

A FAMILY DEALING WITH THE DIAGNOSIS OF AUTISM: FIVE YEARS LATER

Gonzaga da Gama, San Jose State University

This ongoing research study, a portion of which was presented in 2003, grew from a need to expand understanding of how families cope with having children with special needs. Over a quarter of a million children are born in the United States every year with some form of a disabling condition. This translates into about 700 children born every day with special needs, and the number appears to be on the rise (Thompson, 2000). It is interesting to note that about six percent of all the children in the USA from birth to age five have disabilities, and 12 percent of all school children have disabilities because of birth defects, illnesses, accidents, and other causes (Thompson, 2000). So how do families who have a child diagnosed with special needs deal with it? What is the lived experience of such a family? What are the changes, if any in the family system? A review of the literature suggests that having a member with a disability affects the family in many ways, dramatically impacting the roles played by different members of the family (Turnbull & Turnbull, 2001). Though increasing in recent years, literature on how families cope during and post the diagnosis process is limited. A greater understanding of how families cope having a child with a disability will address this gap in literature and help professionals in the fields of recreation and education to be better prepared to meet needs of the family with a member with a disability.

Purpose of the Investigation

In this paper, I present results of an ongoing investigation of how a family copes with having a child with a disability. Since a highly controlled research design would not facilitate a deeper understanding the phenomenon, an ethnographic case study approach was employed to gain an in-depth understanding of the lived experience of one family.

Methods

This paper presents results of an ongoing study of a family (“The Smiths”), who has a child with autism. For detailed description of the methods please refer to my previous research (da Gama, 2003). The family has gone through significant transitions. In the past three years, “Ron” and “Lin” have divorced, and after a contentious legal battle, Lin gained both physical and legal custody of “Monty” and his brother. Lin lives in a subsidized rental unit with her sons. Furthermore, during the last four years, I relocated 3 thousand miles away necessitating a change in the data collection process. New data were collected during this 4-year period via extensive weekly phone conversations, regular email communications, and 3 to 4 in-person visits a year for 1-2 weeks at a time with Lin. Attempts to locate and connect with Ron were unsuccessful. Through Lin, I learned that Ron was living in a foreign country. All of the email communications and copious notes written after each phone conversations and in-person visits amounted to 710 pages of typed transcripts. Multiple means of data collection, multiple sources of data collection, along with member checks assured the credibility and trust-worthiness of the data (Patton, 1990). The observations, with the phone conversations and email communication, and field notes were analyzed as a single case and themes and meanings were allowed to emerge.

Findings

Following data analysis, life and leisure transitions, renewed determination, and disillusionment with spirituality emerged as three distinct themes describing what the family was experiencing. In addition, Lin continued to experience a myriad of emotions.

Life and Leisure Transitions

Lin experienced many transitions. Lin was separated from Ron in 1999 and divorced in 2001. Lin, a college graduate and formerly professionally employed individual, unable to make her monthly mortgage payments was forced to move out of her 3-bedroom suburban home. A lack of ability to pay for childcare and no regular child support payments from Ron left Lin with no other avenue but to seek assistance from governmental and charitable organizations for financial support. She moved into a government-subsidized apartment. She could not afford to maintain a car and had to depend on public transportation for daily activities. As Lin stated, "Trying to get around using the bus with two young boys is a great challenge. You do not feel like going anywhere. Things that would take only a couple minutes in a car take a lot longer and are more difficult. I only do the minimum that I have to do. I do not have anyone who can baby sit the boys, and so I have to take them with me everywhere I go and that can be a big pain." Lin's only income was governmental assistance. She had to depend on food stamps to buy groceries for herself and her sons. She could buy groceries only once a month when her food stamp assistance became available. She expressed that she felt a sense of shame and frustration of having to depend on assistance for buying basic grocery items. She mused about the days when she had the ability of going to the grocery store as and when she pleased.

Family leisure also experienced tremendous transitions. Prior to the diagnosis of disability, the family spent a lot of time engaging in family leisure. The family would consistently go to the local parks, go on walks, host friends over for a barbeque, play games, go to sporting events, amusement parks, visit sites, and friends, and take national and international trips. However, following the diagnosis, the main preoccupation of the family was making all the appointments related to Monty. The main focus became the disability of Monty. Leisure became secondary, and an after-thought. And even when leisure pursuits were engaged in, they took on simple forms such as spending time with a couple of close friends who knew about the diagnosis of the disability. The time spent was also used as way to express how the family felt about the diagnosis. Leisure time became a time for the family to receive emotional support and allow opportunity to vent their frustrations, sadness, and other emotions. Following the divorce, because of limitations of resources, time, and transportation, leisure continued to be relegated to a secondary status. Forms of leisure pursuits have changed from active and expensive leisure, to more simple. Lin and her two sons see themselves as a close family unit and all the activities are used for the purpose of family making. Going to the grocery store as a unit is viewed as a leisure experience. Making choices about specific grocery items allows for decision-making and sense of perceived freedom. Reading together as a family and playing games and watching videos are examples of leisure activities they engage in.

Renewed Determination

Despite all the transitions that Lin has experienced, her determination to find a cure for Monty's autism remained undeterred. She remains determined to do what it takes to find a cure. The following quotes capture her determination. "I will do everything humanly possible to find a cure for autism. I am not going to just sit back and relax and let life take its course. I am going to find alternative treatments, do whatever is necessary and make sure that Monty is cured. I will overcome this autism." To date, Lin has tried homeopathy, water therapy, energy healing, cranial work, medicinal herbs, organic foods, and special diets to name a few. She spent hours at the library with her sons investigating new and improved ways to address and cure autism. Her determination and desire to find a cure is well reflected in her responses when asked how Monty is doing. Lin will always respond stating, "He is doing so much better. He speaks more clearly and he understands and he communicates well. He is not engaging in self-stimulating behaviors, etc." Lin also is single-minded about her determination. Any avenue that provides a glimmer of hope in terms of a cure, Lin is willing and quick to embrace. If anyone presents an opposing viewpoint or questions any of her choices, she is unwilling to listen and is willing to sever ties with them. She has decided that Monty will learn best by being home schooled. So in addition to all of the pressures on her, she has begun home schooling both of her children. She states that she can ensure that Monty will be able to learn in a comfortable environment with a familiar person as his teacher.

Disillusionment with Spirituality

The new and awakened spirituality that Lin experienced following the diagnosis process does not appear to be sustained. The sense of calling on a higher being to help her in her time of need seemed to have dissipated. She felt abandoned by God and felt that there was no point relying on God. When asked if she was praying, she emphatically stated that there was no point in doing that. In her words, "This whole spirituality thing is nonsense. I think it is a waste of time. I have to do what I have to do, and I cannot count on anybody or anything for doing things that I have to do. I just do not think about anything but just all that I have to do and I go about doing it." Lin did mention that she felt her family provided some support for her. However, she felt she did not want to burden them or depend on them." She continues to pursue alternative spirituality, compared to traditional religion she was exposed to all her life. Commonly she will refer to energy in the universe, crystals, etc, deep cleansing for herself and her sons as being necessary to experience healing of the disability.

Intense Emotions

Lin continues to experience a myriad of emotions. These emotions are escalated by the experiences she has had with Ron in the divorce proceedings. On the one hand she felt anger toward Ron and her situation following divorce, but at the same time she felt a sense of freedom, relief, happiness, and calm because she was no longer married to him. When Lin was going through the divorce and custody battle, she experienced a great deal of emotional stress. As she so aptly stated, indicated by the quote, "Dealing with Monty's issues is a breeze compared to having to deal with the whole court system and the custody issue. Now that all of that is behind, I am very happy and I can just focus on my

kids. I can be relaxed, feel a sense of calm and focus on finding ways to help Monty. It is indeed a great relief. I am the happiest I have been in a long time.”

Discussion, Conclusion and Application

The findings of the investigation revealed that coping with a diagnosis of a disability for a child is stressful. It brings forth many emotions, causes many transitions and instills a renewed determination to find a cure for the disability. Though there can be an awakened spirituality and an evolved perspective on life in the beginning, this perspective is quite short-lived and leads to disillusionment. The findings are consistent with the findings reported in literature and provide support for the Family Systems Theory. Further research is necessary to understand how certain families can be brought closer as a result of a difficult experience such as a disabilities and how certain families are drawn apart. Lin held on to her determination to find a cure for Monty’s autism. Additional research on this phenomenon will contribute to growing body of knowledge about families and disabilities. In closing, when recreation professionals, are knowledgeable of all the issues surrounding a disability, they can be more empathetic. This in turn could also help them take on the perspective of placing themselves in the “family’s shoes’ and strive to provide inclusive family leisure opportunities.

References

- da Gama, G. (2003). From a Perfect Baby to a Diagnosis of Autism: An Ethnographic Investigation. In S. Stewart & W. Borrie (Compilers), *Abstracts from the 2003 Symposium on Leisure Research*. Ashburn, VA: National Recreation and Parks Association.
- Thompson, C. E. (2000). *Raising a Handicapped Child: A Helpful Guide for Parents of The Physically Disabled*. New York, NY: Oxford.
- Turnbull, A. P. & Turnbull, H. R. (2001). *Families, Professionals, and Exceptionalities: Collaborating for Empowerment*. Upper Saddle River, NJ: Merrill.

ABSTRACTS
of Papers Presented at the
Eleventh Canadian Congress on Leisure Research
May 17 – 20, 2005
Hosted by
Department of Recreation and Tourism Management
Malaspina University-College
Nanaimo, B.C.
Abstracts compiled and edited by
Tom Delamere, Carleigh Randall, David Robinson
CCLR-11 Programme Committee
Tom Delamere
Dan McDonald
Carleigh Randall
Rick Rollins
and
David Robinson



Copyright © 2005 Canadian Association for Leisure Studies
ISBN 1-896886-01-9



Appropriate Use of Documents: Documents may be downloaded or printed (single copy only). Please note that this document is copyrighted and CREDIT MUST BE PROVIDED to the originator of the document when you quote from it. You must not sell the document or make a profit from reproducing it. You must not copy, extract, summarize or distribute downloaded documents outside of your own organization in a manner which competes with or substitutes for the distribution of the database by the Lifestyle Information Network (LIN). <http://www.lin.ca>