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PREVIEW

**THE STRENGTHS AND CHALLENGES OF INDIVIDUALS
LIVING WITH DEVELOPMENTAL DISABILITIES**

by

Kathleen L. Dubas

A DISSERTATION

Presented to the Faculty of

The Graduate College at the University of Nebraska

In Partial Fulfillment of Requirements

For the Degree of Doctor of Philosophy

Major: Interdepartmental Area of

Community and Human Resources

Under the Supervision of Professor John DeFrain

Lincoln, Nebraska

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DISSERTATION TITLE

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DISABILITIES

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GRADUATE COLLEGE
UNIVERSITY OF NEBRASKA

**THE STRENGTHS AND CHALLENGES OF INDIVIDUALS
LIVING WITH DEVELOPMENTAL DISABILITIES**

Kathleen L. Dubas, Ph.D.

University of Nebraska, 1997

Adviser: John DeFrain

Being an individual living with a developmental disability or parenting a child who is disabled can be emotionally overwhelming. This research project focuses on crisis and family crisis theories as it looks at the effects, adjustment and unmet needs of the individual. Family strengths and positive outcomes are stressed and discussed as are factors influencing the everyday life of individuals living with a developmental disability.

Categories and themes emerge from informants, rather than being identified a priori by the researcher. Quantitative data are used in discussing frequencies, and by using cross tabulation procedures to show how two factors may combine and affect how an individual perceives his/her life as it relates to developmental disability. Thirty-two individuals participated in this research project.

PREVIEW

**“He who has a *why* to live for
can bear with almost any *how*.”**

**Frederich Nietzsche
(1844-1900)**

PREVIEW

ACKNOWLEDGMENTS

To all those individuals in this study who shared their personal lives, their challenges and their strengths. Your contributions, your experiences were lovingly given with painstaking care so others may learn, and understand and grow, therefore, assisting in making a better world for us all.

- To my dear mother, **Florence Prorok Dubas**, who shared and modeled the true meaning of love and family. She is highly intelligent, creative and humorous. She is an expert in dealing with crisis, adjustment, readjustment and the development of personal and family strengths.
- To **Dr. John DeFrain** for being able to guide, not control his students; for showing me his ability to laugh about and enjoy life in the best and even in the worst of times.
- To **Dr. Raedene Combs** who taught me the meaning of an optimistic nature and a yearning for continued learning and new experiences.
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- To **Dr. John Woodward** for demonstrating what depth of character, integrity, and intelligence are all about. He has been a father figure for me for years and I thank him greatly for that. He will not ever be replaced at this University.
- To **Dr. Theo Soderegger** who shared her wisdom and motivation and her wise, realistic perspective on any obstacles I saw in my way.
- To **Susan Dahl** who began a research project with hope and energy but was unable to see it to fruition due to her untimely death.
- To all the souls I have met along my own life's journey.

DEDICATION

I dedicate this dissertation to my father Joseph John Dubas, Jr., who is my own personal hero. He gave his life to his country, his church, and his family.

I will never forget you, your lessons, your role-modeling, or your sacrifices. I will miss you forever.

When my father was nineteen years old and in the Air Corps he proudly served as a turret gunner and a radio operator on airplanes during World War II. He was stationed in India, Burma and at one time China. His planes were shot down three times during hostile actions.

The last time his plane was shot down, he was in Burma. All but three airmen died in the crash. My father was lost in the jungle for ten days; when he was found, he was critically ill, unconscious and taken to a hospital in India.

Because of that crash and the subsequent experience of not being found for so many days, he had developed tropical fever; this greatly affected his heart for the remainder of his short life. After leaving the hospital in India, he was later taken to a hospital in New York and then to a hospital in Kansas City. He was eventually granted a medical discharge.

During the post-crash period and for many years, he was on medication and needed constant medical supervision. He was never healthy again. About three years after being discharged, he again became very ill with a high temperature; his lungs began filling with fluid. He entered a hospital in Grand Island, Nebraska and a week later was transported to the Lincoln Veterans' Administration Hospital. His doctors told him his condition would never improve. They also feared he would never leave the hospital or

that he would die. I believe he was only 24 years old at the time. My dad was in the hospital for approximately six months, from October until March. He was unable to walk, was confined to bed, and was under oxygen. With this special care and his intense will to live, he was eventually released.

But, his heart was dangerously enlarged and was very badly damaged. He had been diagnosed with rheumatic heart disease and was not expected to live. He was considered 100% disabled. My relatives tell me he never complained. My father's physicians warned him to not exert himself in any way, but he tried to live a somewhat normal life and worked as a branch accountant for the International Harvester Company in Grand Island.

On Palm Sunday, 1964, my immediate family attended early Sunrise Services at 5:45 a.m. On that spring day my father had another heart attack before sunset and died in our family home at the age of 41. This was during the month I had my 13th birthday.

This created a huge void in my life as it would in the life of any young woman. You need your father when you graduate from high school, when you go to college, you need him if you marry or have children. Giving up my father has been my life's most difficult challenge.

I am a lucky individual to have had such a kind, gentle, impressive father. It is my father that I hope will greet me and welcome me into the next world.

Fathers and families, strength and courage are interchangeable combinations of inestimable worth.

Kathleen's Father,
Joseph at 3 Years
of Age



Joseph in
High School



Joseph and His
Daughter Kathleen
on her 3rd Birthday



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PREVIEW

Chapter 1

INTRODUCTION

Content of the Problem

Being an individual living with a developmental disability or parenting a disabled child can be emotionally overwhelming. "A child's disability threatens family goals and security, and shatters parental hopes and expectations. Parents often are exhausted, marriages are strained, and families are isolated from the mainstream of the community" (Pearson & Sternberg, 1986, p. 213). Parents have many concerns that must be dealt with: including continuing medical care, common financial problems, social isolation, and an outlook for the future. "If something happens, who will care for my child?" Parents of disabled children or young adults frequently need a great deal of support. The family, or one of its members, can experience different feelings about the disability: personal responsibility, shame, fear and uncertainty, depression, disbelief, and shock. Many experience a sense of being in mourning, a kind of a "death of their dreams." Frequently, the responses of the family members are in response to whatever the mother is feeling or doing (Buscaglia, 1975). "A mother's reaction is primary in dealing with the disabled child" (Kazak, 1986, p. 139).

Featherstone (1992) indicated that a child's disability can affect a marital relationship by creating powerful emotions, reminders of failure, reshaped routines, and fertile ground for conflict. Some handicapped family members make less of a contribution to carrying out family functions, for example, contributing to family income, household maintenance, care of younger siblings, and positive self-definition of parents (Turnbull,

1983). The special needs of the handicapped child often create greater responsibilities for parents in each area of family function.

Some studies have shown that the disabled member may negatively affect the mental health of the non-disabled sibling (Gath, 1973). Non-disabled siblings may be embarrassed or unhappy about their disabled brother or sister. They may be ashamed around their friends. Some observers have suggested that the sibling's behavior and reaction is tied to environmental stressors. In a study by Pearson and Sternberg (1986), members of a sibling support group exhibited anger because their disabled siblings got the most attention. On the other hand, the group members showed strong feelings of protectiveness and responsibility toward their disabled siblings.

Most of the research has a negative outlook about the effect of a disability on the family. Research with a positive approach is becoming more frequent. Some investigators are studying how individuals solve their problems. It has been found that the manner in which the family has dealt with serious problems in the past will be directly correlated with how they will deal with new problems. Having a disabled child or adult in the family does not have to be an overwhelming experience. Power and Dell Orto (1980) listed eight factors which influence family adjustment: age of child, family size and structure, how the child understands the condition, complexity of family demands, visibility of disability, religious beliefs of family, degree of financial burden, availability of community resources, and the stage of family life cycle. The family's adjustment to the disability implies the acquisition or possession of needed skills:

Disability is a family affair. Any family is affected by the onset of a disabling condition in one of its members, and the entire family usually begins a struggle to regain its equilibrium and to adapt to the given situation. Family factors also directly influence the mental and emotional functioning of the disabled individual. The family bears the day-to-day burden of the coping with the disability or illness. Thus the family can become a major help to an individual's rehabilitation or adjustment. (Power, Dell Orto, & Gibbons, 1988)

Current literature suggests that an individual can have different responses to the presence of disability in one of his/her family members. In studying families of disabled persons, two directions have been utilized. "Two main approaches in the literature on disability in the family can be distinguished" (Volker, 1975, p. 14). On one hand, researchers theorize that having a disabled member in the family is a negative situation and a crisis for the family. The other approach makes no assumption about the nature of disability -- bad or good -- and looks more in the direction of what the family is doing to cope. "Other authors directed their attention on the family's subjective definition of the situation and how the family has managed the illness or disability" (Knafl & Deatrick, 1987, p. 300). In the first approach, researchers tend to ignore or discount the family's subjective definition of the situation and to conceptualize the family as responding passively to a member's disability. Viewing the family as a relatively passive victim of disease is a position originally formulated by Parsons and Fox in 1952 (as cited in Parsons, 1975), which remains influential today in spite of numerous critiques and reformulations. These authors maintained that the family would be seriously jeopardized by the strain of caring for illness or disability. Much work has been done in the area of disability and its impact on siblings, marital relationships, self-concept, medical/social/psychological

problems of the mother, parental coping, incidents of divorce, quality of marital relationship, and child rearing practices (Kazak, 1987).

The other approach suggests that the family is more active in its response to the disability. There is no single objective meaning to the disability, and research should be directed toward attention to discovering how individuals and families manage such situations. "Rather than assuming the disabled child is inherently negative, proponents direct their attention to discovering what aspects of the situation are defined as problematic" (Kazak, 1987). The focus is on how they define and manage disability. Research consistent with this orientation focuses on understanding the process, rather than measuring outcome. Related to this approach is family stress and crisis theory. Hill (1949, 1958, 1970) suggested that a family's reactions depend on the way a family defines the event. This definition interacts with the stressor event and the family resources. This well-known model is called the ABC-X model of family crisis coping. In the past, much of the focus on families was on the negative. The common question was: "Why has this individual or family failed?" Today, an increasing number of researchers are turning to new questions: "What are the strengths of this family?" The literature suggests that families can have widely divergent responses to the presence of a disability in one of their family members. Critical determinants of satisfactory adjustment and function following disability appear to be strengths inherent in the family prior to the disability and the positive use of support and coping strategies after the disability occurs.

Purpose of the Study

The purpose of this study was to examine the emotional, social, and physical effects of a disability upon individuals, as well as members of their families, and to determine the ways in which family members endure the day-to-day burden.

The Grand Tour Question and Sub Question

This research was guided by a grand tour question and sub questions.

Grand Tour Question

What factors influence the everyday life of individuals living with a developmental disability?

Sub Questions

Does the marital status of an individual with a developmental disability influence how an individual perceives his/her disability?

Does the age of onset of the developmental disability influence how an individual perceives his/her disability?

Does the sex of the individual with a developmental disability influence how an individual perceives his/her disability?

Does the number of years an individual lives with a developmental disability affect how an individual perceives his/her disability?

Definition of Terms

Definition of terms was tentative since meanings may alter with each informant's responses.

Disability. The term "disability" can be confusing. It means different things to different people. In general, it denotes any relatively severe, chronic impairment of function resulting from disease, accident, or congenital defects. This can occur in one or

more of these categories: physical, mental, social, emotional, or occupational. A condition is considered disabling when it interferes with activity or adjustment in a substantial, material way. According to the National Office of Developmental Disabilities, it is estimated that 10 to 12 percent of the people in the U.S. have disabilities today. This includes children as well as adults, and disabilities of any kind, severe as well as temporary.

Section 102 (7) of Public Law 98-527, "The Developmental Disabilities Assistance and Bill of Rights Act," defines a developmental disability as: "a severe, chronic disability of a person which (a) is attributable to a mental or physical impairment or combination of mental and physical impairments; (b) is manifested before the person attains the age of 22; (c) is likely to continue indefinitely; (d) results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; and (e) reflects the person's need for a combination and sequence of special, interdisciplinary or generic care, treatment, or other services which are of life-long or extended duration and are individually planned and coordinated.

Family. (a) The family is a unit of "interacting persons, each occupying a position within the family to which a number of roles are assigned, the individual perceives norms or role expectations held individually or collectively by other family members for his/her attitudes and behavior" (Hill, 1958). (b) The family is a "semiclosed system of interacting personalities" (Rodgers, 1964).

Crisis. (a) Crisis is referred to as “trouble” (Koos, 1946). (b) Crisis is defined as “situations outside the normal patterns of life-situations which create a sharpened insecurity or which block the usual patterns of action and call for new ones” (Koos, 1946). (c) Crisis is defined as “any situation for which the usual patterns of family living are inadequate” (Duvall, 1971).

Family Strengths. Family strengths are “those forces and dynamic factors which . . . encourage the development of the personal resources and potentials of members of the family and which make family life deeply satisfying and fulfilling to family members” (Otto, 1975; p. 16).

Effects. Effects are changes or results produced by a disability.

Adjustment. (a) Adjustment encompasses a variety of subject areas and group responses to crisis and the effects of crisis. (b) Adjustment is the ability to adapt oneself to new circumstances.

Unmet Needs. These are needs that are not met and come in a variety of forms ranging from external aid to internal support.

Assumptions

This study assumes that the individuals being studied are reasonably honest about their experiences, feelings, thoughts, struggles, and concerns.

Delimitations and Limitations

Delimitations

This study will be narrowed in scope to participation of individuals with a developmental disability living in the United States.

Limitations

The participants are those who read and respond to a newspaper article that described the study and asked for participants with developmental disabilities that would be willing to fill out a questionnaire.

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