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Comparison of Quality of Life Perceptions of Caregivers of Individuals with Intellectual Disabilities in the United States and the Czech Republic

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Abstract

Caregivers of individuals with disabilities in the United States have been reported to experience additional hardships than families with typical children as they attempt to balance family and work (Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008). In this study, 31 caregivers of individuals with intellectual disabilities from the United States and 225 from the Czech Republic completed a qualitative quality of life survey. Similarities in the two groups were found in reported gains and losses from caregiving responsibilities. Differences in perceived spirituality, personal sense of peace and serenity, life optimism, ability to rejoice in life, personal life perspective, health, financial changes, changes in the family social life, feelings of enrichment, family caregiving responsibilities, and attitudes about the future were also revealed. The implications for supporting families through governmental programs and individualized services are discussed.

A disability is a culturally and socially constructed phenomenon in which each society defines the parameters of what is considered “typical” (Linan-Thompson & Jean, 1997). Frequently parents do not perceive a disability the same way as professionals, especially when the diagnosis involves young children. The literature suggests that parents vary in their reactions, and that most parents go through a period of adjustment, with further adjustments as their child ages (Harden, 2005; Raver, 2009). Although parents and guardians expect to perform caregiving tasks during the upbringing of a child, when a child has intellectual impairments, roles and duties may change as caregivers face the possibility that a child may require long-term care beyond the typical child-rearing years (White & Hastings, 2004; Raina et al., 2005). Caregivers 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 the needs of the entire family and work responsibilities (McDonald, Poertner, & Pierpoint, 1999; Plant & Sanders, 2007; Raina et al., 2004; Rosenzweig, Brennan, & Ogilvie, 2002). Providing care for an individual with a disability may drain financial resources and physical and emotional energy (Murphy, Christian, Caplin, &

Young, 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, Broekman, Dosen, & Nauts, 2003). Further, supplementary costs for medical procedures, therapies, and adaptations may increase financial pressures on caregivers, causing more tension (Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008).

Despite this evidence, there are studies that have also shown that there may be positive outcomes from the process of caregiving for an individual with a disability (Grant & Whittell, 2000; Heiman, 2002). Clearly not all reactions to the birth of a child with a disability or the demands involved in caring for this child or adult may be characterized as negative (Turnbull, Turnbull, Erwin, & Soodak, 2006). Many parents and families make successful adjustments to their situation and report positive outcomes from caregiving such as increased family cohesion and a renewed appreciation for life (Raina et al., 2005; Raver, 2005). Over time, most parents and caregivers in the United States seem to adapt to their new realities, while remaining steadfast in their commitment to the family member with a disability (Emerson, 2003; Gallagher,

Fialka, Rhodes, & Arceneaux, 2003; Raver, Michalek, & Simpson, 2009). Policy makers in the United States have historically operated under the assumption that the level of social and educational services provided families will support family adaptation and reduce some of the long-term burden placed on caregivers (King, King, Rosenbaum, & Goffin, 1999). Although this practice has some social validity, few studies (e.g., Parish et al., 2008) have examined the impact of governmental support on the principal caregivers of children and adults with special needs.

Special Education in the Czech Republic

In January of 1993, the Czech Republic became an independent country, joining the North Atlantic Treaty Organization (NATO) in 1999 and the European Union in 2004. Since independence, the Czech Republic has attempted to create more equal opportunities for individuals with special needs and increase access to appropriate education (Special Needs Education in the Czech Republic, 2000). It has attempted to move away from a medical model of serving these individuals, although the majority of students with disabilities continue to be educated in special schools (Special Needs Education with the Educational System: Czech Republic, 2009). This practice thrives largely because special schools continue to be the first choice of parents or caregivers. Educational legislation and the basic principles of special education, health and social policies for individuals with disabilities are outlined in the Legislation for Individuals with Special Needs (1993) and the National Plan to Increase Opportunities for People with Disabilities (Anonymous, 1998), and are similar to those followed in the United States.

There is little research which compares the quality of life perceptions of caregivers in the United States and those in the Czech Republic. The present study examined two research questions; (a) are there differences in the perceptions of quality of life issues of caregivers of individuals with intellectual disabilities in the United States and the Czech Republic, and (b) does the level of governmental educational and social services and supports provided for individuals with intellectual impairments and their caregivers in the United State and in the Czech Republic impact these differences?

Method

Participants

Thirty-one caregivers of individuals with intellectual disabilities (e.g., mental retardation, autism) residing in the United States, and 255 caregivers of individuals with intellectual disabilities (labeled as having mental retardation) in the Czech Republic participated in the study. A caregiver was defined as any individual, at least 18 years of age, who assumed at least 50% daily caregiving responsibility of an individual with any degree of an intellectual disability. Characteristics of respondents from the United States and the

Czech Republic, and the individuals for whom they provided care, are summarized in Table 1. The majority of respondents in both countries were female (U.S. 74.2%; Czech Republic 81.3%) and were responsible for caring for a child (U.S. 77.4%; Czech Republic 67.56%). Most of the caregivers were married or in a partnership (U.S. 58.6%; Czech Republic 68.9%). The majority of respondents from the United States had a college education (61.3%) while the majority from the Czech Republic had completed secondary school (56.1%). Respondents from the United States cared for individuals they identified as having intellectual disabilities or mental retardation and/or autism. Those in the Czech Republic cared for individuals defined as mentally retarded which included some with additional health and physical disabilities. The majority of caregivers from the United States indicated that their family members' disability fell in the mild to moderate level of impairment (70.9%). The largest group receiving care in the Czech Republic was identified to be in the severe to profound level of impairment (72.9%). Finally, the majority of the American and Czech respondents had been employed for 16 or more years (U.S. 64.6%; Czech Republic 61.3%).

Procedure

To determine if there were differences in perceptions regarding quality of life issues and concerns between caregivers living in the United States and the Czech Republic, caregivers completed a paper survey by circling the response that most closely matched their opinion or perception. In the United States, the survey was distributed to two educational facilities and two family support groups in the eastern part of Virginia. Names were not placed on the surveys which contained instructions and a self-addressed, stamped envelope so completed surveys could be returned anonymously. In some cases surveys were placed in an envelope and sealed by the respondent and then handed to an associate of the research team. In the Czech Republic, surveys were distributed to five special and/or residential schools and two rehabilitation resource centers which were located throughout the country. Respondents completed the survey, sealed it in an envelope to keep it anonymous, and handed it to a representative of the research team. The survey took about 25 minutes to complete, and all participants completed it voluntarily. In the United States, 130 surveys were distributed, with a 23% return rate. In the Czech Republic, 250 surveys were distributed, with a 90% return rate. The surveys in the Czech Republic were distributed by administrators of special schools and rehabilitation centers which may have accounted for the higher rate of return in the Czech Republic.

Data Analysis and Instrument

All responses were calculated into percentages, including demographic information, and then compared by survey item and country. Responses to open-ended, write-in questions

Table 1

Characteristics of Caregivers in the United States and Czech Republic and the Family Member Who Received Care

Characteristic		Percent of Respondents	
		United States	Czech Republic
Gender	Female	74.2	81.3
	Male	22.6	18.7
Age	Up to 20 years	3.2	0.0
	Up to 30 years	22.6	4.9
	Up to 40 years	29.0	19.6
	Up to 50 years	25.8	17.3
	Up to 60 years	16.1	57.3
Living Status	Married/Partner	48.4	68.9
	Single	35.5	30.7
Time caring for family member with a disability	Up to 6 years	41.9	38.7
	Up to 10 years	16.1	22.7
	Up to 15 years	12.9	12.0
	Up to 20 years	19.4	12.9
	Longer than 30 years	3.2	10.5
	No answer	0.0	3.5
Residence	In a city	67.7	93.5
	In a small town	29.0	2.2
Education	Primary	3.2	10.2
	Secondary	12.9	56.1
	Vocational training	19.4	12.4
	University	61.3	17.8
Employment Length	0-15 years	32.3	36.5
	16 years and more	64.6	61.3
Currently Employed	Full time	64.5	17.8
	Part time	12.9	8.0
	No	19.4	71.5
Characteristics of Family Member Who Received Care			
Relationship to Caregiver	Child	67.7	67.6
	Sibling	16.1	1.3
	Relative	12.9	24.0
	Not related/Guardian	0.0	4.4
Age	Up to 6 years	32.3	5.3
	Up to 20 years	45.2	40.4
	Up to 40 years	9.7	11.6
	Up to 65 years	6.5	10.7
	Older than 65 years	3.2	32.0
Disability	Mental retardation	77.4	100.0
	Autism/MR	22.6	0.0
Severity of Disability	Mild-moderate	70.9	21.8
	Severe-profound	25.8	72.9
Facility Attending	School program & at home	80.7	92.4
	Year-round program	6.5	4.0
	Other	6.5	0.0
	No answer	0.0	3.6

were clustered into principal ideas, and then summarized by percentages. The survey was developed based on a literature review of caregivers' major quality of life indicators, life stressors, collaborations between American and Czech colleagues, and field interviews with other caregivers prior to the initiation of the study. Some items from The Family Quality of Life Scale (FQOLS) (Park et al., 2003) were adapted for the instrument. Excluding demographic questions, the survey had a total of 26 items and two open-ended questions, and was divided into two parts. Part I addressed demographic information including the following about the caregiver: gender; marital status; residence in city or small town; age; educational level; length of employment; 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; the age of the individual; the relationship of the individual to the respondent; and the identified family member's current educational, work or leisure placement.

Part II was divided into five sections and asked respondents to indicate their emotional, spiritual, social, health, occupational and economic perceptions of their caregiving responsibilities. Section A asked respondents to identify how caring for their family member with a disability had or had not changed certain aspects of their life (e.g., spirituality, altruism). Participants were asked to indicate how these aspects of their life had either "increased," "remained the same," or "had been reduced." Sections B and C probed caregivers' feelings regarding control, fatigue and the social life of their family and how these aspects of their lives had or had not been changed by caregiving responsibilities. Respondents circled one of 4-choices which best matched their perception (e.g., "yes-there was a change," "it is likely there has been a change," "it is likely there has been no change," or "no-there has been no change"). The next sections, Sections D and E, probed the economic impact of caregiving, who in the family provided assistance with care, caregivers' attitude regarding government-sponsored services and supports, and attitudes regarding the future. Respondents circled the 5-choice option that best matched their perception. The last part of the survey asked respondents to write their biggest "gain" and "loss" as a function of providing care (open-ended questions). Figure 1 shows a summary of the survey questions, excluding demographic and open-ended questions.

Results

Differences in Caregivers' Perceptions

This research question attempted to identify similarities and differences in the stressors, perceptions and/or attitudes of caregivers from the two countries. The following are the highest percentage of responses reported for each survey item, by section. *Section A.* Responding to how their level of

spirituality had been influenced by caregiving, the American respondents indicated it had remained the same (48.4%), while Czech respondents indicated that it had increased (49.3%). Indicating how their level of altruism had been influenced, 48.4% of respondents in the United States indicated it had remained the same while 45.8% of the Czech participants indicated so. In reporting how their level of tolerance had been influenced, American respondents reported it had increased (64.5%), while 43.1% of respondents in the Czech Republic indicated that it had increased. Indicating

how their level of peace and serenity had been impacted, respondents in the United States expressed that it had remained the same, while 40.9% of the Czech respondents reported that peace had decreased. Responding to how their level of faith in humanity may have changed, 50% of the American respondents indicated it had remained the same, while 44.0% of respondents in the Czech Republic indicated this response. Noting how their level of life optimism had been influenced, 48.4% of American respondents indicated it had remained the same, while 41.3% of the respondents in the Czech Republic suggested that this aspect of their life had decreased. Responding to how their level of humbleness toward what life brings, 66.7% of the Americans indicated it had increased as 41.8% of the Czech respondents reported the same.

Section B. Responding to whether they felt a loss of control in their lives, 54.8% of respondents from the United States reported that they did “sometimes,” while 51.6% of respondents in the Czech Republic did not answer this question. Fifty-four percent (54.5%) of the American respondents indicated that they “sometimes” experienced depression and despair, while the largest group of respondents in the Czech Republic (29.4%) felt the same. No answer was given to this item by 45.3% of the Czech Republic group. Indicating if they felt fatigue, the highest percentage of respondents in the United States (45.2%) indicated that they did “sometimes” experience fatigue while 34.7% of respondents in the Czech Republic also felt this way. In answering if they were able to enjoy free time, 38.7% of the respondents in the United States indicated that they did “sometimes,” while 29.8% of respondents in the Czech Republic said “yes” they enjoyed their free time and 38.2% did not answer this question. Regarding the ability to rejoice in life, 35.9% of American respondents reported that they were not able to do this, while 24% of Czech respondents indicated that they could “sometimes.” Responding to whether there had been a change in their personal life perspective, 29% of American respondents indicated “no,” while 35.2% of Czech respondents reported there had been no change.

Section C. Reporting whether they perceived their isolation from people had increased as a result of caregiving, 25.8% of American respondents suggested that “yes” it had and the same number reported “no.” Respondents in the Czech Republic (34.5%) indicated that “yes” isolation has increased. Reporting whether their health had deteriorated, 35.5% of American respondents reported “no” to this question, while 25.8% of Czech respondents indicated that their health had “somewhat” gotten worse. In examining if the economic standard of their family had deteriorated, 29% of respondents in the United States revealed that there was “no change,” while 28% of respondents in the Czech Republic indicated that their economic standing had “declined.” Forty-two percent of American respondents in the United States indicated that there had been “no change” in relationships with family members, while 31.1% of respondents in the Czech Republic indicated this response. American respondents

PART II, Section A
Spirituality
Altruism
tolerance toward other people
peace and serenity
faith in humanity
life optimism
humbleness towards what life brings
Section B
loss of control in life
feelings of depression and despair
feelings of great fatigue
loss of ability to enjoy free time
loss of ability to rejoice
loss of personal life perspective
Section C
isolation from other people has increased
state of health has deteriorated
economic standard of family has deteriorated
relations between family members have deteriorated
social life of family has deteriorated
feel enriched by the situation
Section D
who provides most care
help from siblings
help from wider family
Section E
I believe governmental financial support provided to families is sufficient
I believe persons providing care enjoy respect and recognition from my country
I believe the situation of individuals with special needs and the persons providing care for them will continue to improve in my country
I look forward to what the future has to bring

Figure 1. Summarized Items from the Caregivers’ Perceptions Survey

(29%) indicated that the social life of their family had “somewhat changed” while 32% of Czech respondents revealed that “yes their social life had declined.” American respondents (38.7%) reported feeling enriched by their situation and 38.7% percent of the American suggested they felt “somewhat enriched.” Czech respondents (24.9%) indicated that they were not “enriched.”

Section D. In responses to who provided the most care, American respondents (51.6%) indicated that males and females took turns, while 73.3% of respondents in the Czech Republic indicated that the female caregiver provided the majority of care. American respondents (32.3%) indicated that “no” siblings did not help with care, while 42.6% of respondents in the Czech Republic reported feeling this way. Indicating whether the wider family provided assistance with care, 32.3% of American respondents reported “yes,” while 30.7% of Czech respondents reported “no.” Figure 2 shows the ten survey items that revealed a difference in the highest percentage responses between caregivers in the United States and the Czech Republic for Sections A-D of the survey.

Impact of Governmental Services and Supports on Caregivers’ Perceptions

The questions in Section E of the survey attempted to address the impact of governmental support and services on caregivers’ quality of life. Responding to the question which asked if the caregiver believed that governmental financial support to families in their country was adequate, the highest percentage of respondents in the United States (41.9%) indicated that they believed that was the case, while the highest percentage of respondents in the Czech Republic (35.6%) indicated that they did not believe support was adequate. Responding to whether caregivers are given respect and recognition in their country, 75.8% of American respondents indicated “yes,” while 24.8% of the respondents in the Czech Republic indicated a “rather no” to this item. When asked if caregivers believed that the situation for individuals with special needs and the persons who provided their care will continue to improve in their country, 29% of the American respondents indicated “somewhat yes,” while 36% of respondents in the Czech Republic indicated that they “did not know.” When asked if caregivers looked forward to what the future would bring, 29.6% of the respondents in the United States indicated “absolutely,” while 38.8% of Czech caregivers reported they “were afraid of the future.” Figure 3 shows the highest percentage responses to survey items that addressed governmental support and services in the two countries.

Qualitative Responses. This part of the survey allowed respondents to express their opinion in two open-ended questions. The first question asked caregivers to indicate their three “greatest gains from providing care” and the second asked for three “greatest losses from providing care.” Responses were clustered by topic and percentages calculated. Fifty-eight percent of the American caregivers indicated their

most common gain from caregiving involved a renewed positive perspective on life and joy from observing the family member with a disability learn new skills. The largest number of caregivers in the Czech Republic identified their greatest gain to involve “personal gains” such as positive emotions and feelings (31.9%). When identifying their greatest losses from being a caregiver, American respondents most frequently reported strained relationships within and outside the family and a reduction in social or personal time (43%) and others (32%) commented on the financial strain of caring for a family member with a disability. Similarly, respondents in the Czech Republic reported their most common loss as a loss of personal freedom (30.1%).

Discussion

This study found that caregivers of individuals with intellectual disabilities in the United States and the Czech Republic reported similarities and differences in their responses to a survey designed to explore perceptions of their lives, their family’s life, caregiving responsibilities and their country’s willingness to support them and their family member with special needs. In looking at the similarities, caregivers in both the United States and the Czech Republic revealed that their caregiving experiences had increased their feelings of humbleness toward what life brings and their tolerance of others. Both groups indicated that they believed that the isolation of their family had increased, and that they sometimes experienced great fatigue. The majority of respondents, in both countries, reported that their sense of altruism, faith in humanity, and their relationships with family members had remained the same as an outcome of providing care. Further, most respondents noted that their greatest gain from caregiving involved positive personal feelings of enrichment and an increased positive personal perspective.

Several differences were revealed when survey responses were compared. For example, caregivers in the United States noted that their sense of peace and serenity and feeling of life optimism had remained the same while these feelings were described as decreased by caregiving responsibilities by the Czech caregivers. The majority of American caregivers revealed that they were unable to rejoice in life, but Czech caregivers reported being able to do this only sometimes. Spirituality was reported as remaining the same by the Americans and as increased by the Czech group. In terms of their personal life perspective, most American caregivers indicated they did not experience a loss of this while Czech caregivers indicated that their life perspective had been negatively influenced by their responsibilities of caregiving. American respondents reported that their health had not been affected, but Czech caregivers noted their health had been “somewhat” affected. Life optimism was reported as remaining the same for the majority of American caregivers, yet was reported as decreased for most Czech care providers. While the family’s social life was reported as “somewhat” worse because of caregiving demands by the American group,

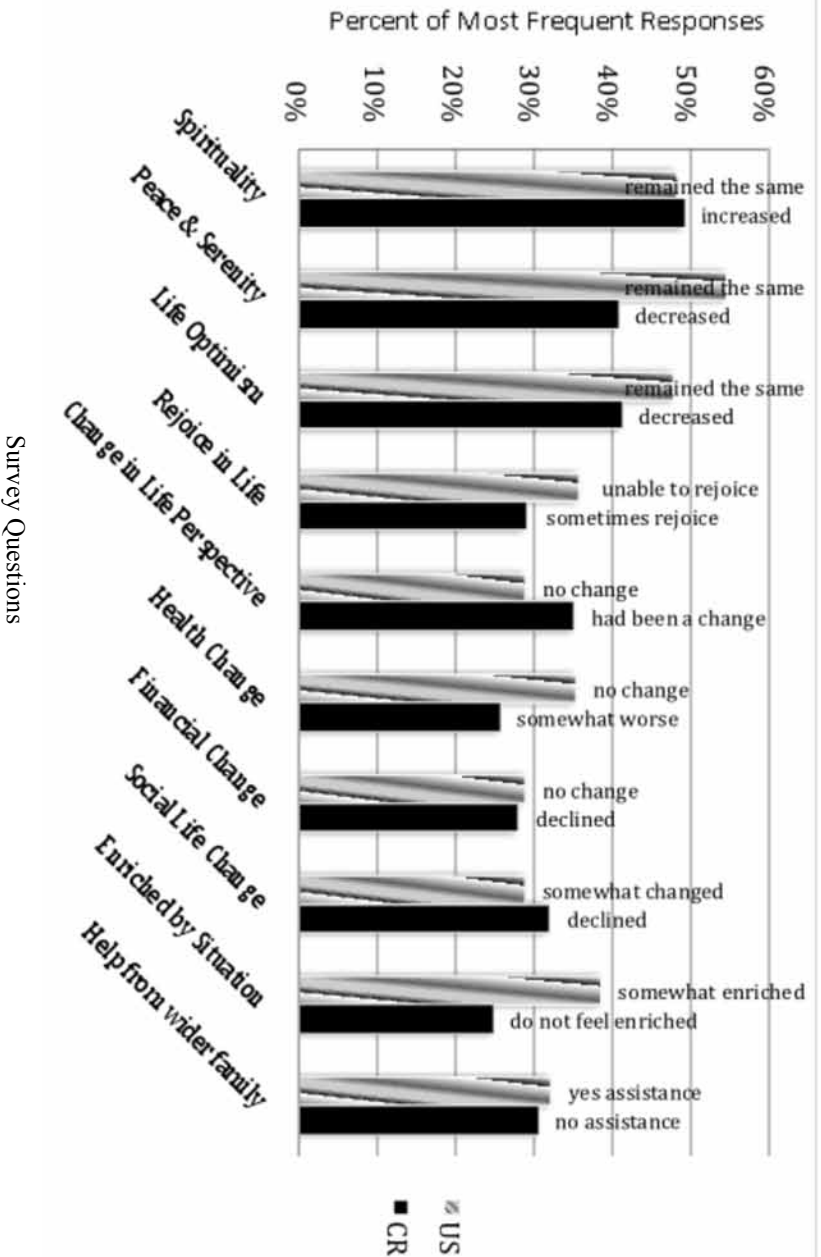


Figure 2. Differences in the Most Common Responses to Survey Items Between Caregivers in the United States and in the Czech Republic.

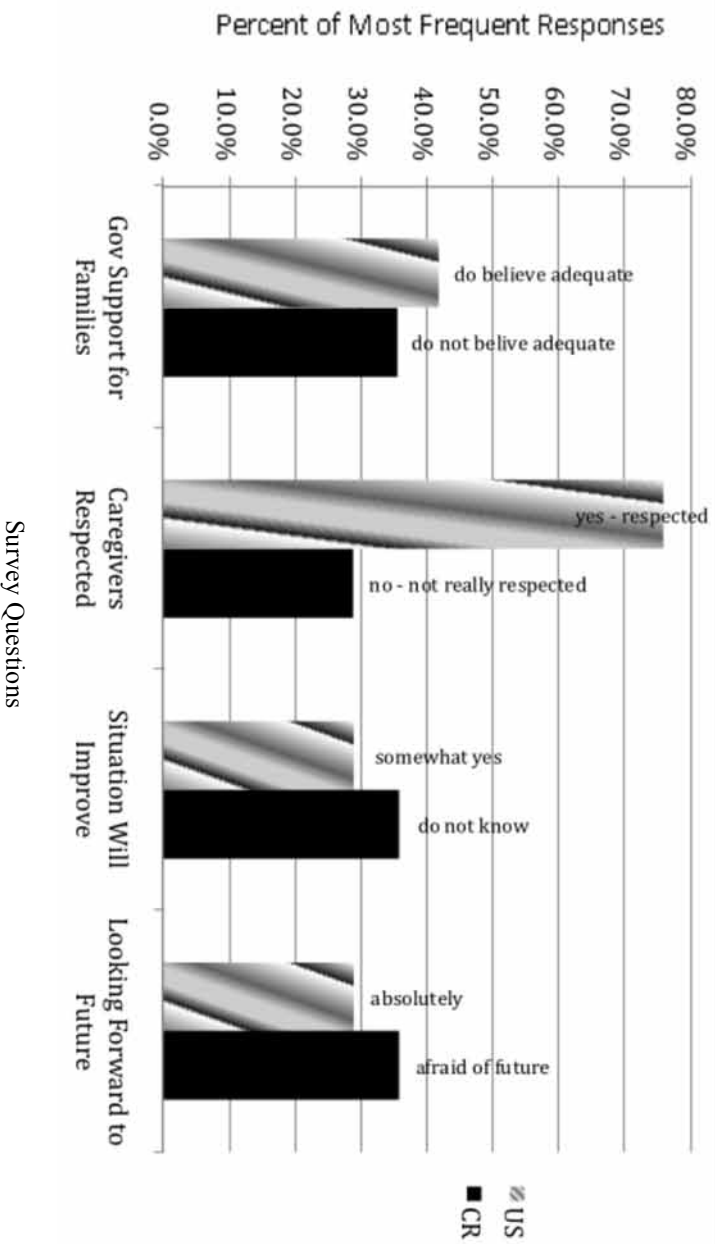


Figure 3. Differences in Caregivers' Most Common Survey Responses to Governmental Support and Services Survey Items in the United States and Czech Republic.

the Czech group indicated that their social life as a family was indeed worse. Most of the U.S. caregivers indicated that they felt “somewhat” enriched by their situation while the Czech group commented they did not feel enriched by caregiving tasks.

It seems clear that cultural differences account for some of the differences found. For instance, respondents in the United States indicated that both the male/father figure and female/mother figure in the home took turns providing care (52%). In contrast, women were reported as the principal caregivers in the Czech Republic (73%). Family practices in the United States, as a general rule, may be described as more egalitarian in terms of parental child rearing responsibilities than those in the Czech Republic so this outcome may not be surprising. Interestingly, most of the American and Czech caregivers noted that siblings did not provide significant assistance with caregiving of family members with disabilities in their families (U.S. 33%; Czech Republic. 47%). But, American caregivers revealed that extended family members were helpful. Most Czech caregivers noted that extended family members were not helpful. Having shared parenting and caregiving responsibilities, as well as assistance from individuals outside the nuclear family, would seem to have a strong positive influence on the quality of life of caregivers living in the United States. It may be that American extended family members and others outside the family are more willing to provide assistance because there is less stigma associated with intellectual disabilities in that country. For nearly forty years, governmental services and inclusion into nearly all aspects of daily life have been commonplace in the United States. For this reason, immediate family members may be more willing to seek assistance from extended family members (Sandler, Warren, & Raver, 1995), and extended family members may be more willing to provide it.

It was uncommon for the American respondents in this study to omit answering a survey item. However, respondents from the Czech Republic did not answer about 20% of the items and occasionally, no answer was the most common response to an item. The omitted items tended to be those that dealt with what may be described as more personal information such as one’s ability to enjoy free time, feelings of depression and despair, feelings of loss of control and the ability to rejoice in life. It may be the caregivers in the Czech Republic, who have enjoyed a shorter history of freedom of speech, may have felt less comfortable answering these questions, fearing formal or informal reprisals to their child or family.

Effect of Governmental Support on Caregivers’ Perceptions of Quality of Life

The second research question in this study dealt with families’ perceptions of governmental support and how this may have influenced their quality of life. Although the majority of American caregivers answered the survey question

by indicating that governmental supports were adequate, many wrote that financial pressures were one of the significant “losses” of being a caregiver. In fact, some caregivers wrote that the American government was *not* doing all that it should financially for families, particularly in helping pay for necessary therapies. In contrast, most Czech caregivers expressed a concern about the adequacy of their government’s supports on this survey item, but did not mention financial needs in the open-ended question dealing with “losses.” In regard to how persons who provided care were respected and/or recognized, there were clear differences of opinions in the two countries. A large portion of the American group answered that they believed caregivers were respected (76%), but the majority response for the Czech group was that this statement was “not really true” (29%).

Vivid differences in how the future was viewed were also expressed. For example, 29% of the American caregivers indicated that they thought that the situation for individuals with special needs and the persons who provided their care would “somewhat” improve. However, the caregivers from the Czech Republic said they did not know if improvement would occur. Additionally, the majority of caregivers in the United States noted that they were “absolutely” looking forward to the future, while the majority of Czech caregivers expressed that they were afraid of what the future could bring. Only about 10% of the American respondents reported feeling this way. It may be that these responses are linked to families’ worries that as government budgets are tightened in a weak economy, services they have learned to depend upon may be in reduced, or even eliminated. Because of a longer history of protecting and supporting the disabled in the United States, the American group may have felt more confident in their knowledge that although services may be reduced, it is unlikely that services and supports would be eliminated altogether. Caregivers in the Czech Republic may fear that the gains they have made in the last decade could be taken away from them.

American Governmental Supports. All students with intellectual disabilities in the United States attend mandatory, free public schools which are supposed to meet their individual needs (Individuals with Disabilities Education Improvement Act, 2004). Many caregivers are eligible or may receive Social Security benefits such as Supplemental Security Income (SSI) or Childhood Disability Benefits (CDB) (Brooke & McDonough, 2008). For children under the age of 18 years, SSI is meant for families with extremely limited income that are providing care for an individual with a disability (Social Security Administration, 2007). If there are no other sources of income, the family will live below American poverty standards since the money is intended to strictly cover food and shelter (Ferrell, Brooke, Kregel, & Getzel, 2002). Individual and family earnings affect eligibility for these programs. The Ticket to Work and Work Incentives Improvement Act of 1999 was crafted to remove disincentives to employment by individuals with disabilities who are over

the age of 21 years. As of 2000, health care coverage was expanded to include more people with disabilities between the ages of 16 and 64 and those who return to work. Despite these supports, more than half of the American caregivers who responded to the open-ended “losses” question, expressed concerns about their family’s financial stability and commented on the financial burden they experienced.

Czech Republic Governmental Supports. The Ministry of Education, Youth and Sport provides financing for compensatory technological equipment, counseling and resource centers that provide special educational support for individuals with special needs. Financial support is available to qualified families (Special Needs Education with the Educational System: Czech Republic, 2009). This support may include paid maternity leave, a social living and care subsidy, and health care when a family qualifies. Assistance is based on the family’s income level and a child’s age. Most Czech respondents indicated that present governmental supports were insufficient but few mentioned financial need in the “losses” question.

General Implications

In general, the caregivers in the Czech Republic may be characterized as slightly less positive in their outlook than the American caregivers since they reported a decrease in life optimism, less ability to enjoy free time, and that they did not feel enriched by providing care for an individual with special needs. American caregivers noted that they felt respected and acknowledged while those in the Czech Republic did not which undoubtedly affected the Czech respondents’ perception of their quality of life. It may be that these findings may also be an outcome of the populations to whom caregivers were providing care. That is, the majority of Czech caregivers were providing care to individuals who they described as falling into the severe-profound mental retardation range while the majority of those receiving care in the United States were described as functioning within the mild-moderate range of intellectual disabilities. It would follow that providing care to individuals with lower levels of personal independence could be more physically draining and demanding, fostering less positive perceptions. Additionally, the individuals receiving care in the Czech Republic tended to be older than those in the United States.

Several factors affect the degree to which the results of this study may be generalized. First, respondents from the United States resided in the same geographical area and were a small sample; those in the Czech Republic represented families from across the country. Second, the majority of the respondents were female. Third, a large portion of the respondents were married or lived with a partner that may have influenced their responses. Finally, although most individuals receiving care were below the age of 20, different results may have been generated if all family members had been of similar age and received comparable services. More research is needed which evaluates caregivers’ quality of life issues and seeks to

develop and identify family-centered supports that may promote the coping capacities of caregivers based on these evaluations. Further, future research needs to focus on the development of standardized evaluation tools which may give caregivers, and other constituents, a voice in shaping the services provided. This is particularly critical in countries in which parents and family members have fewer rights.

The caregivers in this study made it clear that caring for an individual with an intellectual disability presented rewards as well as difficulties. This outcome has been reported by others in the United States (Grant & Whittell, 2000; Heiman, 2002; Judge, 1998). The results of the present study suggest that although caregivers in the two countries reported many strong feelings such as increased fatigue, the majority in both countries were also able to appreciate the positive aspects associated with their caregiving responsibilities such as increased humbleness. Equally informative is that both groups revealed similar advantages (e.g., increased positive personal feelings) and disadvantages from providing care (e.g., loss of personal and family freedom and disruption in family relationships). Bailey and colleagues (1998) and others (e.g., Purcell, Turnbull, & Jackson, 2006; Wallender, Schmidt, & Koot, 2001) have asserted that family quality of life should be used as a determinant of the appropriateness of services governments and service providers offer families. In the past in the United States, services have been based on lawmakers’ best guesses and informal polling of the stakeholders. Attempting to gather more quantifiable data from stakeholders should increase the government’s ability to make informed decision-making.

It is generally accepted that being a caregiver of an individual with a disability can involve time, energy, and frequent disruption of family routines, particularly when health concerns are involved (Floyd & Gallagher, 1997; Murphy et al., 2006; Schultz & Quitner, 1998). Parish and associates (2008), in reporting data from a national survey conducted in the United States, found more material hardship among families raising children with disabilities when they were compared to families raising typical children, primarily due to the costs of therapies and loss of income. The Parish study and this one suggest that current government services and programs may be inadequate in addressing the material, emotional and relationship-based hardships experienced by families. Although more research is needed to identify the specific strains families face, it is evident that caregivers need personalized supports to assist them in managing and meeting the needs of the individuals with a disability for whom they are providing care.

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