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Erika Susan Lazo

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CHOOSING THE GIFT OF DOWN SYNDROME: FAMILIES' EXPERIENCES INTERNATIONALLY ADOPTING A CHILD WITH DOWN SYNDROME

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Erika Susan Lazo
June 2011

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Approved by:

[redacted]
Dr. Carolyn McAllister, Faculty
Supervisor, Social Work

6/7/2011
Date

[redacted]
Dr. Rosemary McCaslin,
M.S.W. Research Coordinator

ABSTRACT

This qualitative study explores the experiences of families who choose to internationally adopt a child with Down syndrome. This study was conducted in order to address the current scarcity of research on this population and their specific needs and strengths in order to equip social work practitioners to more effectively work with these families. Mothers were interviewed about their family's adoption process, the services they utilized, and the process of integrating the newly adopted child into the existing family unit. Overall, this study found that for these families the most difficult part of their experience was the adoption process, which included paperwork, financial, and travel components; the interaction, transition, and bonding with the child, however, was easier than they had anticipated and brought great blessing to the family.

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DEDICATION

This project is dedicated to Elie, who gently took my hand and led me down this beautiful path of joy, acceptance, and unconditional love, and who has helped me to see the inestimable value in every life. The sweet time I spent with you has meant the world to me and will continue to touch lives as I live the lessons you have taught me.

And to God, my Father, the author of my life who has blessed me beyond understanding with love, joy, peace, healing, freedom, transformation, an incredibly loving and supportive family, encouraging and accepting friends, and a destiny for my life that fulfills and exceeds every dream of my heart. You are my everything.

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CHAPTER ONE

INTRODUCTION

This chapter lays the foundation for why families are turning to international adoption of children with Down syndrome, policies that are affecting the availability of domestically adoptable children, and policies that are impacting international adoptions as a whole. The importance of the study to social work micro and macro practice are also explored, and an overview of the research methods is introduced.

Problem Statement

To date, international adoption, the impact of Down syndrome on the family, and adoption of special needs children in general, have been the focus of many research studies. These projects have explored numerous factors that contribute to a family's functioning and well-being, as well as discussed policies that shape the practice of service providers. Until now, however, no studies have focused on the unique challenges, needs, and joys that families experience when they specifically and intentionally adopt a child with Down syndrome internationally and integrate that child into the family.

It is vital for social workers, indeed all service providers, to understand their client's unique experiences when assessing and intervening with them. Though practitioners should strive to know their clients individually, it can be helpful for them to be aware of common needs as well as strengths among a particular population. It is important for families who have internationally adopted a child with Down syndrome to feel that their social workers are familiar with the specific issues related to their situation. While it may be clear that social workers who are working in adoptions need to understand this population, this is also important for mental health providers, school social workers, and those who are working in the disability arena because of the diversity of services an adoptive family may seek out. It is not beyond the realm of possibility for any number of social workers in these fields to encounter families who have internationally adopted a child with Down syndrome as this type of adoption increases in the future.

Although there are no exact numbers available to indicate how many children with Down syndrome were adopted internationally in recent years, it is known that adoptable children with Down syndrome are in short supply in the United States. Robin Steele, founder and coordinator of the National Down Syndrome Adoption Network, currently has 150 families waiting to adopt a child with Down syndrome (personal communication, October 23, 2010). Potential adoptive families on this list may experience a significant wait before being matched with a birth family and child, particularly since more than 50% of birth families who begin the process of creating an adoption plan decide to parent their child once they have been connected to support and resources (personal communication, October 23, 2010).

Another reason there are few U.S. children with Down syndrome available for adoption is the Prenatally and Postnatally Diagnosed Conditions Awareness Act of 2008 (S. 1810) that was signed into law by President Bush. This Act was an amendment to the Public Health Services Act and requires medical personnel to deliver accurate, up-to-date information to parents upon birth or diagnosis of a child with Down syndrome. The information is to be related to medical and developmental areas of health and should also include support and service resources. As a result of this Act, more families are receiving accurate information about their child's condition and prognosis, and are increasingly opting to parent their child with Down syndrome.

Due to the difficulty and long wait for domestic adoption, many families are choosing to look internationally for a child with Down syndrome in need of a home. Andrea Roberts, mother of a son with Down syndrome, founded Reece's Rainbow in 2004 as a resource and support network for parents of children with Down syndrome (Reece's Rainbow, 2010). Since then she has expanded her organization to include working with foreign countries to raise awareness of children with Down syndrome and other disabilities in orphanages around the world. Since 2006, Reece's Rainbow has helped to facilitate over 250 international adoptions of children with Down syndrome by raising awareness and providing adoption grants (Reece's Rainbow, 2010; Tapper & Dennis, 2010).

Purpose of the Study

When working with families who are internationally adopting a child with Down syndrome it is vital for social workers and other social service professionals to understand the specific needs and challenges of this population. It is also important for providers to understand the joys and blessings the families experience as a result of adding the child to the family.

When researchers neglect to focus attention on a particular population or issue, professional and community awareness is lessened. In the case of adoption or developmental disability such as Down syndrome, a lack of awareness can easily lead to a lack of appropriate services as well as to stereotyping and stigmatization. Families that intentionally adopt a child with a visible disability may have different feelings and understandings of their situation than families that unexpectedly experience the birth of a disabled child. Though there is a wealth of research on family needs after giving birth to a child with Down syndrome, there are currently no studies that have explored families' needs after internationally adopting a child with Down syndrome.

Another reason for this study is that there are families waiting to adopt and there are children with Down syndrome waiting to be adopted. By delving into the experiences of families internationally adopting a child with Down syndrome, their joys, struggles, expectations, and resources, it may be possible that more families will consider international adoption of these waiting children.

This study seeks to explore and understand families' experiences adopting a child with Down syndrome outside the U.S., and the process of integrating that child into the family. Services provided to the families, or services that parents wished were available, will be discussed in terms of ease of access and ultimate benefit to the family. Additionally, through the research process, "unexpected blessings" that families experienced through their adoption will be considered.

This study will take the form of a qualitative immersion into the experiences of families and their understanding and perception of their realities. Due to the lack of previous research, a qualitative study allows for the participants to be the experts on the topic and can allow the data gathered to be synthesized and connections discovered, without predetermined relation between any factors. The results of qualitative studies can be used later to provide a basis for further qualitative or quantitative studies to test hypotheses between identified variables (Grinnell & Unrau, 2011; Morris, 2006).

In order to get a thorough understanding of families' international adoption experience of a child with Down syndrome, interviews were conducted with families who had completed their adoption. Participants were given the option to complete the interview either by telephone conversation or by typing their answers to open ended questions using an electronic survey instrument.

Significance of the Project for Social Work

This study is necessary in order to raise awareness of the unique experiences, strengths, and needs of families in all stages of the process of international adoption of a child with Down syndrome. This is an area of adoptions that is growing steadily and will likely become more and more common. For social workers, the ability to understand a sampling of families' realities will increase their knowledge base and therefore, their ability to provide appropriate services to their clients who are also among this population.

Social work practice benefits from this study as families report on the services they received and in what ways they were or were not helpful to them. Families were also asked what types of services or programs they would have liked to receive or would like to see created. Social workers providing pre- and post-adoption services can use this information as a basis of tailoring services to meet their clients' specific needs. In identifying the most important services from the families' points of view, social workers can direct more attention and funding to them.

Additionally, social workers in all areas of micro practice can benefit from an understanding of families' experiences and can use that information to sensitize them to the unique frame of reference by which these families view their life and the world. By integrating common themes found within the "culture" of international adoption of a child with Down syndrome, social workers can provide the most comprehensive and competent care to the families they encounter.

Macro practitioners can use the information obtained in this study to help shape policy surrounding international adoption of a child with a developmental disability as well as to design and implement needed services, both in the U.S. and abroad.

This study has potential benefits for all phases of the generalist model of social work practice. By understanding some of the basic principles that guide families' interaction with each other and with the world, social workers will have a foundation on which to build rapport and comprehensively assess their clients. With the background of other families' experiences to draw on, social workers can help their clients to plan appropriate goals and strategize the most effective intervention(s) for their specific need. This study will also provide insight into how to best evaluate the success of interventions or services provided and will help guide the practitioner in understanding how and when to terminate services with their clients.

Stigmatization

Families who choose to adopt a child or children often face stigmatization from society. Wegar (2000) writes that the stigma that adoptive families experience is perpetuated by social workers in two ways. First, the psychopathological theories that are used to explain problems in adoption create a distrust of the institution itself. These social workers have been identified as having a higher likelihood of portraying adoptive families as less legitimate than biologically based family units. In addition, there is a failure on the part of social work as a whole to understand that there is a stigma attached to adoption that is pervasive in our culture. By not addressing the issue themselves, the social workers do not prepare their clients for potential encounters with stigmatization that they are likely to encounter (Wegar, 2000).

When one accounts for the fact that individuals with disabilities, developmental and intellectual in particular, are also stigmatized and marginalized in this country, it is reasonable to deduce that adoption of a disabled child would create a new category and population that experiences multiple layers of judgment and discrimination. This study uncovered truths about families who internationally adopt children with Down syndrome and investigated how a greater awareness on the parts of professionals and society at large, can make a positive impact on the lives of these families.

This research study endeavors to raise awareness of the experiences of families who have internationally adopted a child with Down syndrome, to understand the process of integrating the child into the family, to identify services that were particularly helpful or that were needed and not received, and to explore the concept of "unexpected blessings" as a result or by product of the adoption experience.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter reviews existing literature on the subjects of Down syndrome and the family, international adoption, and services for adoptive families, and discusses the various theories that have been applied to the study of these issues and the theories that were used to guide this research.

Down Syndrome and the Family

Overview

The impacts of having a child with Down syndrome in the family are as varied as the individuals and families themselves. However, there are certain areas that tend to be affected in any family that includes a child with a developmental disability. Familial issues such as parental time and attention spent on the child as compared to the amount of time given to siblings can be a source of stress (Cox, Marshall, Mandleco, & Olsen, 2003; Vadasy, Fewell, Meyer, & Schell, 1984). Resource depletion can occur in the areas of finances, emotional and physical energy, and time. Interaction with others outside the immediate family, i.e., extended family, medical professionals, teachers, therapists, other social service providers, and the community must be carried out with intentionality, the child's disability taken into account (McCubbin & Huang, 1989; Schilling, Gilchrist, & Schinke, 1984).

Down Syndrome Advantage

Research has shown varying levels of support for the concept of the "Down syndrome advantage" among families raising children with a developmental disability. Essentially, this concept is based on the idea that children with Down syndrome present an easier and more rewarding parenting experience as compared with other developmentally disabled children (Corrice & Glidden, 2009; Glidden & Cahill, 1998; Hodapp, Ly, Fidler, & Ricci, 2001). The results of a 1998 study on the concept did not find that parents who raised a child with Down syndrome had an easier time as compared with parents raising children with other developmental disabilities, though their research did find a decreased instance of maternal depression following a child with Down syndrome's entrance into the family as compared with maternal depression following the birth or diagnosis of a child with different disability (Glidden & Cahill). Though adoption workers in this study indicated a high preference for children with Down syndrome among prospective parents, this was attributed to the familiarity with the disability and prognosis, rather than an expectation of an easier experience raising the child (Glidden & Cahill, 1998).

A later study of the Down syndrome advantage found that "parents of children with Down syndrome report less stress and more child-related rewards than parents of children with other disabilities; indeed, parents of children with Down syndrome may feel equally rewarded compared to parents of same-aged typical children" (Hodapp et al., 2001, p. 317). This study examined factors that accounted for the difference between stress and rewards of families with and without a child with Down syndrome, and noted several key points. First, because Down syndrome is a well-known disability parents can typically access support groups and services without much difficulty, and professionals the families encounter already have some foundational understanding of the disability. Second, it is more likely for a child with Down syndrome to be born to an older woman who may have previous child-rearing experience and/or more well developed coping skills. There were also three characteristics of the children themselves that were identified to contribute to the Down syndrome advantage: decreased incidence of behavior problems, natural social inclination, and an appearance of increased sociability and positivity as perceived by the parents (Hodapp et al., 2001).

Although children with Down syndrome may not necessarily be easier to raise than typically developing children or those with another type of developmental disability, it is obvious that there is a difference in families' experiences and realities that often causes them to feel there are great personal and familial benefits gained because of their child (Corrice & Glidden, 2009; Glidden & Cahill, 1998; Hodapp et al., 2001).

International Adoption

Overview

According to the Office of Children's Issues, there were nearly 13,000 children adopted internationally to the United States in 2009 (Intercountry Adoption, 2009).

The rates of disability among children adopted internationally are about the same as that of children adopted domestically, though the incidence of disability among adopted children overall is more than twice that of the general population (Kreider & Cohen, 2009). The reason for the increased incidence of disability among adopted children, particularly among international adoptees, can be attributed to the health and lifestyle of the birth mother, the lack of basic care in an orphanage, and extended stays in institutional settings before adoption. Included in these explanations is the understanding that some U.S. families intentionally choose to adopt a child with special needs, both domestically and from abroad (Kreider & Cohen, 2009).

Effects of institutionalization

Gunnar, Bruce, and Grotevant (2000) further specify the conditions under which institutionalized children live by laying out "levels of privation" (p. 678) that encompass basic unmet physiological needs, stimulation and action within their environment, and opportunities to create bonds of attachment with caregivers. When these needs aren't met, or are met insufficiently, children suffer negative physical, behavioral, and emotional effects that have the potential to last a lifetime and cause significant disability (Gunnar et al., 2000). In general, the child's likelihood of developing significant problems multiplies with increased length of time spent in an institution, and older age at adoption (Gunnar et al., 2000).

Policy

The Hague Convention on Intercountry Adoption came into effect in the U.S. in 2008. This agreement between member countries serves to protect children by placing regulations on intercountry adoptions. It requires pre-placement parent training, accredited adoption agencies, more stringent guidelines for homestudies, new qualifications for declaring a child adoptable, and preserves adoption records for 75 years (Intercountry Adoption, n.d.a; Intercountry Adoption, n.d.b).

Although the convention seeks to protect children and standardize the adoption process, the extra requirements are resulting in an unintended consequence that extends the time children spend in institutions, and therefore increasing the odds of children developing multiple, significant, and enduring disabilities. "Very young, non-special needs children are becoming a rarity in adoption" (Osborne, 2009, para. 7).

When one considers the implication of the Hague Convention on international adoptions, particularly on the negative health and development effects of the waiting children, paired with increasing interest in children with Down syndrome, it is reasonable to suspect that more families will seek to adopt children with Down syndrome when they decide to adopt internationally.

Services for Adoptive Families

Pre-Adoption

Pre adoption services tend to fall into one of two categories: parenting education and information related to the child to be adopted, which can include data or education regarding medical or developmental concerns. Egbert and Lamont (2004) found that the most significant factor contributing to parents' feelings of preparation for adoption was specific training in parenting techniques for special needs children.

Post-Adoption

Services available following an adoption tend to be more abundant and vary according to the child's and family's needs. A study of families who had adopted a child with special needs found that the services families listed as most needed fell in the categories of financial assistance (government subsidies, medical coverage), legal assistance, mental health services (individual or family counseling), respite, and support groups. Among the needs that were most often unmet were those requiring services that provided support to families in the form of respite and childcare. Counseling services comprised the largest group of requested and utilized services (Reilly & Platz, 2004).

Policy

The area in which policy may play the largest role in service delivery for families who are adopting internationally is the Federal Adoption Assistance Program in which "federal funding is provided to subsidize the cost of medical care and social services for children with special needs adopted within the country" (Gunnar et al., 2000, p. 688). This legislation excludes international adoptees and therefore requires families to rely on their own finances and often inadequate health insurance coverage to provide the necessary services or interventions for their children (Gunnar et al., 2000).

Medical expenses are a significant concern to parents of a child with Down syndrome as the condition can result in congenital or developing problems in nearly every system in the body (Liptak, 2008). It is not uncommon for children with Down syndrome to require surgery to correct heart defects or to prevent aspiration when eating and drinking. Furthermore, children with Down syndrome have a higher incidence of leukemia and autism which require medical and supportive interventions as well (Liptak, 2008).

Theories Guiding Conceptualization

One of the earliest, and yet most enduring theories of understanding adoptive families as well as families with disabled children focuses on pathology (Hodapp et al., 2001; Wegar, 2000). This theory identifies weaknesses and tends to engender negative reactions and foster stigmatization toward families dealing with stress or challenges resulting from adopting or parenting a child with special needs (Hodapp et al., 2001; Wegar, 2000).

Other studies have approached these subjects from a perspective of the interplay between stress and coping (Cunningham, 1996; Hodapp et al., 2001). This framework encourages the identification of strengths and areas of adaptation in developing coping strategies to deal with the stressors of adoption and/or parenting a child with a developmental disability.

The transactional family systems model proposes that the meaning given to an event such as adoption or a child's disability will vary according to the individual, and will therefore result in differing responses within a family unit. The personal, social, and environmental resources perceived and utilized by an individual will play a vital role in determining the understanding of the event and its potential level of difficulty to that family member (Cunningham, 1996). This theory is particularly relevant to social work practice in that it encompasses a wide range of factors that contribute to an individual's reality, and it allows for differing understanding and meaning of the same event within a single family unit.

The human ecology theory has been utilized to view special needs adoptions as a "process of relationships that must interact and adapt to create a new environment" (Egbert & LaMont, 2004, p. 594). This theory views the family as a series of interrelated systems, operating in the context of larger series of interrelated systems that are constantly changing to meet particular needs. As one system changes, the other systems change, adapt, and react in response. Human ecology theory takes into account all the members of the family unit, as well as those in the community, and perhaps most importantly, allows for understanding the child's adaptation as well. This theory "provides a framework for understanding what is currently known about the dynamics of special-needs adoptions...and the preparation needs of special-needs adoptive families" (Egbert & Lamont, 2004, p. 595). It also provides a framework that can guide social workers into more holistic practice as they interact with and assess individual clients and families.

This research study will incorporate themes from the transactional family systems model and the human ecology theory to create a framework for understanding families' experiences of internationally adopting a child with Down syndrome.

In examining the literature, although there is research in many similar areas, there has been no specific study done to understand the specific experiences, strengths, challenges, and needs of families who intentionally choose to internationally adopt a child with Down syndrome. There are categories of study and services for international adoption and for families who have a child with Down syndrome, but as the incidence of international adoption of children with Down syndrome increases, a new population emerges which doesn't fit into any previously determined category. Without a comprehensive understanding of their process and understanding, social workers will be at a disadvantage when attempting to work with these families, and this population of families may experience isolation and discrimination.

Summary

This chapter introduced basic areas of previous research relating to families' experiences of parenting a child with Down syndrome, international adoption, and the services that families find most useful both in preparing for their adoption and for helping to integrate the child into the family. Theories that have helped to guide conceptualization were also discussed in relation to the topic of adoption and parenting a child with Down syndrome.

CHAPTER THREE

METHODS

Introduction

This chapter describes the study design and the methods and rationale for participant sampling. The data collection process, instrument, and analysis procedures are described and protection of human subjects is discussed as pertains to this research study.

Study Design

This study is an exploration of families' experiences internationally adopting a child with Down syndrome. There is a significant lack of data in this area so this project provides a basic understanding of factors that contributed to families' choice in adopting, the services that were or were not beneficial to them, and the process of integrating the newly adopted child into the existing family unit. Family experiences, both positive and negative, were explored and the families' recommendations for professionals, particularly social workers, were gathered and presented.

Due to the newness of this area of research, a qualitative study was the most appropriate research method as it allowed families to share the wholeness of their experiences, rather than to limit and pre-define what areas were most important.

Qualitative studies seek to explore and develop theory to understand participants' experiences and the meanings they ascribe to them. These studies acknowledge the unique qualities and significance that individuals assign to the events in their lives and do not assume that these experiences and related interpretations can be generalized to an entire population. Instead, by presenting a group of individuals' experiences and personal understanding of them, and developing a theory to understand that particular study selection, further areas of research are identified, and professionals working with a similar population can examine whether or not the results apply in their situations (Grinnell & Unrau, 2011; Morris, 2006).

The main limitation in this study involves the transferability of results. Families were selected from a group of individuals who have worked with a particular organization, and therefore may have widely differing experiences from those of families who do not utilize this organization. Also, because ethnicity, age, geographic location, socio-economic level, and family make-up were not controlled in sampling, there may be a lack of diversity in one or more of these areas which may also limit transferability (Grinnell & Unrau, 2011; Morris, 2006).

Sampling

A sample of nine families who had completed an international adoption of a child with Down syndrome were gathered. These families were selected from a pool of families who participate in an online forum through Reece's Rainbow, an organization that seeks to raise awareness of children with Down syndrome and other developmental disabilities waiting for adoption in foreign orphanages. Through their adoption grants and photo listings, they have helped families throughout the U.S. and in other countries to adopt over 250 children with Down syndrome in the last four years.

The director of this organization forwarded an email (Appendix A) to let families within the online forum know about this research project and the request for study participants. There were over 1000 members in the forum which helped to ensure that a sufficient number of participant families were recruited.

Data Collection and Instruments

Data was collected through written responses to interview questions. The goal was to obtain data that provided a holistic and comprehensive understanding of families' experiences.

The instrument (Appendix B) used to collect the data was a survey developed by the researcher specifically for this study and offered in verbal interview format over the telephone or as a written questionnaire for respondents to write answers in. Each participant was given the option to choose the method that appealed to them, and all opted to complete a written interview. The first section of the survey consisted of 17 closed ended demographic questions covering family composition, income, and religious affiliation; the levels of measurement were nominal, ordinal, and ratio questions.

The second section covered the families' decision to adopt and consisted of one closed ended and four open ended questions to explore why a child with Down syndrome was selected and the thought process for choosing international adoption; the level of measurement was nominal.

The third survey section was related specifically to the adopted child: age, living experiences, and diagnosis. It consisted of four closed ended, nominal and ratio level questions and five open ended questions.

Survey section four detailed the services related to adoption and family integration. This section consisted of one closed ended nominal level question and 10 open ended questions regarding services that were or were not utilized, the perceived benefits, and any programs or services that families' felt would have been beneficial.

Section five consisted of seven open-ended questions designed to elicit a more free form response about their subjective experience of integrating the child into the family.

Section six consisted of five open ended questions about the overall experience of the adoption, specifically: any unexpected blessings, and factors for and against adopting again.

Section seven concerned perceived stigmatization and views on society's perception of internationally adopting a child with Down syndrome and included two closed ended nominal level and two open ended questions.

The final section was simply an opportunity for families to share any information they felt would be pertinent to the study that had not yet been addressed.

Procedures

Due to the expected geographic diversity of study participants, data was gathered through a written survey and took approximately 45 minutes of the subject's time. Data collection was completed by the researcher alone and required eight weeks to recruit parent participants and conduct the interviews. The interviews were sent as each subject was recruited into the study; there was no need to wait for the complete number of participants before commencing.

Protection of Human Subjects

In order to ensure the anonymity of study participants, names of subjects were kept confidential and separate from participant interview/survey responses. Families were randomly assigned a number to ensure that their responses were kept anonymous. The informed consent (Appendix C) document was emailed to each participant who then read the document and replied by email to give their consent. Following completion of the research project, any identifying family information that was gained in order to arrange participant recruitment or interview schedules were destroyed to protect the participants. Informed consent and debriefing statements (Appendix D) were utilized to educate subjects on the nature of the study and their participation in it.

Data Analysis

Once the data was collected, via emailed typed or hand written interviews, they were previewed to gain an understanding of the totality of responses. Journaling was also initiated with data analysis and served to record information pertinent to the methods of analysis as well as to document significant steps in the process.

First and second level coding were utilized to begin to identify common themes, patterns, and differences between the data sets. These critical units were categorized and assigned codes. Through the process of exploring the data, more connections became apparent and additional categories were defined (Boeije, 2002; Grinnell & Unrau, 2011; Morris, 2006).

First level coding focused on recognizing obvious characteristics and objective observations within the data set. Second level coding involved uncovering the meaning beneath the obvious concepts. After these steps were completed, the larger categories were considered in relation to each other and patterns between and interactions or correlations among categories were explored. At this point, from the information gathered during these steps, a theory was developed to explain the interrelation of the data and present a picture of the experiences of families who internationally adopt a child with Down syndrome. Throughout this process, detailed documentation to ensure credibility, consistency, and to control bias were maintained (Boeije, 2002; Grinnell & Unrau, 2011; Morris, 2006).

This research study attempted to create a comprehensive understanding of experiences of families who have internationally adopted a child with Down syndrome and the meanings they assign to them. The areas that were explored were the adoption process, services that were or were not utilized by the family, the transition and integration process when bringing the child home, and to explore the concept of "unexpected blessings" as a result or by product of the adoption experience.

Summary

This chapter discussed the methods that were used to select and recruit participants, to gather data through interviews, and analyze the data collected into a supported theory to create a comprehensive understanding of families' experiences internationally adopting a child with Down syndrome.

CHAPTER FOUR

RESULTS

Introduction

This section presents the data that was gathered through the interview surveys. Demographics are presented as well as major themes that arose from the qualitative data analysis. Participant quotes are provided as supporting examples for each main theme.

Presentation of the Findings

Family Demographics

The sample for this study was comprised of nine participant families consisting of married, heterosexual couples and their child(ren). In each family, the wife/mother completed the interview and provided insight on her family's experience. These experiences were of the family's first international adoption of a child with Down syndrome. Since it had been several years since the adoption for a few families, participants were asked to provide demographic information based on the time that the adoption took place, not current information. In the discussion and table that follow, "men" refers to adoptive fathers, and "women" refers to adoptive mothers.

Participant ages ranged from 28-47 for women and 28-57 for men. The mean age for women was 41, and for men was 42. Ethnicity was reported with the majority of individuals identifying as Caucasian/European (17) as well as one Hispanic male. Couples had been married between 4 and 20 years, with a mean length of 11 years. Families' religious affiliation was broken down into two main categories: Christian-Protestant with 11 individuals identified, and Christian-Catholic with five individuals identified. One family did not claim any religious affiliation. Employment status was broken down by gender; of the men surveyed, eight had full time employment and one was working both full and part time jobs. For the women, four were not employed, one was employed part time, and four were employed full time. Annual family income was extremely varied, with two families reporting under $45,000, one reporting income between $45,001-$60,000, three between $60,001-$80,000, one between $80,001-$100,000, one between $100,000-$150,000, and one family that declined to state. For one family, the adopted child was their first child, while the other eight families had between one and five children at home at the time of the adoption.

Parents were asked about experience or exposure they may have had to adoption or individuals with developmental disabilities. Only one parent set responded "yes" to all areas queried, although every other set had at least one area of prior experience through their own family, friends, education, career, or volunteer work. Two families had completed prior domestic adoptions, two families had completed previous international adoptions, four parent sets had experience with individuals with some type of developmental disability, and seven parent sets had experience with Down syndrome in particular.

Of the participating families, eight adopted their child with Down syndrome from Ukraine, and one adopted their child from Vietnam. At the time of the interview, six families had been home with their adopted child between two and six months, two families between seven and 12 months, and two families who had been home just over three years. One family adopted two children together, and the other eight families adopted one child during that process.

Of the adopted children, four were male and six female. They ranged in age from 8 months to nearly six years old at the time they came home. The children also had a number of medical concerns; one had a corrected heart defect, three had uncorrected heart defects, two children had visual issues, one child had respiratory issues, one was diagnosed as failure to thrive, and one child had syndactyly. Three other families also received information related to their child(ren)'s medical condition, but did not provide them for this study.

It is interesting to note that three families are currently considering another adoption, three families are currently in the process of adopting another child, and two families have successfully completed another adoption of a child with Down syndrome, one domestically and one internationally.

Table 1. Demographic

Variable	Frequency (n)	Percentage (%)
Marital Status		
Married	9	100
Length of Marriage (in years)		
5 or less	3	33
6-10	0	0
11-15	3	33
16-20	3	33

Variable	Frequency (n)	Percentage (%)
Age		
men		
25-29	1	11
30-39	2	22
40-49	5	56
50+	1	11
women		
25-29	1	11
30-39	2	22
40-49	6	67
50+	0	0
Ethnicity		
men		
Caucasian/European	8	89
Hispanic	1	11
women		
Caucasian/European	9	100
Hispanic	0	0
Religious Affiliation		
men		
N/A	1	11
Christian (Protestant)	6	67
Christian (Catholic)	2	22
women		
N/A	1	11
Christian (Protestant)	5	56
Christian (Catholic)	3	33
Employment		
men		
not employed	0	0
part-time	0	0
full-time	8	89
full and part-time jobs	1	11
women		
not employed	4	44
part-time	1	11
full-time	4	44
full and part-time jobs	0	0

Variable	Frequency (n)	Percentage (%)
Annual Family Income		
under $45,000	2	22
$45,001-$60,000	1	11
$60,001-$80,000	3	33
$80,001-$100,000	1	11
$100,000-$150,000	1	11
declined to state	1	11
Number of Children Prior to Adoption		
none	1	11
one - two	2	22
three - four	5	56
five +	1	11
Prior Experience		
adoption (domestic)	2	22
adoption (international)	2	22
developmental disability	4	44
Down syndrome	7	78
Country Adopted From		
Ukraine	8	89
Vietnam	1	11
Length of Time Home with Child at Time of Interview		
2-6 months	6	67
7-12 months	2	22
over three years	2	22
Number of Children Adopted at Once		
one	8	89
two	1	11
Gender of Adopted Child		
male	4	40
female	6	60
Age of Adopted Child (in years)		
under one	2	20
one - two	4	40
three - four	2	20
five - six	2	20

Variable	Frequency (n)	Percentage (%)
Medical concerns		
heart defect (corrected)	1	10
heart defect (uncorrected)	3	30
visual	2	20
respiratory	1	10
failure to thrive	1	10
syndactyly	1	10
declined to state	3	30
Subsequent Adoption(s)		
no	2	22
considering	3	33
in process	3	33
yes	2	22

Experience

Participants were then asked a series of questions to describe the processes of adoption and that of transitioning and integrating the newly adopted child into the family and community in order to gain a comprehensive understanding of their experiences and identify areas of strengths and needs. Additionally, families were asked about any "unexpected blessings" they experienced as a result of their adoption.

Adoption Process

Families were asked why they decided to adopt, why they adopted internationally, and why they chose a child with Down syndrome. Their answers for all three questions overlapped a great deal and shared some main themes behind their decisions; often families indicated that there were several factors at play when they chose to adopt a child.

One of the two most common answers to the question "why" came down to the conviction that they wanted to adopt a child with Down syndrome internationally in order to help a child in need. Seven of the nine families expressed concerns over the conditions that the children lived in and the poor outlook for their future, and that this was a main contributing factor to their decision to adopt in the manner they did.

> After having our 4th child, a boy with Down syndrome, we learned a lot about the world of special needs. One of the things we learned was that in some countries, especially Eastern Europe, children born with special needs are hidden away in orphanages. No parents, no love, no therapy or educational opportunities. Sometimes, inadequate food and medical care. After the age of 4 or 5 they are transferred out of the orphanage, or baby house, and placed in an institution, where they can be treated even worse. Tied to a bed, fighting for

> food, no future . . . The chances of children with Down syndrome (in Eastern Europe) having any type of decent future are very nearly nil . . . We had a chance to keep a sweet girl out of an institution and give her a family, love, parents, siblings, education, therapy, and medical care. (005, personal interview, March 2011)

> Through Reece's Rainbow I became aware of the grim conditions in which many kids with Down syndrome live in other countries. At first I was very scared of the DS diagnosis but as I read blogs and yahoo group emails I came to WANT a child with DS. (006, personal interview, March 2011)

The other equally common theme, also encompassing seven families, for understanding why these families chose to adopt was the fact that they felt a connection or emotional bond with a particular child (typically through Reece's Rainbow photolisting) and were compelled to adopt that child, regardless of location or diagnosis.

"We fell in love with our little one, it didn't matter where he was, we had to bring him home" (002, personal interview, March 2011)

> It was not something we chose, but something that chose us. I saw her photo and fell head over heels in love with that little face. I do not know what set her apart. She was so beautiful and had a spark that I could see very plainly (003, personal interview, March 2011).

Six families specified that they felt strongly that having a child with Down syndrome was a blessing and a positive addition to their family. This conviction led them to specifically seek out a child with this condition.

"We believe having a child with Down syndrome is a Blessing" (001, personal interview, March 2011).

"Our [biological son with Down syndrome] brought us so much joy and blessings we were ready to share that with another child" (005, personal interview, March 2011).

Four families cited that adoption itself is a blessing and something they felt led toward and excited to pursue.

"Bringing a new child in to our home is something we are all very used to and we all very much enjoy" (001, personal interview, March 2011).

"To be honest, adoption has always been in my heart" (002, personal interview, March 2011).

The conviction that God had called them to adopt in general, or adopt a specific child in particular, was also a theme that three families shared.

"I believe that God led us to our little one specifically. There is always a reason not to do it, but God gave us all we needed as we thought about whether it was the right time or not" (002, personal interview, March 2011).

"We felt God had called us to give a child a home" (009, personal interview, April 2011).

One family shared a particularly lovely and unique perspective on why they chose international adoption and a child with Down syndrome. It was their desire to honor their late daughter's memory and share the blessings that she had given their family with another child who also had Down syndrome.

> We kept a firm belief that [our daughter with Down syndrome] who passed away from Leukemia, and taught us so much about love and grace, should be remembered in a way that allowed us to live the lessons that she taught to us as a little

> child....we wanted to pay it forward, the love that we had in us for her. (003, personal interview, March 2011).

Families indicated several different reasons for internationally adopting a child with Down syndrome. Layers of intent, such as desiring adoption, passion for Down syndrome, and learning about devastating futures for children in other countries led families to seek out this process.

Services

Families were also asked what types of services or programs they utilized during and after the adoption to address concerns about international adoption, family integration, and medical or developmental issues. They were invited to share whether they sought out the services of if they were offered through an agency, and to what extent they found the services beneficial. Families were also provided an opportunity to discuss service gaps or areas of need.

By far the most universally utilized, sought out, and reportedly helpful programs or services for the families were support groups or online forums specifically designed for families considering, in the process of, or who had completed an international adoption of a child with Down syndrome. Six families utilized the experiences and support of families who were going through, or who had completed the process, for information, resources, referrals, and support before, during, and/or after their own adoption process. Of the three families who did not, one family stated that a program such as this would have been very useful.

"There is strength in being surrounded by people who assume you are not loony for wanting to do this" (003, personal interview, March 2011).

"Fellow adopters were and are extremely helpful. MANY have adopted from Ukraine; MANY have adopted kids with DS" (006, personal interview, March 2011).

"I believe it would be hugely beneficial if they had classes where you could talk to families who have already been through the process" (007, personal interview, March 2011).

In the area of service gaps and program or resource needs, access to a translator or some type of help with the language barrier was most frequently identified. Families met the need to a certain extent with sign language, however four families did specify this as an area of need for them.

"If I had to choose a need that we struggled with, it would have been to have access to a translator in the various times I needed to explain something to [her] in her native language" (003, personal interview, March 2011).

Families tended not to be offered services, or not to find services offered very helpful, and so sought out information on adoption, family integration, and medical issues on their own. They utilized families who had already completed their adoptions as the largest resource but also looked toward books, videos, and specialists. The area of greatest unmet need was regarding communication and language challenges.

Overall Transition and Attachment

Seven participants responded that overall, their child and family's transition process was easier than they had expected. Though there may have been one or two minor issues that came up, they were worked through without excessive difficulty.

"Our children adjusted extremely quickly. The doctors even said that you would never know they were adopted" (004, personal interview, March 2011)

> It, surprisingly has been an easy process. Since this is about special needs adoption, 6 years ago we had previously adopted a "healthy" child from Russia. We had been through enough with him, that we knew what we were doing this time. Also people with the extra chromosome have an ability to love easier and attach themselves to those people they love. So the transition has been smooth. (007, personal interview, March 2011)

Issues related to attachment and bonding were also very commonly reported areas that ended up going more smoothly than they had anticipated. Again, seven families reported that the attachment process of child to parent, parent to child, and sibling relationships went very well.

"It is easier to love her more every day. I would never have guessed that in 3 months I could love another little girl so very very much" (003, personal interview, March 2011).

> Our older daughters transitioned so easily into having a younger sibling. I worried that our 2 year old who was only home from China for a year would have a hard time but it was actually so wonderful for all of us. (008, personal interview, March 2011)

"Helping him attach to us [was easier than expected]. After a few weeks, he wanted no one else. So that made us feel a lot better" (009, personal interview, April 2011)

When questioned, as to why these areas went better than expected, seven families cited positive aspects of the child's personality as a specific contributing or sole factor.

"She was so much more alert and eager to learn that we thought she might be. She responded really well to us" (005, personal interview, March 2011).

"Thankfully [he has a pretty easy-going personality that definitely made the transition easier . . . he is a delight" (006, personal interview, March 2011).

"He has an amazing ability to love" (007, personal interview, March 2011).

"Partly I think it's [her] personality. She is very easy going and interactive and you just want to be around her" (008, personal communication, March 2011).

Overall, the data indicates that transition and attachment are areas which these families found easier than expected and families believe that a major reason for this is based on particular positive characteristics of their child's personality.

Community and Society Integration

Participants were asked questions regarding their perceptions of society's understanding related to international adoption of a child with Down syndrome and any stigmatization or discrimination they have experienced as a result of their adoption.

Overwhelmingly, families stated that they did not feel that society overall understood why anyone would want to adopt internationally, particularly a child with Down syndrome. Eight of nine families responded that they had been challenged by family, friends, and/or people in the community as to why they had not adopted domestically.

"We still get some concerns from people about why we didn't adopt domestically. There is a perception that there are so many children here why would we go to another country" (008, personal interview, March 2011).

When asked about society's understanding of adopting a child with Down syndrome, the results were just as marked. Again, eight families stated that they perceived society in the US as not being supportive of people with Down syndrome or families who would choose to adopt a child with Down syndrome.

"Well, unfortunately some people don't understand. They see the Down syndrome first, instead of the amazing little girl" (001, personal interview, March 2011).

> Everything society thinks they know about DS is a lie. It is not a horrible way of life, rather it is an absolute blast in living outside the box...I also had one woman ask me if they were out of kids that didn't have something wrong with them...I told her nothing was wrong with [her], just that she had DS. She backed out of the conversation by saying 'well, I guess them kids need love too.' Brilliant answer. (003, personal interview, March 2011)

Additionally, eight of the families reported some type of stigmatization or discrimination based on their child's disability. Six families experienced this behavior in the US and two when traveling during the adoption process.

> When we voiced our decision to adopt a child with Down syndrome, we had people begging us to change our minds, giving us all kinds of grim predictions about what a horrible experience we would have and how we'd ruin our lives and how [my husband] needed to "man up" and tell me "no", etc., etc., etc. It was terrible. (006, personal interview, March 2011)

"Actually we did experience a bit while in Vietnam. It is unusual to see children with disabilities out in public so we had several unusual experiences where people appeared to be 'horrified' by our baby" (008, personal interview, March 2011).

When asked what they felt was needed in order to deal with society's lack of understanding and discrimination, the answer was clear: education, awareness, and exposure. Six families specified that education was the key.

"People here need to see and understand how the children are treated there compared to here" (002, personal interview, March 2011).

"I am hoping that as people learn more about the capabilities of kiddos with Down syndrome, they won't be so negative" (006, personal interview, March 2011).

Five families believed that greater awareness of the needs and abilities of children with Down syndrome, particularly in other countries, as well as increased opportunities to meet and interact with individuals with disabilities would go a long way toward improving society's understanding and treatment of these children and their families.

"Greater awareness of the orphans would be great. Greater awareness that kids with special needs are still just kids and nothing to be scared of would be great" (005, personal interview, March 2011).

"Well, for one thing almost everyone who has ever met [our son] loves him. It's a lot easier to be prejudiced against a diagnosis than a smiling, cheery little boy" (006, personal interview, March 2011).

Families reported a nearly unanimous perspective that society does not understand the value of international adoption or adopting a child with Down syndrome. Nearly every family experienced some level of stigmatization and felt as though education, awareness, and exposure would help to bridge the gap of understanding and acceptance.

Unexpected Blessings

The final category that participants were asked about concerned any "unexpected blessings" they have experienced as a result of their child's adoption. The themes that arose in this category were related to the child him/herself, the family's response, and the response of others around them. Five families indicated that the child was a source of blessing:

"I think that seeing the blessing of a chaotic kid...is unexpected" (003, personal interview, March 2011).

"The unexpected bonus is our younger son has a playmate and they really get along well. And they will always have someone else who understands their own issues since they both have Ds" (005, personal interview, March 2011).

"We feel so fortunate to have such a wonderful family and [she] adds so much to it" (008, personal interview, March 2011).

Four families stated that the responses of immediate and extended family were a source of unexpected blessing.

> I also enjoy watching my 5 year old son take on the responsibilities of being a "big" brother very seriously...even though she is 3 months older. He has such a profound world comprehension for a young kid. He has seen death up close and he has traveled to various developing countries and has learned the idea of adoption both into heaven and into our home as real life lessons. (003, personal interview, March 2011)

"We have all learned to love in a greater capacity those who are not loved and accept those who may be different from us" (007, personal interview, March 2011).

"My father has really softened and has fallen in love with [our son], something I never expected" (009, personal interview, April 2011).

Three families experienced unanticipated benefits in the form of others' responses to the new child or the family's decision to adopt a child with Down syndrome.

> I think the most amazing is the people. People who have stepped up to help us, to support our fundraising, who have been here for us since we've been home. People who are genuinely happy for us and our family. (002, personal interview, March 2011)

"Our adoption story has led many of our friends to adopt now" (004, personal interview, March 2011).

Families experienced a great number of unexpected blessings as a result of their child's adoption; some were specifically related to the child's particular personality or characteristics, some had to do with familial responses to the child, and some to do with the reactions and support of strangers or acquaintances.

Summary

This chapter presented the major findings from the data received. Themes from the main categories were provided and are as follows: why the family chose international adoption of a child with Down syndrome, services they found beneficial, the process of transitioning the child into the family and community as well as attachment issues, and finally, unexpected blessings that they have experienced.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter explores and draws conclusions from the data and discusses areas of limitation for this study. Applications for social work practice, policy, and research are presented in light of the National Association of Social Workers [NASW] code of ethics.

Discussion

Demographics

The demographic data on the participants in this study did not provide any specific insight into why some families choose to adopt a child with Down syndrome, or provide factors that might have predicted a positive experience. Parental age, annual income, education level, presence or absence of other children in the home, and particular experience were varied and did not appear to correspond to an easier or more difficult process. Despite diversity in many areas, the overall account of each family's adoption was unanimously positive.

There were commonalities among participants in the areas of ethnicity, father's employment status, and country of adoption, but there is not sufficient data to determine whether or not they played a significant role in the process.

While marriage may very well increase the likelihood of a positive experience, due to the mutual support spouses can offer each other, as well as the policy related issues that can arise in adoptions, it is not possible to ascertain the level of impact from this study since all participants were married.

The fact that eight of nine families ascribe to a Christian religion, regardless of denomination, may suggest that the spiritual component toward deciding to adopt and then as a support during and after the process is important for families. It should be noted that Reece's Rainbow, the agency used to collect the samples, has a Christian affiliation which may also play a part in accounting for the high incidence of families who self identify as Christians in this study.

Adoption Process

Motivation to Adopt. This study found several different motivations for families to choose to internationally adopt a child with Down syndrome. Some families felt drawn to help a child in desperate need of a loving and supportive family in which they could have their medical, developmental, educational, and emotional needs met, and to provide hope for a productive and fulfilling future. Many families felt an intense emotional connection with a particular child or with the idea of international adoption or a child with Down syndrome. Some families held strong beliefs that adoption was a process that held great possibilities for themselves as well as the child they were seeking to add to their family. A large number of parents held firm to the idea that having a child with Down syndrome was a joy and privilege, and other parents cited a conviction from God to adopt a child.

One family was led to adopt by the loss of their young daughter with Down syndrome. It was their desire to honor the memory and love that they had experienced with their daughter and to share that with another child who also had Down syndrome. It is possible that this may be a factor that inspires other families as well, although in this study, only one family indicated that they had experienced the death of a child with Down syndrome.

A comprehensive look at the data evidences a multi-layered motivation for adoption when taking into account the forces leading toward international adoption as well as those that impact specifically and intentionally selecting a child with Down syndrome.

This finding aligns well with the transactional family systems model as it allows for multiple factors to be at play within a single event and can explain varied responses to one event by individuals within a single system and across multiple unrelated systems (Cunningham, 1996). In this instance, families' motivations for adopting in the manner that they did is influenced by the environmental factors and perceptions of social realities unique to their situation. However, the end result was very similar when comparing overall experiences.

<u>Services</u>. The results of this study indicate that support groups and online forums with other adoptive parents were the most beneficial and widely utilized support for families adopting a child with Down syndrome. This supports the findings of Reilly and Platz (2004) that these types of groups have a significant positive benefit for family preparation and transition and are key to ensuring a positive outcome.

Human ecology theory can be used to explain why support groups are such a universally encouraging and positive experience for families as well as how they have formed in the absence of social workers or other professional intervention (Egbert & LaMont, 2004). In order to meet the varied needs of adoptive families, these family systems join together to create a new system of support.

The area of largest unmet need, however, was in the area of communication and translation services which is a common need among all families who adopt internationally, regardless of whether or not the child has a disability. It is important to realize that there may be just as many similarities as there are differences between international adoption of a child with Down syndrome and that of a child with no diagnosed disability.

Overall Transition and Attachment. This study found that for these families, the process of transitioning the adopted child into the family and bonding with and attaching to the child and vice versa, required less effort and produced more rewards than they had anticipated.

When analyzing why that was the case, data indicated that in every family, there was a component of the child's personality or character that facilitated this process. This seems to support the concept of the Down Syndrome Advantage (Corrice & Glidden, 2009; Glidden & Cahill, 1998; Hodapp et al., 2001), although whether that is described or supported in terms of an easier parenting experience or in terms of parent perceptions that they find aspects of the child's personality or temperament pleasing and personally rewarding is unclear. Parents did not as a whole state that they believed, either before or after their adoption, that children with Down syndrome provided an easier parenting experience, although they did report that they felt that a child with Down syndrome was a blessing, regardless of any institutional behaviors the child may have displayed.

While support for the Down Syndrome Advantage may be complicated to determine, what is clear is that this data supports the findings of previous research which cite parental and familial experiences with a child with Down syndrome as rewarding and positive (Corrice & Glidden, 2009; Glidden & Cahill, 1998; Hodapp et al., 2001).

Community and Society Integration. Data from this study support the idea that society does not have a great awareness or appreciation for international adoption. Families felt as though they often needed to defend their adoption decision to family, friends, and strangers alike.

The data also supports a difficulty on society's part to value children with Down syndrome and attempt to understand why families may choose to specifically adopt a child with Down syndrome.

Families reported that they experienced stigmatization regarding both of these aspects of their adoption decision, (i.e., the decision to adopt internationally as well as to adopt a child with special needs), though sometimes it was regarding one specific dimension of the choice, and sometimes toward the combination of factors.

This finding indicates that families who internationally adopt a child with Down syndrome may experience more stigmatization and discrimination than other families who have internationally adopted a child with no diagnosed disability or families who have a biological child with Down syndrome.

The data suggests that society must be more informed about the need for and benefits of international adoption, both for adoptive families and adopted children. Society also lacks accurate information about

Down syndrome. As regards this study, an understanding of the dire living conditions of children with Down syndrome in orphanages abroad is also essential for increasing the support for and decreasing the stigmatization toward families who choose this type of adoption experience.

Families in this study indicated that they believed societal education, awareness, and exposure of international adoption and children with Down syndrome could lead to greater overall acceptance and correcting the misconceptions of adoption and disability that are currently in existence. Participants felt that it was imperative for individuals who know the truth seek to make it known to others.

Unexpected Blessings. Though families entered into the adoption expecting a positive outcome for their family, what was discovered through this study is that though international adoption of a child with Down syndrome did indeed come with rewards for the family, the scope of the positive impact was much greater than they had anticipated. Blessings and benefits of the child him/herself, extended family responses that were positive and supportive, as well as reactions from friends and complete strangers that were encouraging resulted in an overall experience that was more affirming and life changing than any family had initially expected.

Limitations

The limitations of qualitative research come out of its data analysis process. Though every effort is made to understand and present the data in an impartial manner, there is naturally some potential for bias when interpreting meaning within participant answers, in identifying and developing themes, and when selecting quotations to support the themes.

Further, since all participants in this study were selected within one agency, their experiences may share commonalities that may not be evidenced among families who completed similar adoptions through a different agency.

The lack of diversity in certain areas such as ethnicity, country adopted from, and religious affiliation, within the demographic makeup of participant families may also be a limitation for transferability of results (Grinnell & Unrau, 2011; Morris, 2006).

Recommendations for Social Work Practice, Policy and Research

Social Work Practice

This area of research is particularly legitimate for social work practice since as it is reflected so clearly by the values within the Social Work Code of Ethics.

"Social workers' primary goal is to help people in need and to address social problems" (National Association of Social Workers [NASW], 2008, para. 16). Social problems such as poverty, stigmatization, discrimination, and a lack or absence of resources are found both domestically and internationally with regard to the international adoption of children with Down syndrome. Social workers must acknowledge these needs and investigate how to best intervene in these areas. As this research discussed, families did not utilize a great number of services in their adoption process; however, it is important for social workers to be available before, during, and after the adoption process in order to be a resource and support for them should concerns arise.

"Social workers challenge social injustice" (NASW, 2008, para. 17). Social injustice occurs every day in myriad ways, all over the world. Children with Down syndrome and other disabilities are languishing in foreign orphanages and are not receiving the physical, mental, and emotional support and stimulation that all children need and deserve. Social work needs to be a voice for these vulnerable children and must intentionally seek to raise awareness of their plight and the ways in which individuals and families can help.

Social workers must work to increase society's understanding of individuals with Down syndrome and other developmental disabilities and help to educate society in order to reduce the stigmatization that these individuals and families experience. Social workers' own involvement with persons who have Down syndrome, and the agencies that serve them, will naturally provide opportunities for social workers to promote involvement to others in their agencies and communities.

"Social workers respect the inherent dignity and worth of the person" (NASW, 2008, para. 18). This principle dovetails well with the previous principle as they both relate to this research. Individuals have value regardless of their abilities or lack thereof, and it is imperative that social workers move toward practice that imparts to society, the understanding of every individual's innate value, particularly in the area of children with Down syndrome who are "unseen" outside the United States.

"Social workers recognize the central importance of human relationships" (NASW, 2008, para. 19). Human relationships, whether they are family bonds or societal connections, are important for everyone. This is especially obvious in the arena of adoptions (i.e., providing family relationships for orphans), but is also a major principle in determining how to best facilitate successful adoptions, transitions, and attachments for families who have adopted. Support groups promote the creation of new bonds as well as facilitate the growth and strengthening of existing attachments.

"Social workers behave in a trustworthy manner" (NASW, 2008, para. 20). In this area of research, it is most relevant for social workers to examine their own biases and stereotypes toward adoptive families, international orphans, and children with Down syndrome, as well as the formal and informal biases within their agencies. It is unconscionable for social workers to promote their own stigmatization on an already vulnerable population.

"Social workers practice within their areas of competence and develop and enhance their professional expertise" (NASW, 2008, para. 21). It would be an untenable suggestion for every social worker to be familiar with all the concerns that may arise or to know all that is available for families who are internationally adopting a child with Down syndrome; however, social workers need to be comfortable discussing these issues with clients and be willing to help individuals or families locate resources to meet their needs. By raising their own awareness of related issues, social workers increase their ability to provide service to clients they encounter.

Policy

Areas of policy change that are relevant in this area of research are numerous and concern both international and domestic issues.

On the international front, policies that work to improve conditions for disabled orphans abroad would advance the standard of living for children waiting for families. Policies that would allow adoptions of children with Down syndrome regardless of their age or location (i.e., children who "age out" of baby houses and are transferred to adult mental institutions at 5 or 6 years old) would also be a huge step toward improving the odds for orphans with Down syndrome to live a long and fulfilling life. A way to streamline the paperwork on subsequent adoptions for families who have successfully completed an international adoption of a child with Down syndrome may encourage families to adopt again.

There is also an urgent need for policies within other countries to create resources and services that would enable and encourage birth families to parent their own children.

Domestically, increased access for international adoptive families to services and programs that are currently only available for children with disabilities adopted within the United States might provide a level of security and support that some families may need in order to feel comfortable pursuing such an adoption.

Areas of Further Research

Because the nature of this qualitative study was to simply begin the process of understanding families' experiences internationally adopting a child with Down syndrome, there are many areas for further study. One of the areas that may be most beneficial in understanding why these adoptions apparently are so overwhelmingly positive, would be to further examine the concept of the Down Syndrome Advantage, specifically as it relates to international adoption and institutionalization. One of the biggest concerns many families have adopting internationally, regardless of whether the child has a diagnosed disability, is the effect of institutionalization on the child and how that will play out in the family. Attachment problems are common among institutionalized children, but were not present within participants in this study. Rather, that was an area that was the most positive for the families. A hypothesis for a further study could be whether the institutionalization factors are somehow minimized in orphans with Down syndrome by the inherent characteristics of the disability.

It would also be of interest to examine attachment after international adoption of a child with Down syndrome in depth to determine if there are any particular factors, parent perceptions, attitudes, or interventions at play in those situations that could be applied to families struggling with attachment in internationally adopted children without a diagnosed developmental disability.

A sibling study on children who have an internationally adopted brother or sister with Down syndrome would be helpful in providing further understanding the comprehensive family experience.

Another area that is rich for further study is the connection between religion and the decision to adopt, particularly choosing to adopt a child with Down syndrome or other developmental disability. An additional study of Christianity among these families may shed light on why the families in this study decided to adopt in this way and why their experiences where so positive. Principles of Christianity promote care for orphans, the sanctity of all human life, sacrificial service to others, and the doctrine of adoption, and may in turn impact families to varying degrees.

The emotional and spiritual support families may receive from their faith and church communities may also play a large role in their positive outcomes.

Conclusions

When taken as a whole, an international adoption of a child with Down syndrome appears to be an overwhelmingly positive experience for families. Although the pre-adoption process can be grueling and time consuming, the transition, attachment, and overall adoption experience is easier and more rewarding than anticipated. This area of research is particularly valuable and relevant to social work practice and policy and provides many avenues for further study.

APPENDIX A

RECRUITMENT EMAIL

Dear Reece's Rainbow Families,

I am a graduate student at California State University, San Bernardino studying social work and am specializing in developing services for, and providing support to, children with developmental disabilities and their families. I am particularly interested in adoptions of children with developmental disabilities, both domestically and internationally.

This year I am conducting a Master's level research study on families' experiences internationally adopting a child with Down syndrome. I am specifically interested in the process of integrating the newly adopted child into the existing family; the services used before, during, and after the adoption process to facilitate successful transition; as well as any unexpected blessings that families experience as a result of their child's adoption.

Andrea Roberts has graciously offered to forward this email to the Reece's Rainbow Yahoo Group in order to reach families who have completed such an adoption.

In order to carry out this study I am looking to connect with 15-20 families who have completed an international adoption of a child with Down syndrome. Participation would consist of either an approximately 45 minute telephone interview, or if you prefer, the same questions in written form that you may type answers to and then submit to me.

All participant information and interview content will be kept strictly confidential and no identifying information will be included in the final report.

If you would be interested in helping me in this research or have any questions, please feel free to contact me by email at ErikaLazo@live.com or on my cell phone at (909) 912-9803. I am happy to discuss any concerns and answer any questions you may have.

Thank you very much for your help in this exciting project!

With Appreciation,
Erika Lazo

Graduate student at California State University, San Bernardino
MSW intern at the San Gabriel/Pomona Regional Center
ErikaLazo@live.com
(909) 912-9803

APPENDIX B

INSTRUMENT

Families' Experiences Internationally Adopting a Child with Down Syndrome

Survey Instrument/Written Interview

This interview is designed to explore your family's experience internationally adopting a child with Down syndrome.

Although many families have completed multiple international adoptions of children with Down syndrome, *this survey seeks to gather information from your FIRST such adoption and family transition experience.*

If your first experience was of multiple children with Down syndrome, please discuss your experience of the process for you, in light of adopting multiple children at once.

There will be opportunity to discuss subsequent adoption experiences toward the end of the interview.

Demographics

What month and year did you receive your referral?

What month and year did you bring your child home?

At the time of your first adoption, what was your marital status?

single divorced married living together

How long had you been with your partner/spouse?

How old were you?

How old was partner/spouse?

What is your ethnicity?

What is your partner/spouse's ethnicity?

What is the highest level of education you have completed?

What is the highest level of education your partner has completed?

What religion, if any, do you affiliate with?

What was your employment status?

full time outside the home part time outside the home full time from home
part time from home not employed

What was your partner/spouse's employment status?

full time outside the home part time outside the home full time from home
part time from home not employed

What was your approximate household income?

under $45,000 $45,001-$60,000 $60,001-80,000
$80,001-$100,000 $100,001-$150,000 above $150,000

Where did you live? (City, State)

How many children did you have at the time of your first adoption?

What were their ages?

These next questions will explore your decision to adopt

Why did you decide to adopt a child/children?

Why did your family choose a child or children with Down syndrome?

What previous experience, if any, did you or your partner/spouse have with individuals with Down syndrome or other developmental disabilities? (If not answered in the previous question.)

Were there particular reasons for choosing international adoption?

What country did you adopt from?

These questions will be centered on the your adopted child/children

How old was your child when you were matched?

How old was your child when the adoption was finalized and you brought your child home?

Did you visit your child in his/her home country? (yes/no)

> **What were the benefits (if any) for the decision you made?**
>
> **What were the drawbacks (if any) for the decision you made?**

What was your child's living experience before you brought him or her home?

orphanage foster care bio parent(s) other institution

What were you told about your child's diagnosis/diagnoses before the adoption?

How accurate was the information?

What impact, if any, did this have on your adoption/transition experience?

<u>This section explores the services your family used related to your child's adoption and family transition</u>

Did you adopt through an agency?

What services, programs, trainings, or therapies did you receive or participate in PRIOR to bringing your child home and were they offered by the adoption agency or did you seek them out?

Services specifically related to the adoption process

Services specifically related to family integration

Services specifically related to medical or developmental concerns

How beneficial did you find each?

Were there any other services that you felt would have been beneficial to you at that time that were not offered?

What services, programs, trainings, or therapies did you receive or participate in AFTER YOUR CHILD WAS HOME and were they offered by the adoption agency or did you seek them out?

Services specifically related to the adoption process

Services specifically related to family integration

Services specifically related to medical or developmental concerns

How beneficial did you find each?

Were there any other services that you felt would have been beneficial to you at that time that were not offered?

<u>This set of questions explores experiences of integrating the child into your family</u>

At the time you were finalizing your child's adoption, how prepared *did you think you were* for bringing your child home and integrating him/her into the family?

Looking back, how prepared *were you really*?

Tell me about the process of transitioning/integrating your child into the family as it relates to yourself, your spouse/partner, any children previously in the home, your extended family, the community.

Was anything harder than you had expected?

What did or could have helped?

Was anything easier than expected?

Why do you think that was?

Overall Experience

Do you believe that this adoption was a positive decision and/or experience for your family?

Has your family experienced any unexpected blessings as a result of your adoption?

What would be the biggest factor against adopting again?

What would be the biggest factor to encourage you to adopt again?

Has your family adopted again? How did that experience compare to your first adoption experience?

Stigmatization

Have you experienced any stigmatization/discrimination related to your adoption or your child's disability?

> **If so, can you tell me about that?**

Do you feel that society is able to understand why your family made this decision?

> **What do you think would help?**

Additional Information

Is there anything else you'd like to tell me? Anything else that would be important for me to know in order to more fully understand your experience?

Developed by Erika Lazo

APPENDIX C

INFORMED CONSENT

Informed Consent

You are being asked to participate in a research study that is designed to explore and understand families' experiences internationally adopting a child with Down syndrome. This study is being conducted by a graduate social work student from California State University, San Bernardino under the supervision of Dr. Carolyn McAllister. This study has been approved by the School of Social Work Sub-Committee of the CSUSB Institutional Review Board

Your participation will include a recorded telephone interview of questions designed to help you describe your experience of adoption as well as the experience of integrating the child into the family. It is expected that the telephone interview will last approximately 45 minutes. If you prefer, you may request a written document which you can fill out on the computer or print and fill out by hand. The written survey will contain the same questions as the telephone survey and should take approximately the same amount of time to complete.

There are minimal risks associated with your participation in this research study. It is possible that during the interview you may experience an emotional response while sharing the details of your family's experience of adoption and family integration. You may also experience benefits of participating in this study by sharing your story and helping to create an understanding of the process and family experience internationally adopting a child with Down syndrome.

Your participation in this study is voluntary and you are free to end your involvement at any point during the interview if you so choose, by simply stating your desire to stop. There will be no adverse consequences to any such request. You are free to skip any questions in the interview that you do not wish to answer.

Your anonymity and confidentiality in this study are provided for in that no identifying information about you or your family will be linked to the responses you provide in the interview. All names and other identifying information that may have been gathered as a result of communicating and organizing interview schedules will be destroyed at the end of the data collection process. The results of this study will be sent to you automatically upon completion after the summer of 2011.

For questions or concerns about your rights as a research participant, you may contact:
Dr. Carolyn McAllister
California State University, San Bernardino
cmcallis@csusb.edu
(909) 537-5559

I agree to be audiotaped: _______ yes _______ no

APPENDIX D

DEBRIEFING STATEMENT

Debriefing Statement

Thank you for participating in this research study. The time and effort you spent participating in this research study are greatly appreciated. Just as a reminder, your responses are anonymous and your participation will be kept confidential.

I expect that the results of this study will help create a greater awareness of the experiences of families who internationally adopt a child with Down syndrome, and the unexpected blessings they encounter, as well as identify areas in which there is the greatest need for support.

Please feel free to contact Dr. Carolyn McAllister at cmcallis@csusb.edu or (909)537-5559 with any questions or concerns regarding this research study. The results of this study will be sent to you automatically upon completion after the summer of 2011.

For assistance in finding resources in your area, you may wish to call the National Down Syndrome Society helpline at (800)221-4602 or contact your local Down Syndrome Association.

Again, thank you so much for your involvement in this study and your willingness to share your family's experience.

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