# GAINS, LOSSES, AND LIFE GOALS IDENTIFIED BY CAREGIVERS OF INDIVIDUALS WITH DISABILITIES IN THE UNITED STATES

***Sharon A. Raver, Anne M. P. Michalek***
*Old Dominion University*
*Norfolk, VA USA*

## Abstract

It is often reported that caregivers of individuals with disabilities experience stress as they manage caregiving responsibilities while they make the effort to balance family and work. Thirty-one caregivers of individuals with an array of disabilities in the United States completed a qualitative survey in this pilot study that asked them to identify their gains and losses from providing care and to identify their life goals. The gains from caregiving were identified as enhanced empathy and compassion, and the losses as strained family relationships, and less personal time. The most commonly identified life goals were experiencing happiness and achieving financial stability. The implications of these results on professionals' attempts to support caregivers and their families are discussed.

***Key words:*** *caregivers of children/adults with disabilities, life goals, stress, family relationships, disability policy, disability governmental support.*

## Introduction

Parents, siblings, and extended family members may experience stress and an array of other feelings as they adjust to the demands of caring for someone with special needs while trying to balance family, work, and their other responsibilities (McDonald, Poertner, & Pierpoint 1999; Plant & Sanders 2007; Raina et al., 2004). Providing care for an individual with a disability may drain physical and emotional energy, as well as financial resources (Floyd & Gallagher, 1997; Murphy et al., 2006). Research has shown that caregivers of children with disabilities report increased health and psychological problems when compared to parents of children without disabilities (Florian & Findler, 2001; Maes et al., 2003; Murphy et al., 2006). In addition, expenses for medical procedures, therapies, specialized care, and adaptations increase the ongoing financial burdens placed on caregivers of children with special needs, causing parents greater worry and tension (Parish et al., 2008). Although parents and guardians expect to perform caregiving tasks during the upbringing of a young child, these responsibilities take on a new significance when a child is diagnosed with a disability. With a disability, roles and duties may change, and caregivers often face the possibility that a child may require long-term care beyond the typical child-rearing years (Raina et al., 2005).

Most of the studies that have examined the needs and concerns of caregivers of individuals with special needs have focused on the experiences of one kind of caregiver, typically mothers, who care for young children (Florian & Findler, 2001; Harden, 2005; Judge, 1998; McDonald et al., 1999; Murphy et al., 2006; Plant & Sanders, 2007; Rosenzweig, Brennan, & Ogilvie, 2002), examined a specific disability group such as intellectual disabilities (Grant & Whittell, 2000; White & Hastings, 2004) or emotional and behavior disorders (Harden, 2005; McDonald et. al., 1999), or examined relatively few variables that may affect the lives of those in the caregiving role (King et al., 1999). To be responsive, professionals need a better understanding of the broad objectives which guide caregivers as they provide day-to-day care for an individual with special needs, regardless of the disability, the caregiver's relationship to the individual, or whether the individual needing assistance is a child or an adult. These objectives, or life goals, are the foundation of each family's definition of what constitutes a good quality of life (Bailey et al., 1998). Human services professionals may be more effective in implementing policies, making policy recommendations and, ultimately, may be better equipped to offer responsive support services to families if they have more knowledge of what families are striving to achieve in their lives.

**The object of the research**: The present pilot study asked caregivers to identify the benefits and losses from caregiving and to identify their life goals.

**The aim of the research**: It was hypothesized that there may be more commonalities, than differences, in caregivers' goals regarding how they would like to live their lives.

## Methodology and Organization

### *Research sample*

Thirty-one caregivers of individuals with a variety of disabilities participated. A caregiver was defined as any individual, at least 18 of years of age, who assumed at least 50% daily caregiving responsibility of an individual with any type or degree of a disability. A disability was defined as a condition that was identified as a disability by the medical community, such as autism spectrum disorder, cerebral palsy, that required some accommodation or modification in how that individual lived his/her life in order for the individual to reach his/her optimal functioning. The characteristics of respondents, and those for whom they provided care, are summarized in Table 1. The majority of respondents were female (74%) and were responsible for caring for a child (73.0%). Most of the caregivers were married (48.8%) and had completed a college education (61.3%). Respondents indicated that their family members were diagnosed with a range of disabilities with the most common being a physical disability (33.1%). The majority of caregivers indicated that their family members' disability fell in the moderate (46%) level of impairment.

To examine the benefits and losses of adults who served as caregivers of individuals with special needs, and their life goals, a qualitative survey was developed. The survey was distributed to two educational facilities which served children with special needs (preschool through middle school grades) and two family support groups located in the southeastern section of a southern state in the United States. All participants completed a paper survey which contained instructions and a self-addressed, stamped envelope so surveys could be returned anonymously. Responses were written directly on the survey which took about 15 minutes to complete. All participants completed the survey voluntarily. Of the one hundred and thirty surveys that were distributed, thirty-one were returned, a 23% return rate. Many in the potential sample refused participation citing they did not have time to complete the survey, which may explain the low return rate.

*Table 1*

Characteristics of Caregivers and Family Members

| Caregiver | Percent of Respondents | Family Member Who Receives Care | Percent of Respondents |
|---|---|---|---|
| Gender | | Relationship to Caregiver | |
| Female | 74.0 | Child | 73.0 |
| Male | 26.0 | Sibling | 14.1 |
| Age | | Relative | 12.9 |
| Up to 20 years | 3.2 | Age | |
| Up to 30 years | 22.6 | Up to 6 years | 32.3 |
| Up to 40 years | 29.0 | Up to 20 years | 48.2 |
| 50 years and older | 45.2 | Up to 40 years | 9.7 |
| Living Status | | Up to 65 years | 6.5 |
| Married | 48.8 | Older than 65 years | 3.3 |
| Alone | 35.5 | Disability | |
| With a partner | 15.7 | Autism | 19.4 |
| Time caring for family member | | Down's Syndrome | 19.4 |
| with disability | | Multiple Disabilities | 9.7 |
| Up to 10 years | 58.0 | Mental Retardation | 19.4 |
| Up to 20 years | 32.3 | Physical Disability | 33.1 |
| Longer than 21 years | 9.7 | Severity of Disability | |
| Education | | Mild | 29.0 |
| Primary | 3.2 | Moderate | 46.0 |
| Secondary | 12.9 | Severe | 25.0 |
| Vocational training | 23.4 | | |
| University | 61.3 | | |
| Currently Employed | | | |
| Yes | 64.5 | | |
| Part-time | 12.9 | | |
| No | 23.4 | | |

The survey consisted of 5 open-ended questions, in which respondents could write their opinion. The survey asked for demographic information about the caregiver: gender; marital status, age, educational level, length of time the respondent had been caring for the identified family member; and current employment status. Further, information about the individual being cared for was gathered: the disability, the severity of the disability, age of the individual, and the relationship of the individual to the respondent. The next part of the survey requested write-in responses to what respondents considered their "biggest gains" and "biggest losses" from serving as a caregiver. In the last section, respondents wrote their two most important life goals. Life goals were defined as a driving force which gave life purpose and comprised what a person lived for or desired to achieve. All responses were summarized and clustered into principal ideas.

### Results of the research

Respondents' answers to the gains and losses as a result of being a caregiver are summarized in Table 2. The most commonly reported gains were a renewed positive perspective on life and joy from observing a family member learn new skills. The most common losses identified were strained relationships within and outside the family, including concerns for siblings, and a reduction in social or personal time. Finally, respondents were asked to identify their two most important life goals. The most common life goals reported were: 1) experiencing happiness, and 2) achieving financial stability.

*Table 2*

Summarized Write-In Responses to Survey Question: "What do you perceive as the biggest gains and losses from providing long-term care to a family member with a disability?"

| Perceived Gains | Perceived Losses |
|---|---|
| • Knowing I have grown as a person | • Financial stability and security |
| • Patience; Humbleness; Gratitude | • Loss of income |
| • Satisfaction from being helpful | • Frustration and anger when schools do not meet child's needs |
| • A new perspective on life | • No social life and no opportunity to start a relationship |
| • Ability to prioritize what's really important | • No opportunity to have an intimate relationship with spouse |
| • Empathy, compassion, and improved insight about others | • Loss of personal sense of self |
| • Kinder treatment of others | • Loss of free time/freedom |
| • An increased understanding and knowledge about children/adults with special needs | • Having to wait to have more children |
| • Rejoicing while observing my child's constant improvement with independent living | • Loss of ability to sustain normalcy in public |
| • Joy at watching my child learning to talk | • Understanding that child will be different from other children |
| • Excitement at watching my child learn new things due to my consistency and skill in instruction/parenting | • Loss of my original dreams for family member to be independent |
| • Knowing my family member is safe and has a good quality of life | • Siblings have to sacrifice and have a different childhood, with increased responsibilities |
| • Having a strong bond with family member s and knowing my child knows her/his family | • Difficult for grandparents and other family members |
| • Experiencing unconditional love | |

## Conclusions and discussion

It is generally accepted that being a caregiver for an individual with a disability can involve prolonged periods of time, energy, unpleasant tasks, and frequent disruption of family routines, particularly when health concerns are involved (Schultz & Quitner, 1998). Like the present study, others have found that some caregivers report feeling a loss of control over day-to-day events (Murphy et al., 2006). Additional evidence which may support this observation is the large number of caregivers who refused to complete the survey, stating that they did not have time for anything that was not mandatory.

In examining the gains and losses of caregiving, the respondents reported experiencing what may seem as contradictory feelings. That is, the same caregivers who reported feeling a loss of their personal identity simultaneously reported that they felt enriched by their current caregiving role. This may be interpreted to mean that the caregivers in this study could experience strained family relationships, while at the same time, experience an understanding that the source of these was not a singularly negative factor in their lives.

The family member for whom they provided care could cause stressful feelings but these individuals could also provide caregivers with love and, at times, be a source of pride. In this small sample of respondents, this finding appeared to be especially the case when the caregiver was a parent, rather than a relative.

Other research has found both negative and positive outcomes from the caregiving role (Grant & Whittell, 2000; Heiman, 2002). However, as encouraging as this outcome may be, professionals must still be concerned about the long-term resilience of the caregivers they serve. The daily struggles of life can deplete anyone's coping abilities suddenly and unexpectedly. When stress extends beyond what may be viewed as reasonable by a caregiver, any caregiver can crumble under the strain. If caregiver's needs are not acknowledged and sufficiently managed, the situation can create additive stress on caregivers which can affect the entire family's psychological, financial, and emotional well-being. The respondents' responses to the "losses" associated with caregiving responsibilities seemed to support this view. The majority of caregivers reported that constant financial pressure, the difficulty of maintaining "normalcy" in public, the loss of freedom (e.g., personal free time, travel) and the strain on family and extra-family relationships were significant sources of distress. This information, although perhaps not new in itself, is useful to any professional serving families with individuals with special needs. Sometimes through repetition, professionals may forget the urgency with which these emotions may be impacting the caregivers with whom they interact. Staying vigilantly aware of this reality should help service providers better gauge the status and current needs of the caregivers they serve.

### Caregiver Identified Life Goals

Stress has been conceived as a balance between external environmental demands and the perceived internal ability to respond (Raina et al., 2005). The caregivers in this study suggested that their life goals were a source of stress to them if achievement was inhibited by caregiving demands. The implications of each life goal will be discussed.

*Goal to experience happiness.* Consistently caregivers reported that services which focused on the *whole family unit* were the most useful to them, and consequently, added to their desire for happiness. The caregivers in this pilot study seemed to understand that dealing with complex needs for a long period of time can wear one down, both physically and emotionally. The research suggests that this is especially true when the individual receiving care has psychiatric and/or behavioral problems (Maes et al., 2003). As one's energy is depleted, it may be safe to surmise that happiness becomes more difficult to achieve. Respite care and other kinds of care relief programs were a common need identified as fundamental to those surveyed. As they noted, these programs permitted them to recharge emotionally and physically. Unfortunately, during challenging economic times, it is usually care relief programs that are some of the first to be cut, even though families may consider them fundamental to their ability to cope and manage stress.

*Goal to experience financial stability.* Financial stability/security appeared elusive to many of the respondents in this study. The majority of caregivers indicated that present financial supports provided to families in the United States were inadequate. Emerson (2003) indicated that often mothers reduce the number of hours they work or leave jobs to provide care for a child with a disability. In this study, the desire to find or keep a job that met the family's needs was repeatedly indicated as an urgent need by the respondents.

Further, becoming a caregiver of a child with the potential of long-term care introduces additional roles and, therefore, requires substantial rearrangement of priorities and energy within families (Raina et al., 2004). Other researchers have suggested that parents of individuals with intellectual disabilities may be uniquely stressed by concerns about the independent functioning of their child in the future and the need to provide on-going care into adulthood (Floyd & Gallagher 1997). Any professional offering support to these families must remain extremely sensitive to the requests they place on caregivers so they do not unintentionally add additional economic or emotional burdens.

### Limitations of the research

There are several limitations which must be addressed when examining the outcomes of this study. First, the sample was small, the majority were female, college-educated, employed full-time and resided in the same geographical area. Clearly, a larger sample and one with a variety of demographic may have yielded different results. Second, because the survey was first used in this pilot, it lacked reliability and validity data. Third, a large portion of the respondents were married or had a partner which may have influenced their responses. Finally, different outcomes may have been generated if all family members being cared for were the same age and were receiving the same level of educational, instrumental, and social support.

### Conclusion

The caregivers of this study made it clear that caring for an individual with a disability presents challenges, added responsibilities, and rewards. The results suggest that caregivers are often attempting to balance extremely high levels of stress and that timely, concrete supports could be helpful in mitigating their anxiety. In reporting data from a national survey in the United States, Parish and colleagues (2008) noted elevated rates of material hardship among families raising children with disabilities (e.g., cost of therapies, loss of income) when compared with families without a disabled family member. The Parish study, and the present one, highlight the need for policies at the national and state levels which more effectively target support systems which ease family-specific struggles. Clearly, more research is needed to clarify the specific strains families face and to identify where new policies would be most cost-effective. Nevertheless, it does appear safe to say that caregivers believe more needs to be done to support them as they attempt to manage the needs of their entire family.

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