



Arizona Respite Care Throughout the Lifespan: Characterizing Unmet Needs

Final Report
January 15, 2008

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ABSTRACT

Objective

Respite is an important component of comprehensive family support and long-term care services, providing both planned and crisis relief. Accumulating evidence indicates that respite is an effective preventive and health maintenance strategy allowing stressed caregivers to attend to their own, and other family members' health, social, and emotional needs, preserving their ongoing caregiving capability; and preventing costly premature or unnecessary institutionalization of care recipients. The objective of this report was to conduct a study on the need for respite care throughout the lifespan of individuals with a particular emphasis on identifying and characterizing primary caregivers of individuals who **do not** currently qualify for publicly funded respite services.

Methods

We performed a descriptive study. First, a thorough review and synthesis of the evidence base targeted to proposal goal and elements, inclusive of national and statewide census, disease occurrence, and caregiver data was performed. Over 4,000 articles were gleaned, and 21 reports reviewed in detail. Next, by-telephone focused interviews were performed inclusive of four samples: 1) local, state, and national experts on respite care issues (n=32); 2) local, state, and national caregiver organization program administrators (n=18); 3) caregivers calling in to a toll-free phone number (n=3); and 4) social workers (n=6). Interviews explored respite policy and operational issues (e.g., models of care coordination; information, services and training; unmet respite needs; and desired services). The attempt to interview caregivers was consequently difficult due to recruitment issues (n=3). These information-gathering interviews were conducted to better understand the perspective of experts and caregivers regarding unmet respite care across the care continuum.

Findings

An estimated 34 million or more Americans provide care for adult friends or family who cannot carry out basic activities of daily living due to illness or disability and nearly 9.5 million children under the age of 18 who live with chronic or disabling conditions require care. Respite care is one of the most urgent needs of caregivers across the care continuum, yet respite is underutilized, in short supply, inaccessible, or unaffordable to family caregivers.

In general, respite care services are available to caregivers of children with special needs and caregivers of older persons. Caregivers of adults 18-59 with a disability have unmet respite needs.

Extrapolating to the 73.6% of Arizona's 2006 adult population (6,166,300) who are 18+ (4,538,400), nearly 8%, or 570,000 of Arizona's adults are informal caregivers. Of these, nearly 177,000 (31% of the 570,000 caregivers) are caring for someone 18 years of age or older with a high acuity of need (level 4 or 5 level of burden), many of whom would require respite care, while an estimated 97,000 (17% of caregivers) are providing more than 40 hours of care weekly to care recipients, and most of this group would benefit from respite care. Of the 177,000 high acuity caregiver/care recipient dyads, an estimated 57% (101,000) likely have unmet respite service needs, as they are either privately insured or uninsured, and are not eligible for respite services. Of these, 67% (67,000) would be located in urban areas, with the remainder (34,000) in largely underserved rural areas.

According to our assessment, inclusive of findings from the evidence base, expert interviews, caregiver, and social worker interviews, Arizona residents in need of, but presently **not qualifying for respite** include: 1) Residents in cancer treatment or terminally ill residents with greater than 6 months life expectancy; 2) Residents under 60 without a diagnosed disability who are functionally impaired, including those with early Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis (MS), Lupus, Fibromyalgia, Chronic Fatigue Syndrome (CFS), Type 2 Diabetes, Congestive Heart Failure, Chronic Obstructive Pulmonary Disease, Osteoarthritis, Rheumatoid Arthritis, or those experiencing episodic debilitating flares; 3) Residents with early cognitive deficit, yet without a "likely" diagnosis of dementia; 4) Young adults with cognitive deficits not severe enough to qualify as disabled, such as those with traumatic brain injury after rehabilitation; 5) Grandparents or relatives less than 55 years of age caring for children 18 and younger; and 6) Veterans not qualified for Veteran Administration (VA) care (e.g., no service-related disability or income eligibility) who do not qualify for other services. Estimating the exact proportion of these individuals requiring respite services, but not covered through existing state programs is impossible, as individual level data are not available.

Public Health Impact

Better understanding of caregiver needs- who is adequately served, who is underserved, and who is unserved- is important so as to appropriately plan and target Arizona's respite services.

What was learned will be used for two purposes: 1) to inform allocation and targeted outreach for State of Arizona Lifespan Respite Care Program resource use, and 2) to inform statewide Lifespan Respite Care Program information and referral, coordination, reimbursement and training policies, and future research.

Cite this report as: Mohler MJ, Brown V (2008). Arizona Respite Care Throughout the Lifespan: Characterizing Unmet Needs. Tucson, AZ: University of Arizona, Arizona Center on Aging, College of Medicine.

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ACKNOWLEDGEMENTS

This report was funded by the Arizona Department of Economic Security, Division of Aging and Adult Services. The research was conducted at the University of Arizona, Arizona Center on Aging by M. Jane Mohler, RN, MPH, PhD and Victoria Brown, PhD, as directed by the Arizona Lifespan Respite Care Program (LRCP) Advisory Committee.

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This project was funded by the Arizona Department of Economic Security, Division of Aging and Adult Services. Points of view are those of the authors and do not necessarily represent the official position or policies of the Department.

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USING THIS REPORT

The Abstract of *Arizona Respite Care Throughout the Lifespan: Characterizing Unmet Needs* is provided as a useful tool to summarize study methods and findings. Detailed Findings is the full report, inclusive of full details and citations. Each section may be used as a stand alone document.

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I. INTRODUCTION AND RATIONALE

This report is intended to provide state level agencies, communities, health care providers, funding agencies, organizations, policy and decision makers, and consumers with direction and support in the development of a comprehensive and integrated approach to Arizona Lifespan Respite Care.

The federal Lifespan Respite Care Act of 2006 (Public Law 109-442; 109th Congress, Dec. 21, 2006)¹, authorized The Department of Health and Human Services to award grants or cooperative agreements to:

1) Develop lifespan respite care at the state and local levels; 2) Provide respite care services for family caregivers caring for children or adults; 3) Train and recruit respite care workers and volunteers; 4) Provide information to caregivers about available respite or support services; 5) Assist caregivers in gaining access to such services to ensure coordination of respite care services for family caregivers of children and adults with special needs. In addition, this federal statute mandated a statewide Lifespan Respite Care Coalition. The following four states have an existing Federally Funded Lifespan Respite Care Program: Oklahoma, Nebraska, Oregon and Wisconsin.

The State of Arizona passed HB 2789, Lifespan Respite Care Program, which appropriated \$500,000 and 1.0 FTE position to establish a statewide program responsive to this federal statute.² Provisions included the mandate to:

- 1) Establish a respite care program for primary caregivers of individuals who do not currently qualify for other publicly funded respite services.
- 2) Coordinate with other respite services, including services that are provided pursuant to Title 36, Chapter 5.1 and Sections 36-2939, 36-3407 and 46-193.
- 3) Support the growth and maintenance of a statewide respite coalition.
- 4) Conduct a study on the need for respite care throughout the lifespan of individuals.
- 5) Identify local training resources for respite care providers.
- 6) Link families with respite care providers and other types of respite caregiver consultants.
- 7) Create an evaluation tool for recipients of respite care to assure quality of care.

This report is responsive to item “4”, with a particular emphasis on identifying and characterizing primary caregivers of individuals who **do not** currently qualify for funded respite services. What is learned will be used for two purposes: 1) to inform allocation of State of Arizona Lifespan Respite Care Program resource use, and 2) to inform statewide Lifespan Respite Care Program information and referral, coordination, reimbursement, and training policies.

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II. OVERVIEW OF METHODOLOGY

Description of Objective 1

A thorough review and synthesis of the evidence base targeted to proposal goal and elements, inclusive of national and statewide census, disease occurrence, and caregiver data was performed. Four electronic databases were searched with restriction to English language: PubMed (1985-), PsycInfo (1985-), CINAHL (1985-), and Cochrane (1985-) using the term “respite” in combination with the following terms: “caregiver,” “needs,” “coordination,” “training,” “information” and “funding.” Full articles of pertinent resources were downloaded and read by two reviewers and used to inform interviews and research findings. A review of US census data was performed regarding State of Arizona data, inclusive of population and socio-demographic variables. A thorough web search was performed using Google to identify meaningful federal, state, and organization reports, and documents pertinent to the objectives and research elements. An EndNote reference library was populated with results, inclusive of abstracts and PDFs of reports (in Appendix A).

Performance of Objective 1

Over 4,000 articles were identified and gleaned for information pertinent to the objectives for ultimate inclusion of 403 citations including 21 reports in a searchable EndNote library that includes report PDFs.

Description of Objective 2

The overall population of interest was Arizona residents who are primary caregivers that do not currently qualify for publicly funded Arizona respite services and agencies who provide and administer respite care.

A stratified descriptive study was performed inclusive of three samples: 1) local, state, and national experts on respite care issues; 2) local, state, and national caregiver organization program administrators; 3) caregivers; and 4) social workers.

Description of Objective 2A

By-telephone fact-finding interviews with Arizona Lifespan Respite Care Program Advisory Committee members and other state and national respite experts regarding respite policy issues (e.g., models of care coordination, information, services and training, and unmet respite needs) were performed. These informal information-gathering interviews were conducted to better understand the perspective of experts across the care continuum.

Performance of Objective 2A

Eighteen Arizona Lifespan Respite Care Program Advisory Committee members were interviewed. In addition, six representatives from Area Agencies on Aging, five Area Health Education Center representatives, and four Tribal/Regional Behavioral Health Area representatives were interviewed. Four national respite experts also were interviewed.

Description of Objective 2B

Systematic by-telephone interviews of program administrators of caregiving organizations, special needs organizations, and chronic disease community-based organizations (inclusive of those who do and do not provide respite services) were performed.

By-phone structured interviews consisted of questions relating to:

- ▶ Program description
- ▶ Age of Respite Care Program
- ▶ Settings in which the program provides service
- ▶ Type of agency administering the program
- ▶ Respite services provided by the agency
- ▶ Respite funding (cost and source)
- ▶ Hours of operation
- ▶ Service area
- ▶ Clients per year, type, and total hours
- ▶ Unmet needs
- ▶ Care coordination, information, services, and training
- ▶ Barriers to respite care for their population
- ▶ Other issues

Performance of Objective 2B

Eighteen program administrators of caregiving organizations, special need organizations, and chronic disease community based organizations were interviewed.

Description of Objective 2C

Systematic targeted blinded interviews of Arizona residents who are primary caregivers, but who do not currently qualify for publicly funded Arizona respite services, were performed. Caregivers with identified unmet needs were targeted for these interviews based upon findings of Objectives 1A and 2A and B. Arizona clients with unmet needs were approached through caregiver organizations and specifically targeted community organizations and associations.

In addition, outreach was performed using the Lifespan Respite Care Program Advisory Committee members, caregiver fair sign-up sheets, and organizations contacted in Objective 2B by providing flyers and disclosure forms with which to approach their clients. A toll-free number and email contact information were provided. If clients preferred, they were able to leave their contact information with the organizational contact, which then referred them directly to the University of Arizona for contact. Disclosure Forms approved by the University of Arizona Human Subjects Committee

were fully reviewed with subjects prior to conducting the interview. No audio-recording was performed (per IRB stipulation); however extensive notes were taken, and reviewed with the client to assure completeness prior to the end of each interview. General socio-demographic data regarding caregiver/recipient dyad were collected, and de-identified. Collective interview notes were reviewed by two experienced qualitative researchers using standard content analytic techniques, and findings summarized.

Questions discussed included:

- ▶ Understanding of respite services,
- ▶ Respite services desired, including type, provider preferences, and reimbursement,
- ▶ Perceived barriers to respite care, and
- ▶ Preferred method of information, referral, and payment.

Concern regarding response rates for Objective 2C prompted the addition of research Objective, 2D.

Performance of Objective 2C

Three caregivers who do not qualify for respite services were interviewed. One, a woman caring for her husband with lupus who had recently lost her job, appeared to qualify for AHCCCS and was referred for an intake interview. Two others, one who took care of a spouse with Multiple Sclerosis (MS) and one who took care of an adult child with Traumatic Brain Injury (TBI), were interviewed.

Description of Objective 2D

Interviews were conducted with social workers covering the continuum of care in the State of Arizona to better understand their experiences with clients who need, but do not qualify for respite care.

Questions discussed included:

- ▶ Examples of clients with unmet needs (caregiver/recipient dyads),
- ▶ Respite services desired, including type, provider preferences, and reimbursement,
- ▶ Perceived barriers to respite care, and
- ▶ Perceived preferred method of information, referral, and payment.

Performance of Objective 2D

Six social workers working in Arizona Counties: Maricopa (two), Pima (two), Pinal (one) and Yuma (one) were interviewed regarding special need groups.

Limitations

In regard to Objective 1, a review of the evidence base and reliance on secondary data is only as good as the primary data collection. Many of the national sources reported difficulty in finding accurate and detailed quantitative respite data, a limitation of this report, as well. In regard to Objectives 2A and B, telephone interviews have the limitation of other surveys conducted by phone and rely upon honest responses and good recall of the respondents. Interviewed experts, while highly motivated and interested in the topic, have perspectives and biases that may affect their responses. Effort

was made to take into account potential bias prior to interviews and to account for these in the synthesis of findings.

In regard to Objective 2, although individual and aggregate data is collected by state and community-based agencies that provide respite care services, individual level data characterizing unmet respite needs were not readily available. One factor that contributed to the challenge in obtaining data on unmet needs is that the various agencies had differing definitions for the caregiver and care recipient dyad, based upon the eligibility criteria for respites services. Detailed quantitative data regarding allocations, units of respite care provided, number and type of clients served, or characteristics of respite care is generally collected on the person with the functional limitation. Assessment tools differ from agency to agency. In addition, data systems differ from agency to agency with systems being incompatible among the agencies. There is no repository of data on those who do not receive respite care. A second factor that contributed to the challenge in obtaining data on unmet needs is that waiting lists were not consistently maintained by the various agencies. An agency may not document a request for respite services if the caregiver voluntarily declines to be placed on a waiting list. Estimations have been made relying upon prevalence data, census data, and assumptions made in collaboration with caregiver experts and extant data from the evidence-base.

Objective 2C was added in response to Arizona Lifespan Respite Care Program Advisory Committee recommendation, and required Human Subjects Committee approval. Ideally, interviews with unserved clients (who do not qualify for, but need respite care) could have been recruited from Arizona Caregiver fairs during Arizona Caregiver month (November 2007). The project, however, did not receive Institutional Review Board approval until November 19, 2007. Finally, because allocated funds must be spent within FY 2007-2008, this research was requested to be performed in a rapid three month time frame, limiting more comprehensive methods.

Strengths

Despite a tight timeline, working closely with the Arizona Lifespan Respite Care Program Advisory Committee recommendations yielded two new data collection strategies (Objective 2C: Blinded Caregiver Interviews, and Objective 2D: Social Worker interviews) to ensure a deeper understanding of unmet needs and better characterization of caregiver dyads needing, but not qualifying for respite services.

While unable to provide detailed individual level data as desired, this report, the first comprehensive Arizona report regarding respite care needs, is responsive to the study objectives of generally identifying and characterizing primary caregivers of individuals who **do not** currently qualify for publicly funded respite services. Endeavoring to address this original request in order to enable informed allocation of State of Arizona Lifespan Respite Care Program resources in FY08. Additionally, to establish value by addressing issues to inform statewide respite care development, coordination, training, information and referral, and reimbursement policies in order to build a stronger, sustainable, and more responsive Arizona Lifespan Respite Care Program.

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III. DETAILED FINDINGS

A. Challenges of Caregiving

The challenges of caregiving are an increasing reality of day-to-day life for America's families. An estimated 34 million Americans provide care for adult friends or family who cannot carry out basic activities of daily living due to illness or disability³ and nearly nine and one-half million children under age 18 live with chronic or disabling conditions.⁴ Taken together, these data suggest approximately 47 million family caregivers providing care across the age continuum nationally.

Estimating the economic value of unpaid caregiving is difficult as it requires assumptions about the cost of replacing the services of informal caregivers, as well as estimates of the prevalence of caregiving and the number of hours of care given. However, even with conservative estimates, the value of informal caregiving is of significant importance. Assuming 1,080 hours of care per year, "Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving" estimated between \$616 billion to \$780 billion annually—"As much as the total sales of the world's largest companies, including Wal-Mart Stores (\$349 billion in 2006) and ExxonMobil (\$335 billion)."³

Since the massive deinstitutionalization movement of the 1960s, respite care programs have emerged in response to the need to support these families and caregivers. Most would agree that in-home, rather than institutional care is beneficial to individuals in terms of improved quality of life, and to society as related to savings of health care dollars. Most people who need long-term care depend on help from family and friends, and not on paid service providers or institutions. Sociodemographic trends toward higher rates of divorce, smaller families, more people living alone, and more women working, combined with unprecedented increases in the elderly population suggest that the unmet need for care at home will escalate. In fact, the majority (78%) of adults in the U.S. who receive long-term care at home receive all of their care informally, mostly provided by wives and adult daughters. Fourteen percent receive a combination of informal care and paid assistance; and only 8% rely on formal care alone.^{5, 6}

Almost one fifth of workers are informal caregivers, accounting for an estimated \$36 billion in US business productivity loss, with over half of this due to common pain conditions including arthritis, headache, and back conditions.⁶ The health effects of caregiving have other major costs. Sixty percent of adults age 19 to 64 with informal caregiving responsibilities reported having medical bill problems or medical debt, compared with 39% of non-caregivers. Out-of-pocket health costs are much higher for people who have a relative with a disability.⁶ The physical, emotional and social toll of ongoing care on caregivers is considerable, and the importance of supporting caregivers in their role cannot be underestimated.

Respite care is one of the most urgent needs of caregivers across the care continuum—inclusive of those caring for disabled or sick children, adults or elders. The recent “Evercare and NAC Caregivers in Decline Study” found respite to be the most frequently requested service of the nation’s family caregivers.⁷ Yet respite is underutilized, in short supply, inaccessible, or unaffordable to a majority of the nation’s family caregivers. The 2004 survey of caregivers found that despite the fact that the most frequently reported unmet needs were “finding time for myself,” (35%), “managing emotional and physical stress” (29%), and “balancing work and family responsibilities” (29%), yet only 5% of family caregivers were receiving respite.⁷ Respite is unavailable, inaccessible, or unaffordable to a majority of the nation’s family caregivers including those in Arizona, where respite services remain inadequate across all age groups, and types of caregiver needs, even in those who qualify for services. Better understanding of caregiver needs- who is adequately served, who is underserved, and who is unserved- is important to appropriately plan and target State respite services.

B. Definition of Respite Care

According to the National Respite Coalition Taskforce, respite care is the “planned or emergency short-term relief to caregivers from the demands of ongoing care for an individual with special needs or at risk of abuse or neglect.” Lifespan Respite Care is further defined as a “coordinated system of accessible, community-based respite care services for caregivers and individuals regardless of age, race, ethnicity, special need or situation.” As defined in existing Arizona Lifespan Respite legislation², special needs may include any disability, any chronic or terminal illness, or a physical, emotional, cognitive or mental health condition requiring ongoing care and supervision, including Alzheimer’s disease and related disorders, developmental disabilities, children with special medical needs, and any other condition determined by the state. In addition to planned respite care, “crisis” respite may be used to provide a temporary safe haven for the care recipient in the event of an emergency brought on by a situation such as domestic violence, substance abuse, or a housing, health or job crisis.

C. Models of Respite Care

Many models of planned respite exist, ideally to be able to meet the particular needs and preferences of the family. Respite care does not include therapy or medical treatment for the individual with the disability. Various respite models are provided through state or local aging, chronic disease and disability organizations, are privately owned and operated by profit or non-profit entities or individuals, or are organized through faith communities or neighborhoods. In-home respite services are usually provided by agencies that recruit, screen, and train workers, but may also be provided by volunteers known to the family. This type of respite may be less disruptive to the individual with the disability, provided there is a good match between the worker and the individual. Out-of-home respite is provided in residential facilities or day care. This type of respite may provide a stimulating environment for the individual with the disability, or may be disruptive to routine. Centers may restrict length of stay and may exclude individuals based on severity of disability or special needs. Institutional facilities such as skilled nursing facilities, intermediate care facilities, group homes, senior housing, and regular day care or after-school programs for children and hospitals may provide respite.

Licensed foster care providers can also provide respite services in their homes. In addition, periodic respite may be offered by faith communities, or other community-based organizations on an episodic basis including holiday or summer camps, and recreational or after-school programs. Each respite model has its own particular benefits, and each may be utilized by various care providers based upon their needs and those of the care recipient.

D. Estimating the Respite Needs of Arizonans

It is difficult to accurately quantify the number of caregivers requiring respite within the US or the state of Arizona for a myriad of reasons. First, while there have been many national descriptive studies of caregiving they have not used a consistent definition of “caregiver,” nor have they used a consistent age range of care recipient. Second, with the exception of recent findings in the “Caregiving in the US” study⁶, acuity of care recipients has not been addressed in terms of activities of daily living (ADLs) or Instrumental Activities of Daily Living (IADLs), so it is difficult to estimate the percentage of caregivers providing care of a high enough acuity to require respite care.⁶

Table IIIa. Recent Studies Giving Estimates of Caregiving Prevalence and/or Hours

Publication	Source Data & Year	Caregiver Definition
<i>Estimated Prevalence and Economic Value of Family Caregiving, by State</i> (2004), Peter S. Arno, National Family Caregivers Association & Family Caregiver Alliance, 2006 ⁸	Estimates for 2004, updated from 1986 Survey of Income and Program Participation (SIPP) and 1987–88 National Survey of Families and Households (NSFH)	SIPP: Care recipient 15+, with health condition, caregiver 15+, within last month; NSFH: Care recipient 18+, caregiver 18+, with long-term illness or disability, within last month
<i>Many Older Americans Engage in Caregiving Activities</i> , Richard W. Johnson & Simone G. Schaner, Urban Institute, 2005 ⁹	2002 Health and Retirement Study (HRS)	Care recipient any age, caregiver 55+, within last month (for care of spouse) or last 2 years (for care of parents/in-laws)*
<i>A Profile of Frail Older Americans and Their Caregivers</i> , Richard W. Johnson & Joshua M. Wiener, Urban Institute, 2006 ¹⁰	2002 Health and Retirement Study (HRS)	Care recipient 65+, ADL or IADL dependency, caregiver 18+, within last month
<i>Caregiving: A National Profile and Assessment of Caregiver Services and Needs</i> , Sarah L. McKune et al., Rosalynn Carter Institute, 2006 ¹¹	2000 Behavioral Risk Factor Surveillance System (BFRSS)	Care recipient 60+, with long-term illness or disability, caregiver 18+, within last month
<i>Caregiving in the U.S.</i> , National Alliance for Caregiving & AARP, 2004 ⁶	Survey designed for the publication, 2003	Care recipient 18+, ADL or IADL dependency, caregiver 18+, within last year
Borrowed from :Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving, 2007 ³		

A Recent AARP Public Policy Institute Publication, “Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving” published estimates that took into account the findings of five recent reports (see Table IIIa. below) and estimated the

prevalence of caregivers based on nationally representative surveys and state population distributions.⁴ Because the underlying surveys varied in their definitions of caregiving and the age groups represented, researchers adjusted these estimates to a common definition encompassing the entire adult population and projected them forward to 2006. These methods are the most accurate estimates to date. Comparisons of the estimated number of caregivers are provided in Table IVb.

Table IIIb. Estimated Caregivers in US

Source	% Population (reported by source)	Projected Number of Caregivers in Nov 2006	Estimated Number of Caregivers in Nov 2006 using adjusted estimates*
<i>Caregiving in the U.S.</i> * (2003) ⁶	21% 44.4 million	48 million	31 million
Arno (2004 based on 1986 SIPP) ⁸	12% 27 million	28 million	26 million
Arno (2004 based on 1987-88 NSFH) ⁸	14% 30.7 million	32 million	33 million
Low estimate (average of Caregiving in the U.S. and Arno)			30 million
Johnson & Schaner (2002) ⁹	19.2%	13 million	39 million
McKune et al.(2000) ¹¹	15.6%	35 million	37 million
High estimate (average of Johnson & Schaner and McKune et al.)			38 million
Borrowed from :Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving, 2007 ³			
*Adjusted by common year and definition			

“Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving” found that in November 2006, between 30 million and 38 million adult caregivers (age 18 or older) provided care to adults with a limitation of at least one activity of daily living (ADL) or instrumental activity of daily living (IADL).³ Caregivers provided an average of 21 hours of care per week, or 1,080 hours per year. This definition includes the majority of informal caregiving in the United States, including the 17% of “family caregivers” who are non-relatives, but it did not capture all caregiving activities including: 1) those providing care to children under 18 with disabilities, 2) caregivers under age 18 who are providing care to adults (primarily parents or grandparents), 3) or grandparents providing care for grandchildren under the age of 18.⁹ Nor did it include caregivers who provide assistance to adults who have chronic health conditions but do not have functional limitation (and are unlikely to require respite care).³

“Valuing the Invaluable’s” caregiving definition represents a narrow cross-sectional estimate of U.S. adults currently providing care **within the last month**.³ However, caregiving activities may begin or end at any point during a calendar year, so that the total number of people providing care during the year is significantly higher. For example, the widely cited 2004 National Alliance for Caregiving (NAC)/AARP report “Caregiving in the U.S.” estimated for 2003 that 44.4 million adults provided care in the entire year, about 50 percent higher than those who provided care in the month of November 2006.⁶ Since the purpose of this report is to address unmet respite service needs overall (not caregiving per month), the total number of caregivers providing care during the year will be underestimated using these methods.

In addition, “Valuing the Invaluable” took any functional limitation into account.³ However, those with one, two, or even three functional limitations in activities of daily living or instrumental activities of daily living may not require respite services, per se, but may instead require episodic help including assistance with housecleaning, medical appointments, or shopping. Estimates of caregiver need for respite must be subjected to functional status limitation to better represent those in true need of services.

Based upon “Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving” estimates, and averaging the low 30 million and the high 38 million, to 34 million, there were an estimated 570,000 caregivers in Arizona (November 2006), who provided 620 million caregiving hours equivalent to \$5,200 million dollars.³

According to “Caregiving in the U.S.,” an estimated 31% (177,000) if applied to 570,000 caregivers) will care for someone with a high acuity of need (level 4 or 5 Level of Burden), most of whom would benefit from respite services. An estimated 17% (97,000) if applied to 570,000 caregivers) would provide more than 40 hours of care per week, most of whom would benefit from respite care.^{3,6}

Estimating the exact proportion of the individuals requiring respite services, but not covered through existing respite programs is impossible, as individual level data are not available. However, a review of insurance status, disability status and chronic disease data can help us to hone in on categories of unmet respite needs.

Insurance Status

It is important to understand the characteristics of the uninsured population in order to better understand the needs of those requiring respite care services. Approximately 43-48% of state residents receive publicly-funded insurance and an estimated 32-48% are privately insured.¹² The remainder (4-25%) are uninsured.¹² Respite services may be determined by the caregiver’s needs and respite eligibility in some cases (e.g., grandparents, adoptive or foster parents or parents with behavioral issues), or more commonly by the care recipient’s needs and coverage. For the purposes of this report, those who qualify for publicly-funded respite services are not under consideration for Arizona Lifespan Respite Care Program funds, as they have access to respite coverage through their publicly funded insurance or other publicly-funded services. As previously addressed, this coverage may be inadequate for individuals with more intense respite needs, and may be unavailable due to the lack of service providers (especially in rural areas). Arizona residents with private insurance, but who do not have respite coverage, and those who are uninsured, may have unmet respite needs.

Children with Special Needs

Overall, more than 11% of all children in the US (8.3 million) were uninsured in 2005, and more than 64% of all uninsured children were in families with income below 200% of the federal poverty level.¹² SCHIP, together with Medicaid, has served an extremely important role for children: Between 1998 and 2005, the number of uninsured children dropped by more than 2.7 million. Arizona covers children with family incomes up to 200% of poverty (\$34,340 for a family of three in 2007). In 2004, 14.2% of Arizona’s

children were enrolled in Kids Care (48,169) or AHCCCS (171, 638), compared to 2% in 1998. By 2006, KidsCare covered 96,669 of Arizona's children.¹² While uninsurance remains an important public health issue, one purpose of this report--establishing the respite needs of caregivers of children--requires focusing on special need children of high acuity.

A recent Robert Wood Johnson report reported that an estimated 11.4% (201,608) of special health care need children were uninsured in Arizona in 2005/2006 (this likely is an overestimate as it does not take into account children who have been enrolled in SCHIP/AHCCCS in 2006/2007.)¹³ Families caring for special need children report: 1) they spend 11 or more hours per week providing or coordinating child's health care (11.3%); 2) special needs conditions cause family members to cut back or stop working (23.1%); and, 3) they have an unmet need for specific health care services (21.6%). However, only 4.8% of these families reported any unmet need for family support services.¹⁴ In general, children who require respite services in Arizona are eligible for publicly funded insurance and/or services via the Arizona Department of Developmental Disability, Arizona Long Term Care Services, Arizona Early Intervention Program, AHCCCS/ALTCS, Children's Rehabilitative Systems or Regional Behavioral Health Area services. Those without coverage are largely eligible, but their caregivers may be unaware of eligibility, or may choose not to engage with state institutions for various reasons. Special need children's respite care services are available; however even those who are insured who have high acuity needs, may be underserved.

Adults with Disabilities

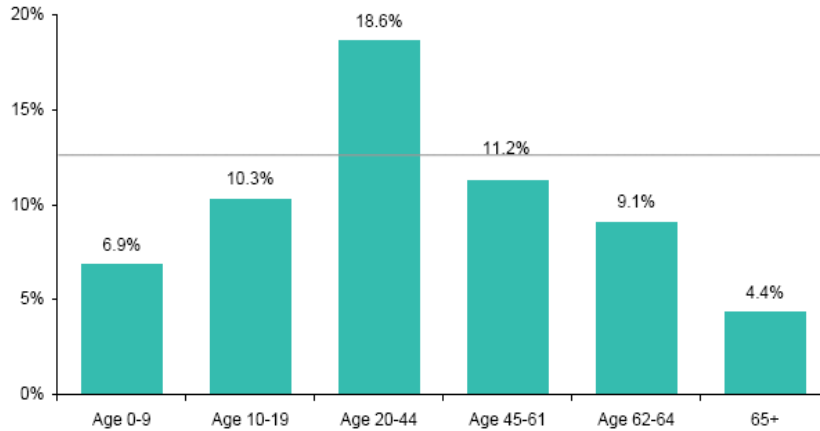
Many adults lack publicly funded or private health care insurance. There are several reasons for adult residents to lack insurance: 1) they may not qualify for private coverage through employers, 2) their incomes are too high to be eligible for AHCCCS, or 3) they are too young to be eligible for Medicare. The young adult segment of the uninsured population includes persons who are able to afford health insurance but choose not to purchase it, relying on their health and discounting their risk of illness or injury in the future. A smaller group of those who choose not to be insured includes individuals of sufficient means to self-insure.¹²

Conservative calculations from a recent 2007 Center for Health Information & Research (CHIR) report performed by the School of Computing and Informatics at Arizona State University estimate that between 226,000 (6%) and 429,000 (11.4%) of Maricopa's adults were uninsured in 2004.¹² Maricopa County represents 61% of the State's population, and is, in general, indicative of the state population.¹⁵ Equivalent statewide estimates would range from 370,000 to 702,000 uninsured residents. These figures are lower than national census based estimates, because more precise, state-based methods were used rather than less precise national methods equally applied to all states without consideration of state-specific differences.

Age distribution of the uninsured is described in Figure IVa. national and state studies have identified age, gender, ethnicity, income, and employment status as important correlates of health insurance coverage. Although there are variations in the results, they can be summarized as suggesting that minority group status, low income, and age (e.g.,

young adult and early middle age) are associated with a lack of health insurance coverage. The current results show that young adults and persons in early middle age (ages 20–44) are least likely to have health insurance coverage. There is little difference in uninsurance rates between males (11.8%) and females (11.1%).¹²

Figure IIIa. Age Distribution of Uninsured Maricopa County Residents



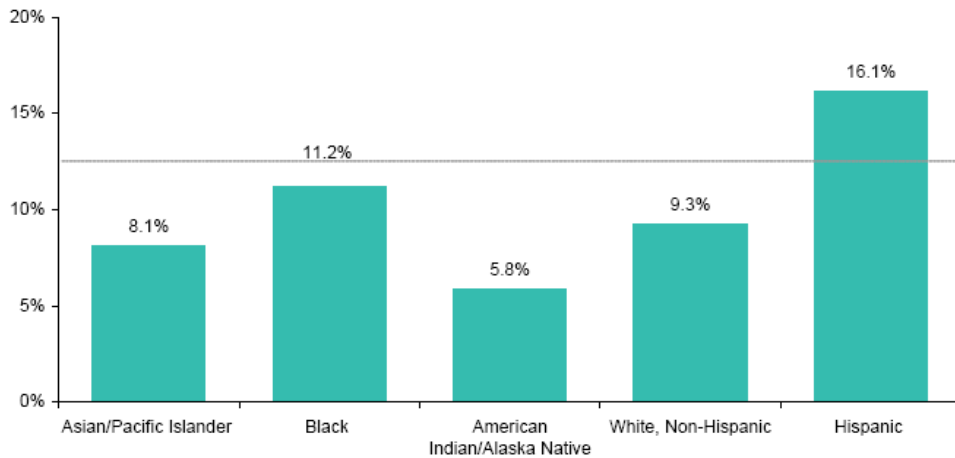
Dashed line depicts overall population rate of 12.5%.
Sources: AZHQ, U.S. Census Bureau, 2004 projections.

Courtesy of Center for Health Information & Research (CHIR) in the School of Computing and Informatics at Arizona State University

Ethnicity and Race

The population of Arizona differs from most areas in the United States because of a very large number of Hispanic (28.5%) and American Indian residents (5.1%), and a relatively small number of African American residents (3.6%) (see Figure IVb).¹⁵ While 64.7% of the <65 adult population is Caucasian, they comprised 48% of the uninsured. Individuals of Hispanic origin are more likely to be uninsured than other groups (34%), in part due to the fact that 65% of the Hispanic population report income less than 200% of the federal poverty level. Hispanic residents have the lowest insurance rates across all minority groups.¹⁶ In addition, even those Hispanics who are covered by respite services, use the services at a significantly lower rate than do Non-Hispanic Whites.⁶ American Indians have the lowest rates of uninsurance as they qualify for the Indian Health Service.¹⁶

Figure IIIb. Race/Ethnicity of Uninsured Maricopa County Residents



Courtesy of Center for Health Information & Research (CHIR) in the School of Computing and Informatics at Arizona State University

Rurality

Arizona is the 6th largest in size of the 50 states, 114,000 square miles, and just over 45 persons per square mile. The majority of the population resides in Arizona's two urban counties, Maricopa and Pima, accounting for 76.3% of the state's population, with the remainder spread throughout the state. These two counties are very similar socio-demographically. Females slightly outnumber males, children younger than 18 years of age comprise 26.5% of the population, and those 65 years and older account for 12.2%.¹⁷

Coconino and Yuma, the two mixed rural-urban counties, comprise 5.4% of the state's population. The remaining 11 counties are designated rural-rural. These 11 counties had an American Indian population of 14.5% and a Hispanic population of 20.4%. There were more children under the age of 17 (26.5%) than seniors aged 65 and older (16.6%).¹⁷

Rural residents are more often disabled and diagnosed with more severe occupation-related illnesses than are urban residents. Chronic conditions are more prevalent and heart disease, cancer and diabetes rates are higher. Availability of services is limited in rural areas, as is public transportation. Residents of rural areas have less contact and fewer visits with physicians; most rural counties have limited health care services and some have none at all, often resulting in worse health outcomes.¹⁷

In response to the challenges presented by a mixed urban/rural state, Arizona has adopted a regional area health model providing information, training, referral, and services by region.

► AHCCCS (Medicaid waiver) acute care services are provided by private or county-owned health plans, which are selected through a competitive bidding process. Arizona's

15 counties have been grouped into nine acute care Geographic Service Areas (GSAs) for service delivery. The ALTCS program is managed by AHCCCS.

▶ Five Arizona Health Education Centers (AHECS) are charged with improving the recruitment, diversity, distribution, and retention of culturally competent personnel providing health services regionally in rural and medically underserved communities.

▶ Area Agencies on Aging (AAA) are public or nonprofit private agencies or offices designated by the State to carry out the Older Americans Act at the local level. Eight AAAs serve to foster the development of more comprehensive and coordinated service systems to primarily serve older individuals.

▶ Regional Behavioral Health Authorities (RBHAs) and Tribal Regional Behavioral Health Authorities (TRBHAs) are public or nonprofit agencies designated by the State to administer behavioral health services. The State is divided into six geographical service areas (GSAs), served by five Regional Behavioral Health Authorities (RBHAs) and three Tribal Regional Behavioral Health Authorities (TRBHAs).

Income

The uninsured tend to be members of low-income families. According to the Employee Benefit Research Institute's 2007 report on Health Insurance and Characteristics of the Uninsured, families with incomes just above the federal poverty level -- 100 percent to 149 percent of poverty -- are the most likely to be uninsured.¹⁶ These residents qualify for publicly funded insurance in our state. Low-income workers are employed generally in industries that are less likely to offer health benefits, may have a weaker attachment to the work force, and have less disposable income to allocate to the purchase of health benefits.¹⁶

Disability

A total of 20.1% (over 900,000) Arizonans aged five or older reported one or more disabilities in the 2000 census.¹⁵ Types of disabilities among those ages 5 or older included:

- ▶ Sensory: 4.2%
- ▶ Physical: 8.8%
- ▶ Mental: 5.0%
- ▶ Self care: 2.8%

Given the increase in population since April 2000, the number of Arizona residents aged five or older with a disability in 2006 was nearly 1 million.¹⁸ Many people with a disability suffer from multiple conditions. Of those with any of the six disabilities, a work disability is most common.¹⁸

The lowest incidence of disability occurs among children and young adults, and the highest incidence among the very elderly, both of whom are likely to be covered by public or private insurance. However, while the aged have the highest proportion of disabilities, the absolute number of Arizonan's with disabilities is greatest among the baby-boom generation (ages 42 to 61 in 2007) because of the large number of people in this age group.

For each of the disabilities, an extremely strong relationship exists with age; the percentage of the population with one or more disabilities rises steadily with age.¹⁸ A little more than 15% of 20-to-29 years old have any of the six disabilities. This percentage gradually rises, increasing to 30% and higher in those 60 and above. The median age of people with a disability in Arizona is 50.¹⁸ The disabled population has a lower average income, with a lower labor force participation rate and a higher unemployment rate, after adjusting for age.¹⁸

A recent New York Times article “Disability Cases Last Longer as Backlog Rises” 12/11/07 noted that “worsening bureaucratic delays at the chronically under-funded Social Security Administration have kept hundreds of thousands of disabled Americans from timely approval of Social Security disability benefits.” The backlog of applicants for disability claims doubled between 2000 and 2007, with an average wait of more than 500 days for an appeals hearing. Recipients must prove that because of physical or mental disabilities they are unable to do “any kind of substantial work” for at least 12 months or prove that an illness is expected “to result in death.” Two-thirds of applicants are turned down initially by state agencies and of those who appeal; two-thirds eventually win a reversal.¹⁹

Chronically III

Chronic conditions and diseases account for seven of the ten leading causes of deaths in the state of Arizona, and are responsible for considerable functional decline and decrement in quality of life.²⁰ Chronic diseases disproportionately affecting those 18-59, which would potentially result in functional decline. Based on the evidence and key informants, the specified chronic-disease related conditions include situations where the care recipient is episodically affected (as with rheumatoid arthritis, lupus or fibromyalgia flares), or with increasingly serious disease, without frank disability. Those affected may have disability applications pending, or may have been denied disability status. Other situations include disabling treatment (e.g., cancer or Hepatitis C) in those without a terminal diagnosis (who do not qualify for hospice). Reported chronic conditions include: Osteo and Rheumatoid Arthritis, Systemic Lupus Erythematosus (SLE), Fibromyalgia, Type 2 Diabetes, Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD), new onset Amyotrophic Lateral Sclerosis (ALS), Early Cognitive Deficit (prior to a “likely” dementia diagnosis), Traumatic Brain Injury (TBI), Parkinson’s disease, and chronic behavioral health issues in those without a formal disability diagnosis, but who experience substantial decrements in functioning including Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs), either chronically or episodically.

E. Respite Coverage in Arizona

Table IIIc, which is located in Appendix B, lists respite services provided through the State of Arizona. Table IIIc includes information on programs that offer respite services in Arizona. Information includes program descriptions, eligibility parameters, funding sources, delivery methods and service limitations.

In general, private insurance does not cover respite services. There are many volunteer respite programs in Arizona (e.g., Neighbor-to-Neighbor, Faith in Action, and Stephen's Ministry) largely sponsored by faith communities and not-for-profit social service agencies. These respite services, while important in bridging respite gaps especially in rural areas, cannot be relied upon to consistently cover all geographic areas, to provide comprehensive respite services, or to provide sustained or consistent care, and so are not included in this needs assessment. State of Arizona residents who need, but do not qualify for, respite care services can be estimated based upon what we have reviewed above.

- ▶ In general, respite care services are available for caregivers of children with special needs and caregivers of older persons.
- ▶ An estimated 570,000 of the Arizona adult 2006 population (nearly 8%) are those over 18 years of age are caregivers caring for someone 18 or older.
- ▶ An estimated 31% of these (177,000) have a high acuity of need (level 4 or 5 Level of Burden), many of whom would benefit from respite care.
- ▶ An estimated 17% of these (97,000) perform at least 40 hours of respite care a week, most of who would benefit from respite care.
- ▶ A conservative 43% of state residents receive publicly funded insurance, a conservative 57% are privately insured or uninsured, and are without respite services.
- ▶ Of the 177,000 high acuity caregiver/care recipient dyads, an estimated 57% (101,000) likely have unmet respite service needs.
- ▶ Seventy-six percent of these 101,000 would be located in urban areas (67,000) with the remainder in rural areas (34,000), where there are limited respite services available.

F. Arizona Residents likely to Qualify for the Lifespan Respite Care Program

According to our assessment, inclusive of findings from the evidence-base, expert interviews, caregiver interviews and social worker interviews, Arizona residents in need of respite, but presently not qualifying for respite include:

- ▶ Caregivers of residents in cancer treatment or terminally ill residents with greater than six month life expectancy.
- ▶ Caregivers of residents under 60 without a diagnosed disability who are functionally impaired e.g., those with early Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis (MS), Lupus, Fibromyalgia, Chronic Fatigue Syndrome (CFS), Type 2 Diabetes, Congestive Heart Failure, Chronic Obstructive Pulmonary Disease, Osteoarthritis, Rheumatoid arthritis, or those experiencing episodic debilitating flares.
- ▶ Caregivers of residents with early cognitive deficit without a “likely” diagnosis of dementia.
- ▶ Caregivers of young adults with cognitive deficits not severe enough to qualify as disabled, such as those with traumatic brain injury after rehabilitation.
- ▶ Grandparents or relative caregivers <55 years of age caring for children 18 and younger,
- ▶ Caregivers of Veterans not qualified for Veteran Administration care (no service-related disability or income eligibility) who do not qualify for other services.

Caregivers of Residents in Cancer Treatment or Terminally Ill >6 Months Life Expectancy

Some residents need respite care services while in the throes of cancer treatment (chemotherapy or radiotherapy), but most of these would be eligible for home health or inpatient care where therapy was debilitating enough to require such high level care. Others, such as those with terminal cancer who are not eligible for hospice, may have a sufficiently impaired function to need respite care, although this is expected to be rare. In a recent study, only 13.9% of patients with cancer had difficulty getting out of bed or a chair 1-year prior to death. This increased from 22.2% to 63.0% in the last five months of life (when they are hospice eligible).²¹ In addition, in urban areas, pre-hospice services are widely available. In 2006, 9,768 Arizona residents died of cancers.²⁰ A small portion of caregivers of persons on cancer treatment or those with terminal cancer greater than 6 months expectancy will require respite services in the year prior to death.

Caregivers of Residents with a Chronic Disease or Condition

Residents between the ages of 18 and 59 without a diagnosed disability, who are functionally impaired and living with a chronic condition or disease (e.g., those with early ALS, MS, lupus, fibromyalgia, CFS, Type 2 Diabetes, Congestive Heart Failure, COPD, osteoarthritis, rheumatoid arthritis or other chronic conditions) may require respite care.

Those who died from chronic diseases (not cancer) had higher rates of functional impairment one year prior to death, and they manifested a more gradual increase in the level of functional decline than did those with cancer (e.g., approximately 35% had difficulty getting out of bed or chair one year prior to death). In 2006, 13,490 Arizona residents died of cardiovascular disease and 5,442 of chronic obstructive pulmonary disease, the top two causes of chronic-disease related death.²⁰ Many of these were over the age of 60, as the median age of death was 71.5 for males and 73 for females in 2006. Many of those with serious chronic diseases are covered by respite services by virtue of insurance status, age or chronic disease and poor functional status.

There are situations in which younger adults have a chronic condition (such as traumatic brain injury) where their caregivers would benefit from respite services, but are not sufficiently impaired, old enough or of financial need to qualify for respite services. This is especially true of those with diseases with episodic flares (MS, lupus, rheumatoid arthritis, chronic fatigue and fibromyalgia,) where the need for episodic or even crisis respite may occur. It is difficult to estimate the number of residents who are 18-59, have one of these conditions, are not disabled, are not eligible for publicly funded insurance or services, and are in need of respite. Four of the six social workers who were interviewed could recall one or more circumstances where these criteria were met. The need for this category of respite care is likely the largest as it represents a myriad of chronic conditions and diseases.

Caregivers of Residents with Cognitive Deficit without Dementia Diagnosis

Residents with early cognitive deficit, yet without a likely diagnosis of dementia may require respite care prior to receiving a diagnosis of dementia. The Family Caregiver Support Program can now serve individuals of any age who have a diagnosis of Alzheimers or related dementia. While the cumulative incidence of Alzheimer's disease has been estimated to be 4.7% by age 70, it is rarely seen in those under 55, as can other less common causes of dementia. Diagnostic and Statistical Manual (DSM-IV) criteria for the diagnosis of dementia require the presence of multiple cognitive deficits in addition to memory impairment. Early in the disease, memory impairment may be the only clinical finding, and this single finding would not meet the diagnostic criteria for dementia; however, caregivers can benefit from respite care services. Therefore, the need for respite care in this sub-population is likely minimal.

Caregivers of Residents with Traumatic Brain Injury

Caregivers of young adults with cognitive deficits not severe enough to qualify as disabled, such as those with traumatic brain injury after rehabilitation, may benefit from respite care. Traumatic Brain Injury (TBI) results principally from vehicular incidents, falls, acts of violence, and sports injuries, and occurs twice as often in males as in females. The estimated incidence rate is 100 per 100,000 persons. The highest incidence is among males 15 to 24 years of age.²² Young adults who have sustained a TBI may be left with multiple impairments that can impact adversely their abilities to return to premorbid functioning in the home, school, and community. Those with severe brain injury outcomes can fully receive respite services, while those with mild chronic impairment may be expected to not require respite care. However, those with sufficient residual damage, who have been discharged from rehabilitation and continue to live in the family home, may not have access to respite services, especially where the family is privately insured. Providing respite for the family caregiver(s) in this case would be important. Three of six social workers discussed this issue. The need for respite service could be expected to be relatively low in this group, due to many being eligible for continued respite care provisions.

Grandparents or Relative Caregivers <55 Years of Age Caring for Children <18

There are 5.8 million co-resident grandparents in the US, defined as living with grandchildren younger than 18 years of age.²³ Nearly 2.4 million of these (42%) are also "grandparent caregivers," who have primary responsibility for their co-resident grandchildren younger than 18.²³ Thirty-nine percent of these have cared for their grandchildren for five or more years.²³ Only 2% of non-Hispanic whites were co-resident grandparents, while 8% were Hispanics and American Indians.²³ In 2000, 3.5 million co-resident grandparents were younger than 60, while 2.3 million were aged 60 and over.²⁰ Respite is available for co-resident grandparents 55 years and older. Census data indicate 114,990 co-resident grandparents in Arizona, 45% of whom are solely responsible for care, and 74.1% of whom are under age 60. Though many grandparents are under the age of 55, most of these are likely relatively healthy and would require few respite services.

Therefore, the need for respite services could be expected to be relatively low in this group.

Another caregiver group that falls under this category is adoptive parents of physically healthy children adopted from foreign countries who may have mild to moderate attachment disorders, but who are not behavioral health clients, making parenting challenging (need was reported in 3 study interviews). Respite could provide these families opportunities to regain their energy, physically and emotionally; strengthen marital relationships; and deal with family emergencies. The need for respite services could be expected to be relatively low in this group.

Veterans Not Qualified for VA Care

The Veterans Administration is the healthcare provider of last resort (low income or disabled veterans). Eligibility for most veterans' health care benefits is based solely on active military service in the Army, Navy, Air Force, Marines, or Coast Guard (or Merchant Marines during WW II), and discharged under other than dishonorable conditions. Veterans whose household income exceeds both the current year VA national income threshold (\$34,117, with one dependent), and who do not have a compensable VA service-connected disability, are not eligible for VA care. Non-eligible veterans, like other Arizona residents, are then eligible for respite based upon funding mechanisms as specified in Table IVc.

G. Barriers to Respite Care

There are many barriers to respite care for those who qualify, both structural and personal. Not every caregiver will require respite care, as some have adequate social support systems and have strong beliefs about caring for their own spouse/parent or child rather than enlisting the help of others, even where the care is of high quality and reliability. In other cases, caregivers do not self-identify as a "caregiver" and may not be aware of respite services, or identify as needing respite services. According to the AARP Caregiver Identification Study, only one in five caregivers actually identify as self-identified caregivers, preferring to think of themselves as performing their social role of spouse, parent or child.²⁴

Included within the structural category are barriers related to availability of respite providers and services, the organization of the health care system, and the geographic environment of the state. Personal barriers include the role of culture, language and ethnicity; provider attitudes; lack of social support, knowledge, and awareness. Many of these barriers are interconnected. From the state's perspective, respite services ideally support and maintain the care needs of those who are sick, disabled, and frail in the home setting, staving off expensive institutional care resources and associated costs.

A significant barrier to respite access is the lack of available health care providers and services, especially in rural areas. The health care work force must be composed of an appropriate number of paid and volunteer respite caregivers located in community facilities, to provide respite services. Arizona has a shortage of trained respite caregivers. There were 9,820 home health aides and 15,030 nursing aides, orderlies, and attendants

working in Arizona in 2000, equal to 190 home health aides and 290 nursing aides, orderlies, and attendants per 100,000 population ranking 46th, among the 50 states.²⁵ These shortages lead to decreased access and contribute to a lack of continuity of care. Respite services must be located near the population needing services, and the hours and days of operation, paperwork required, and other "convenience" factors must not act as significant impediments.

The inability to get care as soon as needed is identified as one of the most important barriers to accessing respite services. As urgent situations arise, an ability to contract for immediate crisis care is needed; however, this care is rarely available on such short notice. Transportation problems, in the case of out-of-home respite services, may also be an issue. The perceptions of the trustworthiness, necessary skills, and level of overall care and kindness of respite providers are also common barriers to respite care.

Health behaviors differ among people of various cultures, ethnicities, and levels of health literacy. Minority caregivers are less willing to access health care for fear that caregiver/care recipient health beliefs and practices will not be respected or integrated into plans of care. Language may be an additional barrier. In addition, worry over having to pay more than expected or that insurance won't cover the respite care services received is a primary obstacle to seeking care regardless of race, ethnicity, and age.

Despite accessing a variety of respite services, caregivers may perceive they get limited respite from paid respite services, because their needs remain unmet.²⁶ It follows that high priority should be given to understanding the conditions and services that enable caregivers to continue to provide in-home care, in addition to those that are satisfying and supportive of quality of life. Understanding the situations where sub-optimal demand for respite puts care recipients at highest risk of subsequent expensive institutional care; or caregivers at risk of illness, family disintegration or unemployment is important in targeting services.

H. Recommendations

Enhance Respite Care Information and Referral

Many Arizonans experience a very complicated and fragmented health care delivery system. Much of the difficulty and confusion is derived from the myriad of services and their lack of coordination. The complexity of the health care system is one of the greatest difficulties clients encounter. The process for accessing health care services varies greatly, and clients must sort through this confusion while simultaneously negotiating complex caregiving issues at home.

There is poor general public awareness of respite as a service. Three recommendations for increased public understanding were made by the Caregiver Identification Study: 1) use both the term "caregiver" and a definition of what caregivers are in publications and brochures. This approach will get the attention of the target audience of both those who correctly identify themselves as caregivers (56%), and those who are caregivers but do not think of themselves as such (44%); 2) develop articles about caregiving issues for the

popular media that target older women (age 50+) because they are the most likely group to provide care and will read brochures, articles, or books about caregiving; 3) caregiving information should be placed in health professionals' offices because older women are also the group who are most likely to have talked to health professionals about the person they are caring for.²⁴

Development of a statewide interagency respite network, with an associated website and materials for dissemination through affiliates, could streamline this effort. A recent Pew Report indicates that 47% of all adult Americans have a broadband connection at home as of early 2007, 31% in rural areas.²⁷ Because each respite dyad receives services and support information depending on their eligibility status and special need category, individualized contact strategies will be required to ensure that their service providers are aware of Arizona Lifespan Respite Care respite services. Communicating with the community, AHECs, RBHAs and AAAs and special populations (rural, grandparents, low-income, minority, and special need categories such as chronic disease) about the program through a variety of methods including press releases, fact sheets, newsletters, health fairs, town meetings, informational vans, caregiver handbooks, presentations, support groups, caregiver campaigns, workshops, technology-based resources, senior journals, caregiver resource sections in public libraries conferences, caregiver Websites, and television and radio announcements will assist in knowledge of the Lifespan Respite Care Program. Developing new partnerships with employers, faith- and community-based organizations, national aging organizations and universities will also assist in program recognition.²⁸

Consider Alternative Respite Care Models

In the long run, consideration should be given to allocating funds to consumer-directed respite options, enabling caregivers to choose who they desire as caregivers. Consumer-directed respite service options, where family caregivers are given flexible alternatives, such as hiring neighbors or friends to provide respite services, may act to help remove barriers to respite service availability and use.^{14,33} Caregivers want to be assured that information is shared, to be included in decision making, that there is someone they can contact when they need to, and that the service is responsive to their needs.²⁵ In addition, consideration should be given to potential funding of coordinators to provide coordination of neighbor to neighbor and faith-based volunteer respite services. A single volunteer coordinator could use a train-the-trainer model to build volunteer services in high need areas statewide, or a 50% coordinator could provide development, coordination and oversight of several volunteers in a single area who can then provide non-medical in-home respite care and/or group out-of-home respite care to many caregivers. These models has been demonstrated effective nationally in rural and urban areas, and also address one important consumer barrier- that of not trusting a paid respite provider hired from an agency who has no connection to the caregiver's community.

Improve Access to Respite Care Training Resources

In an effort to improve access to training and education, minimize costs and enhance learner satisfaction (especially for caregivers in rural communities), a coordinated system of caregiver care training and education should be coordinated with pre-existing training

resources, including state agencies, employer-based training, Area Health Education Centers (AHEC), State Colleges and Universities. Modalities should include innovative learning strategies including on-line web-based training, internet resources, videotapes, and distance learning using satellite technology coordinated through colleges or other entities. However, traditional media, such as books, tapes and one-on-one training, should be included to meet the needs of caregivers and volunteers with different learning styles due to educational background, language barriers or age-related preferences. Respite training needs include:

- ▶ Training for **social workers and intake staff** who perform eligibility assessments so they better understand who might benefit from respite care, state and voluntary respite care services across the continuum, appropriate referral mechanisms, and availability of services in underserved areas. Training and technical assistance identified in the *50 State Study* included training in the areas of best practices in service delivery, outreach/public awareness and caregiver assessment.⁵ A Respite Resource guide, specifying respite services by agency, mapped to caregiver/recipient dyads, would assist this process.
- ▶ Training for **informal caregivers** and volunteers providing direct care including orientation, basic training, self-care and resource information. Training requirements may act as barriers to volunteers and informal caregivers. Sensitivity should be used in providing pertinent information, while minimizing training burden.
- ▶ Training for **paid respite caregivers** including orientation, basic training including CPR, specialty needs training as appropriate, and continuing education. As paid caregivers, more stringent training modalities should be developed to assure quality of care. Training requirements of existing attendant or personal care programs can be used for reference.

Orientation should consist of introductory information on care recipient rights, communication skills, fire and life safety, and universal precautions. Orientation must be provided at a training site or in a class by appropriate staff before the employees have routine interaction with residents.

Basic training should consist of modules on the core knowledge and skills that caregivers need to learn and understand to effectively and safely provide care to care recipients. Basic training must be outcome-based, and the effectiveness of the basic training must be measured by demonstrated competency in the core areas through the use of a competency test. Basic training must be completed by caregivers prior to service provision.

- ▶ For **caregivers serving residents with special needs** such as at-risk children, chronic diseases, developmental disabilities, dementia or mental illness, specialty training is required of caregivers. Specialty training should consist of modules on the core knowledge and skills that caregivers need to effectively and safely provide care to residents with special needs. Specialty training should be integrated into basic training wherever appropriate. Specialty training must be outcome-based, and the effectiveness of the specialty training must be measured by demonstrated competency in the specialty

areas through the use of a competency test. Specialty training should be completed by caregivers prior to caring for a care recipient having special needs. Agencies specializing in specific special need areas should develop and offer such training. Existing training programs should be used or adapted where possible.

▶ **Continuing education** should consist of ongoing delivery of information to caregivers on various topics relevant to the care setting and care needs of care recipients. This can include topics not covered in the orientation and basic training; However, important fundamental topics may be repeated, for example, infection control. Competency testing should not be required for continuing education. Continuing education should be required in each calendar year after initial training.

▶ On-line interactive **basic caregiving training** modules with certification should be developed targeting informal and formal caregivers and made available statewide. Demonstrated curriculum content developers of health education on-line content should be used to develop these materials to include state colleges and universities. Training programs available from other providers nationally should also be explored.

Address Workforce Shortage

By 2050 the U.S. will need three times as many paid long-term care workers as are employed now to meet the needs of the aging baby boom generation.²⁹ The good news is that 2000 census micro data indicates that the estimated size of the home care workforce is much larger than that in previous estimates, and that it has greater ethnic diversity (Hispanics or Latinos comprising a significant proportion of the home care workforce).²⁹ However, interview data indicates a lack of qualified caregivers, especially in rural areas.

The need to retain existing paid care providers, attract new workers, and test new models of recruitment and retention of paid caregivers is critical, especially as these workers will be in increasing demand. Suggested strategies include: 1) exploring use of new technology in recruitment, education and training, recordkeeping and patient care; 2) encouraging and supporting state and local efforts, involving both the private and public sectors to explore use of business partnerships with individual employers or consortiums of employers, training providers and public agencies; and 3) turning to faith and community-based organizations for their potential roles in addressing shortages through recruiting volunteers for respite care for family members, “back-up” services, and home-based support.²⁸ In addition, targeting specific segments of the population may yield some success. The mature workforce, in particular, should be considered since individuals over 55 may be interested in transitioning to human services careers considered personally fulfilling. Also, youth and individuals with disabilities should be approached. Next to recruitment of additional caregivers, retention strategies must be implemented in order to keep trained caregivers in the field. Working conditions, specifically health benefits and wages, need to improve to attract and keep qualified caregivers.

An Example: Faith and Community Based Initiatives

Development of volunteer caregivers can be accomplished using existing models such as faith-in-action, neighbor-to-neighbor and Stephens Ministry programs. Some successful models within the state include Tucson Interfaith HIV and AIDS Network, which provides in home care to those with HIV/AIDS and Catholic Social Services, Neighbor-to-Neighbor and rural out-of-home respite programs.

Robert Wood Johnson Foundation no longer provides start-up funds for faith-in-action projects. However, based upon initial demonstration grant findings from 25 sites, Over 11,000 volunteers provided service to over 26,000 people, an average of 1,040 per site over the first three years of the program.²⁸ It appears that the concept can be applied in a wide range of communities. Churches, synagogues and other houses of worship were able to come together, form local governing boards, recruit competent directors, mobilize volunteers, and provide informal care to substantial numbers of individuals in need, including respite to their families. Programs that were not able to obtain sufficient funding to pay a director had problems implementing the model.

In most cases the faith coalitions built slowly; mature projects typically involved 20 or more congregations and provided care to an average of 500 individuals at a time – a significant return for the cost of one project director.²⁸ The interfaith model appears to be financially sustainable. Local sources of continuing support include the United Way, local civic groups and businesses, and individual contributions, as well as the congregations themselves. Part of the reason for the projects' durability is that the operating costs are low and able to be spread across multiple funding sources.²⁸

Enhance Respite Service Evaluation

Individual level data indicating caregiver/recipient dyad, special needs type, ADL/IADL score of recipient, geographic location, units of respite service used, type(s) of respite services received, and associated cost across state respite services need to be collected in a more systematic manner. These data are essential to understanding how to target and plan for effective future respite services.

In addition, caregiver satisfaction with services and caregiver stress scores related to respite care could help us to better serve those in need, and to better understand what services are effective and satisfying, and which are not.

I. Continue Future Research

Suggestions for future research discovered in this research effort include:

► Characterize Respite Service Utilization and Characteristics of Users in Arizona, and Extrapolate to the State

The Center for Health Information & Research (CHIR) at Arizona State University has successfully used Arizona HealthQuery (AZHQ) data to track the use of health care services over time and the nature of the conditions for which care is provided. The data are contributed by more than fifty data partners including more than eight million persons who have received health care in Arizona. Using these data, they have successfully

extrapolated to the uninsured and privately populations estimations of expected care. They invite requests for Community Reports at chir@asu.edu.

▶ **Clinical Demonstration Project: Self-sustaining Caregiving Communities**

Consider applying for clinical demonstration funding to establish statewide respite volunteer program through faith, service organization and neighborhood associations.

▶ **On-Line Caregiver Training Content Development and Evaluation**

Consider partnering with the University of Arizona, Arizona State University or content development experts to submit an National Institutes of Health (NIH) Small Business Innovation Research SBIR or Small Business Technology Transfer Research (STTR) grant to develop and test the effectiveness of on-line caregiver training.

▶ **Development of a Caregiver Workforce**

Consider partnering with the University of Arizona or Arizona State University to develop a more comprehensive understanding of the characteristics of the paid caregiver workforce to facilitate more effective development of programs designed to enhance recruitment and retention of these workers to meet the increasing demands of future years.

▶ **Perform a Statewide Study Similar to “Caregiving in the U.S.”⁶**

Consider performing a well-designed statewide survey of caregiving using a randomly selected sample of the population weighted by race/ethnicity, gender and age. Caregiver/care recipient dyad and caregiving characteristics, functional status, and reasons necessitating caregiving should be collected; institutions of higher learning are well suited to perform such a survey.

Cite this report as: Mohler MJ, Brown V (2008). Arizona Respite Care Throughout the Lifespan: Characterizing Unmet Needs. Tucson, AZ: University of Arizona, Arizona Center on Aging, College of Medicine.

Arizona Respite Care Throughout the Lifespan: Characterizing Unmet Needs



V. BIBLIOGRAPHY

1. Ferguson MR-N. Lifespan Respite Care Act of 2006. In: US House of Representatives HR 3248; 2005.
2. House Bill 2789 (NOW: budget reconciliation; health and welfare) Section 18: Lifespan Respite Care Program Chapter :263.
3. Gibson M, Houser A. Valuing the Invaluable: A New Look at State Estimates of the Economic Value of Family Caregiving. Washington DC: AARP; 2007. Accessed: 12/02/2007:
<http://www.google.com/search?q=Gibson+M%2C+Houser+A.+Valuing+the+Invaluable%3A+A+New+Look+at+State+Estimates+of+the+Economic+Value+of+Family+Caregiving.+Washington+DC%3A+AARP%3B+2007.&rls=com.microsoft:en-us:IE-SearchBox&ie=UTF-8&oe=UTF-8&sourceid=ie7&rlz=117GWYG>
4. DHHS. National Survey of Children with Special Health Care Needs Chartbook; 2001. Accessed: 12/02/2007: <http://mchb.hrsa.gov/chscn/pages/prevalence.htm>
5. FCI. The State of the States in Family Caregiver Support: A 50-State Study: Family Caregiver Institute; 2004. Accessed: 12/02/2007:
<http://www.google.com/search?q=The+State+of+the+States+in+Family+Caregiver+Support%3A+A+50-State+Study%3A+Family+Caregiver+Institute%3B+2004.&rls=com.microsoft:en-us:IE-SearchBox&ie=UTF-8&oe=UTF-8&sourceid=ie7&rlz=117GWYG>
6. NAC, AARP. Caregiving in the U.S.; 2004.
7. Evercare, NAC. Evercare Study of Caregivers in Decline; 2006. Accessed: 12/02/2007:
<http://www.caregiving.org/data/Caregivers%20in%20Decline%20Study-FINAL-lowres.pdf>
8. Arno P. Estimated Prevalence and Economic Value of Family Caregiving, by State. Albert Einstein College of Medicine; 2004. Accessed: 12/02/2007:
http://www.caregiver.org/caregiver/jsp/content/pdfs/State_Caregiving_Data_Arno_20061107.pdf
9. Johnson RW, Schaner SG. Many Older Americans Engage in Caregiving Activities; 2005. Accessed: 12/02/2007:
<http://www.urban.org/publications/311203.html>
10. Johnson RW, Wiener JM. A Profile of Frail Older Americans and Their Caregivers; 2006. Accessed: 12/02/2007:
http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822
11. McKune SL. Caregiving: A National Profile and Assessment of Caregiver Services and Needs; 2006. Accessed: 12/02/2007:

- http://www.rosalyncarter.org/UserFiles/File/UFL_RCI_FinalCaregiverReport.pdf
12. CHIR. Health Insurance in Arizona: Residents of Maricopa County: Center for Health Information & Research (CHIR) in the School of Computing and Informatics, Arizona State University; 2007. Accessed: 12/02/2007: http://chir.asu.edu/downloads/Insurance_in_AZ_Maricopa04.pdf
 13. RWJ. Going Without: America's Uninsured Children: Robert Wood Johnson Foundation; 2005. Accessed: 12/02/2007: <http://www.rwjf.org/files/newsroom/ckfresearchreportfinal.pdf>
 14. CAHMI. 2005/2006 National Survey of Children with Special Health Care Needs Children and Adolescent Health Care Measurement Institute; 2007.
 15. U.S. Census Bureau: State and County QuickFacts. 2006. (Accessed at <http://quickfacts.census.gov/qfd/states/04000.html>.)
 16. Fronstin P. Sources of Health Insurance and Characteristics of the Uninsured: Updated Analysis of the March 2007 Current Population Survey.: EBRI Issue Brief #310 (Employee Benefit Research Institute); 2007.
 17. County Population Trends. 2004. (Accessed 12/12/07, at http://www.rho.arizona.edu/Resources/Dataline/Population_Characteristics/city_population_trends.aspx.)
 18. CBR. The Disabled Population in Arizona: Data From the 2000 Public Use Microdata Sample: Arizona State University; 2003. Accessed 12/02/2007: <http://wpcarey.asu.edu/seidman/ccpr/PDFs/disabledreport.pdf>
 19. Editorial. Disabled, and Waiting for Justice New York Times 2007 December 11, 2007. Accessed 12/1 <http://www.nytimes.com/2007/12/11/opinion/11tue1.html>2/2007:
 20. CDC. Chronic Diseases: The Leading Causes of Death, Arizona: Centers for Disease Control: 2006. Accessed 12/02/2007: <http://www.cdc.gov/nccdphp/publications/factsheets/ChronicDisease/arizona.htm>
 21. Teno JM, Weitzen S, Fennell ML, Mor V. Dying trajectory in the last year of life: does cancer trajectory fit other diseases? *J Palliat Med* 2001;4:457-64.
 22. Winstanley J, Simpson G, Tate R, Myles B. Early indicators and contributors to psychological distress in relatives during rehabilitation following severe traumatic brain injury: findings from the brain injury outcomes study. *J Head Trauma Rehabil* 2006;21:453-66.
 23. USCB. Grandparents Living with Grand Children: US Census Bureau; 2000. Accessed 12/02/2007: <http://www.census.gov/prod/2003pubs/c2kbr-31.pdf>
 24. AARP. Caregiver Identification Study; 2001.
 25. HRSA. The Arizona Health Workforce: Highlights from the Health Workforce Profile Background 2000. Accessed 12/02/2007: <http://bhpr.hrsa.gov/healthworkforce/reports/statesummaries/arizona.htm>
 26. Whitlatch CJ, Feinberg LF. Family and friends as respite providers. *J Aging Soc Policy* 2006;18:127-39.
 27. Pew. Broadband Adoption 2007: Pew Internet and American Life; 2007. Accessed 12/02/07: http://www.pewinternet.org/PPF/r/217/report_display.asp

28. RWJ. Interfaith Volunteer Caregivers Program, Faith in Action(R), Generation 2 and Generation 3; 2006. Accessed 12/02/07:
<http://www.rwjf.org/pr/product.jsp?id=16241&topicid=1321>
29. Montgomery RJ, Holley L, Deichert J, Kosloski K. A profile of home care workers from the 2000 census: how it changes what we know. *Gerontologist* 2005;45:593-600.

APPENDICES

Appendix A

See Table IIIc on next page