

ARCH National Respite Network and Resource Center

Outcome Evaluation Phase II Results

A Summary Report



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The mission of the **ARCH National Respite Network** is to assist in and promote the development of quality respite and crisis care programs; help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.

The ARCH National Respite Network consists of two divisions. The **ARCH National Resource Center for Respite and Crisis Care Services**, the training and technical assistance division, provides support to service providers and families through consultation, training, evaluation and research.

The policy division, the **National Respite Coalition**, works on the state and federal policy level to secure quality, accessible, planned and crisis respite services for all families and caregivers in need of such services in order to strengthen and stabilize families, and enhance child and adult safety.

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ARCH Outcome Evaluation Initiative

Phase II Field Test Results

Abstract

*The ARCH National Respite Network and Resource Center launched an Outcome Evaluation Initiative in 1998 to develop instruments, in the form of surveys, for measuring the efficacy of planned and crisis respite programs. After being field tested and revised, the instruments were field tested again in 2002. Just over 1,000 caregivers from 43 sites participated in the second field test by responding to the surveys. The surveys asked questions designed to examine how respite affected such things as caregiver stress, health and family relationships. Phase II data indicate that respite has an overall therapeutic effect on caregivers and their families. Following the Phase II testing, the instruments were revised based on feedback from participants and published in *Evaluating and Reporting Outcomes: A Guide for Respite and Crisis Respite Program Managers* (ARCH, 2nd ed.).*

Introduction

The need to demonstrate program outcomes is critical in today's climate of limited and more competitive funding. Respite programs, both planned and crisis, must be able to demonstrate that their programs are achieving worthy outcomes—outcomes related to the improvement of quality of life, and outcomes related to saving taxpayer dollars on more costly interventions such as foster care, nursing homes, or other institutional care. While programs providing both planned and crisis respite view their services as both necessary and obviously beneficial, there are scant data to validate the efficacy of their programs. The ARCH National Respite Network and Resource Center's (ARCH) Outcome Evaluation Initiative was a response to the need for greater program accountability and demonstration of results. ARCH launched the Outcome Evaluation Initiative in 1998 by publishing *Evaluating and Reporting Outcomes: A Guide for Respite and Crisis Respite Program Managers*. The guide included a set of instruments in questionnaire form, for measuring outcomes.

After an initial field test, the tools were revised and then in 2002 field tested again in Phase II of the ARCH Outcome Evaluation Initiative. The field tests were conducted to refine the evaluation tools and to see if the resulting data would help demonstrate the benefits of respite. Forty-three program sites participated in the second round of field testing: 30 offered planned respite, 10 crisis respite, and 3 both planned and crisis respite. Over 1,000 caregivers were surveyed using the ARCH evaluation tools.

It is critical to remember that this field test was not an experimental evaluation with the use of experimental and control groups, but rather an outcome evaluation. The results are not portrayed as “proof” of the effectiveness of respite, nor should they be interpreted as such. Having said that, it should also be noted that field test results can be viewed as strong indicators of respite trends and clearly suggest that respite services play a key role in improving the lives and circumstances of caregivers and their families.

Planned Respite

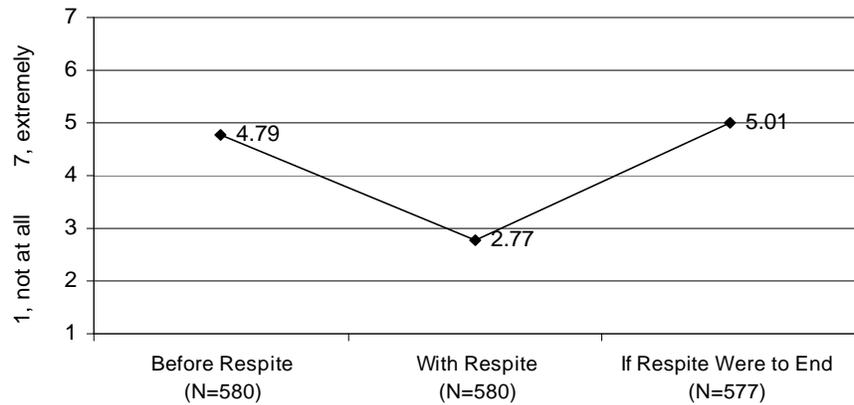
Planned respite is generally provided for caregivers of dependant children or adults who have special care needs. Those care needs can include developmental disabilities, medical conditions, emotional/behavioral disorders, Alzheimer’s disease, and other forms of dementia. Caregivers schedule respite services according to their needs. For example, the parent of a child with a disability may schedule three hours of respite every other day; an adult child caring for her elderly mother may schedule a weekend of respite every six months, etc.

The majority of caregivers were white, married homeowners who were fairly well educated; only 17% had not graduated from high school. However, 45% of caregivers earned less than \$20,000 per year, and 37% had been separated or divorced at some time in the past—at least in part because of their caregiving responsibilities. Fifteen percent had placed their dependent family member(s) in out-of-home care at one time or another prior to receiving respite, but this was true for only 3% with respite. Thus, respite seems to help families maintain continuity and delay out-of-home placements.

Respite care recipients were about evenly split between males and females, with four-fifths less than 18 years old. More than half had received respite for more than a year. According to a level-of-care rating based on the degree of monitoring, supervision, and assistance each needed, 40% had mild needs, 32% had moderate care needs, and 28% had severe care needs.

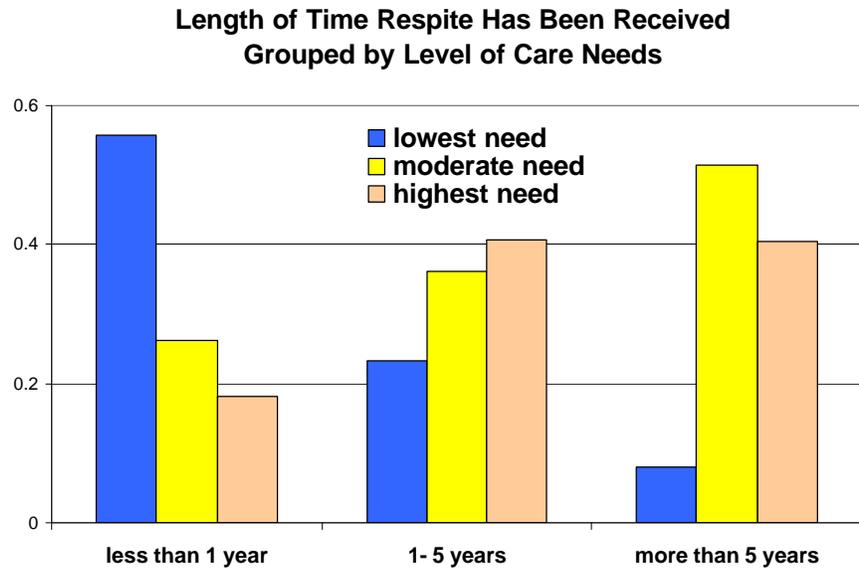
One of the recurring themes in caring for dependent family members is stress. The greater the care needs, the longer the care-giving period, and the fewer the care-giving resources (particularly if the care-giving falls to only one person), the higher the stress is likely to be. Prior to receiving respite, caregivers reported being “quite stressed;” this dropped to “somewhat stressed” with respite. However, if respite were removed, the perceived level of stress was “very stressed”—higher than pre-respite levels (see Figure 1).

Figure 1. How "stressed" were you as a result of caring for your family member?



The length of time respite was received is significantly related to the stress anticipated if respite were to be removed. The longer respite has been received, the higher is the anticipated stress. The majority of those who had received respite for more than a year had the highest anticipated stress. Level-of-care need is also predictive of caregiver stress. Prior to respite, the highest level-of-care needs are associated with the highest levels of stress, and vice versa. Although overall stress levels are greatly reduced when respite is provided, the pattern holds: caregivers whose family members need the highest level of care had higher stress levels than caregivers whose family members needed less care. The relationship between level-of-care need and anticipated stress if respite were withdrawn is striking: 42% of caregivers in the lowest level-of-need group, 44% in the moderate need group, but a full 68% in the highest level-of-need group said they would be “very” or “extremely” stressed.

Caregivers may suffer their own health-related problems due to care-giving responsibilities, and those responsibilities also contribute to social isolation and limit opportunities for recreation. Caregivers in this study reported that their physical, mental, and emotional health was “somewhat” negatively affected by their care-giving responsibilities. That level was reduced to “slightly” with respite but was anticipated to increase beyond the pre-respite level if respite were removed.



Before respite, caregivers perceived their own opportunities for social and recreational opportunities as only “slightly” sufficient but with respite as “moderately” sufficient. Again, they sensed that these activities would retreat to nearly the pre-respite level were respite to be removed. Level-of-care need is highly predictive of caregivers’ time to enjoy normal social and recreational pursuits (see Figure 2). Prior to respite, the overwhelming majority of caregivers for persons with moderate and highest needs had the least social and recreational opportunities.

Crisis Respite

Crisis respite is unplanned, emergency respite. It is provided to families whose children need a safe environment while their parents/guardians deal with a situation that places their child at risk. Crisis respite is also called Crisis Nursery services and Emergency Respite. For the most part, the families who use crisis respite services have few resources or personal networks of friends and family to provide safe and reliable childcare in an emergency. Crisis respite is available 7 days a week, 24 hours a day. When space is available, families can access the care any time of the day or night.

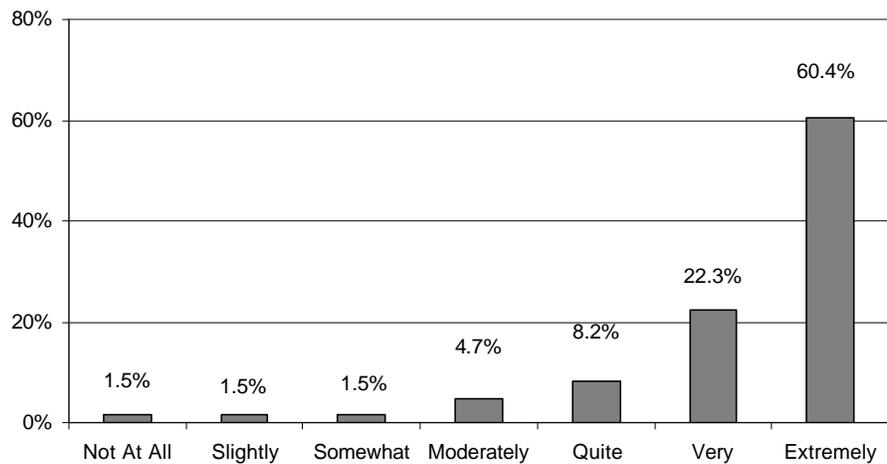
As a group, caregivers receiving crisis respite were more racially diverse and less well educated than those using planned respite. More than three-fourths earned less than \$20,000, and 70% were single. A large majority were in rented housing, while 15% described their housing as transitional, and 7% were homeless.

Reasons for Using Crisis Respite

There were a number of different reasons that caregivers sought crisis respite, and it is clear that caregivers are predisposed to work on more than one “issue” during the period of time that they are receiving crisis respite. By far the most frequent reasons given were “self-care” (74%), followed by “parenting difficulties (45%), employment (34%), and both “medical health” and “mental health” (30% and 27%, respectively). Resolving “housing issues” accounted for 22% of respondents, and all remaining reasons (alcohol/drug treatment, domestic violence, risk of abuse and neglect, legal issues, and “other”) accounted for 8% to 14% of respondents.

Although caregivers were (perhaps understandably) reluctant to say that their personal situations placed their children at risk of harm, they overwhelmingly agreed that crisis respite services provided a large measure of protection for their children. Fully 91% said they felt their children were “very” to “extremely” safe in the provider’s care, and 82% said they would use the service again, should the need arise. Eighty-two percent indicated that crisis respite helped them personally (to a “very” or “extremely” large degree) keep their children safe (see Figure 3); and 82% also indicated that they felt the crisis respite program reduced risk of harm to children (again to a “very high” or “extremely high” degree).

Figure 3. Did Crisis Care You Received Help You Keep Your Child Safe?



Crisis respite appears to have been very successful at reducing recipients’ stress levels. Nearly a fourth rated themselves as “extremely stressed” prior to receiving crisis respite, with 46% of all respondents reporting high stress levels. After receiving crisis respite, however, respondents described a dramatic shift: 32% were “not at all” stressed while 73% reported less than moderate stress.

Crisis Respite as an Aid to Child Protection and Risk Reduction

Among the important reasons for providing crisis respite services is to protect children from harm, or increased risk of harm. Caregivers were asked what they would have done if crisis respite had not been available. Only 2% said they would have left their child unattended, but 20% said that they would have left their child with someone that they did not feel comfortable with as a caregiver. Only 3% said that they would have kept the child with themselves in a dangerous situation, but 20% said they would have kept the child with them in situations that were not appropriate for children. It is clear that the availability of crisis respite increased the “safety” options for a large number of caregivers and their children.

Crisis respite also seems to have reduced the likelihood of “high cost” options as well. About 11% of caregivers said that they would have requested out-of-home placement of their children if crisis respite had not been available, and an even larger number (36%) indicated that it was “moderately” to “extremely” likely that their children would have been placed in foster care without crisis respite as an option.

Summary

Following the evaluations, ARCH staff queried program managers about their use of the instruments, their opinions about the content, and their recommendations for revisions, if any. Both forms were revised accordingly. Approximately half the planned respite program managers felt that questions about maltreatment, divorce and separation, and out-of-home placements were intrusive and not useful. These questions were moved from the main body of the form to an optional section. Only minimal changes were made to the Crisis Respite Questionnaires. The revised forms, PR 1 and CR1 can be found in ARCH’s revised guidebook, *Evaluating and Reporting Outcomes: A Guide for Respite and Crisis Respite Program Managers*.[†]

Phase II data indicate that respite has an overall therapeutic effect on caregivers and their families. Using the ARCH evaluation instruments, programs will be helped to quantify the results of their services to funders, policy makers, and other stakeholders.

[†]For more about *Evaluating and Reporting Outcomes*, including price and ordering information: <http://www.archrespite.org/archout.htm> or contact Tom Cabarga at 800-473-1727, ext. 229
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