it's important because the workers there pay attention to [child's name]. [child's name] isn't a normal child and [child's name] needs extra care. The day care workers are great and they pay attention to what [the child's] needs are and they work with her on her goals and things.

Well, I wish that there were good day cares that were open 24 hours. It would be nice because it's not as if the whole world works 8 to 4. I mean there are day cares open 24 hours but I looked and them....I would never leave [child's name] there.

... day care. It's so hard to get a head and pay for the cost of day care. There is assistance out there but it's not enough and it is hard to find a quality day care. I guess if I was dreaming up a service, I would say that I would really like it if the state or whoever would pay for me to hire a sitter to come into my home and watch [child's name] when I'm at work or school. I would get to interview the person or people and they would be available when I needed them. Day cares are so strict on times and routine. My life just doesn't always fit a 7am to 5pm schedule. Also, I must admit, sometimes it would be nice to get out of here for something other than work or school. So it would be nice if I had somebody I could trust to take care of [child's name].

We don't have a child care center equipped with things needed to take care of children like [child's name]. And another thing is it's hard to find people that you know and can trust to do things right We should have a facility here that is equipped, even if they can only take a few kids. We need that so that we can take our kids there and go on with our lives, lives outside of the home.

Theme 4: Navigating The System

Participants acknowledged several times that their experience of having a child with special needs had brought them into contact with agencies and resources that they never had experienced before. Some of the programs that they used were helpful and others were full of red tape that left them feeling lost. Their comments illustrate how overwhelming and difficult the system of services can sometimes be. Nevertheless, these single mothers had grateful comments to make about the parts of the system that they felt did work well.

. . . the First Steps [early intervention] program really has been helpful, extremely helpful, it may be the only program ever that is really helpful because other programs have all this criteria that you have to meet. You have to have a certain income, be going to school or have a job. I never did understand that, it's about the child. The child should never be denied the things they need

. . . the mental health center, that's been helpful, they've gotten us respite services.

I mean, really and truly, I think this area has failed children and adults with special needs, because like I said there is a lot still to be done that's not getting done. It's like you have to use a pitch fork to get them to do what they need to do. I have to stay on people a lot to do there jobs. And the paperwork involved, it's ridiculous, sometimes because of that paperwork, it takes months to get the things you need. And that's stress on a parent too. It's not fun to nag on people to get there job done, it's there job they need to do it. Children need what they need. If people don't do what their job is, they don't suffer, it's the children and the families that suffer.

. . . [child's name] loves to see the therapists coming over and he works well with them on his goals. He has improved a lot He also gets SSI and DCP which has helped pay for extra stuff like developmental toys and formula.

. . . I worry about the future. [child's name] is only eligible for early intervention until she is three. Then she has to get services from the school system. I know that will be different.

. . . the programs that I do benefit from are great. I wish there wasn't so much paperwork involved. It seems like I'm always having to keep up with so much stuff...Then I have to make sure my income is at the right level so that [child's name] can keep her medical card and her therapists are always needing signatures and testing [child's name] to keep her in that program.

... sometimes I get mad, it's like you have to really forget your pride sometimes. I work hard and then sometimes I feel like [child's name] and I get treated different because I do rely on her medical card and the assistance we get.

Theme 5: Advising A Positive Attitude

These three single mothers who have children with special needs all expressed the importance of keeping a positive attitude. Comments displayed that they found reaching out to others, and consistently advocating for the needs of the child, to be cornerstones to their success as mothers. The following comments illustrate this theme.

... you have to get out there and get to know other parents who have children with special needs ... it helps because people know about things that you might not know.

If you have a child with special needs, you have to learn to ask for help without letting it bother you.

... I don't get angry about the things I don't have or the opportunities that I have missed. I am a mother and that is my responsibility.

... it all just takes time and you have to learn to love and care for your child and not focus on the negative. I look at other children who have it a lot worse than [child's name] and I realize how blessed we are.

Get somebody to support you. Anybody! It really helps to be able to talk with somebody. I found that the more I can talk about it with people, the better I feel.

... be strong and get support and don't ever give up. They need to take one day at a time and don't ever give up, no matter how many doors get slammed in your face.

CHAPTER IV

DISCUSSION

Although the experiences of these three single mothers were different in many ways, there were definite themes that this researcher saw emerging from the interviews regarding the experiences of these single mothers. Identified in these themes are issues such as quality child care, respite services, adequate resources, stress related to finding and receiving services, and a series of adaptive behaviors which keep these single mothers forging on through their daily lives. These mothers have all had to change many aspects of their lives and their ways of thinking to adapt to the fact that they have children with special needs; special needs that have thrust them into experiences that were completely new to them. These experiences at times left them feeling depressed and angry. Even though their experiences were stressful, there is no doubt that these women have adapted and drawn strength from within.

The transcript of participant 3 evoked the most feedback from each reviewer. Each reviewer made comments regarding the intensity of the participant's comments and overall experience. It is this researcher's opinion that the intensity in participant three's interview is due to the fact that participant three's child has a very complex disability that requires an immense amount of attention.

Strong comments and feelings emerged from these single mothers when the discussion turned to unmet needs. Although they had positive comments to make about the medical and early intervention services, they had negative comments in regards to their struggle to find quality child care and respite services. There is no mistaking that respite and quality child care is an invaluable asset to these single mothers. Respite and

quality child care can provide a single mother with peace of mind which in turn provides the ability to go forward with other aspects in life (Krikham, Schinke, Schilling, Meltzer, & Norelius, 1986; Wilker, Haack, & Intagliata 1984; Bristol, Reichie, & Thomas, 1987). Participants reported a lack of providers in the area for quality child care, a lack of flexibility in hours and a lack of financial assistance to make payment feasible. As for respite services, only one of the three participants reported that they had access to respite services from a community mental health agency. Those respite services, although extremely limited, were invaluable to the participant.

Reliance on families for support and assistance with child caring was another evident theme throughout the interviews. These single mothers spoke of their good fortune to have families close by who were willing to assist them on several levels. Family was clearly a precious resource to these single mothers.

Throughout the interviews it became clear that for these single mothers, taking one day at a time was their mode of operation. There was not much feedback when asked about the future for their family. Comments centered around the fact that their day to day lives were filled with challenges, challenges which require immediate action on their part. On several occasions throughout the interviews it became clear to this researcher that these participants are keenly aware of the fact that they cannot predict the future nor can they be sure tomorrow will come. They all were very fixated on the challenges at hand, giving their full attention to the day to day needs of their child with special needs. They all displayed a drive to ensure that their children receive quality care. The quality care sometimes came with minimal effort and at other times these single mothers have advocated at a vicious pace for the needs of their children.

This experience of interviewing these three single mothers was invaluable to this researcher. The purpose of this study was to gain knowledge from the experiences of three single mothers who have children with special needs. It was expected by this researcher that the participants would talk and that they would share personal information, which at times would perhaps bring some uncomfortably. Unexpected was the powerful effect these interviews had on this researcher. This researcher left the interviews feeling overwhelmed by the powerful devotion and strength of these three women. It is the opinion of this researcher that these women had been put into a situation with the birth of their children that at first left them with fear and doubts about their own ability to provide adequately for their children. Clearly they have all adapted to a lifestyle where they consistently display great strength and an ability to shift their lives into a style that allows them to care for their children the best they can. This researcher left each interview feeling humbled and inspired by these women and their experiences.

Future research would be valuable with these participants. A follow-up interview would be beneficial to clarify some of the themes that emerged in the data. If this researcher could have conducted a longer study, it would have been beneficial to analyze data and then go back and get the participants to clarify comments and provide additional comments about the proposed themes. Due to the intensity of the interview for participant three, it is this researcher's opinion that future studies would be wise to factor in the complexity of the children's disabilities when analyzing the mothers' experiences.

It would also be beneficial to interview these mothers once their children have transitioned into the school system since this transition seemed to be a strong anxiety mentioned during two of the interviews. The transition process is often a concern pointed

out in the literature pertaining to the experience of families with special needs children. It is a time when services providers are changing along with the manner in which services are delivered (Beavers, Hampson, Hulgus, & Beavers, 1986). Therefore, perhaps some further understanding of the adaptation process along with coping strategies used during and after the transitioning process occurs, would add a greater understanding of the experience as a whole.

Overall, this researcher felt that there were several comments made by participants that hinted at certain stressors which at times left them with a great deal of anxiety. Although this study did not specifically explore anxiety and stress, past research has consistently found that stress levels are higher in families who have children with special needs (Dyson, 1997; Innocenti, Huh & Boyce, 1992; Kazak, 1987). Exploring the stress and anxiety experienced by these participants would also be a direction for further study.

Regardless of the anxiety or frustrations experienced by these three single mothers, it is this researcher's opinion that these women have adapted through a challenging role and come out with coping techniques that can be described as strong and resourceful. As research has pointed out in the past, parents who have children with disabilities gain valuable information and experience that could be used to assist in designing services that meet the needs of the families (Harman, Drew, & Egan, 1999). It is this researcher's opinion that these women who participated in this study are already well versed in the role that community services plays in meeting the needs of their children, and they have less than three years experience. Therefore, it is reasonable to think that as they continue through the experience they will continue to face challenges

and gain experience that would be very useful to those in charge of designing the services. As pointed out in the research earlier in this study, the birth of a child with special needs forever changes the family, and the response of that family to their situation forever affects the child (Crnic, Friedrich & Greenberg, 1983). Therefore, if it is the intention of service providers to design community programs for the overall health of the child, which it is, then including the parent in that designing process is vital to the health of the child.

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APPENDIX A

APPENDIX A

10-26-01

Meeting Notes Re: Topics for interview single mothers who have a child with a severe developmental disability.

Present: Employees of the Pennyroyal Mental Health Center

Sharon Oliver, Initial Service Coordinator – First Steps Early Intervention Program

Rheanne Marlow, Initial Service Coordinator-First Steps EIP

Theresa Melton, Primary Service Coordinator –First Steps EIP

Molly Moller, Primary Service Coordinator – First Steps EIP

Kristen Gomez, Primary Service Coordinator – First Steps EIP

David Girdner, Director of Developmental Disabilities Services

Topics:

How often do these single mothers think and worry about their personal future and that of their child? Issues such as marriage, dating, friendships, work & career, for both the child and the mom.

Do these single mothers feel isolated due to the increased caretaking burden? If so, what would help, do they want help? Do they feel they are the only one who can care adequately for their child?

Do these mothers feel an overall lack of trust, in themselves, their family, their community, their health care providers? Did their level of trust change after the birth of their child? What could help with their trust level?

Do mothers want more social support in the form of a support group? If so, what would make that support group feasible for them to attend?

What respite and day care needs do these single mothers have? How do they think the services should be provided and paid for? Do they feel a need to spend time away from their child? Do they recognize the importance of their own personal needs?

Do these mothers feel typical stages of grief (Kubler-Ross Model)?

How could community programs improve to meet the needs of single mothers?

What experiences, both negative and positive, do the mothers feel have assisted them in the adaptation process?

APPENDIX B

APPENDIX B

Interview Questions

1. Tell me what you think about when you look ahead into your own future?
2. How would you describe the experience of being a single parent caretaker?
3. What types of support if any, do you see as currently benefiting you and your family?
4. What unmet needs, if any do you have regarding the care of your child and family?
5. What types of services would you like to see offered for you, your child, and family that are not currently available to you?
6. Could you tell me what might be helpful for another parent to know about your experience in raising a child with a disability?

VITA

Kristen Marie Gomez was born in Waukon, Iowa, on January 22nd, 1974. She graduated from Caledonia High School in Caledonia, Minnesota, in 1992. She began her college career in 1992 at Mankato State University in Mankato, Minnesota. She also attended the University of Wisconsin-LaCrosse in LaCrosse, Wisconsin, where she graduated in 1996 with a Bachelor's degree in Psychology and English in 1996. She began her work in the master's program at Austin Peay State University in the fall of 2000. The degree in which she pursues at the present is in Community Counseling.