

Student Work

12-1-2006

Perceptions of Respite Care Benefits and the Measures of Leisure Satisfaction and Life Satisfaction among Informal Caregivers

Natalie J. Nauman
University of Nebraska at Omaha

Follow this and additional works at: <https://digitalcommons.unomaha.edu/studentwork>
Please take our feedback survey at: https://unomaha.az1.qualtrics.com/jfe/form/SV_8cchtFmpDyGfBLE

Recommended Citation

Nauman, Natalie J., "Perceptions of Respite Care Benefits and the Measures of Leisure Satisfaction and Life Satisfaction among Informal Caregivers" (2006). *Student Work*. 2084.
<https://digitalcommons.unomaha.edu/studentwork/2084>

This Thesis is brought to you for free and open access by DigitalCommons@UNO. It has been accepted for inclusion in Student Work by an authorized administrator of DigitalCommons@UNO. For more information, please contact unodigitalcommons@unomaha.edu.

**Perceptions of Respite Care Benefits and the Measures of Leisure
Satisfaction and Life Satisfaction among Informal Caregivers**

A Thesis

Presented to the

Department of Health, Physical Education, and Recreation

And the

Faculty of the Graduate College

University of Nebraska

In Partial Fulfillment

Of the Requirements for the Degree

Masters of Science in Recreation and Leisure Studies
Recreation Therapy Option

University of Nebraska Omaha

By

Natalie J. Nauman

December 2006

UMI Number: EP73624

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



UMI EP73624

Published by ProQuest LLC (2015). Copyright in the Dissertation held by the Author.

Microform Edition © ProQuest LLC.

All rights reserved. This work is protected against unauthorized copying under Title 17, United States Code



ProQuest LLC.
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 - 1346

THESIS (OR THESIS-EQUIVALENT PROJECT)
(OR ED.S. FIELD PROJECT) ACCEPTANCE

Acceptance for the faculty of the Graduate College,
University of Nebraska, in partial fulfillment of the
requirements for the degree (name the degree),
University of Nebraska at Omaha.

Committee

Frank M. Brasile

[Signature], Ed.S.

Lisa J. Scherer, Ph.D.

Chairperson Frank M. Brasile
Date 11-30-2006

Perceptions of Respite Care Benefits and the Measures of Leisure Satisfaction and Life Satisfaction among Informal Caregivers

Natalie J. Nauman, MS

University of Nebraska, 2006

Advisor: Dr. Frank Brasile, Ph.D.

The purpose of the proposed study was to determine the perceived benefits of respite care by informal caregivers who are actively pursuing respite services, and to evaluate their expectations after receiving respite services. In addition the study also was undertaken to better understand the roles of “leisure satisfaction” and “Perceived Stress Levels” in the lives of informal caregivers who are currently receiving respite services versus those who are not currently receiving services, in both a pre and post format for both groups of caregivers. The study group of caregivers was given a total of four surveys in the pre-respite package and three surveys in the post-respite package. The comparison group was also given four surveys in their initial package and two surveys in their second package. The findings indicate an increase in leisure satisfaction among the study group, with all caregivers exhibiting value for respite services. The implications from this study indicate that although there were no significant changes noted in state stress levels or overall leisure satisfaction levels, caregivers receiving respite confirmed the positive impact of respite services on their lives.

I would like acknowledge those who have
spent many hours helping me and guiding me
through this project. To my committee, Dr. Brasile,
Dr. Stacy, and Dr. Scherer I appreciate so
Much your time and
input and will take away
so much from this experience.

I would like to dedicate this project
To my Sweet daughter Marley Joy, and
To the never ending love and support
From my parents.

Table of Contents

Chapter One - Introduction	1
Research Questions.....	3
Limitations and Assumptions.....	4
Significance	4
Chapter Two – Review of Literature	7
Deinstitutionalization Movement.....	7
Informal Caregivers.....	9
Professional Training.....	11
Abuse and Neglect.....	13
Financial Benefits of Respite Care.....	15
Emotional Benefits of Respite Care.....	16
Leisure Satisfaction.....	17
Pre-Service Perceived Benefits.....	18
Chapter Three – Methodology	20
Sample.....	20
Data Collection Instruments.....	20
Data Collection Procedure.....	22
Human Subjects Concern.....	22
Data Analysis.....	23

Chapter Four – Survey Results	24
Data Collection.....	24
Demographics.....	25
Table 1.....	26
Leisure Satisfaction Measure/ Perceived Stress Levels.....	26
Table 2,3,4.....	27
Expected Benefits.....	28
Table 5.....	29
Table 6.....	30
Comparison Group Evaluations/Comments.....	31
Study Group Evaluations.....	33
Chapter Five – Discussion	35
Leisure Satisfaction and Stress.....	35
Expected Benefits/Post Evaluation Comparison.....	36
Limitations.....	37
Suggestions for Further Research.....	38
References.....	40
Appendix 1.....	44
Appendix 2.....	45
Appendix 3.....	46

Chapter One

Introduction

The value of care provided by informal (family) caregivers in 2000 was moderately estimated in 2003 by the US Department of Health and Human Services [HHS], to be \$257 billion. One in three Americans can expect to spend some time over the course of a year caring for family, friends, and neighbors without payment. This adds up to 52 million caregivers a year, helping 37 million family members and 15 million friends (Smith et al., 2000). It is no surprise with these numbers that respite care has emerged over the past 35 years as an ever-important component of disability support services. There are many variations in respite definitions. In a study by Laverty and Reet (2001) they defined respite as allowing therapeutic opportunities, quality time, independence and the living of life for all family members, and recommended family members be empowered through respite care, and siblings be shielded from being overshadowed by the child with complex health needs (as cited in Thurgate, 2005). For purposes in this proposal respite care was defined as temporary relief for the caregivers and their families from the day-to-day stressors of caring for a mentally or physically disabled family member or friend. In addition, for the sake of this report, the term “informal caregiver” encompassed any individual providing unpaid care to a friend or family member whether elderly, ill, or disabled.

At the “macro” governmental level, respite care has been developed primarily through agency or professional-directed programs designed to maximize the numbers of individuals who could utilize these services. Given the predominance of agency-directed

services, research on consumer direction, especially within the USA, has been limited to small-scale pilot and individual state-funded projects. Yet, current research is beginning to emphasize the importance of focusing respite programs to suit the needs of each individual family (informal caregiver/dependent/other family members) (Caldwell & Heller, 2003, p.353). The Robert Wood Johnson “Cash and Counseling” demonstration projects highlighted flexibility as a desired aspect of programs. Receiving services on days and times when needed, flexibility in hiring that includes hiring family and friends, and flexibility in using money to purchase different services or home modifications were frequently reported reasons of interest in consumer-direction (Simon-Rusinowitz et al., 1997, 2001; Mahoney et al., 2002). Studies by Clark & Montgomery found caregivers often make subtle judgments about the relative ‘costs and benefits’ of accepting help and are likely to reject services that are not consistent with their own perceived needs or which they do not see as being of suitable quality (as cited in Ingleton et al., 2003, p.569). Additionally, Zarit et al. conducted a recent study that indicated what caregivers want is help that is consistent, yet flexible and responsive, and which addresses the needs of the person they care for, respects their individuality, and promotes a good quality of life (as cited in Ingleton et al., 2003, p.569). Therefore, it seems of utmost importance to understand the needs and expectations of informal caregivers and to design appropriate, flexible programs with those specific needs in mind. If caregivers are not receiving “temporary relief” through the current respite programs, a new approach must be taken in order to achieve the intended goal.

However, no research studies have been found that surveyed the informal caregiver prior to receiving respite services in regards to their perceived expectations of respite care and its purposes and benefits. Furthermore, there have been no studies to date examining the level of “leisure satisfaction” for both informal caregivers who do not receive respite services, and those who do currently receive services.

Therefore, the purpose of this study was to determine the expected benefits of respite care prior to receiving services, and to evaluate their respite experience after receiving respite services. The second purpose of this study was to determine the levels of “leisure satisfaction” and “state stress levels” in the lives of informal caregivers in both the study group and the comparison group. This information may aid informal caregivers and respite care providers by creating a better understanding of the expectations caregivers have of respite care, and evaluating the most effective and efficient services to provide. In addition, collecting data concerning “leisure satisfaction” and “perceived stress” among informal caregivers could allow Certified Therapeutic Recreation Specialists to better understand the needs and desires of informal caregivers so as to provide appropriate services.

Research Questions

Therefore, the following research questions are further investigated throughout this project.

- 1.) What are the perceptions and expectations of respite care services as determined by informal caregivers prior to receiving respite services?

- 2.) What are the perceptions and evaluations of respite care services as determined by informal caregivers after receiving respite care services?
- 3.) Are there any significant differences in leisure satisfaction or perceived stress levels between informal caregivers who receive respite services and those who do not?
- 4.) What are the reasons and concerns of informal caregivers who are not currently receiving respite services?

Limitations and Assumptions

Due to the fact surveys will only be administered in the state of Nebraska; there is always a possibility of a geographical effect on survey results. Therefore, generalizing results nationwide may be a limitation. Additionally, there may be a limitation on generalizing to all informal caregivers in the state of Nebraska due to a lack of a statewide database representing all informal caregivers, both receiving respite and those not receiving respite. There may be other variables including, but not limited to, certain demographical data, the amount and intensity of informal care given, and the mental, emotional, financial, or psychological state of the informal caregiver that can not be analyzed through the survey questions, and could affect the responses given. The assumption of accurate results using survey research is dependent upon the honesty of the informal caregiver in their responses.

Significance

Recreation Therapy is a profession that not only incorporates treatment for the individual with an illness or disability, but as one of its unique features, also works to aid

the caregiver and other family members in developing appropriate and independent leisure lifestyles. The American Therapeutic Recreation Association states,

Therapeutic Recreation is the provision of treatment services and the provision of recreation services to person with illnesses or disabling conditions. The primary purposes of treatment services, often referred to as Recreational Therapy, are to restore, remediate or rehabilitate in order to improve functioning and independence, as well as reduce or eliminate the effects of illness or disability. The primary purposes of recreation services are to provide recreation resources and opportunities in order to improve health and well-being. (ATRA Board of Directors 1987)

Obviously, the primary purpose of Recreation Therapy is for the individual seeking treatment. Yet, in order to improve the “health and well-being” of the individual with special needs, the caregiver and family must be considered. Having a solid understanding of Respite Care and where necessary, utilizing its resources, can play a key part in this overall goal.

Respite care has been shown to increase life satisfaction; and leisure satisfaction and life satisfaction have been shown to be positively correlated (Ragheb, M.G., & Griffith, C.A. 1982). Therefore, it seems logical that having a better understanding of respite care and the services provided would benefit a recreation therapist as they plan and implement a program for each individual client and his or her support system. In addition, if my hypothesis is accepted, the study will show a higher leisure satisfaction for caregivers receiving respite care. If this is shown in the data, it should bear wide implications for the profession of recreation therapy, as we continue to advocate and promote not only the value of rehabilitation and restoration, but also the importance of leisure and recreation in the lives of individuals with illness or disabilities, and their caregivers.

The proposed study could also bear significance in the areas of programming and funding of respite services. Acquiring information concerning the perceptions and expectations of respite care from informal caregivers prior to receiving services could benefit governments, states, and various programs as they seek to create respite services that are both cost-effective and fulfilling to the recipients.

Definition of Terms

Respite care – The temporary relief for the caregivers and their families from the day-to-day stressors of caring for a mentally or physically disabled family member or friend.

Informal caregiver- Encompassed any individual providing unpaid care to a friend or family member whether elderly, ill, or disabled.

Chapter Two

Review of Literature

Historical Background-Deinstitutionalization Movement

In order to better understand how respite care has emerged as a significant and vital part of today's ever-changing health care continuum, it is necessary to take a brief look back at some of the legislation and societal changes that have brought respite care to where it is today. In North America, following Western European tradition, persons with mental retardation were included in more general institutional provision founded from the 17th Century onward (Braddock, Emerson, Felce, & Stancliffe, 2001, p.115). Specialized residential care for persons with mental retardation grew in the United States and Canada from the mid-19th Century [Braddock and Parish, in press]. The United States has been one of the leading nations to embrace the deinstitutionalization movement and recognize the rights and needs of individuals with illness or disability.

The impact of a very prominent political family must be noted in the historical context of deinstitutionalization here in the United States. In 1918, a young woman named Rosemary Kennedy was born to Joe and Rose Kennedy. This young woman, a sister to the late President John F. Kennedy, was a special needs child. After years of not knowing how to understand or deal with her condition, the Kennedy family eventually took it upon themselves to become strong advocates of Individuals with Disabilities, and to use their political power to aid those with disabilities. In 1961, John F. Kennedy created the first President's Panel on Mental Retardation and used its findings to make mental retardation a national priority stating: "We as a nation have for too long postponed

an intensive search for solutions to the problems of the mentally retarded. That failure should be corrected” (Mailman Center for Child Development and the University of Miami, 2002).

At the same time, the Civil Rights movement was in full force here in the United States and played a vital role in spurring the deinstitutionalization movement. This was a movement to give more rights to individuals with disabilities, and to move them out of institutions and into the community setting. In the 1960s, legislation under Presidents Kennedy and Lyndon Johnson facilitated construction of community health centers and the movement of patients out of institutions. The late 1980s and early 1990s brought about another swing of legislative support for individuals with disabilities and their support systems, including informal caregivers. The underlying belief behind these policy changes was that the best place for individuals with illnesses or disabilities is in their homes and communities (Olson, 1998). In a report to the President in 2004, Tommy G. Thompson, Secretary, U.S. Department of Health and Human Services stated:

At HHS, we have a special responsibility to help remove barriers to community integration. Too often, people with disabilities have been forced to live in institutions, many times because the services that would enable them to live in their communities are not available. We need to help provide for those services, and at the same time, we need to support the many informal caregivers, and family and friends of people with disabilities, who dedicate themselves to providing the informal help with routine life in the community.

Additionally, in a 2004 letter to the President entitled, *“A charge we have to Keep: A Road Map to Personal and Economical Freedom for Persons with Intellectual Disabilities in the 21st Century,”* the Administration for Children and Families stated:

We must address the “personal” needs of the individual with an intellectual disability as well as the “collective” needs of the family. The Committee has identified three critical areas that will help to chart a new course for families: personal health and mental care, respite care for families and caregivers, and access to safe and affordable housing.

This committee brought forth the importance of informal caregivers in public policy, and advocated for their needs as part of the vital support system of individuals with disabilities.

Informal Caregivers

Informal caregivers have always been an integral part of the American health care system, particularly in the area of long-term care. It is also necessary to take a closer look at the additional needs and stressors involved with informal caregiving to best keep this arrangement a vital part of American health care. According to a 2000 report by the HHS entitled, *Understanding Medicaid Home and Community services: A Primer*, the primary factors that could make it difficult to sustain the current level of informal caregiving are: (a) continuing numbers of women employed full time; (b) continued growth in the number of people requiring long-term care, mainly as a result of population aging; and (c) an increase in the proportion of persons age 85 and older, the group most likely to need long-term care.

Unfortunately, a significant number of family caregivers describe their own health as “fair to poor”. Recent research findings suggest:

- The combination of loss, prolonged distress, and the physical demands of caregiving hurts the health of caregivers, resulting in more vulnerability to infectious diseases, such as colds and flu, and chronic diseases, such as heart disease, diabetes, and cancer;
- Elderly caregivers, who themselves may have a history of chronic illness and are experiencing stress related to caregiving, have a 63% higher mortality rate; and

- Depressive symptoms are twice as common among caregivers as among the general population (HHS, 2003)

In addition, Hoare stated consequently, exhaustion- both physical and emotional- is one of the principle reasons for a caregiver's use of respite services. Yet, some studies have questioned the benefits of respite care. Stalker found, evaluating a family-based respite service, found that some parents withdrew from the program because the child's absence appeared to create stress within the family. Finally, McNally reviewed seven studies on the effect of respite care on the social activities of caregivers, and found only one study that cited respite care as improving social life, possibly resulting from a lack of supportive relationships (as cited Hartrey & Wells, 2003, p.336).

Therefore, an Irish case study concluded the benefits of respite care to caregivers are not clear and may be dependent on subjective interpretations and feelings around placing a child in respite care and dealing with their return (Hartrey & Wells, 2003, p.336). This is also an issue here in the United States. In a large-scale survey of respite services in the USA, Knoll & Bedford found the majority of families felt they had little or no control over their respite services (as cited in Caldwell & Heller, 2003, p.354). With regard to different respite models, families ranked in-home respite services as provided by family, friends and neighbors as the most strongly preferred model. Families indicated that limited allocation of respite time, inflexibility in scheduling to meet their needs and leaving their family member with a disability with a stranger were major problems for them (Caldwell and Heller 2003). Beresford and Cotterill echoed, the goal is to tailor the service to suit the particular needs of the child and the family, but the demand for short breaks often exceeds the supply and families may take whatever form is

available rather than the one that best suits the needs of their child (as cited in McConkey & Adams, 1999, p.430). This further indicates a need to better understand of the expectations and concerns of informal caregivers as a primary determinant to the type of respite services offered. One aspect of creating respite programming is though having individuals who are professionally trained to take care of the individual with special needs and to be a support to the informal caregiver and family.

Professional Training

A New Zealand study looked at the caregivers' perceptions of in-hospital respite care and specifically the role nurses play in ameliorating, or exacerbating these perceptions. The study results found variations in the value of respite care ranging from acceptance, caregivers used the in-patient care services with confidence and accepted the need to take respite from caregiving; qualified acceptance, accepted the need to take respite from caregiving but were more reluctant to take full advantage of the respite time and felt the need to visit frequently to check up on their relatives' welfare; and marked ambivalence, families had difficulty relinquishing care because of concerns about the negative impact on the person needing care and visited for protective reasons. The authors concluded the above findings constitute necessity for nurses to locate themselves in a secondary and supporting caregiving role in in-hospital respite care setting. Recognition that in the respite care context the family caregiver is the authority on the personal and intimate care required, rather than the nurse, is fundamental to meaningful nurse-family relationships. Families were most able to fully relinquish care when they

were confident their relative was receiving comparable care to that in the home (Gilmour, 2002)

Another supporting study done in the United Kingdom, looked at the needs of caregivers through interviewing professionals, dependents, and the caregivers themselves to see if there were any discrepancies between the three groups. Conclusions found caregivers reported more unmet needs for themselves for short breaks than their dependents and the professionals had indicated. The authors determined the needs of caregivers must be independently addressed and services must be developed to specifically meet those needs (Kersten, McLellan, George, Mullee, & Smith, 2001, p.241). Additionally, Thurgate (2005) highlighted the importance of collecting information from those who receive care rather than those who provide it. Respite providers and funders must work with individual families to ensure fair expectations and equality in provision for all.

Ingleton et al. (2003) stated, we suggest that much greater attention be directed to understanding the assumptions of professionals in their dealing with caregivers. This can be addressed by training professionals and respite providers to better understand the term “caregiver burden” that has long been misconstrued. Underpinning ‘this burden mode’ is the perception that caregiving relationships are rarely reciprocal, and are characteristically unrewarding. As a result, the focus of interventions has almost primarily focused on relieving ‘burden’ in a therapeutic model context in which the professional is the expert. This again returns to the agency-centered vs. consumer-directed models for respite care and the impact of both on the quality of respite care

services, and satisfaction of informal caregivers based on whether or not their direct, individual needs are being met through such services.

Meeting the needs of the informal caregivers is a continual process. One affect of caregivers becoming too overwhelmed with their responsibilities and not having a break from caregiving duties can unfortunately be abuse or neglect.

Abuse and Neglect

“In 1991, the *Individuals with Disabilities Education Act* (P.L. 102-119) stated that Congress found there to be eight million children with disabilities under the age of 21 living in the United States” (National Resource Center for Respite and Crisis Care Services, 1994). “It has been estimated that over 90% of children with disabilities live at home instead of in institutions” Boggs and Henny (as cited in National Resource Center for Respite and Crisis Care Services, 1994). “In 1992, it was also estimated that 2,936,000 children were reported to public social service/child protective service agencies for abuse and /or neglect” NCPA (as cited in National Resource Center for Respite and Crisis Care Services, 1994). This number was nearly the same in 2000; with 879,000 of those children sustaining substantiated or indicated abuse and neglect. HHS (as cited in Kagan, 2002). In the absence of adequate family support, “it is estimated children with disabilities are 3.76 times more likely to be victims of neglect, 3.79 times more likely to be physically abused, and 3.88 time more likely to experience emotional abuse than children without disabilities” Sullivan & Knutson (as cited in Kagan, 2002).

Cowen and Reed (2002) conducted a study on the *Effects of Respite Care for Children with Developmental Disabilities; Evaluation of Intervention for At-Risk*

Families. The findings in this study indicate that the extensive care needs of the children or the families' inability to meet or cope with those needs are major factors contributing to the high stress in the parent-child relationship. The statistical trends indicate that parenting stress significantly decreased following respite care interventions resulting in a decreased risk for the development of dysfunctional parental behavior. This study also reemphasized findings by May and Hu that families often seem unaware of a nurse's potential for helping them identify beneficial community resources and Saideman and Kleine found "parents of children with developmental disabilities often felt that health care professionals did not understand their home situation" (as cited in Cowen & Reed, 2002)

Another study out of Australia looked at planned respite services and the importance of social supports to reduce maltreatment and abuse, especially in families of children with disabilities. Research by Rodriguez has demonstrated that child abuse rates are positively correlated with the amount of stress that perpetrators experience, and Garbarino found an inverse relationship between the incidence of child abuse and the extent and depth of parent social support. (as cited in O'Brien, 2001). Planned respite is intended to help alleviate some of that stress through giving caregivers a chance to build or rekindle support networks, and to feel they have available support when necessary. Research has confirmed that mothers who abuse or neglect their children often do not feel supported. A final conclusion of this study stated "the substantial literature on the negative impact of stress on family functioning and the positive effects of social support provide a strong theoretical base for the provision of planned respite care (O'Brien,

2001). Another valuable aspect of planned respite care is the financial benefits of these programs when compared to other options such as out of home placement.

Financial Benefits of Respite Care

It seems today one of the main venues in which to help those with disabilities is to offer adequate support to those informal caregivers, often in the form of respite care services. Respite care is often referred to as the “gift of time,” as it provides a break for families to tend to other needs, vacation, spend time with their other children, or just have a moment to relax knowing their child is being properly cared for during that time.

Kagan states in the NRC (2002), “Without respite and other supports for family caregivers, many children would receive more costly care in institutional or foster care placements.” Research has confirmed the positive financial benefits of informal care versus group homes or institutions for their loved ones with disabilities. “An estimated average investment of \$4,800 per year in crisis nursery childcare can save over \$52,000 in institutional care in California for one child” Miller (as cited in ARCH 31, 1994). In addition, the average savings for respite services versus institutional care for a child with disabilities amounts to \$49,000 per year. Braddock, Hemp, Fujiura, Bachelder, Mitchell (as cited in ARCH 31, 1994) Salisbury and Intaglata (1986) found this to be a 65-70% savings over out of home placements (Olson, 1998).

The Temporary Child Care for Children with Disabilities and Crisis Nurseries Act of 1986(as amended) has been the first step in providing these much needed respite programs throughout the country (National Resource Center for Respite and Crisis Care Services, 1994).

On June 22, 1999, the U.S. Supreme Court ruled in the case of *Olmstead V. L.S. and E.W.* that the “integration mandate” of the Americans with Disabilities Act requires public agencies to provide services “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” Disabled people segregated in institutions have used it to require states to provide services in the community (www.accessiblesociety.org). Yet, with each state having control as to where the funds are dispersed and what versions of the services will be provided, families soon discovered many flaws in the legislation Brill (as cited in Olson, 1998). The latest evaluation data from an annual survey of 175 formerly federally funded respite and crisis care grantees found that, during an average week, 1,493 families representing 3,425 children were turned away because programs do not have the proper resources (NRC, 1998). Yet the most recent figures from the ARCH research report titled *Planned and Crisis Respite for Families with Children: Results of a Collaborative Study*, showed it is estimated that planned respite care costs \$120.24 per month or \$1,422.88 per year to provide twelve hours of respite to an individual each month, compared to Child Welfare League of America figures for foster care costing \$402.67 per month, adding up to \$4,832.04 per year.

Emotional Benefits of Respite Care

In addition to the financial benefits of in-home care with sufficient respite, there are also studies that indicate improved emotional benefits for the caregivers and other family members, and also for the children with disabilities. “Respite care not only provides caregivers a break, but also gives the child a change in his or her daily routine.

It can provide the child opportunities to build new relationships and move toward independence” Valdivieso (as cited in Ingram, 1992). Respite also provides valuable time for parents to devote to the other siblings in the household who may otherwise feel neglected due to all of the care and attention required by their sibling with special needs. Respite has been shown to improve family functioning and life satisfaction, enhance capacity to cope with stress, and improve attitudes toward the family member with a disability. In a family support survey, 82% of families who use respite and crisis care services responding to the survey identified respite as a critical component of family support (NRC, 1998). Another study of family support services in the San Francisco Bay area showed “over 90% of the families using services reported reduced stress (93%), improved family relationships (90%), improved positive attitudes toward their child (93%), and other findings that help reduce the risk of abuse” Owens, Sandra, et al., (as cited in NRC, 2002). Upon further examination of the emotional benefits of respite care, leisure satisfaction, another aspect, was also very important and was one of the main study points in this project.

Leisure Satisfaction

Leisure satisfaction not only has implications for informal caregiving and respite services, but it also plays a large role in the philosophical basis for the recreation therapy profession. As was stated above in the emotional benefits of respite care section, having access to respite care has been shown to increase life satisfaction (as cited in NRC, 2002). Additionally, Ragheb and Griffin (1982), surveyed over 500 adults over 55 and found, leisure satisfaction showed the greatest contribution to overall life satisfaction. This

study also found the higher the frequency of participation in leisure activities, the higher the life satisfaction; the more the leisure participation, the higher the leisure satisfaction; and the greater the leisure satisfaction, the greater the life satisfaction. Finally, all six leisure satisfaction components (leisure satisfaction, satisfaction with standard of living, satisfaction with family relations and activities, satisfaction with health, leisure participation, and marital status) correlated positively with life satisfaction (p.295).

An additional study by Kinney and Coyle (1992) examined life satisfaction among adults with physical disabilities. Data was collected using the Center for Epidemiological Studies Depression Scale, Rosenberg's Self-esteem Scale, and the Life 3 Scale. Results found leisure satisfaction was the most significant predictor of life satisfaction, explaining 42% of the variance of life satisfaction for this population (p.863-869).

McConkey and Adams (2000), also found parents show a preference for respite services that benefit the child as well as giving the caregivers a break. Families were nearly unanimous in their desire for more leisure activities and holiday breaks. Learning more about the informal caregivers' expectations is a critical part of creating effective respite services and allowing caregivers to feel comfortable leaving their child with a provider.

Pre-Service Perceived Benefits

Another vital aspect of respite is examining the perception of respite benefits informal caregivers expect to receive as a result of these services, prior to actually receiving the services. There has not been found any existing research or documentation

covering this specific area, and purpose one is to determine these perceptions for this specific population of caregivers through this study. It could be proposed this would be necessary to help facilitate the most efficient and effective respite programs and educational services to those requesting them. In addition, this would give a better indication of whether the perceived benefits of respite care were similar when comparing those who currently receive services with those who do not receive services.

Chapter 3

Methodology

Sample

Subjects in this study were informal caregivers of individuals with illnesses or disabilities. The control and study groups were determined by whether or not they would receive respite services within the course of the proposed study time. The study group was a selection of informal caregivers who contact Nebraska Respite Network to inquire about respite services. These caregivers were surveyed prior to receiving respite services and then again after receiving respite services. The control group was composed of informal caregivers who had not and did not receive respite services during the study time. Contact information will be obtained through the Nebraska Respite Network database, other local respite providers, and support groups for informal caregivers. The total number of surveys sent out to the study group was 30, and the total number of surveys sent out to the comparison group was 40. The sample size was not determined by age, gender, or race. In addition, for the final analysis, the comparison group was not only examined as a whole group, but also broken down into sub-categories based on whether or not they had previously pursued respite services. Proper research ethical concerns for privacy and confidentiality were observed during this study.

Data Collection Instruments

Two surveys will be used for both groups of caregivers in the pre and post survey groups. These surveys are the Leisure Satisfaction Measure (Beard and Ragheb) and the Perceived Stress Scale (MacArthur). The *Leisure Satisfaction Measure* indicates the

degree to which an individual feels his/her general “needs” are being satisfied through leisure. The six subscales of satisfaction are 1. psychological, 2. educational, 3. social, 4. relaxation, 5. physiological, and 6. aesthetic. It is useful for establishing that an individual's needs for leisure are being met by the existing programs and for finding areas where interventions may increase the individual's level of satisfaction with leisure. The alpha reliability coefficient for the entire scale is high, .96, and ranged from .85 to .92 for the six components. Correlation among the subscales was determined by summing the scores of the items of each subscale for each of the subjects (N=347) and computing the intercorrelations among the subscales. These correlations ranged from .38 to .66 with a median value of .52.

In addition, a self-developed questionnaire was added to the pre-respite study group package in which to examine the expected benefits of respite care to use in a qualitative manner. This expected benefits survey was created based on common leisure activities and activities of daily living.

The ARCH Evaluation Form PR1 for Planned Respite was administered to those informal caregivers who are currently receiving respite services in the post-respite survey group. Dr. Kirk and a group of respite providers, parents and other ARCH staff developed the first evaluation tool that, after 2 field-tests, became the PR1. He also consulted with ARCH Respite Network each step of the way as he worked on the field test and the development of the final product.

An Informed Consent Sheet and a Demographic Sheet were also attached to both of the first survey packages. The Demographic information included gender of care

recipient, date of birth, caregiver's relationship to care recipient, and level of care required. The second part of the demographic survey includes information about the caregiver's ethnicity, marital status, housing, family income, and education level

The comparison group also received the Leisure Satisfaction Measure and the Perceived Stress Scale in both sets of surveys, in addition to the Informed Consent and Demographic Information. Additionally, it was determined that in order to better understand the reasons for abstaining from respite services, a questionnaire would be added in which the caregivers can further express their reasons for not utilizing respite services.

Data Collection Procedure

Surveys were sent out by the Nebraska Respite Network and PTI Nebraska via self-addressed stamped envelopes for return. In addition, a cover letter was attached to each packet with information concerning the purpose of the study, contact information for questions or concerns, an indication of when the enclosed survey should be returned, confirmation that their responses are confidential and anonymous, and what was intended to be gained from participating in this research project. Follow-up was also conducted by the Nebraska Respite Network for the study group and PTI Nebraska for the comparison group in order to maintain confidentiality.

Human Subjects Concerns

Participation in this research project could benefit the informal caregivers by using this data, and other studies to create more effective respite services, to increase funding and availability of services, and to train better qualified respite care providers.

There was no risk of physical harm for participation in this study, due to the fact the survey was mailed to caregivers, and there was no face-to-face contact with the participants. There was a slight risk of psychological harm for caregivers, due to the sensitive nature of some of the survey questions. Having a “not applicable” box as an option for a question that they may not desire to answer minimized the psychological risk.

Data Analysis

Basic descriptive statistics were run on the surveys to determine the mean, and standard deviation for each group separately. In addition, descriptive statistics were run on the Leisure Satisfaction Measure as a whole, to determine the overall leisure satisfaction of informal caregivers, and separately based on whether the informal caregiver was, or was not receiving respite care services. These statistics should give a good indication of any significant differences or trends comparing informal caregivers who do, and do not receive respite services, both in the areas of perceived benefits, and also in regards to leisure satisfaction.

Chapter Four

Survey Results

Data Collection

This survey research project was completed via informal caregivers on a voluntary and anonymous basis. The caregivers were divided into two groups. The comparison group consisted of informal caregivers who had not received respite care in the past and would not be receiving respite for the duration of this study. The study group consisted of informal caregivers who contacted the Nebraska Respite Network and inquired about respite services, and were then asked to complete surveys both prior to receiving respite services, and after receiving services.

Nebraska Parent Training Information was contacted and Nina Baker their family partner worked to help distribute and collect the comparison group surveys. Nina speaks to many groups of informal caregivers all across the state and she also has a very wide database of informal caregivers through PTI. Initially there were forty surveys distributed for the comparison group. In addition, there were thirty surveys sent out through the Nebraska Respite Network for the study group. Logistically it was much easier to access informal caregivers for the comparison group as opposed to the study group. This was in part because it was difficult to find a large number of informal caregivers who inquired about respite services during our study period and actually pursued, and received respite services in order to complete the follow up questionnaires.

This study was a combination of a qualitative and a quantitative study. Although the number of participants was not high, there was very valuable information received

though open-ended questions and comment sections by both groups. This information will be added to the study in order to give a more complete picture of the expectations and opinions in regards to respite services.

Demographics

In the study group (n=5) three of the informal caregivers were birth parents and two of the caregivers were spouses. In addition, three caregivers were married and two were divorced. The comparison group (n=10) consisted of seven caregivers as a birth parent, two caregivers as foster parents, one caregiver is an adoptive parent and one caregiver abstained. In order to perform a compared match of subjects, two comparison group members were initially eliminated due to their lack of knowledge of respite services. Then for the eight subjects that were remaining, five comparison subjects were chosen based on those who had completely filled out their survey information. Each of these individuals had previous knowledge of respite services so as to make a more even comparison to those the study group who was actively pursuing respite services during the course of this project.

Table 1*Demographic Information for Study Group and Comparison Group Participants*

Caregiver Information	Study A	Study B	Study C	Study D	Study E
Ethnicity	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian
Marital Status	Divorced	Married	Married	Divorced	Married
Housing	Rent	Own	Own	Rent	Own
Family Income (per year)	\$60,000-up	\$30-39,999	\$20-29,999	\$30-39,999	\$40-49,999
Education	4yr degree/higher	Some College	Some College	4yr degree/higher	4yr degree/higher
	Comp A	Comp B	Comp C	Comp D	Comp E
Ethnicity	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian
Marital Status	Separated	Married	Married	Married	Divorced
Housing	Rent	Own	Own	Own	Rent
Family Income (per year)	\$0-9,999	\$40-49,999	\$40-49,999	\$60,000-up	\$10-19,999
Education	H.S. or GED	Some College	4yr degree/higher	4yr degree/higher	Some College

Leisure Satisfaction Measure/ Perceived Stress Levels

There were two surveys that were given to both sets of caregivers in the pre-respite package and the post-respite package. These surveys were the Leisure Satisfaction Measure, and the 10-item Perceived Stress Scale. The Leisure Satisfaction Measure is a 24-question survey set up on a Likert scale (1=almost never true - 5=almost always true), which is designed to determine the degree to which an individual is currently content with their leisure lifestyle. The attached Tables 2,3,4 will help further break down these questions into various categories including psychological, educational, social, relaxation, physiological, aesthetic.

Table 2*Comparison group paired Sample t-tests for Leisure Satisfaction Measure Pre and Post*

Variable	Mean Pre	SD	Mean Post	SD	t	Sig
Psychological	4.25	0.46	3.35	0.52	3.88	0.01
Education	3.80	0.32	3.40	0.48	2.75	0.05
Social	3.50	0.47	3.75	0.81	-1.05	0.35
Relaxation	4.20	0.41	3.70	0.66	2.10	0.10
Physiological	3.00	0.31	2.80	0.78	0.61	0.58
Aesthetic	3.75	0.25	3.50	0.35	1.12	0.33

Table 3*Study group paired Sample t-test for Leisure Satisfaction Measure Pre and Post*

Variable	Mean Pre	SD	Mean Post	SD	t	Sig
Psychological	3.45	0.97	3.75	1.3	-1.23	0.284
Education	3.35	0.8	3.35	0.91	0.00	1.00
Social	3.75	0.64	3.75	0.85	0.00	1.00
Relaxation	4.15	1.12	4.15	1.40	0.00	1.00
Physiological	2.80	1.00	3.05	0.57	-1.00	0.37
Aesthetic	3.50	0.79	3.70	0.78	-0.65	0.55

Table 4*Both groups Independent Samples t-test for LSM*

Variable	Comparison		Study		t	Sig
	Mean	SD	Mean	SD		
Psychological	3.35	0.52	3.75	1.3	0.64	0.54
Education	3.45	0.48	3.35	0.91	0.22	0.83
Social	3.75	0.81	3.75	0.85	0.00	1.00
Relaxation	3.75	0.66	4.15	1.4	0.57	0.58
Physiological	2.80	0.78	3.05	0.57	0.58	0.57
Aesthetic	3.50	0.35	3.7	0.78	0.52	0.65

Among the t-tests performed for the comparison group and the study group the only significant findings were a decrease in leisure satisfaction in the Psychological and Educational categories for the comparison group

In addition, the Perceived Stress Scale was utilized for both groups to help determine their state stress levels. A reliability coefficient alpha test was run on the stress scale for the entire group of participants. The alpha level was found to be 0.58 (Reliability, SPSS). The Perceived Stress Scale was set up in a Likert format (0=never – 4=very often) and asked respondents to answer based on their feelings within the last month. There were 10 questions on this survey, therefore the means are based on a scale from 0-40. For purposes of testing, some of the scales have been changed due to the reverse coding of the questions. This makes it possible to compare all of the questions on the same scale. The study group showed a pre respite stress level of 22.2 with a standard deviation of 5.45. The post stress level for the study group was 21.4 with a standard deviation of 7.82. The comparison group had a first survey average of 17.4 with a standard deviation of 5.64. The second survey average for the comparison group was 19.6 with a standard deviation of 5.03. A independent t-test was run on these findings and none were found to be significant.

Expected Benefits

In conjunction with the Leisure Satisfaction Measure and the Stress Scale, an expected benefits survey was included for additional qualitative information. The various benefits were selected based on common activities of daily living and the open-ended question at the end was to be used to allow caregivers to address any other activities or

expected benefits. This survey was not intended to be used for statistical purposes; instead it was used to give a better understanding of the desires and expectations of caregivers prior to receiving services. This measure was developed to assist in determining the expected benefits of respite care prior to receiving services. The caregiver was asked to respond to this 24 question survey on a five point Likert scale that ranged from one, not important, to five, very important. The caregivers were also asked to write down any other activities or expected benefits not listed above. The following chart shows the 24 possible choices and how the caregivers ranked them in importance.

Table 5

Study group findings for the Expected Benefits of Respite Survey

	<u>Expected Benefits of Respite</u>	<u>Mean</u>	<u>Rank</u>
1	Spend more time with Spouse	3.4	1
2	Spend more time with Family	3.2	2
3	Reduced Daily Stress	2.8	3
4	Clean the House	2.8	
5	Increased Leisure Time	2.6	5
6	Spend more time with other Children	2.6	
7	Just Relax	2.6	
8	More Free time	2.4	8
9	Spend more time with Friends	2.4	
10	Exercise More	2.4	
11	Cook Healthier	2.4	
12	Go Shopping	2.4	
13	Fix up House	2.4	
14	Work in the Yard or Garden	2.4	
15	Read	2	15
16	Pay Bills/ Catch up on Finances	2	
17	Watch TV or Movies	2	
18	Pursue a Hobby	1.8	18
19	Pursue Education	1.6	19
20	Going on a Vacation	1.6	

21	Take a Nap	1.6	
22	Volunteer	1.4	22
23	Write Letters	1.4	
24	Play an Instrument	1.4	

In addition to marking their reasons for pursuing respite they were also asked to write any additional comments in regards to this issue at the bottom. Some of those comments are included in the Table 6 below.

Table 6

Study Group Caregiver Comments in regards to Expected Benefits of Respite

<i>“I have some extra activities with teaching...the main reason for respite for our family is to provide some down time for mom and dad to go out on a date or just hang out.”</i>
<i>“I am well satisfied in my role as the caregiver for my wife...when I contacted respite I was looking more for a back up in case I was unable to care for her.”</i>
<i>“There are occasions when I have to attend one of my other children’s activities, and than is when I require respite care.”</i>

Based on these findings and the comments from caregivers there seems to be a trend in caregivers wanting respite services in order to give more time to others who are close to them. This could possibly be due to the amount of time needed to tend to the individual with special needs and the feeling that others (namely spouses and other family members) are not receiving adequate attention. This is also supported by previous

findings in the review of literature by the NRC (1998, 2002) in which respite care was shown to improve family functioning.

Another aspect of this study is to look at some of the possible reasons why caregivers are not currently receiving respite services. This factor can help us determine a more comprehensive picture of not only the expected and perceived benefits of respite care services, but also some of the barriers that hinder some caregivers from utilizing these services.

Comparison Group Evaluation/Comments

While working with the Nebraska Respite Network on this study, it was determined that it would be of value to also include a qualitative survey for those caregivers who will not be receiving respite services to better understand their reasons and concerns. This survey is intended to ascertain further insight into possible reasons why caregivers are not utilizing respite services and will also aid respite programs as they continually seek to revise and build respite programs that will be efficient and effective for caregivers.

To assist in better understanding the dynamic of respite care, it is important to include some of the caregiver comments as they give some additional insights into this project. The survey asked caregivers to mark and respond to the reasons why they do not currently receive respite services. They were also asked to write any additional comments either positive or negative about respite care.

Three themes seemed to be apparent in these caregiver comments and they are: caregivers did not qualify for respite programs, a general lack of trust of other providers to care for their loved one, and a lack of time or need for respite at this time.

Of those who did not qualify for respite services, some of their remarks were, *“finding respite care was impossible, and it uprooted the children from routine”* *“our income is too high...so what happens is that we can't afford the \$15-20 an hour respite provider and we never have a break from caregiving”*. Another caregiver wrote about their previous attempts to receive respite services and acknowledged *“frustration of finding and qualifying for respite”*. A third caregiver simply wrote, *“I find it difficult to find someone...I feel it is unfair to ask teenage girls”*

A second prevalent theme throughout the caregiver comments was a general lack of trust for outsiders to come in and care for their loved one. One respondent answered, *“I am very cautious of who watches my daughters so I think that is what keeps me from using the services if needed...nothing against the service, but very cautious”*. One individual, a foster parent, wrote about the difficulties in leaving their foster children due to complex needs, she said, *“some of my (foster) children have major behavioral problems with high medical needs, difficult to find adequate respite care”*. This next caregivers also echoed those last sentiments by stating, *“respite care for attachment disorder children is very difficult because more people do not understand the needs or services necessary for RAD children”*. And finally, another participant expressed concerns over the safety of their private information, *“respite care is expensive and most generally requires extensive financial information from the family with no security of*

where the information is going or who will see it. Providers are not required to not gossip or reveal information about families which places some families in very uncomfortable situations in the community". Another mother shared her concern by stating, *"not sure if anyone else could take care of our son..., and be able to leave him with someone we didn't know"*. All of these caregivers shared some common concerns and reasons for abstaining from respite care which can hopefully be addressed in the future.

Finally, a third theme that emerged from the written comments was in regards to a lack of time to pursue respite or just a general lack of need for services at this time. One caregiver expressed her frustration in regards to the initial process to receive respite wrote, *"I would like to take the time to phone interview providers...when I found out I have to hire them and interview them and pay them \$8-10 an hour the night out for my husband and I became much more hassle and expense than I need"*. Yet, this final caregiver explained their own feelings about respite stating, *"I believe it is a great resource for individuals in need of this care. We were well aware of respite care and it was available to us if we needed the service"*.

These sentiments from informal caregivers exemplify some of the challenges with respite services and also illustrate some of the expectations of caregivers in order to utilize respite in the future.

Study Group Evaluations

Lastly, in the follow-up surveys, four informal caregivers completed an evaluation of their respite services, which was produced by the ARCH National Respite

Organization. This is a commonly used evaluation by many respite providers as it looks at various areas of life and how the caregiver felt about them prior to respite services, currently, and if respite services were to end. Tables 6,7 look at these various areas based on a seven point Likert scale with one meaning not at all, to seven meaning extremely, and are included as an Appendix 3.

In summary, although the findings for the Leisure Satisfaction Measure and the Perceived Stress Scale were not deemed significant, there were some interesting findings about the value of respite services to caregivers. All of the respondents reported that respite had helped them, and would hurt them if it were to end, and 75% requested more respite hours showing their desire for the program.

Chapter Five

Discussion

Introduction

The previous chapters have discussed the purpose of this study, the current literature concerning respite care and its' components, and the results of the informal caregivers. This final chapter is intended to give further insight into the reasons and implications behind those findings and how they relate to respite care services and their impact for future studies.

Leisure Satisfaction and Stress

In chapter four, the statistics and tables were included to demonstrate the leisure satisfaction and stress levels of informal caregivers. The Leisure Satisfaction Measure showed levels decreasing in every area of the survey for the control group. While at the same time, the study group levels either stayed the same or increased. The results do not indicate a significant trend that respite may have given caregivers a chance to expand their leisure options, which as a result increased their leisure satisfaction. The data, however, has shown based on the need for respite services and the evaluation answers, that caregivers feel that other areas of their lives and responsibilities are negatively affected due to the increased time and energy required to care for the individual with special needs. Therefore, these respondents indicate both through comments and leisure satisfaction that the purpose of respite services is to allow the caregiver more "free time". The primary purpose of this free time is often utilized spending more time with a spouse or family and friends.

It is also interesting to note that stress seemed to be a constant factor in both the pre and post testing of both the control group and the study group. Although respite services are to be used to aid the caregiver, and one may assume reduce stress, it appears that stress levels seem to be a constant whether a caregiver is receiving respite or not. It should be noted that these stress levels were not extremely high, and they could be based on many factors at the time of the survey completion. State stress is an indication of stress levels at the present time of completing the survey and although the caregivers indicated a major expectation for utilizing respite services was to decrease stress levels, their overall state stress levels were not particularly high. This could be explained through an acceptance of their current situation and even though respite care does provide a temporary relief, those ongoing caregiver responsibilities and duties are still there.

In addition, the final evaluations for the study group indicated that three of the four respondents were not satisfied with the monthly hours of respite and requested more. This could play a factor in possibly allowing caregivers to not only get “caught up” with those daily responsibilities, but to maybe even branch out to seek more leisure opportunities for themselves.

Expected Benefits/ Post-Evaluation Comparison

There are some trends that seemed to become clear through the post respite evaluation through which caregivers showed despite a lack of significant changes in stress levels or leisure satisfaction. All four of the caregivers who responded to the evaluations of respite care (one participant did not complete the survey) showed almost every area their situation was either worse or harder prior to respite, had improved with

respite, and they perceived it would worsen again if respite were to end. These seem to be the most telling figures of this project in that there is still a great value in respite based on the common findings of these four caregivers. In addition as mentioned before, three out of the four caregivers requested more respite time each month. Also, when comparing the findings of the expected benefits survey given prior to respite and the findings of the post respite evaluations, they both seem to desire more time with family and friends. These findings would lend themselves to the notion that informal caregivers may not have enough time to pursue their own leisure interests, which may be remedied through a leisure education program coupled with increased respite hours.

Limitations

There are certain limitations that need to be addressed in this project. The total number of subjects in both the study and control groups is a limitation. The low number of respondents makes it difficult to use the data collected in a strictly quantitative method. Therefore, as mentioned above, we have also incorporated a qualitative aspect to this project through analyzing and reporting some of the personal comments and concerns brought about by informal caregivers. Another limitation is the variation of respite services. All respite care providers are different and so are the times, locations, and length of respite services. That is an aspect of respite care that makes it hard to definitively use as an “intervention” because of all of the variables in how it is utilized. Although there were six months between the pre and post surveys, it must still be noted that in order to have a more comprehensive picture of respite and its’ effects, an ongoing study would be a better fit. Additionally, it must be noted that the study group was

composed of caregivers who were actively seeking respite services and the comparison group was composed of caregivers who were not necessarily actively seeking respite. As a result, the controlled comparison was used to determine five comparison subjects that were aware of, and had pursued respite at one time in order to bridge this gap. This project was used to help determine an initial baseline of information from caregivers and hopefully further research could continue to build upon and monitor this information over time.

Suggestions for Further Research

Further research in this area could focus on the spouse/family relationship because both the control and study groups expressed those as a top priority in utilizing respite services. Another intervention that may be beneficial to examine in a future study is the effect of implementing a leisure education program in conjunction with the respite program. Due to the slight increase in leisure satisfaction among the study group, it would be interesting to continue to examine their leisure lifestyle and interests and to educate them further in this area to best utilize their respite hours. Another common concern by caregivers that could be examined in future research is the need for further flexibility in respite services (i.e. using vouchers, or family and friends as providers). These types of programs are available here in Nebraska, but there seems to be a disconnect between the caregivers expectations about respite and the actual programs in this regard. Finally, further research should examine the aspect of state stress levels remaining constant while at the same time leisure satisfaction increased. This finding may indicate a disconnect between these two variables.

All in all, hopefully this project will give some further insight into the expectations and the reality of caregivers lives in regards to stress, leisure satisfaction, and utilization of respite services. This study has produced some useful information to offer an initial baseline of information into the concept of respite care and leisure satisfaction levels in informal caregivers.

References

- Administration for Children and Families. (2005, March 19). A CHARGE WE HAVE TO KEEP A Road Map to Personal and Economic Freedom for Persons with Intellectual Disabilities in the 21st Century – 2004. Retrieved March 19, 2005 from http://www.acf.hhs.gov/programs/pcpid/2004_rpt_pres/2004_report.html
- Braddock, D., Emerson, E., Felce, D., Stancliffe, R. (2001) Living Circumstances of Children and Adults with Mental Retardation or Developmental Disabilities in the United States, Canada, England and Wales, and Australia. *Journal of Mental Retardation and Developmental Disabilities*, 7, 115-121.
- Caldwell, J., & Heller, T. (2003). Management of Respite and Personal Assistance Services in a Consumer-Directed Family Support Programme. *Journal of Intellectual Disability Research*, 47(4/5) 352-366.
- Center for An Accessible Society. (n.d.). Supreme Court upholds ADA ‘Integration Mandate’ in Olmstead decision. Retrieved March 19, 2005 from <http://www.accessiblesociety.org/topics/ada/olmsteadoverview.htm>
- Cowen, P. S., & Reed D. A. (2002). Effects of Respite Care for Children with Developmental Disabilities: Evaluation of an Intervention for At Risk Families. *Journal of Public Health Nursing*, 19(4), 272-283.
- Dougherty, S., Yu, E., Edgar, M., Day, P., & Wade, C. (n.d.) Planned and Crisis Respite for Families with Children: Results of a Collaborative Study. Retrieved June 18, 2005 from <http://www.arch.org>

- George, S., Kersten, P., McLellan, L., Mullee, M., Smith, J. (2001). Needs of Carers of Severely Disabled People: Are they Identified and Met Adequately?. *Health and Social Care in the Community*, 9(4), 235-243.
- Gilmour, J. (2002) Dis/Integrated Care: Family Caregivers and In-Hospital Respite Care. *Journal of Advanced Nursing*, 39(6), 546.
- Hartrey, L. & Wells, J. S. G. (2003) The Meaning of Respite Care to Mothers of Children with Learning Disabilities: Two Irish Case Studies. *Journal of Psychiatric and Mental Health Nursing*, 10, 335-342.
- Ingleton, C., Payne, S., Nolan, M., Carey, I. (2003) Respite in Palliative Care: A Review and Discussion of the Literature. *Journal of Palliative Medicine*, 17, 567-575.
- Ingram, D. (1992). Respite Care. *The Arc/s Q&A on Respite Care*. Retrieved March 19, 2005 from <http://www.thearc.org/faqs/respite.html>
- Kagan, J. (2002, July). Respite and Crisis Care Help Prevent Child Abuse and Neglect and Out-of-Home Placements. *National Respite Coalition*. Retrieved March 19, 2005 from <http://www.archrespice.org/NRC-Respite%20and%20Crisis%20Care.htm>
- Kinney, W. B., Coyle, C. P. (1992) Predicting Life Satisfaction among adults with Physical Disabilities. *Arch Physical Medical Rehabilitation*, 73(9), 863-869.
- Mahoney, K. J., Desmond, S. M., Simon-Rusinowitz, L., Loughlin, D. M. & Squillace, M. R. (2002) Consumer Preferences for a cash option versus traditional services: Telephone Survey from New Jersey Elders and Adults. *Journal of Disability Policy Studies*, 13, 74-86.

Mailman Center for Child Development and the University of Miami. (2002). History Disability Art Project. Retrieved April 25, 2005, from

<http://pediatrics.med.miami.edu/HistoryDisabilityArt/ArtTimeLine.htm>

McConkey, R., & Adams, L. (2000) Matching Short Break Services for Children with Learning Disabilities to Family Needs and Preferences. *Child: Care, Health and Development*, 26(5), 429-444.

National Resource Center for Respite and Crisis Care Services. (1994, January).

Understanding the Temporary child Care Act. *ARCH Factsheet Number 31*.

Retrieved March 19, 2005 from <http://www.archrespite.org/archfs31.htm>

National Respite Coalition. (1998, February). Respite in Community Based Family

Resource & Support (CBFRS) Grant Programs. Retrieved March 19, 2005 from

<http://www.archrespite.org/cbfrsfs.htm>

National Respite Coalition. (1998, June). Respite: Key Component of a Comprehensive, Inclusive Child Care Strategy. Retrieved March 19, 2005 from

<http://www.archrespite.org/key.htm>

National Respite Coalition, (2005, February 11). Legislative Update. Retrieved March

19, 2005 from <http://www.archrespite.org/NRC.htm>

O'Brien, J. (2001). Planned Respite Care: Hope for Families Under Pressure. *Australian Journal of Social Issues*, 36(1), 51.

Olson, N. (1998). Respite: a Positive and powerful Piece to Strengthening families.

Parenthood in America. Retrieved March 19, 2005, from

<http://parenthood.library.wisc.edu/Olson/Olson.html>

- Ragheb, M.G., & Griffith, C.A. (1982). The contribution of leisure participation and leisure satisfaction to life satisfaction of older persons. *Journal of Leisure Research*, 14, 295-306
- Respite Care. (n.d.). Retrieved March 19, 2005, from <http://www.autism-pdd.net/respice.html>
- Simon-Rusinowitz, L., Mahoney, K., Desmond, A., Shoop, D., Squillace, M., & Fay, R. (1997) Determining Consumer Preferences for a cash option: Arkansas Survey results. *Health Care Financing Review*, 19, 73-96.
- Simon-Rusinowitz, L., Mahoney, K., Shoop, D. M., Desmond, S. M., Squillace, M. R., & Sowers, J. A. (2001) Consumer and surrogate preferences for a cash option versus traditional services: Florida Adults with Developmental Disabilities. *Journal of Mental Retardation*, 39, 87-103.
- Smith, G., O'Keefe, J., Carpenter, L., Doty, P., Kennedy, G., Burwell, B., Mollica, R., & Williams, L. (2000, October) Understanding Medicaid Home and Community Services: A Primer. *U.S. Department of Health and Human Services*. Retrieved April 12, 2005, from <http://aspe.hhs.gov/daltcp/reports/primer.htm>
- Thurgate, C. (2005) Respite for Children with Complex Health Needs: Issues from the Literature. *Journal of Pediatric Nursing*, 17(3) 14.
- U.S. Department of Health and Human Services. (2003, December 16). Family Caregivers: Our Heroes on the Frontlines of Long-Term Care. Retrieved April 13, 2005 from <http://aspe.os.dhhs.gov/daltcp/CaregiverEvent/factsheet.htm>

Appendix 1

Expected Benefits of Receiving Respite Care

The purpose of this survey is to determine some of the perceived benefits informal caregivers expect, or wish to receive from participating in respite care services prior to receiving the services. Please consider the following statements and rate them according to their importance to you as the informal caregiver by circling the appropriate number using the following scale.

	Not important 1	2	Somewhat Important 3	4	Very Important 5
			Not Important	Somewhat Important	Very Important
1. More free time	1	2	3	4	5
2. Reduced Daily Stress	1	2	3	4	5
3. Increased Leisure time	1	2	3	4	5
4. Pursuing Education	1	2	3	4	5
5. Going on a Vacation	1	2	3	4	5
6. Spend more time with other children	1	2	3	4	5
7. Spend more time with spouse	1	2	3	4	5
8. Spend more time with family	1	2	3	4	5
9. Spend more time with friends	1	2	3	4	5
10. Exercise More	1	2	3	4	5
11. Cook Healthier	1	2	3	4	5
12. Pursue a Hobby	1	2	3	4	5
13. Take a nap	1	2	3	4	5
14. Go Shopping	1	2	3	4	5
15. Volunteer	1	2	3	4	5
16. Read	1	2	3	4	5
17. Write Letters	1	2	3	4	5
18. Clean the House	1	2	3	4	5
19. Pay Bills/ Catch up on Finances	1	2	3	4	5
20. Play an instrument	1	2	3	4	5
21. Fix up House	1	2	3	4	5
22. Work in the yard or garden	1	2	3	4	5
23. Watch TV or Movies	1	2	3	4	5
24. Just Relax	1	2	3	4	5

Appendix 2

John D. and Catherine T. MacArthur -Research Network on Socioeconomic Status and Health

Perceived Stress Scale- 10 Item

Instructions: The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way.

1. In the last month, how often have you been upset because of something that happened unexpectedly?

0=never 1=almost never 2=sometimes 3=fairly often 4=very often

2. In the last month, how often have you felt that you were unable to control the important things in your life?

0=never 1=almost never 2=sometimes 3=fairly often 4=very often

3. In the last month, how often have you felt nervous and "stressed"?

0=never 1=almost never 2=sometimes 3=fairly often 4=very often

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

0=never 1=almost never 2=sometimes 3=fairly often 4=very often

5. In the last month, how often have you felt that things were going your way?

0=never 1=almost never 2=sometimes 3=fairly often 4=very often

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

0=never 1=almost never 2=sometimes 3=fairly often 4=very often

7. In the last month, how often have you been able to control irritations in your life?

0=never 1=almost never 2=sometimes 3=fairly often 4=very often

8. In the last month, how often have you felt that you were on top of things?

0=never 1=almost never 2=sometimes 3=fairly often 4=very often

9. In the last month, how often have you been angered because of things that were outside of your control?

0=never 1=almost never 2=sometimes 3=fairly often 4=very often

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

0=never 1=almost never 2=sometimes 3=fairly often 4=very often

Appendix 3

Study Group Evaluations responses of Respite services all but hours are based on a seven-point Likert Scale with 1 being not at all and 7 being extremely

	Caregiver A	Caregiver B	Caregiver C	Caregiver D
Stress Pre	5	6	5	5
Stress Current	3	5	4	3
Stress Post	6	6	4	5
Spouse Pre	6	6	7	3
Spouse Current	2	5	X	2
Spouse Post	6	6	X	2
Family Pre	4	5	5	X
Family Current	3	3	2	X
Family Post	5	5	7	X
SNI Pre	6	5	7	X
SNI Current	2	3	2	X
SNI Post	6	5	7	X
Health Pre	1	5	3	X
Health Current	1	2	1	X
Health Post	1	5	6	X
Social Pre	2	2	2	1
Social Current	6	5	4	4
Social Post	3	1	1	1
Hours/ month	10	16	2	15
Hours Sufficient	4	5	1	2
Ideal Hours	15	X	6	40
Location Options	6	5	4	4
SNI Opinion	5	5	X	5
Hourly Comp	7	6	10	8

X = No Response

Key terms to understanding the evaluation surveys in table above

Stress: Stress levels due to caring for family member
Spouse/Partner: Was your relationship with spouse/partner strained due to caregiving responsibilities
Family Members: Was your relationship with other family members strained due to caregiving responsibilities
ISN: Was your relationship with the individual with special needs strained due to your caregiving responsibilities
Health: Did your caregiving contribute to any health problems you may have
Social/Recreational: Were your opportunities and time to engage in social/recreational activities of your choice sufficient
Hours: Total Respite Hours per Month, are those hours sufficient, and if unsatisfied how many hours would be ideal
Location Options: Are your options for receiving respite appropriate to you and your family members needs
ISN Opinion: If your family member expresses an opinion about respite, is it positive
Hourly Comp: What is the Hourly compensation the care-provider receives