The National Family Caregiver Support Program

Resource Guide

Administration on Aging

Table of Contents

FOREWARD i

ACKNOWLEDGEMENTS ii

ABBREVIATIONS AND ACRONYMS iv

I. OVERVIEW OF THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM I-1

Older Americans Act Context **I-1**
NFCSP in Brief **I-2**
New Client Population **I-2**
Program Goals **I-3**
Funding **I-4**
Program Policies **I-4**
Challenges and Opportunities for the Network **I-4**

II. ROLES OF THE AGING NETWORK II-1

Administration on Aging **II-2**
State Units on Aging **II-3**
Area Agencies on Aging **II-5**
Indian Tribal Organizations **II-7**
Service Providers **II-7**

III. PROFILE OF FAMILY CAREGIVERS III-1

Number of Caregivers **III-1**
GRANDPARENTS CARING FOR CHILDREN III-2
NFCSP CAREGIVERS III-7
Caregiver Characteristics **III-9**
CAREGIVERS OF INDIVIDUALS WITH A LONG-TERM ILLNESS OR DISABILITY III-9
NFCSP TARGET POPULATIONS III-9
NFCSP CARE RECIPIENTS III-13
Effects of Caregiving on Caregivers **III-17**
Meeting the Needs of Caregivers **III-19**

IV. SYSTEMS DEVELOPMENT IV-1

Guiding Principles for Systems Development IV-1
Systems Development Strategies IV-2
Integration with Other Programs and Service Systems IV-3
Partnerships and Collaborations IV-4
Networking IV-7
Building Partnerships and Collaborations IV-8
Financing IV-10
Visibility and Advocacy IV-11
Systems Development Planning and Assessment IV-13
Systems Assessment IV-13
Needs Assessment IV-16

V. PROGRAM EFFECTIVENESS AND OUTCOMES V-1

Conceptualizing Caregiver Program Effectiveness V-2
Assessing Program Effectiveness V-2
Individual Level V-4
Organizational Level V-5
System Level V-7
NFCSP Measurement Development Issues V-8
AoA's Performance Outcome Measures Project V-11
Information System Investment and Development V-13

VI. WORKING WITH FAMILIES AND OTHER CAREGIVERS VI-1

Understanding the Family VI-1
Understanding the Caregiver Context VI-2
Caregiver Assessment VI-4
Constructs of Existing Assessment Instruments VI-4
Assessment Design VI-7
Assessment Implementation VI-7
Care Management-Support Coordination for Caregivers VI-9
Roles and Skill Sets VI-9
Care Management - Support Coordination Infrastructure VI-11
Caregivers' Use of Formal Services VI-13

VII. NFCSP SERVICE COMPONENTS..... VII-1

Information **VII-2**
Service Description VII-2
Strategies and Program Examples..... VII-3
Assistance **VII-9**
Service Description VII-9
Strategies and Program Examples..... VII-9
Counseling, Support Groups, and Training **VII-18**
Service Description VII-18
Strategies and Program Examples..... VII-19
Respite Care **VII-27**
Service Description VII-27
Strategies and Program Examples..... VII-28
Supplemental Services **VII-35**
Service Description VII-35
Strategies and Program Examples..... VII-36

VIII. DESIGNING THE NFCSP IN THE CONTEXT OF DIVERSE CAREGIVER POPULATIONS..... VIII-1

Demographic Factors **VIII-2**
Ethnicity, Race, and Culture..... VIII-2
Strategies and Program Examples..... VIII-4
Sexual Orientation VIII-16
Special Caregiver Circumstances **VIII-19**
Grandparents and Other Relatives Raising Children VIII-19
Caregivers of Children and Young Adults with Developmental Disabilities..... VIII-22
Environmental Conditions **VIII-25**
Working Caregivers..... VIII-26
Rural Caregivers VIII-29
Long-Distance Caregivers VIII-32

IX. NONTRADITIONAL APPROACHES IX-1

Consumer Direction **IX-1**
Strategies and Program Examples.....IX-3
Self-Advocacy **IX-7**
Strategies and Program Examples at the Program Level.....IX-8
Strategies and Program Examples at the System LeveL.....IX-19
Volunteer Models **IX-10**
Technology Applications for Caregivers **IX-13**
Strategies and Program Examples..... **IX-13**

APPENDIX A NFCSP POLICY INFORMATION

Title III – Grants for State and Community Programs on Aging..... A-1
Title V I- Grants to Indian Tribes..... A-6
AoA Program Instruction 01-02..... A-7
NFCSP Frequently Asked Questions.....A-11
Interim Reporting Guidelines, Issued on October 31, 2001.....A-14
Financial Status Report, AoA Supplemental Form to SF-269 – Title III ..A-17

APPENDIX B NFCSP PROGRAM RESOURCES

Special Contributors B-1
Innovation Grants, Fiscal Year 2001..... B-2
Native American Elder Caregiver Grants, Fiscal Year 2001..... B-11
American FactFinder Tool..... B-15
Request for Collaboration, Senior Spectrum..... B-19
NFCSP Data Collection, North Carolina..... B-27
Statewide I&A Reform: Self Assessment..... B-30

Table of Exhibits

Chapter II

Exhibit II.1 Network on Aging (OAA Structure Chart) II-1

Exhibit II.2 Washington Aging and Adult Services Administration Role in NFCSP Implementation II-4

Exhibit II.3 North Carolina Department of Aging Role in NFCSP Implementation.....II-4

Exhibit II.4 Senior Spectrum Role in NFCSP Implementation.....II-6

Exhibit II.5 Minnesota AAA Role in NFCSP Implementation II-7

Exhibit II.6 Faith-Based Organization's Potential Role in NFCSP Implementation.....II-8

Exhibit II.7 Nonprofit Community Organization's Role in NFCSP Implementation.....II-8

Exhibit II.8 Provider's Potential Role in NFCSP Implementation.....II-9

Chapter III

Exhibit III.1 Alternative Estimates of Caregivers..... III-3

Exhibit III.2 Estimates of Grandparents Caring for Grandchildren III-5

Exhibit III.3 Narrowing to the NFCSP Definition of Grandparents Caring for Grandchildren III-6

Exhibit III.4 Estimates of the Number of Grandparent Households and Grandparents Caring for Grandchildren (Parents Absent), by Grandchild Minor Status and Grandparent Age, 2001 ..... III-6

Exhibit III.5 Estimating the Number of Caregivers in an Area III-8

Exhibit III.6 Characteristics of Primary Caregivers of Older Americans, 1999 ..... III-10

Exhibit III.7 Characteristics of Grandparent Households Caring for Minor Grandchildren, 2001 ..... III-12

Exhibit III.8 Characteristics of Older Americans Receiving Care from Family and Friends, 1998 ..... III-14

Exhibit III.9 Characteristics of Grandchildren Meeting NFCSP Requirements, 2001 ..... III-15

Chapter IV

Exhibit IV.1 AAA Partnership with Primary Care Providers IV-6

Exhibit IV.2 AAA Partnerships with the Faith Community.....IV-6

Exhibit IV.3 SUA Partnership with a University to Facilitate Capacity Building and Exchange among Geographically Separated AAAs.....IV-7

Exhibit IV.4 AAA Established Advisory Task Force.....IV-8

Exhibit IV.5 State Initiated, Cross-Agency Collaborations to Create a Multifaceted and Responsive Caregiver Support System IV-9

Exhibit IV.6 AAA-Initiated Partnerships with Community Organizations to Identify and Provide Services and Supports to Caregivers IV-9

Exhibit IV.7 Public Awareness Effort IV-12
Exhibit IV.8 Social Marketing and Service Policy Strategy..... IV-13
Exhibit IV.9 Caregiver Systems Change Capacity Assessment Framework..... IV-15
Exhibit IV.10 Caregiver Needs Assessment IV-16

Chapter V

Exhibit V.1 Program Effectiveness Framework and Feedback Loop..... V-4
Exhibit V.2 Incorporating the NFCSP into Ongoing Quality Assurance V-6
Exhibit V.3 Measuring Outcome from a Specific Intervention..... V-7
Exhibit V.4 Adapting Outcome Measures from Other Family-Centered Interventions V-10
Exhibit V.5 NFCSP Innovative Grant for Outcome Development..... V-11

Chapter VI

Exhibit VI.1 Dimensions of the Caregiving Context VI-3
Exhibit VI.2 Caregiver Assessment Instruments VI-6
Exhibit VI.3 Combined Support Coordination at the Local Level VI-13
Exhibit VI.4 Tips for Encouraging Families to Accept Assistance VI-15

Chapter VII

Exhibit VII.1 Strategies to Provide Information to Caregivers VII-3
Exhibit VII.2 Communication for Caregiving in Minnesota VII-4
Exhibit VII.3 Expanding Outreach to Caregivers VII-4
Exhibit VII.4 Effective Outreach Strategies to Ethnic Communities VII-6
Exhibit VII.5 Individual Face-to-Face Outreach Examples VII-8
Exhibit VII.6 Self-Serve I&A for Working Caregivers VII-10
Exhibit VII.7 National Information and Assistance Movements..... VII-11
Exhibit VII.8 Local Level I&A Coordination..... VII-14
Exhibit VII.9 Development of Aging Connection and CONNECT Database... VII-15
Exhibit VII.10 Comprehensive Statewide I&A Reform in New Jersey..... VII-16
Exhibit VII.11 I&A Staff for Caregivers VII-17
Exhibit VII.12 Caregiver Counseling, Support Group, and Training VII-19
Exhibit VII.13 Training and Education for Dementia Caregivers VII-20
Exhibit VII.14 In-Home Support and Education..... VII-23
Exhibit VII.15 Leveraging Existing Service Providers VII-23
Exhibit VII.16 Caregiver Conferences to Train Caregivers VII-24
Exhibit VII.17 Train-the-Trainer Approach to Family Caregiver Education Program..... VII-25
Exhibit VII.18 Responsive Trainers and Evaluative Issues of Caregiver Workshops VII-27
Exhibit VII.19 Respite Care VII-28
Exhibit VII.20 Expanding Eligibility for Respite Care..... VII-29
Exhibit VII.21 Out-of-Home Respite Care VII-30

Exhibit VII.22 Multi-component Programs VII-31
Exhibit VII.23 Supplemental Services VII-36

Chapter VIII

Exhibit VIII.1 Skills Training for African Americans VIII-7
Exhibit VIII.2 Outreach to Asian Americans and African Americans VIII-8
Exhibit VIII.3 Stress Management for Mexican Americans VIII-9
Exhibit VIII.4 Caregiver Programs for Native Americans VIII-10
Exhibit VIII.5 Strategies for Addressing Cultural Differences VIII-12
Exhibit VIII.6 Partnerships with Ethnic Organizations VIII-15
Exhibit VIII.7 Barriers to Care for LGBT Caregivers VIII-17
Exhibit VIII.8 Support Groups for LGBT Caregivers VIII-18
Exhibit VIII.9 Information Dissemination to Relatives Raising Children..... VIII-21
Exhibit VIII.10 Outreach and Linkages with Developmental Disability Agencies..... VIII-25
Exhibit VIII.11 Public/Private Partnerships VIII-28
Exhibit VIII.12 RURAL Caregiver Program Planning Model..... VIII-30
Exhibit VIII.13 Building a Seamless Dementia-Specific Service Delivery System in Rural Iowa VIII-32
Exhibit VIII.14 Information Exchange with Long-Distance Caregivers VIII-34

Chapter IX

Exhibit IX.1 Principles of Consumer Direction..... IX-2
Exhibit IX.2 Range of Consumer-Directed Approaches IX-2
Exhibit IX.3 Respite Care Self-Determination Model..... IX-4
Exhibit IX.4 Direct Payments to Caregivers for Needed Services IX-5
Exhibit IX.5 Multiple Levels of Self-Advocacy..... IX-7
Exhibit IX.6 Caregivers Serving as Caregiver Specialists..... IX-9
Exhibit IX.7 Development of Advocates IX-10
Exhibit IX.8 Recruitment and Training of Volunteers Providing Respite..... IX-11
Exhibit IX.9 Building on RSVP Activities to Support Caregivers IX-13
Exhibit IX.10 Caregiver Specialist Listserv and Web Page IX-16

FOREWORD

The Older Americans Act (OAA) Amendments of 2000 authorized the creation of the National Family Caregiver Support Program (NFCSP) to help many thousands of family members with the care of their older loved ones.[1] Although caregivers always have been an implicit responsibility of the aging network under the OAA, the NFCSP makes this responsibility explicit and defines it to encompass those family and other caregivers supporting older individuals, as well as grandparents and older relatives caring for children. The NFCSP bestows significant new authority and resources to reach these target populations with support services and make them a priority under the OAA.

Responsibility for implementation of the program rests with the aging network, i.e., the Administration on Aging (AoA), State Units on Aging (SUA), Area Agencies on Aging (AAA), Indian Tribal Organizations (ITOs), and service providers (SPs). Intended for the staff of these agencies, this Resource Guide offers practical information to help implement the new program. As a "resource guide"—*not* a handbook of program policies or prescribed procedures—it features examples and resources to stimulate members of the aging network to pursue approaches that afford caregivers flexibility and assistance in meeting caregiver service needs.

AoA drew on a number of resources to compile this Guide, including: 1) a Technical Advisory Group (TAG) comprising researchers and aging network representatives who informed its content; 2) more than 20 issue briefs commissioned from prominent researchers and staff of the aging network; 3) the September 2001 *National Family Caregiver Support Program: From Enactment to Action* Conference during which more than 700 participants shared implementation information; 4) site visits to five states (Maine, Minnesota, North Carolina, Pennsylvania, and Washington) for discussions on implementation issues; 5) a listserv to disseminate research-based information and exchange program information among network staff; and 6) an extensive literature review on topics related to caregiving.

Among the Guide's noteworthy features are:

- A concise narrative with references for further information provided through Web links, footnotes, and appendix materials; and
- Numerous exhibits that highlight examples of implementation approaches and provide program contact information.

This Guide is being directly disseminated to SUAs, AAAs, ITOs, and selected national organizations and will be posted on the NFCSP Web site at http://www.aoa.gov/carenetwork. CDs of the document, which have been inserted into the Resource Guide binder, can be used to make additional hard copies of the Guide. SUAs and AAAs are *strongly encouraged* to work together to make copies available to local service providers in their state.

This Resource Guide has been developed during the early stages of the NFCSP when program implementation experience is relatively limited. As appropriate, we plan to issue occasional

[1] Public Law 106 – 501, November 13, 2000.

updates of Guide chapters through postings to the NFCSP Web site. With this intention in mind, we welcome your feedback on the usefulness of the Guide and on important program developments that might interest others.

ACKNOWLEDGEMENTS

In developing this Resource Guide, we enjoyed the good fortune of tapping many leading experts in caregiver and long term care research as well as aging network individuals actively involved in innovative developments before and after the initiation of the National Family Caregiver Support Program.

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Josefina G. Carbonell
Assistant Secretary for Aging

For more information about home and community-based programs and services that support the well-being, health and independence of older persons and their caregivers, contact AoA's Center for Communication and Consumer Services at 202-619-7501. The Center directs and coordinates AoA's public information, education and outreach activities concerning our nation's large and growing aging population.

ABBREVIATIONS AND ACRONYMS

AAA	Area Agency on Aging
ADDGS	Alzheimer's Disease Demonstration Grants to States
ADL	activities of daily living
AIRS	Alliance of Information and Referral Systems
AoA	Administration on Aging
APS	Adult Protective Services
ARC	formerly the Association for Retarded Citizens
ASPE	Office of the Assistant Secretary for Planning and Evaluation
CARF	Commission on Accreditation for Rehabilitation Facilities
CDF	Children's Defense Fund
CMS	Centers for Medicare and Medicaid Services
CWLA	Child Welfare League of America
CPS	Current Population Survey
CRC	Caregiver Resource Center
C2SS	Census 2000 Supplementary Survey
DD	developmental disabilities
DHHS	Department of Health and Human Services
EAP	employee assistance programs
FCA	Family Caregiver Alliance
GPRA	Government Performance and Results Act
GU	Generations United
HCBS	Home- And Community-Based Services
I&A	information and assistance
IADL	instrumental activities of daily living
IFF	intrastate funding formula
ITO	Indian Tribal Organization
LGBT	Lesbian, Gay, Bisexual, and Transgender
LTC	long-term care

MR/DD	Mental Retardation / Developmental Disabilities
NAC	National Alliance for Caregiving
NAPIS	National Aging Program Information System
NASUA	National Association of State Units on Aging
NFCSP	National Family Caregiver Support Program
NHIS-D	National Health Interview Survey-Disability Supplement
NIA	National Institute on Aging
NIH	National Institutes of Health
NINR	National Institute on Nursing Research
NLTCS	National Long-Term Care Survey
NSFH	National Survey of Families and Households
N4A	National Association of Area Agencies on Aging
OAA	Older Americans Act
POMP	Performance Outcomes Measures Project
PSA	planning and service areas
RAPP	Relative as Parents Program
REACH	Resources for Enhancing Alzheimer's Caregiver Health
RFC	request for collaboration
RFP	request for proposal
RSVP	Retired Seniors Volunteer Program
RWJ	Robert Wood Johnson Foundation
SHIP	Senior Health Insurance Information Program
SIPP	Survey of Income and Program Participation
SP	service providers
SUA	State Unit on Aging
TAG	Technical Advisory Group
TANF	Temporary Assistance to Needy Families
VA	Veteran's Administration

I. OVERVIEW OF THE NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

This chapter outlines the key features of the Older Americans Act (OAA) and specifically Title III, Part E, the National Family Caregiver Support Program and Title VI, Part C, the Native American Caregiver Support Program. Although authorized separately under Title III and Title VI, these two components make up the National Family Caregivers Support Program (NFCSP). This chapter provides a brief description of the program; a discussion of the new client population, the program's goals, funding, and program policies; as well as opportunities and challenges for the network.

OLDER AMERICANS ACT CONTEXT

The OAA of 1965 established the Administration on Aging (AoA) within what is now called the Department of Health and Human Services (DHHS). When originally passed, the OAA authorized grants to State Units on Aging (SUAs) for community planning and services programs. Later amendments to Title III of the OAA, "Grants For State for State and Community Programs on Aging", authorized Area Agencies on Aging (AAAs) for planning and funding of services at the sub-state level. Under Title III, specific service programs include:

- Congregate and homebound nutrition programs for the elderly;
- Health promotion and disease prevention activities;
- In-home services for frail elders;
- Support services, such as transportation; and
- Services that protect the rights of older persons, such as the Long-Term Care (LTC) Ombudsman Program.

The OAA also authorized grants under Title VI to be awarded directly to Indian tribal organizations and organizations representing Native Hawaiians. Service programs are similar to Title III: e.g. congregate and homebound nutrition programs, information and assistance, transportation services, and services that protect the rights of older persons.

The NFCSP builds on these OAA programs and a number of other initiatives during the past 15 years:

- Research sponsored by AoA, the National Institute on Aging (NIA), and others that focused on demonstrating the effectiveness of providing support services to caregivers;
- State-funded caregiver support programs created in the 1980s and 1990s as a response to the growing numbers and needs of caregivers serving an expanding population of older persons wanting to remain in the community; and
- Advocacy by organizations representing caregivers, such as the Alzheimer's Association and the Family Caregiver Alliance (FCA).

The NFCSP acknowledges and encourages the vital role caregivers play in the country's home- and community-based services (HCBS) system. The program seeks to support caregivers in a coordinated and responsive manner.

NFCSP IN BRIEF

Title III-E of the OAA authorized the NFCSP, and Title VI-C authorized the Native American Caregiver Support Program. These amendments (Public Law 106 – 501), both passed in 2000, constitute the first major nationwide program initiatives under the OAA since the 1970s.

Family caregivers have always been the mainstay underpinning LTC for older persons in this country. In 1994 among non-institutionalized persons needing assistance with activities of daily living (ADLs), about two-thirds depended solely on family and friends, and another one-fourth supplemented family care with services from paid providers. Only a little more than 5 percent relied exclusively on paid services.[2]

The program calls for all states and tribes, working in partnership with AAAs and local community-service providers, to offer five basic services for family caregivers, including:

- Information to caregivers about available services;
- Assistance to caregivers in gaining access to supportive services;
- Individual counseling, support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their roles;
- Respite care to temporarily relieve caregivers from their responsibilities; and
- Supplemental services, on a limited basis, to complement the care provided by caregivers.

NFCSP Service Components

1. Information
2. Assistance
3. Individual counseling, support groups, and training
4. Respite
5. Supplemental services

AoA, in developing the program design for the NFCSP legislation, included these service components based on the preponderance of research evidence that indicated they would best meet the range of caregivers' needs and provide the necessary flexibility through the supplemental service category. AoA also drew on the experience of successful state programs, such as those in Pennsylvania, California, and Wisconsin, to identify the services that might constitute an effective multifaceted system of support services for caregivers.

NEW CLIENT POPULATION

The network has always been involved with both the care recipient and caregivers, but now it is charged with addressing caregiver needs explicitly. The OAA identified the following specific caregiver populations:

- Family caregivers of older adults, which encompasses non-relatives.
- Grandparents and relative caregivers of children 18 years of age and younger (including grandparents who are sole caregivers of grandchildren and children who are affected by mental retardation or who have developmental disabilities [MR/DD], although disability

[2] Liu, K., Manton, K.G., and Aragon, C. (2000 January). *Changes in Home Care Use by Older People with Disabilities: 1982–1994*. Washington, DC: AARP Public Policy Institute.

of the grandchild is not required). The caregivers must be a grandparent or step-grandparent of a child or a relative of a child by blood or marriage, be over age 60, live with the child, act as the primary caregiver of the child, and have a legal relationship to the child or raise the child informally.

	NFCSP TARGET POPULATION REQUIREMENTS	
	Any Informal Caregiver	**Family Caregivers Age 60+**
Caring for:	Older Adults	Children < age 18 and older adults
Priority Title III-E and Title VI-C Populations:	Those providing care to older individuals in the greatest social or economic need with particular attention to low-income individuals	Older individuals providing care to children ≤ age18 with MR/DD and older adults with MR/DD

The statute also requires states to give priority consideration to persons in greatest social and economic need (with particular attention to low-income older individuals and older relatives caring for children or older adults with MR/DD). The term "family caregiver" is used generically in this Resource Guide to reflect the legislative language, including any informal caregiver of older adults and grandparents or other relative caregivers over age 60. The NFCSP was enacted as an effort to meet the needs of this segment of the caregiver population. Expansions to the population covered by the OAA only can be effected through an amendment to the Act.

PROGRAM GOALS

The OAA calls for all states and tribes, working in partnership with AAAs and local service providers, to develop multifaceted systems of support services for family caregivers, including information; assistance; individual counseling, support groups and training; respite; and supplemental services. AoA envisions that each of the five service components ultimately will become available to caregivers in every state. Like other OAA services, the program is expected to leverage existing resources to best serve the new target population. It also is designed to stimulate development of a multifaceted system that spans and integrates OAA services and other relevant programs.

- Assistant Secretary Josefina Carbonell, in her opening statement during The National Family Caregiver Support Program: From Enactment to Action conference, elaborated on her vision of the program, specifying some features she hopes to see emphasized, including:
- Creation of optimum flexibility and choices for consumers;
- Partnering with and improving access to faith-based and other community-based providers to enhance support for older Americans and their families;
- Renewal of our focus on intergenerational care; and
- Increasing access so every American will know about the NFCSP, particularly disadvantaged and hard-to-reach families.

Assistant Secretary Carbonell also discussed important implementation strategies, urging the aging network to emphasize *family* services, communicate directly with caregivers, and learn from other programs while recognizing that every state, community, and family is different.

FUNDING

Congress appropriated $125 million for Fiscal Year 2001 and $141.5 million for Fiscal Year 2002 for the NFCSP. In Fiscal Year 2001, SUAs received the greatest proportion of these funds ($113 million), allocated through a congressionally mandated formula based on a proportionate share of the over-70 population, while providing a minimum to each state. Another portion, approximately $5 million in Fiscal Year 2001, supported grants to Indian Tribal Organizations (ITOs). The remainder of the funds go to National Innovation Program, competitive innovation grants and activities of national significance for program evaluation, training, technical assistance, and research. (See ***Appendix B*** for a list of Fiscal Year 2001 Native Americans Elders Caregiver Grants and National Innovation Programs).

PROGRAM POLICIES

Appendix A provides relevant documents related to program policies, including the NFCSP legislation, the AoA Program Instruction 01-02, and the Interim Reporting Guidelines. Regulations for the reauthorized OAA, including the new NFCSP, will be developed after AoA completes a series of "Listening Sessions" to solicit input from the field.

CHALLENGES AND OPPORTUNITIES FOR THE NETWORK

Implementing the NFCSP provides the aging network with both potentially difficult challenges and exciting opportunities. Among these are:

- Integrating the NFCSP with other OAA activities;
- Developing multi-faceted service systems for caregivers in collaboration with agencies within and outside the network;
- Tailoring programs to the diverse caregiver populations that exist in all jurisdictions;
- Focusing on the needs of caregivers as well as those of care recipients and, to the maximum degree possible, integrating these efforts;
- Building flexible and innovative approaches to providing caregiver support services; and
- Developing planning information based on the characteristics and needs of caregivers, and mechanisms for conceptualizing program effectiveness and outcome measures.

This Resource Guide cannot fully address all the issues that arise in the implementation of the new program. It can, however, provide useful information, based on established research and early practice experience, which can assist network agencies as they attempt to resolve these issues.

As a brief overview of the rest of the Guide, listed below are thumbnail summaries of the chapters that follow. Readers are urged to refer to chapters that might be most helpful in meeting their implementation needs.

Chapter II: Roles of the Aging Network describes the ongoing roles and responsibilities of the aging network, including policy development, technical assistance, advocacy, networking, service provision, and reporting, as well as how the NFCSP fits into these roles and responsibilities.

Chapter III: Profile of Family Caregivers examines data on caregiver characteristics and needs, including those of grandparents and relative caregivers of children.

Chapter IV: Systems Development provides a framework for placing the NFCSP within the larger context of the long-term care system and possible strategies for developing partnership opportunities with other agencies.

Chapter V: Program Effectiveness presents mechanisms for conceptualizing program effectiveness in relation to caregiver services and considerations for developing useful outcome measures.

Chapter VI: Working with Families and Other Caregivers explores how the network might move from focusing almost exclusively on care recipients to considering caregiver needs.

Chapter VII: NFCSP Service Components discusses each of the five major service components specified by the NFCSP, providing service descriptions, program examples, and discussion of implementation issues.

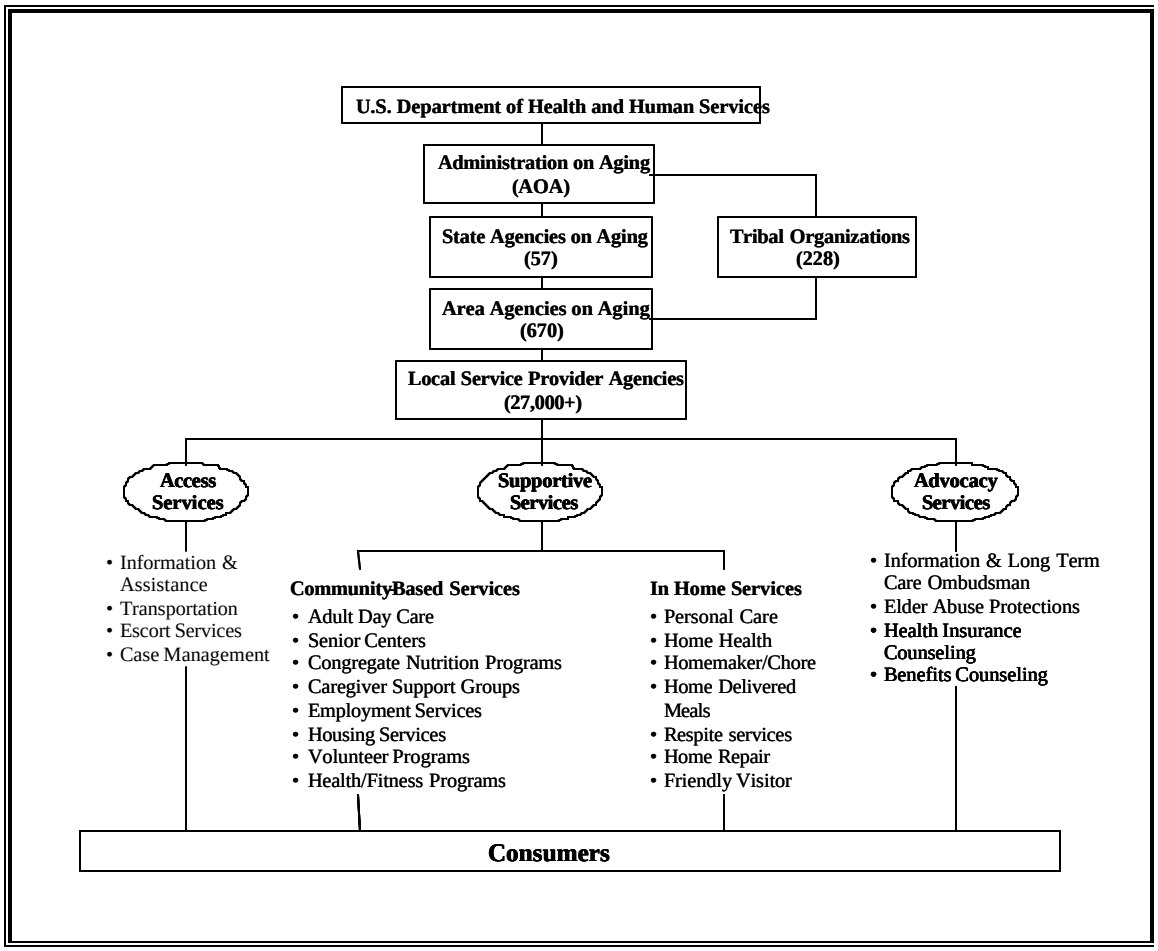
Chapter VIII: Designing the NFSCP in the Context of Diverse Caregiver Populations examines the considerations in serving diverse target populations distinguished by: 1) demographic factors, e.g., ethnicity, race, and culture; 2) special caregiver circumstances, e.g. grandparents raising children; and 3) environmental conditions, e.g., working caregivers, rural caregivers, and long-distance caregivers.

Chapter IX: Nontraditional Approaches highlights several innovative strategies and approaches to enhance caregiver support through: 1) consumer direction, 2) caregiver self-advocacy, 3) volunteer models, and 4) technology applications.

II. ROLES OF THE AGING NETWORK

This chapter details the primary roles of the aging network as they relate to the National Family Caregiver Support Program (NFCSP). Under the authority of the Older Americans Act (OAA), the Administration on Aging (AoA) works closely with other partners in the national aging network to plan, coordinate, and provide home- and community-based services (HCBS) to meet the unique needs of older persons and their caregivers. The aging network includes AoA, 56 State Units on Aging (SUAs), 655 Area Agencies on Aging (AAAs), 233 Indian Tribal Organizations (ITOs) representing 300 American Indian tribes, two organizations serving Native Hawaiians, plus thousands of service providers (SPs). ***Exhibit II.1*** provides an overview of the aging network before the enactment of the NFCSP.

Exhibit II.1
Network on Aging (OAA Structure Chart)



Source: The National Association of State Units on Aging.

Agencies of the aging network may be involved in policy development; service system development; advocacy at the system, program, and consumer levels; service provision; and management. However, AoA, SUAs, AAAs, ITOs, and SPs will have varying degrees of responsibility for each of these activities.

Service provision is a good example. While AoA has no direct role in providing services, SUAs and AAAs may have a limited role. Under the OAA, they can provide direct services if the SUA determines: 1) it is necessary to assure an adequate supply of services; 2) the service(s) is directly related to SUA or AAA administrative functions; or 3) SUAs or AAAs can provide comparable quality more economically. In some states, SUA and AAA staff carry out functions that range from information and assistance (I&A) to care management for OAA programs as well as state-funded and Medicaid HCBS programs. However, in most cases, SUAs and AAAs provide services indirectly, coordinating programs, identifying gaps and weaknesses in services delivery, and directly funding local agencies that actually provide the services required. On the other hand, nearly all ITOs deliver services directly and all SPs do so.

The NFCSP not only adds a sizeable new categorical program for the aging network to administer, it also adds a new priority population to take into account. Thus, the program provides the network agencies an opportunity to re-examine how they carry out their overall roles and responsibilities, particularly in relation to implementing the NFCSP.

ADMINISTRATION ON AGING

Under the NFCSP, AoA, through its central office staff and nine regional offices, performs a number of tasks, including policy development, technical assistance, research and demonstrations, and systems development.

AoA issued program guidance to initiate program implementation and first-year reporting requirements and will issue both regulations and ongoing reporting requirements for the NFCSP. Measures used in the National Aging Program Information System (NAPIS), including those for the NFCSP, are currently under review by AoA and a workgroup of aging network representatives.

AoA has provided technical assistance through a number of activities, including:

- Establishing a technical advisory group (TAG) comprising researchers and aging network representatives who informed the content of this Resource Guide and advised on other AoA technical assistance activities;
- Creating a Web page devoted to the NFCSP;
- Commissioning more than 20 issue briefs from prominent researchers and staff of the aging network and posting them to the NFCSP Web site;
- Sponsoring the September 2001 *National Family Caregiver Support Program: From Enactment to Action* conference at which more than 700 participants exchanged information and generated new ideas;
- Organizing a structured listserv to disseminate research-based information and to generate the exchange of information among network staff; and

- Commissioning this Resource Guide, which brings together information gained from all of the above activities in a practical, easy-to-use format.

AoA also is administering the National Innovation Program under the NFCSP (see ***Appendix B*** for Fiscal Year 2001 awards) and is engaged in systems development work related to caregivers with other federal agencies (e.g., Centers for Medicare and Medicaid Services [CMS] and the Office of the Assistant Secretary for Planning and Evaluation [ASPE]), and national organizations.

STATE UNITS ON AGING

A state's governor designates a state government agency as the SUA to serve as the focal point for all matters relating to older persons within the state. SUAs are located within a multipurpose state agency, such as a department of family services or human services, or their own independent, single-purpose agency, such as a department on aging or commission on aging. SUAs are responsible for ensuring effective implementation of the NFCSP broad policy objectives.

In brief, SUA functions include:

- **Management and Administration.** With input from the AAAs' local plans, advisory bodies, and consumers of services, SUAs develop a state plan inclusive of the NFCSP. SUAs also assume the primary role for the development of an intrastate funding formula (IFF), approving AAA area plans, and monitoring the activities and expenditures under the approved area plans.
- **Service System Development.** SUAs develop a state-level multi-faceted service system in keeping with the NFCSP and integrate this system into the social and health services system for older persons. ***Exhibits II.2 and II.3*** summarize two states' approaches to service system development. ***Exhibit II.2*** shows Washington's program requirements and guidance conveyed to the AAAs regarding the NFCSP. Just before the passage of the NFCSP, Washington had a fledgling caregiver support program. As a result, the state had to cope with the challenge of blending Title III-E requirements and funds with other funding sources. ***Exhibit II.3*** illustrates how North Carolina took a fresh perspective on the caregiver program development.
- **Services Development.** SUAs set policies on quality assurance, provide guidance, and facilitate information exchange among AAAs to make resources available that help shape services development in the state.
- **Advocacy.** SUAs identify areas in which caregiver support programs might need legislative support and might advocate greater state funding. SUAs also advocate for programs with other public agencies and private organizations and promote caregiver support programs with the public at large.

Exhibit II.2
Washington Aging and Adult Services Administration Role in NFCSP Implementation

Title: Washington SUA Approach

Affiliation: Washington Aging and Adult Services Administration

Status: Operational

Approach: The Washington SUA saw its role as shaping local processes rather than prescribing the exact way in which AAAs should provide services. An existing state funded Respite Care program and state funds during the previous year for their Family Caregiver Support Program influenced policy decisions in the development of the National Program. The SUA role included developing a framework for and facilitating discussions with AAAs, distributing materials to AAAs, and expecting that AAAs develop a multifaceted system rather than focus on one specific service category. To do so, the SUA limited funding for respite to 35 percent. In addition, the state required AAAs to develop NFCSP plans that demonstrate how the federal funding will allow them to do something new and that addresses each of the five core service categories.

Contact Information: Hilari Hauptman, Program Manager, Washington Department of Social and Health Services, Aging and Adult Services Administration at haupthp@dshs.wa.gov or (360) 725-2556; Lynne Korte at kortelm@dshs.wa.gov or (360) 725-2545.

Exhibit II.3
North Carolina Department of Aging Role in NFCSP Implementation

Title: North Carolina SUA Approach

Affiliation: North Carolina Division of Aging

Status: Operational

Approach: The North Carolina SUA encouraged each AAA to hire a regional caregiver specialist to lead in leveraging resources, developing partnerships, identifying and supporting critical needs, expanding successful services, and evaluating the program to guide its future direction. The SUA is encouraging specialists to develop a comprehensive system of services that includes each of the five core service categories. To avoid duplication of efforts and ensure cost-effectiveness, the specialists are partnering with many different organizations, including the regional Alzheimer's chapter, vocational rehabilitation's Independent Living Program, social services, support groups, Cooperative Extension, mental health, hospice and end-of-life care, respite care providers, and local lead agencies for planning home- and community-based services. The SUA is also collaborating with AARP and the Duke Family Support Program. To promote a continuous exchange of ideas with regional specialists, the SUA arranged through the University of North Carolina for bimonthly videoconferences between the SUA and the AAAs. The two-hour videoconferences include equal thirds of information sharing, training opportunities, and technical assistance, offering a great opportunity for SUA staff to hear AAA concerns and provide guidance on program development.

Contact Information: Chris Urso, Family Caregiver Program Specialist, North Carolina Division on Aging, at chris.urso@ncmailnet or (919) 733-8400.

AREA AGENCIES ON AGING

AAAs are public or private nonprofit agencies designated by SUAs to carry out the OAA at the sub-state level. AAAs assume many of the same broad responsibilities as the SUA—management and administration, service system development, services development, and advocacy—but focus more on the local area and on direct involvement in services development and delivery. In the 13 states designated as single planning and service areas (PSAs), the SUAs carry out the functions of both the SUA and AAA. AAAs can be public agencies located within county governments, a regional planning council, a unit of city government, an office within an educational institution, or an independent nonprofit organization.

How AAAs carry out their role in implementing the NFCSP likely will be heavily influenced by their role relative to other OAA functions. For example, needs assessment, contract development, and monitoring will be foremost for AAAs that primarily fund providers to deliver services. For AAAs more active in service delivery, e.g., provision of information and referral and care management by in-house staff, issues regarding staff development, assessments, and service coordination might be of primary concern. AAAs at both ends of the spectrum will benefit from improved understanding of caregiver needs and strategies for meeting their needs.

Exhibits II.4 and II.5 summarize two AAAs' approaches to service development. ***Exhibit II.4*** explains the approach of Senior Spectrum, a Maine AAA that also administers the assessment and care management functions of the Medicaid Home- and Community-Based Waiver (HCBW). This AAA chose to have one person become the caregiver specialist for both I&A and care management and also encourage innovative approaches by community organizations through competitive grants. ***Exhibit II.5*** describes the plans of a Minnesota AAA that primarily contracts out most services to develop services otherwise unavailable.

Exhibit II.4
Senior Spectrum Role in NFCSP Implementation

Title: Developing Community Partnerships

Affiliation: Senior Spectrum (AAA, Maine)

Status: Operational

Approach: Senior Spectrum supplemented existing services rather than built an entirely new caregiver infrastructure. The AAA hired one fulltime family caregiver specialist to present information about caregiving and the NFCSP to the public, facilitate relationships with businesses, work with two advisory councils, and develop marketing materials. In addition, the AAA hired a family caregiver coordinator to conduct one-on-one outreach to caregivers, in person and over the telephone, and work with support groups. The coordinator examined existing support groups to determine the style and content of each for referral purposes. If no group meets a caregiver's need, the AAA plans to create additional support groups in such a way that caregivers can take over the group and call on the AAA only when they need support. In addition, the AAA created a seed money fund to support collaborations with community organizations or businesses for effectively identifying and providing resources to caregivers in their community. The AAA targeted specific organizations, including home health agencies and boarding homes, and placed a notice in the daily news asking interested parties to respond to a request for collaborations (RFC). The AAA selected four of eight applicants based on their plans to meet documented guidelines, reach caregivers, staff tasks, meet reporting requirements (which include a one-page progress report halfway through the year-long grant and a two-page final report), build capacity, and sustain the collaborative relationship beyond the seed money. A total of $5,000 was set aside for the fund. Awarding grants of $500 to $2,500, the AAA fully funded three organizations and partially funded a fourth.

Contact Information: Debra Halm, Senior Director, Senior Spectrum, at dhalm@seniorspectrum.com or (800) 639-1552 ext. 119; Leslie Shaffer, Senior Spectrum, at lshaffer@seniorspectrum.com or (800) 639-1552 ext. 106.

Exhibit II.5
Minnesota AAA Role
in NFCSP Implementation

Title: Planning and Collaboration

Affiliation: Region Nine Development Commission AAA, Minnesota

Status: Developmental

Approach: The State of Minnesota's Long Term Care Task Force included supporting the informal network of caregivers as one of its six policy recommendations for reshaping the long term care system. This particular AAA has organized a stakeholder group including caregivers; providers of adult day services, nursing homes, and home health agencies; members of advisory boards; and nurses to help identify priorities for NFCSP funding and provide guidance on AAA requests for proposals (RFPs). In-home respite was identified as one of the greatest unmet needs in the AAA's regional analysis, compiled from the legislatively mandated county gaps analysis. The AAA is striving to expand its role beyond the allocation of funds by offering technical assistance and best-practice information to agencies that serve caregivers, providing materials to distribute to caregivers, and recognizing and supporting caregivers. Finally, the AAA hopes to develop caregiver support and volunteer respite services in the unserved areas of their region, forming a region wide support system for caregivers.

Contact Information: Linda Giersdorf, Director, Region Nine AAA, at lindag@rndc.mankato.mn.us or (507) 389-8866.

INDIAN TRIBAL ORGANIZATIONS

ITOs, comprising Indian tribes, Alaska Native villages or corporations, and organizations serving Native Hawaiians, provide the overall leadership for implementation of the Native American Caregiver Support Program (Title VI-C) and the Native American component of the NFCSP. Through Title-VI programs, ITOs provide multifaceted systems of support services for family caregivers and for grandparents or older individuals who are relative caregivers. ITOs take on the same broad responsibilities as both SUAs and AAAs. In addition to management and administration, service systems development, service development, and advocacy, ITOs provide direct services.

A major challenge for ITOs in implementing the new program involves development of core services. Unlike other communities, many Indian communities lack services, such as home health, adult day services, hospice, and support groups. If services are available in neighboring non-Native American communities, ITOs might consider developing relationships with the providers in these communities and assist in making their services culturally appropriate.

SERVICE PROVIDERS

All local SPs concerned with older persons should consider their role in NFCSP implementation. AAAs will fund some SPs directly. These and other SPs and community organizations might consider serving as a potential referral source as they identify a caregiver in need, raising public awareness of caregivers, offering support groups, training caregivers, or generating funds to supplement caregiver programs. AAAs can foster this type of service development through small service development grants, training providers, regular information exchange meetings, or co-location of services. ***Exhibit II.6*** outlines a faith-based

organization's development of a program to support Jewish caregivers, and ***Exhibit II.7*** details a nonprofit organization's efforts to offer comprehensive services to caregivers. ***Exhibit II.8*** describes how a provider has used OAA dollars through a contract with the state of New Jersey SUA to offer a statewide respite program to local caregivers.

Exhibit II.6
Faith-Based Organization's Potential Role in NFCSP Implementation

Title: As Families Grow Older

Affiliation: Winter Park Health Foundation, Grotta Foundation

Status: Operational

Approach: Grotta Foundation's use of Winter Park Health Foundation's As Families Grow Older (AFGO) curriculum, which consists of a six-part volunteer- and clergy-facilitated workshop, is designed for use by faith communities to educate congregations and the wider community about the aging and caregiving processes. It includes a hands-on planning and program guide; technical assistance materials on volunteer recruitment, training, program publicity, and outreach; and a series of user-friendly participant workbooks to help families make informed choices when dealing with eldercare challenges.

Contact Information: Cathy Michaelson Lieblich, Miller Center for Older Adult Services, at clieblich@wphf.org or (407) 629-5771; See the description in *Caregivers Loss: Family Needs Profession Responses*, Hospice Foundation of America (2001), pages 153–156.

Exhibit II.7
Nonprofit Community Organization's Role in NFCSP Implementation

Title: IONA Senior Services Adult Day Health Center and Caregiver Support Groups

Affiliation: IONA Senior Services, Washington, DC

Status: Operational

Approach: IONA's Adult Day Health Center, a medical model program, assists medically frail older adults having cognitive or physical limitations with a stimulating environment of activities, including Tai Chi, weight lifting, music, art, and pet therapy. The Center provides a place of respite to families responsible for caregiving. The program employs a fulltime nurse to monitor medications, communicate with physicians, and provide support and guidance to caregivers. IONA also sponsors caregiver support groups for adult children caring for older relatives. The six-week sessions are open to family members of participants in the Adult Day Health Center as well as to the larger community.

Contact Information: Mary Ann Fiske, Information and Assistance Coordinator, at mafiske@iona.org or (202) 895-9448. Visit IONA's Web site at http://www.iona.org/ index.html.

Exhibit II.8
Provider's Potential Role in NFCSP Implementation

Title: Statewide Respite Program

Affiliation: Visiting Nurse and Homemaker Services, Division of Senior Affairs (SUA), New Jersey Department of Health and Senior Services

Status: Operational

Approach: Visiting Nurse and Homemaker Services, under a three-year contract with the state of New Jersey SUA, provides a respite program to financially eligible caregivers. Referrals for caregivers in need come from hospitals, social services, and caregivers themselves. The program serves individuals with liberal eligibility criteria, allowing individuals and couples to possess up to $40,000 in liquid assets. Services are delivered in the following ways: in-home services, funding for medical or social ADS, private duty nursing, companion services, temporary respite in institutional settings, and alternate family care. Alternate family care offers short-term placement for the older adult in the home of a New Jersey resident who is willing, trained, and approved to offer temporary respite.

Cost/Funding: The funding supports multiple salaries, including the director, field nurses for assessments, and a financial person. Visiting Nurse and Homemaker Services sponsors the program in two counties with grants: Burlington ($245,180) and Gloucester ($153,385). Seventy-five percent of funds support direct purchase of services and the remaining 25 percent support administrative costs.

Contact Information: Bonnie Mangle, Director of Special Programs, Visiting Nurse and Homemaker Services, at bonnie_mangle@toadmail.com or (609) 267-7417.

III. PROFILE OF FAMILY CAREGIVERS

This chapter profiles informal caregivers and the individuals they assist. An understanding of caregiver characteristics and needs informs program planning and development. As a result, the information presented might be of greater interest to planners and program developers than to others in the aging network. The data compare alternative estimates of the total number of caregivers and relies on the best available sources for describing the target population of the National Family Caregiver Support Program (NFCSP). No single data source captures all the aspects necessary to characterize this population.

Developing a new caregiver support program, or revisiting an existing one, requires a clear understanding of:

- The potential number of caregivers,
- Their characteristics and how these correspond to legislative requirements,
- The characteristics of the individuals to whom they provide care,
- The effects of caregiving on caregivers, and
- Meeting the needs of caregivers.

NUMBER OF CAREGIVERS

Overall Caregiver Estimates

As ***Exhibit III.1*** indicates, estimates of the number of caregivers range from 7 million (3.4 percent) to 54 million (26.6 percent) individuals. Although the exhibit reflects only some of the reasons for differences in caregiver estimates, differences can result from variations in:

- **Population for whom assistance was provided** (age range for the population to whom assistance was provided [e.g., all ages or age 65 and over] and whether the care recipient population considered needed to have a specific level of impairment);
- **Population providing care** (restrictions in terms of the relationship of the caregiver to the care recipient [e.g., relatives versus others] and the caregiver and care recipient living together);
- **Degree of help** (providing any assistance at all versus providing regular assistance, as well as a primary caregiver designation);
- **Timeframe considered for having provided care** (questions structured in terms of a timeframe [e.g., past month or past year] with longer timeframes resulting in more caregivers);
- **Data collection methods** (1] identification of caregivers by asking individuals with a disability or their proxies about all people who provide assistance [care recipient identified] and 2] identification of caregivers by asking a general sample if they provide assistance [self-identified]); and
- **Unit of observation** (counting households rather than individuals).

> Using the two main data collection methods—care recipient identification and self-identified caregivers—surveys have approached estimates of caregivers. Estimates that rely on care recipient identification could double count individuals because some caregivers provide assistance for more than one individual. Data from the Survey of Income and Program Participation (SIPP) suggests this overlap might be as much as 15 percent. In addition, the numbers of helpers the care recipient can identify can affect estimates. In contrast, self-identification might undercount caregivers because it fails to capture some individuals who do not consider themselves caregivers, even though they provide substantial assistance.

Other things being equal, counting households rather than individuals results in smaller estimates because fewer households exist and some households have more than one individual providing care. But, because only one individual in a household would have to provide care for the whole household to be counted, counting households can also increase prevalence estimates (the percentage providing care).

Grandparents Caring for Grandchildren

None of the data sources presented in ***Exhibit III.1*** fully accounts for older grandparents caring for their grandchildren because most data sources fail to consider care provided to children and the estimates that include child recipients also require that the care recipient have a disability. ***Exhibit III.2***, however, presents estimates of the number of grandparents caring for grandchildren from tabulations of the March 1997 and March 2001 Current Population Survey (CPS) and the Census 2000 Supplementary Survey (C2SS). Key distinctions in grandparent caregiver estimates parallel some of those for the broader caregiver estimate, 1) whether the grandchild must be a minor and then whether those age 18 are considered minors, 2) age requirements for the grandparent caregiver, 3) whether the grandparent must be the primary caregiver and how that status is defined (e.g., absence of parents or grandparent currently assuming responsibility for most of the child's basic needs), 4) whether the household must be headed by a grandparent, 5) permanence of the primary caregiver role (e.g., temporarily primary caregiver due to incarceration of the parent), and 6) timeframe and unit of observation. Although the CPS estimates require a grandparent-headed household, the C2SS did not make that stipulation but asked whether the grandparent took responsibility for the minor grandchildren. These approaches resulted in differing estimates, with the lack of the grandparent-headed requirement of the C2SS and the direct question about grandparent responsibility resulting in higher estimates relative to the CPS (2.35 million versus 1.28 million).

Exhibit III.1
Alternative Estimates of Caregivers

	1987 NAC	1997 NAC/AARP	1992 NSFH	1982 NLTCS	1984 NLTCS	1994 NLTCS	1999 NLTCS	1997, 1996 SIPP Wave 5	1998, 1996 SIPP Wave 7	1997 NCOA/Pew	2000 NFCA
Caregivers (in millions)	7.0 4.4 primary 1.1 long distance (20+ min.)	22.4 8.6 primary 5.0 long distance (20+ min.)	52.0	7.6	7.3	7.1	7.0 2.8 primary	13.0	9.5 6.7 primary	7.0 long distance (1+ hr.)	54.0
Unit of observation	Households		Individuals	Individuals				Individuals	Individuals	Individuals	Individuals
Prevalence	7.8%	23.0%	31.0%	4.3%	4.0%	3.6%	3.4%	6.2%	4.5%	3.5%	26.6%
Degree of help	Assistance with 2+ IADLs or 1+ ADLs	Any unpaid care	Any help	Who regularly helps?				Who generally helps?	Provide regular assistance?	Provide or manage care services or financial or legal assistance	Provide support services or personal care
Care Recipient Characteristics											
Age	50+	50+	All ages	65+				15+	All ages	55+	All ages
Functional status	2+ IADLs or 1+ ADLs	Need help to take care of self	Physical or mental condition, illness or disability	ADL or IADL impairments of 3+ months				ADL or IADL impairment	Long-term illness or disability	Unspecified	Disability or chronic illness
Methodological Considerations											
Timeframe for reporting	Past 12 months	Past 12 months	Past 12 months	Not specified				Not specified	Past month	NA	NA
Caregiver designation	Self-identified	Self-identified	Self-identified	Care recipient identified up to 5 helpers				Care recipient identified up to 2 helpers	Self-identified	Self-identified	Self-identified

Exhibit III.1
Alternative Estimates of Caregivers, continued

	1987 NAC	1997 NAC/AARP	1992 NSFH	1982 NLTCS	1984 NLTCS	1994 NLTCS	1999 NLTCS	1997, 1996 SIPP Wave 5	1998, 1996 SIPP Wave 7	1997 NCOA/Pew	2000 NFCA
Methodological Considerations, cont.											
Mode of interview	Telephone	Telephone	1 hour 40 minutes in person	2 hours in person for care recipient; in 1982 and 1999, generally, 30 minutes in person if caregiver lived with care recipient, by phone if not				2 hours in person	2 hours in person	Telephone	Telephone
Sample size	754 Caregivers	1,509 Caregivers	10,005 Individuals about 3,000 caregivers	About 6,000 age 65+ individuals with disabilities				36,700 Households about 60,000 individuals about 2,500 with ADLs or IADLs	36,700 Households about 60,000 individuals 2,829 caregivers	200 Caregivers	1000 Individuals 266 caregivers

1987 National Alliance for Caregiving (NAC) – Wagner, D. (1997). *Comparative Analysis of Caregiver Data for Caregivers to the Elderly 1987 and 1997.*

1997 NAC and AARP (1997). *Family Caregiving in the U.S., Findings from a National Survey, 1997*. Washington, DC: AARP.

1992 National Survey of Families and Households (NSFH) – Administration on Aging (AoA) and Office of the Assistant Secretary for Planning and Evaluation (ASPE). (1998). *Informal Caregiving: Compassion in Action*. Available at http://aspe.hhs.gov/daltcp/reports/carebro2.pdf.

1982 National Long Term Care Survey (NLTCS) – Stone, R., Cafferata, G.L., and Sangl, J., (1987). Caregivers of the Frail Elderly: A National Profile. *The Gerontologist*, 27: 616–626.

1984 NLTCS – Stone, R. and Kemper, P. (1989). Spouses of Disabled Elderly: How Large a Constituency for Long-Term Care Reform? *The Milbank Quarterly*, 67: 485–506.

1994 NLTCS – AoA and ASPE (1998). *Informal Caregiving: Compassion in Action*. Available at http://aspe.hhs.gov/daltcp/reports/carebro2.pdf.

1999 NLTCS – tabulated by The Lewin Group.

1997, 1996 Survey of Income and Program Participation (SIPP), Wave 5, Adult Disability Topical Module – tabulated by The Lewin Group.

1998, 1996 SIPP, Wave 7, Home Care (Caregiver) Topical Module – tabulated by The Lewin Group.

1997, National Council on Aging and Pew Charitable Trusts – Wagner, D. (1997). Long-Distance Caregiving for Older Adults. *Healthcare and Aging*, National Council on the Aging, Spring 1997.

2000, National Family Caregivers Association (NFCA). (2000). Caregiver Survey-2000. Kensington, MD: NFCA.

Over time, the CPS estimates show significant increases in the number of grandparents taking on the role of primary caregiver for their grandchildren. In 1990, parents were absent in 691,000 grandparent-headed households compared to 904,000 in 1997 and 1.26 million in 2001— an increase of more than 80 percent.[3]

Exhibit III.2
Estimates of Grandparents Caring for Grandchildren

	Number (in millions)	Grandparent-Headed Households	Minor Grandchildren Only
Current Population Survey			
1997	3.69	Yes	No
2001			
All grandchildren	4.18	Yes	No
Minor grandchildren	3.61	Yes	Yes
Minor grandchildren and parents absent	1.28	Yes	Yes
Census 2000 Supplementary Survey			
Minor grandchildren	5.60	Not required	Yes
Grandparent responsible	2.35	Not required	Yes

Source: 1997 CPS data from Bryson, K. and Casper, L. (1999). *Co-resident Grandparents and Grandchildren*, Current Population Reports, Special Studies, P23-198, Washington DC: U.S. Bureau of the Census; 2001 CPS data based on unpublished tabulations by The Lewin Group; Census 2000 Supplementary Survey data from the Bureau of the Census Web site summary tables, QT-02 Profile of Selected Social Characteristics: 2000.

Exhibit III.3 shows the impact of the NFCSP requirements regarding grandparents. At the broadest level, the 2001 data indicated 2.81 million households headed by a grandparent where at least one grandchild lives in the same household. Restricting to where the grandparent took on the primary caregiver role by only considering households where the parents of the grandchild were absent reduced the number of households to 1.26 million. The further condition that the grandchild be a minor resulted in 825,000 households. Finally, the NFCSP requirement that the grandparent be age 60 or older produced 327,000 households, or 456,000 grandparents. These data indicate that both the minor grandchild and the older grandparent restrictions significantly narrow the grandparent caregivers for whom NFCSP funds can be used. ***Exhibit III.4*** indicates that about one-half of older grandparents cared for non-minor grandchildren, and nearly two-thirds of grandparents caring for minor grandchildren were under age 60.

[3] Casper, L. and Bryson, K. (1998). *Co-resident Grandparents and Their Grandchildren: Grandparent Maintained Families.* Population Division Working Paper No. 26: Washington, DC: U.S. Bureau of the Census.

Exhibit III.3
Narrowing to the NFCSP Definition of Grandparents Caring for Grandchildren

Grandparent-Headed Households	Considerations	Grandparents
2.81 million	Grandparent-headed households	4.18 million
1.26 million	Parents absent	1.84 million
0.82 million	Minor grandchildren (age 0–18)	1.28 million
0.33 million	Older grandparents (age 60+)	0.46 million

Source: The Lewin Group calculations using data from the March 2001 (CPS) Income Supplement.

Exhibit III.4
Estimates of the Number of Grandparent Households and Grandparents Caring for Grandchildren (Parents Absent), by Grandchild Minor Status and Grandparent Age, 2001

	Total	Grandchild < age 19	Grandchild 19+	Total	Grandchild < age 19	Grandchild 19+
Households						
Total	1,260,216	824,958	435,258	100.0%	65.5%	34.5%
Grandparent age 60+	722,589	326,621	395,968	57.3%	25.9%	31.4%
Grandparent < age 60	537,627	498,337	39,290	42.7%	39.5%	3.1%
Individuals						
Total	1,844,968	1,281,004	563,964	100.0%	69.4%	30.6%
Grandparent age 60+	951,192	455,692	495,500	51.6%	24.7%	26.9%
Grandparent < age 60	893,776	825,312	68,464	48.4%	44.7%	3.7%

Source: The Lewin Group calculations using data from the March 2001 (CPS) Income Supplement.

Some portion of grandparents and possibly other older relatives and non-relatives provide assistance to children with mental retardation or developmental disabilities (MR/DD). Based on data from the 1984 National Health Interview Survey Disability Supplement (NHIS-D), approximately 120,000 children under age 18 with MR/DD lived with other relatives.[4] [5] The number of caregivers associated with these children would be greater because in some households more than one individual would provide assistance. However, just as with the grandparent estimates, we would expect that a significant portion of these non-relatives were under age 60.

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[4] Non-relative living arrangements were negligible.

[5] Larson, S., Lakin, C., Anderson, L., and Kwak, N. (2001). Demographic Characteristics of Persons with MR/DD Living in Their Own Homes or with Family Members: NHIS-D Analysis. *MR/DD Data Brief*. University of Minnesota: Minneapolis, MN. Institute on Community Integration, 3(2).

NFCSP Caregivers

No single data source lends itself to an estimate of the number of caregivers potentially covered by NFCSP definitions. Our best estimate of approximately 8.2 million combines SIPP data for the number of caregivers for individuals age 60 and older with functional limitations (7.7 million) with the CPS data for the number of grandparents age 60 and older caring for grandchildren under age 19 (456,000). This estimate used the absence of parents to define the primary caregiver role, and it lacks non-relative caregivers age 60 and older caring for someone under age 19, but non-relatives age 60 and older caring for minors would be expected to be small. In addition, it fails to consider long-distance caregivers of individuals age 60 and older, who likely exceed 5.0 million.

SUAs and AAAs lacking sufficient resources for a survey-based needs assessment might use 2000 Census data and prevalence estimates of caregivers to approximate the total number of NFCSP caregivers in their area (state, county, city, or census tract). The characteristics of age, sex, and race/ethnicity in ***Exhibit III.5*** were chosen because, 1) data from the 2000 Census are available for many geographic levels for age by sex by race/ethnicity, and 2) the prevalence of caregiving differs by these characteristics. The prevalence estimates for caregivers of older individuals focus on primary caregivers of those with disabilities who are age 65 and older. Additional factors to consider in customizing an estimate for a geographic area include the mobility of the population (e.g., in areas with military bases, this highly mobile population would suggest fewer caregivers) and urban/rural status (central city urban areas are much more likely to have grandparents meeting the NFCSP requirements as a caregiver). While the caregiver prevalence rates for race and ethnicity groups other than those provided in ***Exhibit III.5*** may differ from these broader groups, the national data sources used to estimate the rates did not support statistically reliable estimates for these groups. SUAs and AAAs with high concentrations of Asian, Hispanics, Native Americans or other minorities may wish to supplement any estimates derived based on ***Exhibit III.5*** with their own data collection efforts.

Exhibit III.5
Estimating the Number of Caregivers in an Area

Step 1: Obtain 2000 Census Estimates of Population by Age, Sex, and Race/Ethnicity.

These data can be found using the Bureau of the Census Web site's American Factfinder tool at http://factfinder.census.gov (***Appendix B*** includes screen shots for these instructions). First, select "Advanced National Summary File 1". In the bottom paragraph of the resulting page, click "detailed tables". On the new page, choose "list" as the selection method, and choose "State" as the geographic type. Next, select the state for which you want data and click "Add". Then click "Next". On the resulting page, select "show all tables" as the search. Select the following tables:

- PCT12-Sex by Age (Total Population)
- PCT12I-Sex by Age (White Alone, Not Hispanic or Latino)
- PCT12J-Sex by Age (Black Alone, Not Hispanic or Latino)

Click "Add" and then click "Show Table". Copy the tables into Excel. To calculate "Other," subtract Hispanic, White Alone, and Black Alone from Total. For the White, Black, Hispanic, and Other race categories, sum the ages into the same age groups provided in the matrix below.

Step 2: Multiply the Census data by the prevalence matrix below for each of the corresponding cells. Non-relatives should be multiplied by the total population by age.

Caregivers of Older Individuals

	Male			Female		
	Relative			Relative		
Age	White Non-Hispanic	Non-White and Hispanic	Non-Relative	White Non-Hispanic	Non-White and Hispanic	Non-Relative
18–34	0.17%	0.09%	0.04%	0.34%	0.21%	0.22%
35–44	0.34%	0.16%	0.08%	0.65%	0.39%	0.24%
45–54	0.45%	0.18%	0.09%	1.52%	1.26%	0.51%
55–64	1.06%	0.28%	0.16%	3.14%	2.19%	0.80%
65–74	2.32%	2.11%	0.40%	3.30%	2.97%	0.36%
75+	4.99%	1.70%	0.16%	2.61%	1.85%	0.74%

Older Grandparents Caring for Minor Grandchildren

Age	White	Black	Hispanic	Other
60–64	0.9%	6.3%	4.2%	0.9%
65–69	0.3%	3.2%	1.1%	0.8%
70+	0.6%	4.5%	2.5%	0.6%

Step 3: Sum the results of Step 2 to generate a total estimate of potential caregivers.

CAREGIVER CHARACTERISTICS

This section reviews caregiver characteristics for the broad group of those caring for individuals with a long-term illness or disability and then focuses on the best available estimates of the characteristics of the target populations for the NFCSP.

Caregivers of Individuals with a Long-Term Illness or Disability

The SIPP provides the most recent estimates of caregivers of a chronically impaired population.[6] These data confirm previous research regarding caregiver characteristics, including that:

- People at all stages of life gave and received informal care.
- Adults of all ages assumed caregiving responsibilities, but those in middle-to-late middle age (age 45–64) had the greatest likelihood of being a caregiver.
- Men and women provided informal care; however, women found themselves in this role more often and for longer, more intense periods.
- Caregivers included individuals with competing demands—about one-half employed, one-third with minor children in their home, and one in five both employed and with children.

Additional details on caregiver characteristics, the average hours per week and average number of years spent caregiving, can be found in the issue brief *Characteristics of Caregivers Based on the Survey of Income and Program Participation* by Lisa Maria Alecxih, Sharon Zeruld, and BrieAnne Olearczyk, The Lewin Group at http://www.aoa.gov/carenetwork/issuebriefs.html.

NFCSP Target Populations

Caregivers of Older Care Recipients

The National Long-Term Care Survey (NLTCS) Caregiver Supplement provides the most comprehensive information about caregivers of older care recipients. The care recipient population for whom the caregiver data were gathered is a little more restrictive than that of the NFCSP because it includes individuals with disabilities age 65 and older, rather than 60 and older. In addition, the data include only primary caregivers. Nevertheless, the NLTCS Caregiver Supplement contains the most information about primary caregivers focused on older Americans. ***Exhibit III.6*** suggests that caregivers of older Americans are a vulnerable group with almost one-half over age 65 themselves and nearly one-third in fair-to-poor health status. As with general caregivers, women provided care in the majority of cases. However, for older care recipients, husbands played a notable role, constituting 16 percent of primary caregivers, the oldest subgroup of caregivers, and often the lone caregiver (no additional informal or paid assistance). Just like the general caregivers, the subgroup caring for older care recipients must contend with competing familial and employment demands.

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[6] Alecxih, L., Zeruld, S., and Olearczyk, B. (2001). *Characteristics of Caregivers Based on the Survey of Income and Program Participation*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/IssueBriefs.html.

Exhibit III.6
Characteristics of Primary Caregivers of Older Americans, 1999

Caregiver Characteristic	All Caregivers	Relationship of Caregiver to Disabled Person				
		Wife	Daughter	Husband	Son	Other
Population (1,000s)	2,767	639	837	463	284	543
Row Percentage	100.0	23.1	30.3	16.7	10.3	19.6
Column Percentage Distribution						
Type of Caregiver						
Primary caregiver only	34.4	48.3	29.1	41.8	25.8	24.4
Primary caregiver with unpaid help only	52.4	39.4	57.4	49.0	58.4	59.7
Primary caregiver with paid help only	4.5	5.9	4.7	3.6	4.2	3.6
Primary caregiver with paid and unpaid help	6.0	2.8	6.8	3.7	8.9	8.8
Missing	2.7	3.6	2.1	2.0	2.6	3.5
Race/Ethnicity						
Age in Years						
14–44	11.4	1.0	16.5	0.5	23.2	18.7
45–64	38.0	15.1	65.6	2.2	57.7	42.7
65–74	21.2	35.8	12.3	34.3	10.0	12.6
75+	22.4	37.7	2.3	58.0	1.8	16.0
Missing	7.0	10.4	3.4	4.9	7.3	9.9
Mean age	62.7	71.6	54.8	76.9	53.6	57.4
White	64.9	74.6	78.4	88.1	80.9	0.0
Black	6.2	7.3	11.5	4.2	3.5	0.0
Hispanic	6.4	11.2	7.6	7.1	12.0	0.0
Other	1.8	2.9	2.1	0.7	3.6	0.0
Unknown	20.7	3.9	0.4	0.0	0.0	100.0
Living Arrangements						
Lives with disabled person	68.9	98.4	49.3	97.8	53.3	48.0
Lives separately from disabled person	31.1	1.6	50.7	2.2	46.7	52.0
Marital Status						
Married	71.3	99.5	57.3	99.5	46.1	49.1
Widowed	6.0	0.0	9.7	0.0	1.4	14.7
Divorced/separated	11.5	0.5	19.9	0.0	23.9	14.8
Never married	10.0	0.0	12.0	0.5	27.8	17.4
Missing	1.2	0.0	1.1	0.0	0.9	3.9
Household Members Under 18 Years of Age						
None	89.7	95.1	83.9	98.0	86.8	86.9
1	5.6	3.5	8.5	0.3	4.4	8.5
2	3.4	0.8	5.8	1.1	6.7	3.1
3 or more	1.3	0.7	1.9	0.6	2.1	1.5
Employment Status						
Working	31.7	5.5	50.1	8.5	60.2	38.7
Not working	67.2	93.2	48.7	91.5	37.8	59.7
Missing	1.2	1.3	1.2	0.0	2.1	1.6

Exhibit III.6
Characteristics of Primary Caregivers of Older Americans, 1999, continued

Caregiver Characteristic	All Caregivers	Relationship of Caregiver to Disabled Person				
		Wife	Daughter	Husband	Son	Other
Unemployed Caregivers						
Had to care for care recipient	9.5	9.5	13.4	3.9	11.8	12.1
Not working for other reasons	90.5	90.5	86.6	96.1	88.2	87.9
Health Status						
Excellent	23.6	13.1	27.6	16.1	31.8	31.8
Good	43.2	44.5	45.9	48.5	35.8	36.7
Fair/poor	30.6	39.5	25.4	31.8	29.0	27.8
Missing	2.7	2.9	1.1	3.6	3.4	3.7

Note: Data are based on caregivers for individuals age 65 and older. Race/ethnicity based on the race/ethnicity of the care recipient and, therefore, unavailable for non-relatives.

Source: The Lewin Group tabulation of the 1999 National Long-Term Care Survey.

Older Grandparents Caring for Minor Grandchildren

Tabulations of the March 2001 CPS provide a clearer picture of the characteristics of older grandparents caring for minor grandchildren, as ***Exhibit III.7*** shows. To facilitate an understanding of the characteristics of those grandparents in the NFCSP target population relative to grandparents caring for grandchildren who fall outside the age requirements, the exhibit includes the two groups, plus a comparison to general households with an age 60 and older householder. Based on the characteristics of the householder, all of the comparisons reside at the household level. The NFCSP grandparent population compared to non-NCFCSP grandparents tended to:

- Care for more grandchildren,
- Be a male head of household,
- Be Black and live in a city center,
- Have a lower level of education,
- Be no longer in the labor force,
- Have lower income, and
- Have poorer health status.

Within the NFCSP grandparents, grandfather-headed households were much more likely to have both grandparents present (93.8 percent were married) compared with grandmother-headed households (27.7 percent married). These patterns held true relative to the general householder age 60 and older, with the following exceptions: NFCSP grandparents were more likely to have female-headed households, and among those employed, the NFCSP grandparents were more likely to hold a part-time job, while employed householders age 60 and over tended to have a full-time job.

Exhibit III.7
Characteristics of Grandparent Households Caring for Minor Grandchildren, 2001

Characteristics	Grandparent <Age 60 or Child Age 19+	NCFSP Target Population	Total Grandparent Households	Grandparent <Age 60 or Child Age 19+	NCFSP Target Population	House-holders Age 60+
Total	933,595	326,621	1,260,216	100.0%	100.0%	100.0%
Number of Grandchildren						
1	715,745	210,735	926,480	76.7%	64.5%	NA
2	154,512	74,568	229,080	16.6%	22.8%	NA
3+	63,339	41,317	104,656	6.8%	12.6% *	NA
Sex						
Male	306,815	138,491	445,307	32.9%	42.4%	49.9%
Married	234,933	129,898	364,832	76.6%	93.8%	72.2%
Female	626,780	188,129	814,910	67.1%	57.6%	50.1%
Married	167,789	52,131	219,920	26.8%	27.7% *	20.7%
Race/Ethnicity						
White non-Hispanic	464,202	150,640	614,842	49.7%	46.1%	80.1%
Black non-Hispanic	282,815	126,335	409,150	30.3%	38.7%	9.2%
Hispanic	128,279	39,429	167,708	13.7%	12.1% *	5.4%
Other	58,300	10,216	68,516	6.2% *	3.1% *	5.3%
Metropolitan Area Status						
Central city	226,037	114,356	340,393	24.2%	35.0%	22.6%
Suburbs	321,353	103,951	425,304	34.4%	31.8%	39.4%
Non-metropolitan area	386,205	108,314	494,519	41.4%	33.2%	38.0%
Education						
Less than high school	325,525	152,201	477,726	34.9%	46.6%	28.1%
High school graduate	357,423	99,521	456,944	38.3%	30.5%	33.7%
Some college	178,619	44,325	222,944	19.1%	13.6% *	20.0%
College graduate+	72,029	30,574	102,603	7.7%	9.4% *	18.2%
Employment Status						
Not in labor force	497,758	232,148	729,906	53.3%	71.1%	77.7%
Part-time	287,944	52,790	128,876	30.8%	16.2%	7.7%
Fulltime	93,731	35,145	340,735	10.0%	10.8% *	13.8%
Unemployed	54,162	6,537	60,699	5.8% *	2.0% *	0.8%
Family Income/Poverty Level (2000)						
Under 100%	931,595	324,620	1,258,216	19.2%	24.9%	12.4%
100 – 149%	114,761	62,633	177,394	12.3%	19.2%	14.8%
150 – 199%	94,689	43,280	137,968	10.1%	13.3%	12.3%
200+%	544,805	139,308	684,113	58.4%	42.7%	60.5%
Health Status						
Poor	89,543	31,762	121,305	9.6%	9.7% *	11.4%
Fair	202,176	87,643	289,818	21.7%	26.8%	22.0%
Good	314,784	99,264	414,048	33.7%	30.4%	32.6%
Very good	220,985	74,781	295,766	23.7%	22.9%	22.7%
Excellent	106,107	33,171	139,279	11.4%	10.2%*	11.4%

Note: * Based on fewer than 30 observation and might be statistically unreliable.

Source: The Lewin Group calculations using data from the March 2001 CPS Income Supplement.

Exhibit III.7
Characteristics of Grandparent Households Caring for Minor Grandchildren, 2001, continued

Characteristics	Grandparent <Age 60 or Child Age 19+	NCFSP Target Population	Total Grandparent Households	Grandparent <Age 60 or Child Age 19+	NCFSP Target Population	House-holders Age 60+
Family Income/Poverty Level (2000)						
Under 100%	931,595	324,620	1,258,216	19.2%	24.9%	12.4%
100 – 149%	114,761	62,633	177,394	12.3%	19.2%	14.8%
150 – 199%	94,689	43,280	137,968	10.1%	13.3%	12.3%
200+%	544,805	139,308	684,113	58.4%	42.7%	60.5%
Health Status						
Poor	89,543	31,762	121,305	9.6%	9.7% *	11.4%
Fair	202,176	87,643	289,818	21.7%	26.8%	22.0%
Good	314,784	99,264	414,048	33.7%	30.4%	32.6%
Very good	220,985	74,781	295,766	23.7%	22.9%	22.7%
Excellent	106,107	33,171	139,279	11.4%	10.2%*	11.4%

Note: * Based on fewer than 30 observation and might be statistically unreliable.

Source: The Lewin Group calculations using data from the March 2001 CPS Income Supplement.

NFCSP Care Recipients

Older Adults

The aging network is intimately familiar with the characteristics of older Americans receiving informal care because it constitutes the traditional service population; but it has less knowledge of grandchildren cared for by grandparents that the NFCSP targets. Based on 1998 data from the SIPP, 5.1 million individuals age 60 and older received care from family and friends. ***Exhibit III.8*** summarizes the key socio-demographic characteristics as well as functional status for this group by the relationship to the first listed caregiver. ***Appendix B*** contains data for those age 75 and older and for those with 2 or more activities of daily living (ADLs). Some highlights include the following:

- In general, individuals age 60 and older receiving assistance from family or friends were more likely female, unmarried, living with others, had moderate income, and an instrumental activity of daily living (IADL) impairment relative to ADL impairments.
- Care recipients age 60 and older more often had adult children as primary caregivers (38 percent), followed by spouses (33 percent) and others (28 percent).
- For the age 60 and older care recipient population, females made up the majority of spouses providing care (58 percent wives) and children providing care (70 percent daughters).
- Adult children care for parents who were older on average than those cared for by spouses; however, spouses cared for individuals with more ADL impairments on average than children.

- Recipients of care from their spouse were better off financially than those receiving care from a child or others, primarily because the former enjoyed two social security benefits, while the majority of the latter were widowed.
- Care recipients with 2 or more ADLs were about one-half as likely to live alone, and their spouse was more likely to be the primary caregiver.
- Older care recipients (those age 75 and older) were more likely to be widowed and, as a result, less likely to be receiving care from a spouse.

Exhibit III.8
Characteristics of Older Americans Receiving Care from Family and Friends, 1998

	All Care Recipients Age 60+	Relationship of Caregiver to Disabled Person				
		Wife	Husband	Daughter	Son	Other
Population (1,000s)	5,154	1,001	731	1,379	578	1,465
Row Percentage	100.0	19.4	14.2	26.7	11.2	28.4
	Column Percentage Distribution					
Age in Years						
60–69	25.3	32.6	41.0	18.7	15.2	22.8
70–79	35.2	38.0	38.5	32.9	36.4	33.5
80+	39.4	29.5	20.5	48.5	48.4	43.7
Mean age	75.5	73.6	72.1	77.1	77.4	76.4
Gender						
Male	35.6	100.0	0.0	16.9	25.0	31.3
Female	64.4	0.0	100.0	83.1	75.0	68.7
Marital Status						
Married	45.0	100.0	100.0	17.6	22.5	14.7
Widowed	41.3	0.0	0.0	70.3	66.6	53.1
Divorced/separated	8.0	0.0	0.0	10.1	10.0	14.5
Never married	5.7	0.0	0.0	2.0	0.9	17.8
Living Arrangements						
Lives alone	30.2	0.0	0.0	40.9	37.7	51.7
Lives with spouse only	34.3	81.2	85.3	11.0	10.8	9.0
Lives with children	18.5	12.5	11.1	27.2	30.9	13.2
Other arrangements	17.1	6.3	3.6	20.9	20.7	26.1
Family Income/Poverty Level (1998)						
Below 100% poverty	18.4	7.5	4.7	22.1	18.5	29.0
100%–150% poverty	21.0	17.8	16.1	22.9	22.8	23.0
150%–300% poverty	37.7	41.7	48.9	34.3	37.6	32.4
Above 300% poverty	23.0	33.0	30.3	20.7	21.2	15.6
ADL Score						
No ADLs	52.1	43.9	40.1	55.1	57.6	58.6
1–2 ADLs	26.0	26.5	31.8	25.7	24.7	23.8
3–4 ADLs	9.4	13.3	12.5	7.9	10.9	6.0
5–6 ADLs	12.5	16.3	15.7	11.3	6.8	11.5
Mean ADL Score	1.35	1.73	1.71	1.25	1.04	1.14

Exhibit III.8
Characteristics of Older Americans Receiving Care from Family and Friends, 1998, continued

	All Care Recipients Age 60+	Relationship of Caregiver to Disabled Person				
		Wife	Husband	Daughter	Son	Other
IADL Score						
No IADL	4.2	7.8	8.2	2.3	1.9	2.4
1–2 IADLs	53.4	43.2	45.2	53.2	56.7	63.5
3–4 IADLs	23.1	22.2	29.7	24.9	23.4	18.6
5–6 IADLs	19.3	26.9	16.9	19.6	18.1	15.6
Mean IADL Score	2.51	2.74	2.46	2.59	2.48	2.31

Source: The Lewin Group tabulations of the 1996 SIPP, Wave 5.

Minor Grandchildren

To understand the characteristics of minor grandchildren receiving care from older grandparents, ***Exhibit III.9*** presents data from the March 2001 CPS. For grandmother-maintained relative to grandfather-maintained households meeting the NFCSP criteria, grandchildren in grandmother-maintained households more likely:

- Were Black,
- Had public health insurance (Medicare or Medicaid),
- Lived in city centers in households with three or more members under age 18,
- Had lower income, and correspondingly
- Were more likely to receive assistance from a variety of public programs.

Exhibit III.9
Characteristics of Grandchildren Meeting NFCSP Requirements, 2001

Characteristics	NFCSP Grandfather-Maintained	NFCSP Grandmother-Maintained	NFCSP All Grandparent-Maintained	All Children
Children (number)	226,440	387,502	613,942	72.6M
% distribution	100.0%	100.0%	100.0%	100.0%
Race/Ethnicity				
White non-Hispanic	50.2%	29.9%	37.4%	61.5%
Black non-Hispanic	30.7%	59.8%	49.1%	15.3%
Hispanic	16.0% *	6.3%	9.9%	16.6%
Other non-Hispanic	3.2% *	4.0%	3.7%	6.6%
Age in Years				
Under 6	18.6% *	15.2%	16.4%	32.6%
6–11	41.3%	33.5%	36.4%	34.2%
12–17	40.1%	51.3%	47.2%	33.2%

Exhibit III.9
Characteristics of Grandchildren
Meeting NFCSP Requirements, 2001, continued

Characteristics	NFCSP Grandfather-Maintained	NFCSP Grandmother-Maintained	NFCSP All Grandparent-Maintained	All Children
Gender				
Male	49.3%	54.1%	52.4%	51.2%
Female	50.7%	45.9%	47.6%	48.8%
Nativity				
U.S. born, U.S. parents	91.7%	95.4%	94.0%	78.1%
U.S. born, 1 foreign parent	2.9% *	2.5%	2.6%	6.0%
U.S. born, 2 foreign parents	4.0% *	1.2%	2.2%	11.0%
Foreign born	1.4% *	0.9%	1.1%	4.9%
Health Status				
Good, fair, or poor	26.3% *	29.0%	27.9%	19.5%
Very good	27.7%	20.8%	23.4%	29.3%
Excellent	46.0%	50.2%	48.7%	51.2%
Insurance Coverage				
Private insurance	44.0%	25.2%	32.2%	70.6%
Public insurance only	20.6% *	50.7%	39.6%	17.9%
No health insurance	35.3%	24.1%	28.2%	11.6%
Metropolitan Area Status				
Central city	31.5%	45.3%	40.2%	23.7%
Suburbs	38.6%	25.9%	30.6%	44.6%
Non-metropolitan area	29.9%	28.9%	29.2%	31.6%
Household Members under 18 Years of Age				
One	43.8%	42.2%	42.8%	22.4%
Two	34.4%	20.3%	25.5%	39.7%
Three or more	21.9% *	37.5%	31.7%	37.9%
Family Income/Poverty Level (2000)				
Under 100% of poverty level	19.9% *	33.9%	28.7%	16.7%
100%–149% of poverty level	17.4% *	25.6%	22.6%	10.7%
150%–199% of poverty level	10.5% *	11.5%	11.1%	10.5%
200% of poverty level	52.2%	29.0%	37.6%	62.1%

Exhibit III.9
Characteristics of Grandchildren
Meeting NFCSP Requirements, 2001, continued

Characteristics	NFCSP Grandfather-Maintained	NFCSP Grandmother-Maintained	NFCSP All Grandparent-Maintained	All Children
Household Public Assistance				
No public assistance	64.6%	36.6%	46.9%	71.0%
Any public assistance program	35.4%	63.4%	53.1%	29.0%
School lunch program	25.4% *	53.3%	43.0%	23.6%
Food stamps	10.8% *	26.8%	20.9%	10.7%
AFDC, ADC, TANF, GA**	6.6% *	23.0%	17.0%	5.5%
SSI	9.8% *	12.2%	11.3%	3.3%
Housing assistance	1.9% *	10.3%	7.2% *	5.7%
Energy assistance	1.0% *	8.0%	5.4% *	3.2%

Note: * Based on fewer than 30 observation and might be statistically unreliable.

** AFDC-Aid to Families with Dependent Children, ADC-Aid to Dependent Children, TANF-Temporary Assistance to Needy Families, GA -General Assistance, and SSI-Supplemental Security Income.

Source: The Lewin Group calculations using data from the March 2001 (CPS) Income Supplement.

Grandchildren in households meeting the NFCSP requirements differed substantially from all children in that they more likely:

- Were non-White,
- Were school age (as a result of the age requirement for the grandparents),
- Were U.S. born (as well as their parents),
- Suffered poorer health and were without health insurance,
- Lived in a city center as opposed to the suburbs,
- Had family income less than the poverty level (28.7 percent versus 16.7 percent), and
- Received public assistance (53.1 percent versus 29.0 percent).

The data indicate a vulnerable group of children, with those in grandmother-maintained households more vulnerable but also more likely tied into the public support system.

EFFECTS OF CAREGIVING ON CAREGIVERS

This section borrows heavily from Rhonda Montgomery and Karl Kosloski's issue brief *Change, Continuity and Diversity Among Caregivers,* found at http://www.aoa.gov/carenetwork/IssueBriefs.html. Depending on the caregiver's familial role, the types and intensity of tasks that caregivers perform vary dramatically. The variability in caregiving behaviors indicates that the caregiving experience can differ significantly for caregivers. Montgomery's "marker framework" captures caregiving as a dynamic process and serves as a tool to gauge shifts in

caregiving stages and receptivity to services and supports.[7] The seven markers of this caregiving trajectory are, 1) performance of initial caregiving task, 2) self-definition as a caregiver, 3) provision of personal care, 4) seeking out or using assistive services, 5) consideration of institutionalization, 6) actual nursing home placement, and 7) termination of the caregiver role. An important consideration is that the order and timing of these markers vary, depending on the individual and type of caregiver (e.g., spouse versus adult children caregivers), and these factors have direct relevance for implementing caregiver support programs. In addition to the type of caregiver, an individual's culture might play a significant role in the spacing of these markers.

The caregiving experience of adult children in contrast to spouses illustrates Montgomery's marker framework and the other factors she emphasizes. The careers of adult children and spouses tend to differ both in terms of the factors that define the onset of the role and the factors that prompt family members to abdicate the role. Adult children have greater choice initially assuming the caregiving role and later leaving it than do spouses.[8] The types of tasks that adult-children caregivers initially assume, such as assistance with banking or shopping, represent a major role change. Therefore, children tend to identify themselves as caregivers at an earlier point in the caregiving process than do spouses. As a result, children more readily associate strains that they experience in their lives (impacts on their time, energy, and other familial relationships) as a result of added care tasks with the caregiving role. This attribution of strain to the caregiving role, prompts adult children to seek information and assistance earlier in the caregiving process and also contributes to their leaving the role at earlier stages in the disease and dependency process. For children, the lack of legal obligations and limited familial expectations to provide care make it easier for some not to assume the role in the first place. Children who do become caregivers leave the role feeling less guilt than spouses.[9]

Despite the fact that spouses might more likely be the sole caregiver and experience greater stress than children, they are less likely to identify as caregivers and seek and use formal support. Factors other than a greater level of obligation felt contribute to spouses' greater propensity to provide more care at a higher intensity than do adult children. Many tasks that children perform as caregivers (e.g., assistance with transportation, banking, and household chores), spouses perform as part of their marital role. Failing to recognize early care tasks as unique from the marital role, spouses likely experience burden and stress in association with the caregiver role only after their afflicted mate becomes dependent and the caregiving spouse begins to provide personal care. Even then, their greater commitment appears to make them persist and endure in the caregiving role even if it involves extensive personal care.[10] The

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[7] Montgomery, R.J.V. and Kosloski, K. (2001). *Change, Continuity and Diversity Among Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/ carenetwork/IssueBriefs.html.

[8] Montgomery, R.J.V. and Kosloski, K.D. (1999). *Family Caregiving: Change, Continuity and Diversity*. In P. Lawton and R. Rubenstein (Eds.) Alzheimer's Disease and Related Dementias: Strategies in Care and Research. New York, NY: Springer Publishing Company.

[9] Montgomery, R. J. V. (1999). The Family Role in the Context of Long-Term Care. *Journal of Aging and Health*, 11(3), 383–416.

[10] Doty, P. (1986). Family Care of the Elderly: The Role of Public Policy. *The Milbank Quarterly*, 64, 34–75.

significant change in the marital relationship associated with providing personal care results in spouses reporting greater emotional stress than adult-children caregivers.[11]

Grandparent and other relative caregivers contend with many of the same issues as those caring for older adults, but most do not have to deal with the disease progression aspects. They do face similar challenges related to their assumed role that place them at significantly increased risk for depression, functional limitations, and financial difficulties.[12] More than one in four grandparent-headed households meeting the NFCSP requirements were poor, and among grandmother caregivers, nearly one-third suffered depression and more than one-half experienced at least one limitation in an ADL.[13] Relative caregivers also often face multiple challenges in accessing needed health and other services for the children in their care. In 2000, for example, almost one in three grandchildren living in grandparent-headed households that met the NFCSP requirements had no health insurance. For the majority of caregivers who do not have legal custody or guardianship of the children they are raising, such problems are particularly acute.

MEETING THE NEEDS OF CAREGIVERS

For both caregivers of older Americans and grandparents and other relatives caring for grandchildren, the many often interrelated needs of relative caregivers and their families underscore the importance of developing comprehensive and multilevel interventions flexible enough to meet the full range of needs of the community being served. In addition, remaining cognizant of limited resources, states should create services for the most prevalent types of caregivers in their community. Further, to reach caregivers at the "servable moment" rather than after it is too late, as Montgomery indicates, the network needs to consider effective targeting of services and marketing of services. In offering respite, for example, only when caregivers reach the point at which they are providing extensive care and have identified themselves as caregivers will they become receptive (the servable moment) to respite programs. Strategies to increase receptivity should be based on the understanding that different types of caregivers arrive at the servable moment for different reasons and that caregivers use services only when they perceive the benefits to outweigh the monetary, emotional, or physical costs of using the service. Lastly, programs should create institutional links between service providers to assist the caregivers in identifying services that best meet their needs at any point in the caregiving trajectory. Service provider referrals will enable a program to contend with the changing nature of the caregiving role. In the future, providers will be far more effective in their support efforts if they acknowledge and target both the diversity and the consistencies that social contexts create.

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[11] Stoller, E.P. (1992). Gender Differences in the Experiences of Caregiving Spouses. In J.W. Dwyer and R.T. Coward (Eds.), *Gender and Family Care of the Elderly*, (pp. 49–64). Newbury Park, CA: Sage Publications.

[12] Minkler, M. (2001). Grandparents and Other Relatives Raising Children: Characteristics, Needs, Best Practices, & Implications for the Aging Network, Issue brief prepared for the U.S. Administration on Aging. Available at: http://www.aoa.gov/carenetwork/IssueBriefs.html.

[13] Fuller-Thomson, E. and Minkler, M. (2000). The Mental and Physical Health of Grandmothers Who Are Raising Their Grandchildren. *The Gerontologist*, 37(3): 406–411.

Clearly the social context of the caregiving role has significant impact on the caregiving experience and its consequences. The marker framework reminds us that attention must be given to ensuring the appropriate content of the support service or interventions, the appropriate "dosage" of the intervention, and flexibility of support programs to contend with the changing nature of the caregiving role. In the future, providers will be far more effective in their support efforts if they acknowledge and target both the diversity and the consistencies that social contexts create. Factors that must be considered for targeting include the family relationship and cultural background of the caregiver, and the marker at which a caregiver is located in the career process.[14]

For example, educational programs can be designed to deliver the information that best matches a caregiver's current needs. Because children often self-identify as a caregiver earlier in the caregiving process, they are likely to seek help before to the provision of personal care. Hence, their need for information is going to be different than that of a spouse who seeks services much later in process. Children are more likely to seek information about the disease process, the availability of community services, and legal and financial information. Spouses need help with coping skills and information about behavior management and about in-home support services.

[14] Montgomery, R.J.V. and Kosloski, K. (2001). *Change, Continuity and Diversity Among Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/ carenetwork/IssueBriefs.html.

IV. SYSTEMS DEVELOPMENT

The National Family Caregiver Support Program (NFCSP) should serve as a catalyst for the aging network to construct a multifaceted and coordinated system of supports and services to respond to the needs of caregivers. In general, "system" refers to structures and organization around which customers and services come together. Creating strong infrastructure becomes critical to establishing and sustaining such a system, yet the infrastructure must also be flexible enough to support appropriate and integrated services.

Caregivers currently face a highly fragmented "system" of services that operates within and outside what is traditionally considered the aging network. This system relies on diverse public and private funding mechanisms as well as uncompensated supports provided by volunteers. The advent of the NFCSP offers the network a unique opportunity to leverage and transform this uncoordinated assortment of services and funding mechanisms into a true system that meets the diverse needs of caregivers.

This systems change opportunity also brings a fundamental challenge for the aging network—to transition from an emphasis on service delivery to longer-term capacity building efforts for creating an integrated system to support caregivers. To maximize the NFCSP effect, most resources should be used to leverage existing programs and expertise rather than delivering services to individuals. Generating a critical mass of stakeholders to establish and sustain a system of services and supports for caregivers is in the interest of the aging network. Because of limited funding, the ability to effectively reach and serve the caregiver population becomes inextricably tied to partnerships with other agencies and organizations to leverage and coordinate resources for creating positive outcomes at the state, local, and caregiver levels.

This chapter addresses some of the key issues that should be considered in developing strategies for systems change to implement a responsive caregiver service and support system. Topics covered include:

- Guiding principles for systems development;
- Strategies, including integration with other programs and service systems, partnerships, financing, and visibility; and
- Practical information for planning and assessment to develop viable strategies.

GUIDING PRINCIPLES FOR SYSTEMS DEVELOPMENT

Whether designing a new or expanding an existing caregiver support program, developing goals to guide the effort is important. As Lynn Feinberg suggests, goals for a caregiver support program should promote: 1) seamless support services, 2) efficient use of resources, and 3) positive outcomes for caregivers.[15] The meaning of these goals might vary, depending on the

[15] Feinberg, L.F. (2001). *Systems Development for Family Caregiver Support Services*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/ issuebriefs.html .

perspective of each particular stakeholder. Therefore, in developing program goals, involving a full-range of stakeholders, including caregivers, in the process is beneficial.

The following eight guiding principles, developed by Feinberg, represent key considerations for developing an effective and responsive caregiver support system:[16]

- **Family Role.** Family and informal caregivers are legitimate clients within the organizational field of long-term care.
- **Access.** Services should be available throughout the caregiving process, and caregivers of all ages and income levels should have access to good quality information and support services wherever they reside.
- **Coordination.** Caregiver support systems must coordinate services and leverage existing infrastructures and resources, rather than reproduce the patchwork of services that vary from state to state and community to community.
- **Comprehensive Services Offering Choice.** Caregiver support services should offer a seamless array of services that address a range of caregiver needs and be flexible enough to meet these needs as they change over time.
- **Diversity.** Systems must strive to meet the increasingly culturally diverse and changing population of caregivers, such as working caregivers.
- **Participation.** Families and care recipients must be involved in service planning and delivery as well as care decisions.
- **Respect.** Systems must respect the needs of the caregiver while preserving the dignity and autonomy of the care recipient.
- **Accountability.** Systems for assuring good quality care and outcomes must be integrated into all caregiver support programs.

SYSTEMS DEVELOPMENT STRATEGIES

The NFCSP strives to stimulate the development of a responsive caregiver support system at the state and local levels. The ideal system will offer caregivers a continuum of services that will meet their needs at all phases of their caregiving careers—helping them identify as caregivers, reaching out and supporting their needs, and providing information and services such as respite when necessary. This system will promote seamless services, use resources efficiently, and achieve positive outcomes for caregivers by reaching them at the "servable moment."[17] To develop and sustain this system capacity, a subtle, yet important, shift must occur in the imaginations of aging network planners. A responsive system for caregivers is less about individual assistance through services and more about information brokerage and enhancing service capacity to ensure that the system can reach a broader population base. To develop or

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[16] Feinberg, L.F. (2001). *Systems Development for Family Caregiver Support Services*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/ issuebriefs.html .

[17] Montgomery, R.J.V. (2001). *Change, Continuity and Diversity among Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

expand existing programs into a seamless and responsive system, a number of strategies can be employed.

Integration with Other Programs and Service Systems

As the aging network establishes priorities and plans for the NFCSP over time, a key consideration will be the desired level of coordination between caregiver programs and the broader long-term care system. Establishing the caregiver program separately can preserve the program's primary focus on caregivers, avoid restrictions on flexibility imposed by other programs, simplify the long-term program planning process, and maintain clearer reporting. Integration permits the aging network to leverage resources with other efforts, directly address the problem of system fragmentation, and approach the needs of the "family" unit more holistically. Medicaid, particularly 1915(c) waivers, provides an opportunity to capitalize on existing services for care recipients to provide support for caregivers.[18] Several factors influence decisions to integrate or segment the caregiver support system from the broader system, including the existing system's configuration, the current role of State Units on Aging (SUAs) and Area Agencies on Aging (AAAs) within the system, the presence of funding for caregiver support programs from non–Older Americans Act (OAA) sources, advocacy groups representing caregivers, and the political and economic environment at the state and local levels.

Currently, states use different approaches to develop and expand the capacity of caregiver systems. For example, Maine operates through some AAAs a state-sponsored respite program for caregivers of people with Alzheimer's Disease. The program functions apart from the long-term care system at the state and local levels. To implement the NFCSP, the state is using a similar approach and will keep the program separate from the long-term care system. Moreover, to ensure that the new program meets the state's goal of reaching a broader population than Alzheimer's caregivers, the state is requiring AAAs to demonstrate that they are serving new populations in their plans and reports. Maine determined that segmenting the NFCSP effort from other long-term care programs, such as those covered by Medicaid, would preserve local flexibility and eliminate administrative issues such as incompatible service definitions and rigid reporting requirements.

Pennsylvania's approach is an example of a program that started as a separate initiative and evolved into a more integrated system of caregiver support. The program began as a state-funded pilot effort with dedicated staff and, in many AAAs, as an initiative segmented from other ongoing programmatic activities. Over time, the Department of Aging encouraged greater integration of the program into the broader system by integrating service components funded through the Medicaid Home and Community-Based Waiver (HCBW) program, quality monitoring reviews, computerized systems for assessment and reporting, and regular communication among the AAAs. The program is based on an integrated care management model. NFCSP activities will operate with a similar goal of service integration.

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[18] Smith, G., Doty, P., and O'Keefe, J. (2000). *Supporting Informal Cargiving (under Medicaid)*. Available at http://www.aoa.gov/carenetwork/Fin-Smith.html.

From the start, Minnesota and North Carolina used an integrated approach to plan and implement the NFCSP. For Minnesota, the timing of the NFCSP coincided with a broad, legislatively mandated long-term care system reform, which includes such efforts as expanding existing information, assessment, and consultation services; funding the development of new community-based services; and enhancing quality and improving consumer satisfaction. The lead state agency, the Department of Human Services, views the NFCSP as an opportunity to augment this broader state effort and is seeking ways to integrate the program into the broader system. The existing centralized information and assistance function—Senior LinkAge Line®—offers a visible place to begin this integration. The Senior LinkAge Line® is a 1-800 number that provides information and assistance, if needed, to the elderly and their families regarding programs and services available across the health and social service sectors. Under the NFCSP, this service will be enhanced to offer more consultation to a broader population of caregivers. Minnesota is also exploring ways to integrate NFCSP reporting into a broader effort to develop a streamlined data reporting system that integrates data from all programs associated with the long-term care system. Given the variability of reporting requirements and service definitions associated with the different funding streams involved, this effort represents no small task.

Despite the administrative and planning challenges, both Minnesota and North Carolina decided that coordination and integration offered worthwhile benefits, such as reduced startup costs and other efficiencies associated with aligning their programs with other components of the system. Given the limited resources and large demand for caregiver support programs, any opportunity to leverage resources should be carefully considered. Whether SUAs and AAAs choose to pursue separate programs or work to integrate caregiver supports into the broader system, the aging network is encouraged to examine the advantages and disadvantages of these strategies, seek the appropriate blend of these strategies as the NFCSP evolves over time, and identify barriers to integration and collaboration, or both.

Partnerships and Collaborations

In both integrated and independent caregiver support systems, partnerships, and collaborations with state and local agencies, providers and other stakeholders serve as cornerstones for effective and responsive program development. The aging network has long used partnerships to build programs. SUAs and AAAs commonly partner with each other and providers to carry out OAA Title III programs. In the past, they also have partnered with non–aging network entities to improve service delivery for special segments of the over-60 populations, such as older persons with disabilities. The 1987, 1992, and 2000 OAA amendments, for example, encourage SUAs and AAAs to work with state and local disabilities agencies to plan and develop services for older disabled persons and allow younger disabled adults to be served at congregate meal sites when they accompany their eligible parent or caregiver. Developing a strong network of partners offers the aging network the opportunity to build a more coordinated and effective system while maximizing resources to increase access to caregiver programs.

A diverse group demographically, caregivers demonstrate a variety needs. One of the fundamental challenges inherent in building a responsive caregiver system is developing a system with more than a crisis-response capacity. This difficulty entails building capacity for early identification and programmatic elements sufficient to deliver the right service at the right

time.[19] To build this capacity, the aging network must become creative and consider forming alliances with traditional and non-traditional sectors and organizations. In the broadest sense, the NFCSP spans at least four major sectors within states and communities: the political system, health and human services system, employers, and the faith community. That these sectors recognize their respective roles and responsibilities for caregivers is essential. The list of potential partners and collaborators will vary by state, but could include such entities as:

- State Government – governors, legislators, legislative committees, senior legislatures, and state agencies (e.g., mental health, developmental disabilities, facility services, medical assistance, Medicaid, vocational rehabilitation, housing, agriculture, etc.)
- Advocacy Groups – caregiver alliances, AARP state and local chapters, Alzheimer's state and local chapters, long-term care advocacy groups, disability groups, councils on developmental disabilities, state associations on aging, and ARC (formerly the Association for Retarded Citizens)
- Providers and Their Representative Groups (both long-term care-oriented and broader health) – state assisted-living associations; state health care facilities associations; respite providers; hospice and end-of-life care organizations; home care associations and organizations; physician, nursing, social work, allied health provider, geriatric medicine, and gerontology associations (***Exhibit IV.1***)
- Employers – chambers of commerce and other business associations, employers with interest, large employers that offer caregiver programs, minority business coalitions
- Faith-Based Associations and Organizations – social service organizations, caregiver and home care agencies (***Exhibit IV.2***)
- Others – legal services, state cooperative extension services, state alliances of information and referral services (AIRS), universities, research institutes, community colleges, and area health education (AHECs) (***Exhibit IV.3***)

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[19] Montgomery, R.J.V. and Kolsloski, K. (2001). *Change, Continuity and Diversity Among Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/ carenetwork/issuebriefs.html.

Exhibit IV.1
AAA Partnership with Primary Care Providers

Title: Primary Care Physicians Partnership

Affiliation: Eastern, Aroostook, and Senior Spectrum AAAs (Maine)

Status: Developmental

Approach: These three AAAs are working collaboratively with medical providers on supporting family caregivers. They hired staff from the University of Maine to set up educational and measurement tools. The project involves screening all adults (age 18 and over) who visit a participating primary care practice for routine health care. Patients are asked to complete a brief screen, identifying caregiver stress, as they wait to see the physician. If the screen identifies stress, AAA project staff will contact the caregiver to offer assistance. The program encourages physicians, physician's assistants, and nurses to take a more proactive and holistic approach. It is hoped that these steps will allow the AAAs to reach caregivers earlier in their caregiving career and, thus, decrease their burden.

Cost/Funding: Three-year AoA grant funded.

Contact Information: Roberta Downey, Executive Director, Eastern AAA, at redowney@eaaa.org or (207) 941-2865, ext. 121.

Exhibit IV.2
AAA Partnerships with the Faith Community

Title: Development of Community Partnerships

Affiliation: Pierce County Aging and Long Term Care (Washington AAA), Respite and Crisis Care Coalition of Washington

Status: Operational

Approach: Pierce County is working with the Respite and Crisis Care Coalition of Washington (RCCCW), a consortium of agencies that provide respite for caregivers, to track caregiver needs and available resources that may not be utilized or are underutilized. The goal of this effort is to expand options for service provision by enlisting the assistance of programs such as Interfaith Care Team Ministry, which relies on members of faith communities to assist older adults in a variety of ways, and Senior Companion, which recruits seniors to provide practical help to those in need.

Contact Information: David Hanson, Program Specialist, Pierce County Aging and Long Term Care, at dhanson@co.pierce.wa.us or (253) 798-3807.

Exhibit IV.3
SUA Partnership with a University to Facilitate Capacity Building and Exchange among Geographically Separated AAAs

Title: Staff Videoconferences

Affiliation: North Carolina Division of Aging (SUA)

Status: Operational

Approach: The SUA collaborates with UNC Cares to facilitate bimonthly videoconferences between the SUA and the AAAs. Seven to eight sites across the state have between 3 and 10 participants. Lasting two and one-half hours, the videoconferences are productive, with one-third dedicated to information sharing, one-third offering a training opportunity, and the last third devoted to technical assistance. Participants feel most comfortable participating if at least three people are at each site. The videoconferences allow staff to save travel and time.

Cost/Funding: Because UNC Cares operates the videoconferences through the university system, no cost is associated with them. Some community colleges also offer free sites. However, if they ran the videoconferences through the state system, each conference would cost a few thousand dollars.

Contact Information: Dennis Streets, Planning, Budget and System Supports Section Chief, North Carolina Division of Aging, at dennis.streets@ncmail.net or (919) 733-8400.

For more detail on building partnerships and collaborations around issues related to caregivers of people with developmental disabilities and grandparents as caregivers, refer to the Janicki and Minkler issue briefs at http://www.aoa.gov/carenetwork/IssueBriefs.

The following sections discuss three forms of partnership, i.e. 1) networking, 2) formal partnerships, and 3) financing, and strategies currently being used by the network to carry them out.

Networking

SUAs, AAAs, and ITOs can begin to develop caregiver programs through informal networking within and outside the aging network. Networking permits the identification of individuals and organizations with interests in caregiver issues. Informal networking helps to: 1) identify and build a critical mass of interest around caregiving; 2) build constituencies for support, advocacy, and visibility; 3) spawn creative strategies and approaches; and 4) identify core programmatic goals for short- and longer-term strategic planning and action. Informal networks can become more formalized through conferences and regular meetings.

In the planning phase of caregiver system development, networking offers an invaluable means by which SUAs, AAAs, and ITOs can identify and prioritize issues as well as learn about and leverage existing programs, resources, and services to create a responsive caregiver program. An effective way to create and extend networks around caregiver interests and issues is to establish task forces and advisory councils, at both the state and local levels. Numerous state and local governments already sponsor task forces to address issues concerning aging and long-term care. These groups can serve as natural launch points for developing task forces or committees on caregiver issues. However, to increase visibility and enhance opportunities for buy-in across a broader base of stakeholders, establishing task forces and advisory groups separate from groups with a core focus on aging interests might prove advantageous. These

established groups and constituencies can be invited to sit on the caregiver task force, but opening the forum to a broader range of stakeholders is vital, including providers, social service agencies, mental health programs, Alzheimer's chapters, adult day services programs, the business community, universities, caregiver advocates, and consumers. ***Exhibit IV.4*** highlights one AAA's efforts to establish an advisory task force that networks across several sectors.

Exhibit IV.4
AAA-Established Advisory Task Force

Title: Inland and Coastal Advisory Councils

Affiliation: Senior Spectrum (Maine AAA)

Status: Operational

Approach: Staff at the AAA contacted a diverse group of community members with interests in supporting caregivers to serve as members of two advisory councils that will consult with the AAA about NFCSP issues and plans. Staff either emailed or called individuals at known organizations, stating the purpose of the council and ensuring that all meetings would be efficient and task oriented, which led to successful recruitment. Members range from elder law attorneys, to caregivers, to grocery store workers and members of the chambers of commerce. Enthusiastic council members considered the first meetings of the advisory councils and the AAA, which took place in September 2001, successful and wanted to meet bimonthly instead of quarterly.

Contact Information: Debra Halm, Senior Director, Senior Spectrum, at dhalm@seniorspectrum.com or (800) 639-1553, ext. 119; Leslie Shaffer, Senior Spectrum, at lshaffer@seniorspectrum.comor (800) 639-1553, ext. 106.

Building Partnerships

Compared to networks, partnerships and collaborations among agencies and providers tend to be more formalized and occur after program goals, desired outcomes, and specific approaches for achieving these outcomes have been identified. Opportunities to establish partnerships and collaborations exist at and between the state and local levels and across the public and private sectors (***Exhibit IV.5***). As with other OAA programs, SUAs, AAAs, and ITOs typically create relationships by defining a particular service that will be offered using NFCSP funding and then issuing a request for proposals (RFPs) to solicit vendors and providers. ***Exhibit IV.6*** describes a new approach undertaken by Senior Spectrum, a Maine AAA, when it issued a request for collaboration to seek *partners* for implementing the program, as opposed to *contractors* to provide services.

Exhibit IV.5
State-Initiated, Cross-Agency Collaborations to Create a Multifaceted and Responsive Caregiver Support System

Title: Cross Agency Collaboration

Affiliation: North Carolina Division of Aging (SUA)

Status: Operational

Approach: The SUA is collaborating with a number of organizations to serve caregivers. Partnerships have been formed with the following organizations: Cooperative Extension, which trains staff regarding eldercare and grandparents raising grandchildren; Hospice and End of Life Care, which provides training to health care professionals, faith-based leaders, and the public on end-of-life planning, and is working on the upcoming PBS caregiver series; Duke Long Term Care Support Center, which is acting as a consultant to the SUA and AAAs in NFCSP training; UNC Cares, which is facilitating the videoconferencing and assisting in data collection planning and evaluation; and AARP, which is getting the word out to caregivers and has worked with the SUA in the Grandparents Raising Grandchildren National Teleconference. In addition, the Division on Aging (DoA) is encouraging AAAs to partner with other agencies serving caregivers and to leverage funds. The DoA provided a list of required agencies for AAAs to speak with regarding collaborative efforts.

Contact Information: Dennis Streets, Planning, Budget and System Supports Section Chief, North Carolina Division of Aging, at dennis.streets@ncmail.net or (919) 733-8400.

Exhibit IV.6
AAA-Initiated Partnerships with Community Organizations to Identify and Provide Services and Supports to Caregivers

Title: Developing Community Partnerships

Affiliation: Senior Spectrum (Maine AAA)

Status: Operational

Approach: Senior Spectrum created a seed-money fund to support collaborations with community organizations or businesses for effectively identifying and providing resources to caregivers in their community. The AAA targeted specific organizations, including home health agencies and boarding homes, and placed a notice in the daily news asking interested parties to respond to a request for collaborations (RFC). The AAA selected four of eight applicants based their plans to meet documented guidelines; reach caregivers; staff tasks; meet reporting requirements, which include a one-page progress report halfway through the year-long grant and a two-page final report; build capacity; and sustain the collaborative relationship beyond the seed money.

Cost/Funding: A total of $5,000 was set-aside for the seed money. The AAA was willing to award grants of $500 to $2,500. Three organizations were fully funded and a fourth was partially funded.

Contact Information: Debra Halm, Senior Director, Senior Spectrum, at dhalm@seniorspectrum.com or (800) 639-1553, ext. 119; Leslie Shaffer, Senior Spectrum, at lshaffer@seniorspectrum.com or (800) 639-1533, ext. 106.

Financing

Before the NFCSP, many states, AAAs, and tribes identified the need for caregiver supports for their communities and developed programs accordingly using a variety of federal, state, local, and private funding sources. A less common, but possible, funding approach is the use of cost sharing or sliding scale fees to fund programs.

During the planning and implementation phases of the NFCSP, states, AAAs, and tribes should examine the full array of financing options, including opportunities to blend and leverage funding streams. As noted in the introduction of this chapter, system and service fragmentation, a common attribute of caregiver programs, partially stems from the diversity of funding sources. These disparate funding streams have led to incremental and uncoordinated development of programs and services and have threatened the realization of an effective caregiver support system. Because of the fragmentation within the reimbursement environment for caregiver support programs, estimating the relative contribution each funding source represents for a caregiver support system is difficult. In Pennsylvania, an estimated 50 percent of the funding comes from local sources, 13 percent from federal sources, and 37 percent from state general funds and the Medicaid HCBW (including the state match).

The diversity of funding streams creates some inconsistencies in eligibility and service implementation across and within states and localities. Moreover, within states, a great deal of variability in financing and resource availability among AAA planning and service areas can exist. Further complicating the resource and planning picture for AAAs is the existence of other community-based funders and providers, such as United Way chapters, local foundations, and local community group fundraising, which create additional streams of resources that support large and small caregiver support efforts. These efforts often are outside the purview and control of the AAA or ITO. That AAAs and ITOs seek and identify strategies is important to coordinate with and encourage other existing community-based caregiver support efforts. This procedure will enable AAAs and ITOs to ensure that their activities avoid duplicating or competing with other programs in their communities, and, in the long run, facilitate the creation of a more robust and multifaceted system to support the diversity of caregivers.

In addition to the traditional funding sources, the aging network should examine and consider the viability of policy reforms and other options that will generate additional resources for the caregiver support system. For example, the state of North Carolina identified sources such as corporate tax incentives to create subsidies for eldercare, tax relief for long-term caregiving and expenditures, state expansion of medical leave policies, integration of work and family issues with planning for economic development, and consumer-directed care. Pennsylvania uses a cost-sharing strategy for reimbursing caregiver services. Services like counseling and training are provided free, regardless of income. For services such as respite and durable medical equipment, reimbursement is based on a sliding fee scale. If income is less than 200 percent of the federal poverty line, services are free. Between 200 percent and 380 percent of the poverty line sliding fee scale applies, with clients required to pay 10 percent of services for every 20 percent income increment. If income is greater than 380 percent of the poverty line, clients must pay the full cost of the service or product.

Visibility and Advocacy

Once programs and services are ready to operate, visibility and advocacy becomes an essential component of caregiver systems development. Promoting awareness of and support for caregiver issues can occur in a variety of sectors, including state residents, health and human services agencies and providers, employers, the faith community, and state and local governments. Without expanded visibility and active advocacy, establishing a responsive and successful caregiver system will be a constant challenge.

Many SUAs, AAAs, and ITOs use social marketing strategies to increase awareness and recognition of caregiver issues and needs and to generate support for and knowledge of caregiver supports and services. These marketing strategies vary widely in their goals, scope, and cost and include such activities as developing and disseminating brochures, fact sheets, and other educational materials; producing newspaper, newsletter, and television advertisements containing information about assistance services and caregiver support groups; and conducting public awareness campaigns using billboards, print ads, and television and radio spots.

SUAs, AAAs, and ITOs realize the advantage of coordinating visibility efforts to maximize resources, minimize duplication, and ensure a uniform, consistently communicated vision for the caregiver support system. For example, the SUAs in Maine, Minnesota, and North Carolina work actively with AAAs to develop and coordinate educational and marketing efforts. In Maine, the SUA decided from the start to earmark a percentage of the NFCSP allocation for marketing and educational material development and currently works with the AAAs to develop materials that will convey a consistent message statewide. North Carolina has drafted an RFP to solicit a vendor to develop an Integrated Marketing Communications Plan for Family Caregiver Support Programs in North Carolina.

Many efforts are also being initiated at the local level. For example, the South Central Kansas AAA received a grant award from Administration on Aging (AoA) to support a statewide Caregiver Marketing and Information Campaign, detailed in ***Exhibit IV.7***.

In developing brochures and other marketing materials, several elements of successful social marketing efforts should be considered:

- **Targeting Audiences and Understanding Information Needs.** To develop the most effective messages for educating and effecting changes in a particular population's understanding of or behavior around caregiving, a solid understanding of the target audience is imperative. This knowledge encompasses the social and demographic characteristics (e.g., economic status, age, education, etc.), their psychosocial characteristics (e.g., attitudes, values, motivations, behavioral patterns), and their needs. Obtaining this information, particularly data on psychosocial characteristics and needs, will require application of tools common in market research, including conducting surveys and focus groups. The objective of obtaining this information is to ensure that the messages and materials developed are effective for each population segment you are trying to reach. Realizing this objective will ensure that the message is compatible with the cohort, cultural, and religious morays of each group. In many cases, tailoring your messages to the specific needs of different target populations is necessary.

- **Identifying Information Distribution Channels.** Information distribution channels include television and radio as well as billboards and bus stop shelters, magazines, newspapers, posters, and other print media. Caregivers can also be reached through the care recipient. A vital consideration in the selection of information channels is what source the target groups access regularly and which sources they perceive as most credible. Social marketers note that familiarity with the medium and the performers enhances message acceptance.
- **Evaluating Cost.** Cost is an important factor to consider when developing a visibility or marketing campaign. Television advertisements can be extremely expensive, especially during prime time. Bearing in mind the goals of the campaign and matching the chosen approach to these goals is important. For example, if the goal is to reach working caregivers, a logical communication channel might be a television advertisement or feature on the evening news. However, a lower tech, but potentially more effective and direct, approach might be developing a partnership with a local business and including a brochure on caregiver issues in employee pay checks. Similarly, a brochure advertising a 1-800 information and assistance (I&A) number could be tucked into the monthly utility bills.

Exhibit IV.7
Public Awareness Effort

Title: Caregiver Marketing and Information Campaign

Affiliation: South Central Kansas Area Agency on Aging

Status: Developmental

Target Population: Family caregivers

Approach: The objective of this campaign is to increase public awareness of caregiving through a statewide paid media campaign, providing caregiver tips and resources using television (e.g., half-hour shows, commercials, news segments), radio, and billboards. In addition, the campaign will advertise a 1-800 caregiver line. The NBC affiliate is committing a $75,000 in-kind match. The outcomes of the campaign include increased earlier self-identification by caregivers and greater use of caregiver resources. Campaign products will include training videos, reports on effective marketing tools for reaching caregivers, and copies of caregiver shows that can be shared with other states.

Cost and Funding: AoA grant funded

Contact Information: Stacey Boothe, Caregiver Campaign Manager, South Central Kansas Area Agency on Aging, at ksaaaa@hotmail.com or (316) 681-2144.

Exhibit IV.8 demonstrates each of the elements of a successful social marketing campaign and applies knowledge gained from these activities to service delivery.

Exhibit IV.8
Social Marketing and Service Policy Strategy

Title: OAA Caregiver Programs

Affiliation: Area Agency on Aging of Pasco-Pinellas AAA (Florida)

Status: Operational

Target Population: Family caregivers of individuals age 60 and older.

Approach: The NFCSP Title III-E Program has a three-phase implementation plan that consists of: a determination of needs, caregiver forums, and service implementation in both Pasco and Pinellas Counties. The needs assessment phase, conducted largely through a contract with the University of South Florida, included a review of caregiver literature, interviews with stakeholders, focus groups, public hearings, and an evaluation plan to provide a blueprint for evaluating the effectiveness of implementing the final recommendations. During the next phase, caregiver forums were held on a variety of topics to offer support to caregivers and to gain feedback concerning their needs. Service implementation will be based on recommendations gleaned from the first two phases to ensure that money and energy are applied to development of services that caregivers want and need.

Cost/Funding: AoA grant funded.

Contact Information: Beverly Burton at burtonb@elderaffairs.org or (727) 570-9696 ext. 253; Sally Gronda, Executive Director, at Grondas@elderaffairs.org or (727) 570-9696 ext. 266.

SYSTEMS DEVELOPMENT PLANNING AND ASSESSMENT

A key to the aging network's success in implementing Title III programs is the balance of local-level flexibility with state-level accountability. The success of a caregiver support system requires a similar commitment to flexibility, but not just between the state and local levels. To realize the potential of the NFCSP to create systems change and expand support for caregivers, a commitment to flexibility and coordination must exist, coupled with systematic planning across all facets of the long-term care system.

Systems Assessment

The structure and capacity of long-term care and caregiver systems varies by state. Some states, such as California, have legislated and financed, using state general funds, separate programs to support caregivers. Others, like Wisconsin, Minnesota, and North Carolina, have integrated caregiver support programs and funding into the community-based long-term care system. A significant first step in planning or expanding a caregiver support system at the state level is assessing the capacity of the existing long-term care system to address the needs of caregivers. Program planners must examine the existing capacity and potential building blocks of the system for:

- Type of Caregiver Served/Eligibility Criteria for Existing Services – any caregiver: low socio-economic status, grandparent, parent of the developmentally disabled, Alzheimer's Disease, etc.

- Services and Supports Offered – information and assistance, respite, support groups, supplemental services, caregiver assessments, caregiver planning, adult day services, in-home services, home-delivered meals, "best practices" related to family-centered practice and employer eldercare, etc.
- Sponsoring Agencies – aging, health and human services, developmental disabilities, mental health, education, etc.
- Reimbursement and Financing Sources – Medicare, Medicaid, OAA, state general funds, tribal funds, foundations, philanthropic organizations, and financial assistance programs such as tax credits, low-income housing, and medication assistance, etc.

Exhibit IV.9 provides a framework for assessing the caregiver support capacity of a state or local system. This framework can be used to organize a variety of planning-related activities, including assessing NFCSP readiness; identifying the functions for the state in terms of providing technical assistance, data collection, and tool development; as well as goal setting for each component of the NFCSP.

The framework provides an approach for assessing an existing system and service environment for each of the NFCSP service components by population. Completing this exercise by population coincides with the way grants and programs are funded. This approach also offers a way to think about potential for moving the overall system and services toward universal access. Another application of this framework is to use it as a point of discussion with partners to identify caregiver activities occurring outside of the aging network.

Exhibit IV.9
Caregiver Systems Change Capacity Assessment Framework

Repeat for each service component: 1. Information, 2. Assistance, 3. Respite, 4. Education, 5. Supplemental Services

Programs and Services							
Populations	**In Network**	**Outside Network**	**Partnerships**	**Integration**	**Advocacy**	**Funding**	**Caregiver-Directed Support**
OAA Priority							
Socio-economic Status Disadvantaged							
Developmental Disability							
Grandparents							
State Priority[1]							
Alzheimer's							
Working							
Minority							
Rural							

[1] Example caregiver populations that SUAs and AAAs might target.

Step 1: **Environmental Scan.** Record existing programs, services, and activities by population for each of the five NFCSP service components.

Step 2: **Goal Setting.** Specify short- and long-term goals for each framework element (i.e., column headers).

Step 3: **Identify Barriers and Facilitators.** Identify barriers and facilitators for implementing, achieving, and sustaining program goals.

Step 4: **Goal Analysis and Refinement.** Analyze capacity to achieve goals and refine objectives, if needed.

Needs Assessment

An additional approach commonly used in program planning and implementation is conducting a needs assessment (see David Hanson's issue brief at http://www.aoa.gov/carenetwork/issue.briefs.htm). The goal of this exercise is to determine how many people need what types of services and supports. Various methods can be used to conduct a needs assessment, including surveys, secondary data estimates (e.g., census data) (see ***Exhibit III.5***), focus groups, and public hearings. However, knowing where to begin with developing a survey sampling strategy or even how to frame the questions for the survey and focus groups can prove difficult. Key issues to consider include the following:

- What is the target population (e.g., caregivers associated with current care recipients, caregivers unassociated with current care recipients)?
- What are the needs of the caregivers, especially the priority populations specified in the NFCSP legislation and those identified by the state or locality?
- Which of these needs is most immediate?
- Which stakeholders should be involved in the planning process?
- What is the timeframe for the planning process and program implementation?
- What state, tribes, and local agencies and providers (e.g., disability, social services, education, health care) currently fund or deliver services to the caregiver population?
- What resources currently are available for the target caregiver population or populations?
- What challenges that will affect the development of a caregiver support system are anticipated?

Exhibit IV.10 discusses the efforts of the AAA in Pierce County, Washington, to conduct a needs assessment.

Exhibit IV.10
Caregiver Needs Assessment

Title: Needs Assessment

Affiliation: Pierce County Aging and Long Term Care (Washington AAA)

Status: Operational

Target Population: Caregivers ` questionnaire distributed to more than 500 caregivers (see Appendix B for a copy of the survey instrument) and a focus group that included caregivers and professionals who work with caregivers. In preparing to conduct the needs assessment, staff consulted data from caregiver surveys, articles, and books on the subject of caregiving; attended a national conference featuring sessions on caregiving; and followed the progress of local studies that focused on the availability and accessibility of information for caregivers. The focus group included caregivers, a caregiver support group facilitator, and staff members from an Alzheimer's/dementia caregiver support program. The focus group generated a number of ideas for conducting outreach to caregivers, refining I&A services, and involving caregivers in the NFCSP planning and evaluation processes.

Contact Information: : David Hanson, Program Specialist, Pierce County Aging and Long Term Care, at dhanson@co.pierce.wa.us or (253) 798-3807.

V. Program Effectiveness

Measuring the quality, benefits, and accomplishments of the National Family Caregiver Support Program (NFCSP) can assist agencies in a variety of ways, by providing vital information for setting and refining program goals, identifying training and technical assistance needs, allocating resources efficiently, recruiting volunteers, and improving the effectiveness of services. Moreover, structuring quality assurance activities and assessing program effectiveness and outcomes enables agencies to ensure that programs provide value to consumers. Title III-E and Title VI-C of the Older Americans Act (OAA) includes a requirement for State Units on Aging (SUAs) and Indian Tribal Organizations (ITOs) to develop quality assurance mechanisms designed to assure the quality of services provided.[20]

Assessing program effectiveness involves the following concepts:

- Context – sponsoring group's organizational structure and program partnerships (e.g., independent state aging department or housed within a broader state agency that includes the Medicaid single state agency)
- Process – program resources (inputs) and type or level of program activities conducted (e.g., the availability of each of the five NFCSP service components)
- Outputs – direct measurable results of the program (e.g., number of caregivers that received respite services)
- Outcomes – results of program activities that capture whether objectives and goals have been met (e.g., new knowledge gained)
- Performance Measures – ongoing monitoring and reporting of program accomplishments, which can include process, outputs, and outcomes
- Impact Evaluation – one-time or periodic assessment of program results relative to the absence of the program

Given the early stage of development of the NFCSP, this chapter focuses on performance measurement rather than on impact evaluation. Performance measures indicate what actually occurred in terms of implementation and meeting program goals and objectives. As a result of their ongoing nature, performance measures can serve as early warning mechanisms for management and a vehicle for improving public accountability. Reaching consensus on these measures and establishing mechanisms for their ongoing measurement early in the program's development will put the network in a better position to respond to caregiver need and eventually determine program impact.

This chapter provides a starting framework for assessing the effectiveness of the multifaceted caregiver support program. It builds on the 2001 Administration on Aging (AoA) NFCSP conference presentations of David Lindeman, Lynn Feinberg, and Ken Wilson.[21] Due to the

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[20] Older American Act, Title III, Part E, Section 373(e)(1).

[21] Lindeman, D., Feinberg, L., and Wilson, K. Presentation at the Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action.* September 6, 2001. Available at http://www.aoa.gov/carenetwork.

newness of the NFCSP, the sections emphasize key quality assurance and evaluation issues associated with the early stages of a program lifecycle. Topics covered include conceptualizing and assessing effectiveness, information system development, and current measurement efforts under way at AoA.

CONCEPTUALIZING CAREGIVER PROGRAM EFFECTIVENESS

As outlined in previous chapters, the NFCSP presents the aging network with an ambitious goal to develop a multifaceted and coordinated system of supports and services responsive to the ever-changing needs of caregivers. To do so, the program will transform the way states and communities view community-based long-term care by integrating a central, yet often invisible, population—caregivers—into the service system. Developing and sustaining a delivery system around caregivers requires the aging network to shift the focus from primarily care recipients to both recipients and caregivers. A similar shift will be necessary in conceptualizing program effectiveness.

A responsive caregiver system requires the aging network to know which implementation efforts work, for whom, and under what conditions. Additionally, because the NFCSP connects to the larger long-term care system, understanding how and to what extent caregiver support services mesh with other services, including the health, behavioral health, and social services, becomes critical. Ultimately, policymakers will want to know whether these programs merit the investment. Such knowledge entails developing short-term (e.g., initiation of a program), intermediate (e.g., enhanced caregiving skills, reduced social isolation), and long-term measures (e.g., establishment of an integrated system).

NFCSP effectiveness can be assessed according to the overall goals of the program and for each of the specific service components. The specific measures of effectiveness will depend on the level of analysis (e.g., state or community system, organization, and individual) as well as on the specific goals of each activity implemented. NFCSP presents a particular challenge because its inherent flexibility makes prescribing concrete outputs to measure difficult. The focus must be on outcomes that are often more problematic to observe and measure partly because of the need for follow-up. The nature of the program will require a heavy emphasis on caregiver and family perceptions to measure progress.

ASSESSING PROGRAM EFFECTIVENESS

Tracking and measuring context, process, outputs, and outcomes can help determine the extent to which the NFCSP makes a difference, strengthening and improving existing services, and serves as a component of quality assurance. A range of stakeholders (e.g., administrators, frontline staff, consumers, community members, partners, etc.) involved in defining the intended goals of the program or particular intervention helps ensure relevance. Documenting the goals in the form of a mission statement can facilitate consensus. This type of focused discussion about the purpose of and outcomes expected from specific program activities forces all parties involved to express and examine their beliefs about what works, for whom, and under what conditions. With systematic examination, planned activities can be refined, if necessary, and brought into better alignment to achieve the desired program outcomes. This process also offers the opportunity to examine the feasibility and potential burden of collecting

data to analyze desired outcomes. If the staff involved understand the value of collecting the data necessary for assessing outcomes, they might be more diligent in the quality of their data collection.

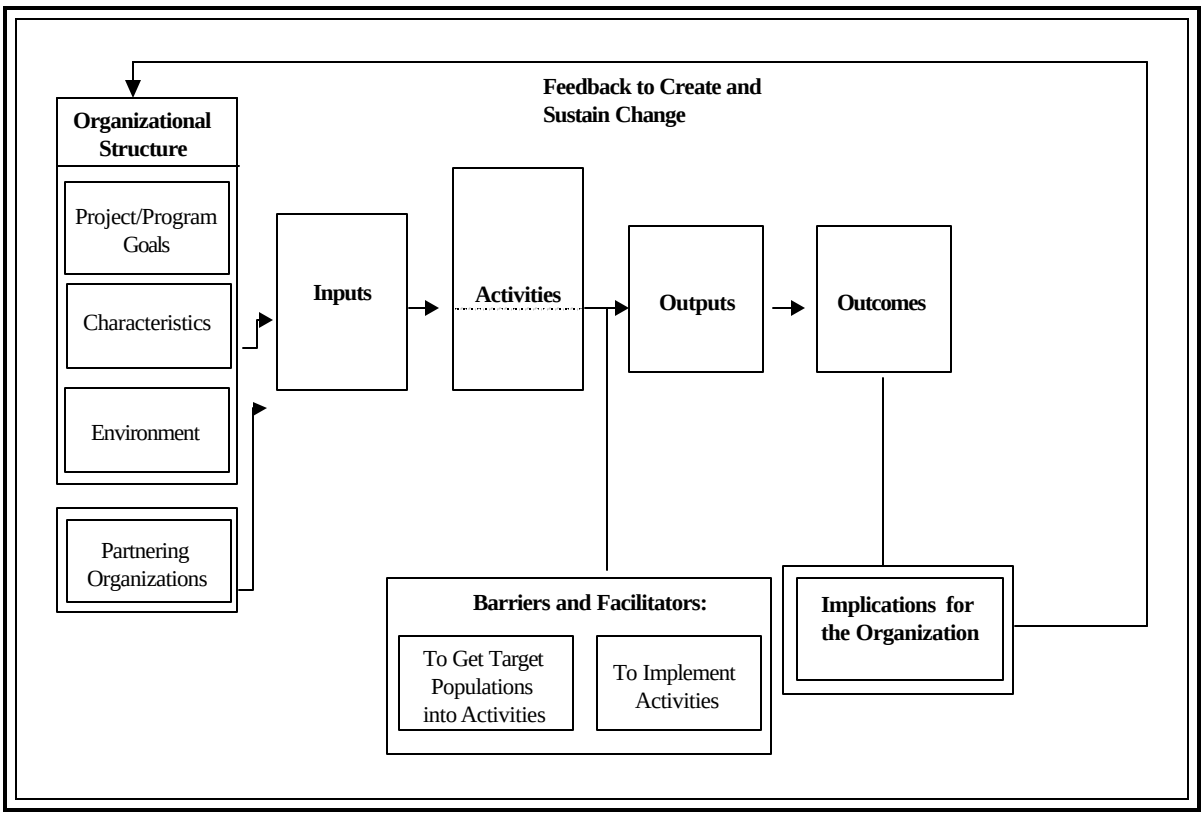
Exhibit V.1 presents a framework for tracing the logic of a program and the relationships between the different components that influence program effectiveness. In addition to context, process, outputs, and outcomes described previously, two components that straddle context and process and can be helpful for conceptualizing indicators and outcomes include:

- Barriers (structural and other impediments that will affect the ability of activities to achieve intended outcomes, such as regulations, funding requirements, lack of available and appropriate staff and volunteers, inadequate infrastructure, etc.) and
- Facilitators (structural and other factors that will augment or affect favorably the ability of activities to achieve intended outcomes, such as partnerships and community linkages, internship arrangements, etc.).

The context and process heavily influence a program's ability to produce the desired outputs and outcomes. A feedback loop from program outcomes to the program then formalizes an important mechanism by which programs can understand what does and does not work and then use this information to adapt and refine the program, program activities, or both to improve effectiveness.

Measuring and demonstrating program effectiveness typically occurs at the levels of the individual and the program. Yet, also examining how these outcomes can contribute to broader organizational- and system-level goals provides an opportunity to consider broader implications of the NFCSP, such as expanding system capacity for caregiver programs, leveraging funding and maximizing resources through partnerships and linkages with other entities within the system, and creating other possible system-level changes.

Exhibit V.1
Program Effectiveness Framework and Feedback Loop



Source: The Lewin Group Program Effectiveness Framework

Individual Level

The focus on the caregiver, care recipient, or both involves the development of new program goals and expectations. Because of the variability and mutability of caregiver needs for services and supports, traditional methods of measuring and assessing the effectiveness of services might be inadequate. The aging network can use the existing knowledge base regarding service and support needs of caregivers to plan and develop a responsive system of supports for this population. However, assessing the effectiveness of this type of system, and the programs within it, presents a challenge similar to other social service programs.

Ensuring a truly effective and responsive system necessitates a re-conceptualization of program outputs and outcomes to include assessing the value programs provided to caregivers.[22] For example, examining the concept of program responsiveness to the caregiver would likely combine context, process, and output and outcome measures at the individual level, such as the following:

[22] Feinberg, L.F. and Pilisuk, T.L. (October 1999). *Survey of Fifteen States' Caregiver Support Programs: Final Report*. San Francisco, CA: Family Caregiver Alliance.

- What are the characteristics of the caregiver and his or her current situation? (context)
- Were the individual's needs assessed and preferences elicited? (process)
- What were the number and types of service units received by an individual? (output)
- Did a match exist between what the caregiver asked for, qualified for, and received? (outcome)
- Was the caregiver satisfied with the service availability and the services received? (outcome)
- Did the caregiver's initial depression scale score improve after the FCSP intervention? (outcome if the program's goal or mission includes reducing caregiver stress)

The initial program emphasis on caregiver information and assistance as critical components of systems change suggests the network might want to focus first on issues related to caregiver access.

Organizational Level

The overarching system goals, as well as the goals organizations specify for planned and implemented activities, will influence conceptualizing the effectiveness goals at the organizational level. Potential measures from the same example goal of program responsiveness from the individual level discussed above can be framed for the organizational level:

- What are the general characteristics of the caregivers accessing the program, and how do subgroups differ? (context)
- What percentage of caregivers has a documented assessment? (process)
- Have caregivers been involved in program planning? (process)
- What percentage of caregivers receives each of the five service components? (output)
- What percentage of applicant caregivers received the help he or she requested? (outcome)
- What percentage of caregivers was satisfied with the service availability and the services received? (outcome)
- What percentage of caregivers' has reduced depression following the FCSP intervention? (outcome if the program's goal or mission includes reducing caregiver stress)

Other goals specific to organizations could include the following:

- Broad dissemination of information about available services
- Ensuring sufficient capacity to meet demand for caregiver services
- Establishing responsive and collaborative service networks with families
- Leveraging resources (e.g., funds from other sources and volunteers) and developing partnerships with other agencies and businesses
- Involving caregivers in program development and implementation
- Improved timeliness of interventions
- A specific percentage of caregivers indicating that he or she was very satisfied with services provided.

A critical component of program-wide and system-wide effectiveness is leadership that promotes the consumer's perspective of effectiveness throughout the activities of an

organization and system.[23] ***Exhibit V.2*** describes one of Pennsylvania's SUA activities to monitor and improve services provided by Area Agencies on Aging (AAAs) as an integral part of their existing quality assurance activities. Organizations that actively solicit input and suggestions about quality improvement from consumers ultimately prove to be more responsive to consumer needs. ***Exhibit V.3*** provides an example of an evaluation of a specific intervention that solicits feedback from participants and measure outcomes that should change as a result of the training, measures which could inform whether the training appears to be worth the investment and should be expanded.

Exhibit V.2
Incorporating the NFCSP into Ongoing Quality Assurance

Title: Clinical Consultants

Affiliation: Pennsylvania Department of Aging (SUA)

Status: Operational

Approach: Six clinical consultants work in the state of Pennsylvania to monitor AAA quality. Each clinical consultant is assigned AAAs, and he or she visits each AAA four times a year. Over three years, at least one visit must focus on the caregiver program. The consultants review a 50 percent case sample and evaluate the assessment, the care plan, the statement of accountability, and the generic care management notes. They also look at nursing facility eligibility. If the facility is eligible, the consultant makes sure a registered nurse (RN) reviewed and signed the plan and checks why the caregiver is in the FCSP rather than in the Medicaid Home- and Community-Based Waiver (HCBW) program. When problems are identified in the care plan, the consultant looks for and reviews the plan of action.

Contact Information: Dan McGuire, Chief, Division of Managed Care, Pennsylvania Department of Aging, at **dmcguire@state.pa.us**.

[23] Polister, B.H., Blake, E.M., Prouty, R.W., and Lakin, K.C. (1998). Reinventing Quality: The 1998 Sourcebook of Innovative Programs for the Quality Assurance and Quality Improvement of Community Services. Minneapolis, MN: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration (UAP).

Exhibit V.3
Measuring Outcome from a Specific Intervention

Title: Caregiver Training Evaluation

Affiliation: Olympic AAA, Washington

Status: Operational

Target Population: Caregivers who complete the "Powerful Tools for Caregiving" training. (For a discussion of this program, see *Exhibit VII.17* in *Chapter VII*.)

Approach: Participant caregivers in the "Powerful Tools for Caregiving" training complete a survey before and after the training to quantify a number of aspects of caregiver health. The survey includes questions such as "How much have you slept? Exercised? Had social contact? Avoided Conflict?" Comparing the results of the post-training survey with those of the pre-training survey to evaluate caregiver stability, evaluators can see if caregiver health declines, remains stable, or improves.

Contact Information: Hilari Hauptman, Program Manager, Aging and Adult Services Administration, at **haupthp@dshs.wa.gov. or (360) 725-2556**

System Level

At the system level (federal, state, and community), definitions and indicators of program effectiveness can be linked directly to the requirements specified in the NFCSP legislation, the program guidance issued by AoA, and goals established by the aging network more broadly. Examples of these goals include the following:

- Implementation of the NFCSP at the state and local levels, including all five program elements, serving the priority populations
- State implementation of a quality assurance system
- Establishment of an accessible, responsive, and multifaceted caregiver support system at the AAA and ITO level, funded by multiple sources, including Title III-E
- Formation of broad-based coalitions to leverage and enhance caregiver support, which involves and solicits feedback from caregivers
- Evidence of a shift in focus from individual care recipients to both the caregiver and care recipient
- Increased public awareness of caregiver issues and needs

These program goals are broad yet flexible enough to allow for regional and local responsiveness to specific community needs. Their general nature opens the opportunity for SUAs, AAAs, and ITOs to determine specific performance indicators that make sense given their specific political and economic contexts, the current capacity and starting point of their systems, and what is appropriate and culturally relevant for their caregiving populations.

Some of these goals easily translate into output and outcome measures. For example, counts of individuals receiving each of the five service components by priority population designation for each AAA in a state would measure the degree of success relative to the first goal. Other goals will present a greater challenge to develop outcome measures. Demonstrating that an accessible, responsive, and multifaceted caregiver support system at the AAA level, funded by multiple sources, including Title III-E, has been established will require measures that follow up with caregivers regarding these aspects of the system or measure broader activities. One

measure of the program's being multifaceted might be the extent to which states and local communities mobilize working task forces with diverse membership. Measures of access might include the following questions: Do families know what services are available? Do families know how to access services? What is the evidence of accessibility?

The aging network can build on activities and outcome measures at the individual level to develop outcome measures at both the organizational and system levels. For example, caregiver assessments conducted by AAAs allow a care manager to document the caregiver's characteristics, expressed needs, and measures of burden and stress. These factors can be used to develop a responsive approach to meet the individual's needs. At the organizational level, generating regular reports summarizing the characteristics of the caregivers served and their needs can assist AAAs in refining the target audience and the interventions that must be developed further. At the system level, if a statewide, electronic uniform assessment has been developed, data from across AAAs could be combined to examine the degree to which priority populations are served. In the absence of statewide electronic systems, AAAs could report the data to the SUA.

Reassessments provide an opportunity to measure change over time and inquire whether the caregiver and his or her family feel that the AAA has responded to their needs and can be relied on going forward. If the proportion of caregivers indicating that the AAA has been responsive proves lower than expected, the organization has to determine the cause and adjust its manner of doing business. This feedback aspect of outcome measurement can enhance clinical practice of individual staff, processes of the organization, and development of resources at the system level.

NFCSP MEASUREMENT DEVELOPMENT ISSUES

As noted above, programs commonly measure and assess program activity outputs without ever assessing program outcomes. This situation occurs for a variety of reasons, including insufficient measures, data, and knowledge about how to operationalize outcome measures and the perception that measuring outcomes requires too much time relative to the value of the information obtained through this activity. Notwithstanding, in the interest of sustaining and expanding the NFCSP, the aging network must develop evidence of program effectiveness and value to caregivers.

The framework presented above offers a way to begin thinking about measuring program effectiveness and value to caregivers. However, the multifaceted nature of the NFCSP means that the connection between cause and effect will sometimes be unclear or difficult to measure. Mapping interventions directly to outputs and outcomes can prove complex because many factors (i.e., barriers and facilitators) intervene and influence the implementation of activities associated with interventions. In addition, many factors beyond the influence of the intervention can affect program outcomes on individuals. Therefore, to the extent feasible, those developing outcome measures have to anticipate and attempt to measure these factors and ensure that expected outcomes are attainable through the intervention.

As discussed in ***Chapter IV***, based on her review of 15 state-funded caregiver programs, Feinberg outlined eight systems development principles that underpin the goals of the NFCSP

and can provide a framework for thinking about potential outcomes: 1) family role, 2) access, 3) coordination, 4) comprehensive services offering choice, 5) diversity, 6) participation, 7) respect, and 8) accountability.[24]

Also discussed in ***Chapter IV***, an important tenet of the NFCSP is to leverage funding and resources with other systems and services in the community. This opportunity to blend funding and integrate services presents another complexity to measuring and accounting for the effectiveness of caregiver services. Further, the NFCSP might encompass other AoA services. For example, the information and assistance (I&A) program might be the primary provider of information for caregivers, and provision of home-delivered meals might be a part of in-home respite services. Developing a data system that appropriately counts units of caregiver support provided by other aging programs presents a major challenge. SUAs, AAAs, and ITOs involved in partnerships and service linkages will have to think carefully about the definition and measurement of effectiveness in the context of these complex, yet necessary, arrangements. Methods of gathering and measuring caregiver's perceptions will likely emerge as the core of these efforts.

As noted earlier, the very nature of supporting caregiving as a program requires coordination and cooperation across the aging network and other networks that serve caregivers. This coordination and cooperation could be accomplished by mobilizing working task forces within and across states. An expanded base of supporters might help strengthen the system of caregiver support, enabling program expansion across the state. For reasons of sustainability, each task force member needs to benefit from his or her involvement, either personally or for the organization represented. The aging network is positioned to learn from and collaborate with others oriented to family support, such as the developmental disabilities agencies and agencies administering Temporary Assistance to Needy Families (TANF). ***Exhibit V.4*** provides an example of how approaches targeting other populations that focus on families could be adapted to measuring outcomes for NFCSP caregivers.

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[24] Feinberg, L. F. (2001). *Systems Development for Family Caregiver Support Services*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork /IssueBriefs.html .

Exhibit V.4
Adapting Outcome Measures from Other Family-Centered Interventions

Early Childhood Intervention Outcomes	Possible Adaptation for NFCSP
Do the family see early intervention as appropriate in making a difference in their child's life?	Do the caregiver, family, or both see the NFCSP services as appropriate for making a difference in their (caregiver recipient's) life?
Do the family see early intervention as appropriate in making a difference in their family's life?	Do the caregiver, family, or both see NFCSP services as appropriate in making a difference in their family's life? Measurements could include stress and routines and activities constructed by families to achieve basic functioning.
Do the family view professionals and the special service system positively?	Do the caregiver, family, or both view professionals and the special service system positively?
Did early intervention enable the family to help their child grow, learn, and develop?	Did NFCSP enable the caregiver, family, or both to continue providing assistance to the care recipient or reach resolution as to the appropriate course of action?
Did early intervention enhance the family's perceived ability to work with professionals and advocate services?	Did the NFCSP enhance the perceived ability to work with professionals and advocate services for the caregiver, family, or both?
Did early intervention assist the family in building a strong support system?	Did the NFCSP assist the caregiver, family, or both in building a strong support system?
Did early intervention help enhance an optimistic view of the future?	Did the NFCSP help enhance an optimistic view of the future?
Did early intervention enhance the family's perceived quality of life?	Did the NFCSP enhance the perceived quality of life for the caregiver, family, or both?

Source: Bailey et al. (1998). Family Outcomes in Early Intervention: A Framework for Program Evaluation and Efficacy Research. *Exceptional Children*. 64(3): 313–316.

In the future, the network should benefit from the results of an AoA Innovation Grant awarded the Ohio SUA, detailed in ***Exhibit V.***5, to develop a model outcome-based quality assessment system for caregiver programs that will incorporate the recommendations of caregivers, older adults, the aging network, and service providers. Project Director Richard LeBlanc, summarized the importance of the project as follows: "We believe that the key innovation here is that the mechanisms of accountability implemented as a result of this grant will be perceived and will, in fact, be directly supportive of the efforts of family caregivers rather than being perceived as an 'inspection' to monitor if the services are delivered according to structural specifications. Consumers will not feel at the mercy of the service system." [25]

[25] LeBlanc, R. Email to Lisa Alecxih. February 14, 2002.

Exhibit V.5
NFCSP Innovative Grant for Outcome Development

Title: An Outcome Based System for Enhancing the Quality of Caregiver Support Services

Affiliation: Ohio Department of Aging (SUA)

Status: Operational

Target Population: Caregivers that receive service from the FCSP

Approach: In Ohio, as in most other states, agencies take responsibility for the quality of support services. This project is predicated on the premise that traditional notions of quality assurance rely heavily on structural and process requirements that, all too often, are unrelated to what consumers define as "quality" service. The project is designing and testing an outcome-focused quality monitoring system for the range of OAA services that benefit caregivers as well as older people. Developed with input from caregivers, older consumers, the aging network, and service providers, the system will place primary emphasis on the needs of the caregiver, recognizing and supporting management of services by the family, including voucher-based reimbursement approaches. With the assistance of the Scripps Gerontology Center, the project includes a literature review, the organization of an advisory group and regular meetings, focus groups, and development and evaluation of measures. The resulting outcome-based measures are being used to create a guide for SUAs, AAAs, and providers interested in improving the quality of caregiver support services delivered through the aging network.

Cost/Funding: This program is funded through an AoA grant.

Contact Information: Richard LeBlanc, Program Manager, Ohio Department of Aging, at **dleblanc@age.state.oh.us** or (614) 644-7967.

AOA'S PERFORMANCE OUTCOME MEASURES PROJECT

In this early phase of NFCSP implementation, AoA is working actively with the aging network to develop data reporting requirements and assessment requirements that maximize the utility of information gathered while minimizing reporting burden. Currently, states report a number of outputs as a stand-alone report—expenditure data, units of service, and number of people served for the five categories of service (i.e., information; assistance; individual counseling, support groups, and training; respite care; and supplemental services). AoA is still determining the most effective way to incorporate Title III-E reporting into the Title III reporting system.

In conjunction with output reporting, AoA has sponsored a project, Performance Outcomes Measures Project (POMP), to develop and test a core set of performance measures for state and community programs on aging operating under the OAA. (For further information on POMP, please visit http://www.gpra.net/.) This initiative aims to assist SUAs and AAAs address their respective planning and reporting requirements, while helping AoA meet the accountability provisions of the Government Performance and Results Act (GPRA).

Given the advent of GPRA and related state and local initiatives that link continued funding to demonstrated benefits and outcomes, collecting timely, accurate, and comparable data becomes particularly significant. GPRA requires federal agencies to develop performance plans and set specific, measurable outcomes for their programs to achieve. Through annual performance reports, agencies provide detailed information on their progress in meeting performance objectives. Notably, Congress now uses GPRA information to support decisions on

appropriation levels and reauthorization of programs. Many state and local governments demand similar systems of accountability to document results and justify funding.

POMP could offer a potential source of effectiveness measures for the aging network. One of POMP's eight client-service domains includes caregiver well-being, support, and satisfaction questions. (For the most recent and past versions of the caregiver survey tool as well as methodological information, visit http://www.gpra.net/CGmain.htm). The 2001 version included 64 primarily categorical questions that asked caregivers to:

- Rate the quality of services provided to the care recipient and themselves, a subset of which are specific to NFCSP services;
- State their level of satisfaction with services and benefits of the services;
- Identify areas of unmet need in both services and information;
- Delineate the amount of care they provide and other support available;
- Enumerate burden and benefits of caregiving; and
- Provide information about their personal characteristics and situation.

The responses to this set of questions, or a subset of them, could be used to develop:

- Individual-level measures of outputs (e.g., how many individuals receive what types of caregiver services or combination of services) and outcomes (e.g., the percentage of caregivers rating services as very good or excellent) that could then be aggregated for the organization,
- Information for targeting (e.g., what are the characteristics of caregivers accessing particular types of services), and
- Areas for improvement (e.g., the most prevalent area of unmet need identified).

If other POMP domains focused on the care recipient (e.g., physical functioning, social functioning, and emotional well-being) were administered to individuals receiving care from caregiver survey respondents, the combination could more robustly assess the interaction of services related to the care recipient and caregiver.

Another POMP component involves developing measures that address program-level outcomes, such as capacity building, to measure the results of work conducted by SUAs and AAAs to enhance the size and scope of services for the aging. These activities include fundraising, coordination, advocacy, legislation development, and policy initiatives that affect service systems, often outside the scope of SUA and AAA programs. They also cover expanding the availability of nursing home alternatives, such as Medicaid HCBW among other alternatives to institutionalization. To improve access to and streamline the availability of existing services, these capacity-building activities also include such service system enhancements as centralized intake and assessment across multiple agencies and programs. These process measures provide tested methods to round out and possibly model NFCSP-specific measures for a program effectiveness assessment.

INFORMATION SYSTEM INVESTMENT AND DEVELOPMENT

The aging network recognizes the need to incorporate mechanisms for assuring program quality and effectiveness in caregiver support programs. Information systems that promote systematic collection and data analysis are a necessary component to any caregiver program. To be most effective and efficient, data collection systems must be developed before, rather than after, programs begin to provide services and supports. The majority of state programs apply some form of assessment tool to determine the care plan for the care recipient; however, before the NFCSP, most states assessed inconsistently and unsystematically the needs and situation of the family caregiver. A systematic assessment of the care recipient and not the caregiver, places the care recipient at an advantage over the caregiver in documenting, and possibly responsiveness to, identified need.

Developing a uniform, statewide information system would be an important investment to improve the quality of care and advance policies and programs to support and strengthen caregiver systems. As Feinberg notes, caregiver information systems, at a minimum, should include: 1) data from uniform, psychosocial assessment of the caregiver needs; 2) data from reassessments of caregiver need at regular intervals to track change over time; 3) community resources for the caregiver and care recipient; 4) information on the numbers of caregivers served, types of services provided, costs and amount of services delivered; and 5) data on outcomes achieved.[26] The initial investment for developing information systems might appear costly; however, over time, this type of system can actually reduce costs and provide a firm foundation for efficient care planning and service delivery. In addition, this type of system enables ongoing assessments of program outcomes and quality and strategic planning for new services and initiatives.

Many states are developing information systems to incorporate program data from NFCSP efforts. The challenge is to create a system that enables tracking of both care recipients and caregivers and to build in a mechanism that links the populations. Moreover, considering the technological capacity (i.e., computer hardware, software, and staff training) of AAAs is important. Ideally, new data system development would be compatible with data systems already in place so information could be integrated, if needed. Some states, such as Minnesota, are considering a more comprehensive overhaul of their data reporting systems. Minnesota is examining the feasibility of integrating Title III-E data with other OAA data as well as with a comprehensive state long-term care (LTC) database. Other states are seeking more targeted solutions to building databases to collect and assess caregiver program information. For example, North Carolina plans to build a database using spreadsheet software that will allow collection and assessment of caregiver data over time (see ***Appendix B***). In developing this information system, a core consideration was creation of a user-friendly system that was compatible with their existing hardware and software.

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[26] Feinberg, L.F. (2001). *Systems Development for Family Caregiver Support Services*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/ IssueBriefs.html .

VI. WORKING WITH FAMILIES AND OTHER CAREGIVERS

This chapter provides information to help understand the family and the caregiver context, the application of caregiver assessment and care management, and caregiver use of the formal service system.

When designing and implementing family interventions, the objective is to emphasize the family strengths and resources and build on existing resources, rather than focusing on problems and weaknesses. Likewise, caregiver system developments and enhancements must support and not disturb the "fabric of the family relationship."[27]

UNDERSTANDING THE FAMILY

The National Family Caregiver Support Program (NFCSP) calls for the aging network to expand its focus to support caregivers as direct consumers—with needs distinct from, but circumstances intertwined with, the care recipient. The broad definition of *family caregiver* under the NFCSP allows flexibility in supporting the needs of those who care for close family members, other relatives, friends, neighbors, domestic partners, and others. It involves working with individual caregivers and with families.

In working with families, the network should consider the following set of reminders, developed by Lisa Gwyther.[28]

Basic Concepts

- Family care is an adaptive challenge; the family is not necessarily the problem.
- The family is rarely a single voice, and few families have only one person needing care at a time.
- No one right or ideal way or place to offer family care exists. Many families are forced to choose among equally unacceptable options.
- No perfectly fair and equal division of family care responsibility exists. Families can expect a permanent imbalance in the normal give and take of family relationships but still work toward a more equitable sharing of responsibility.

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[27] McGuire, D. AoACarenet Listserv, April 30, 2001.

[28] Adapted from Gwyther, L. Caregiver Counseling, Education and Support Groups, October 15, 2001.

Elements for Success

- Successful family caregivers are flexible in adjusting expectations of themselves, the dependent elder, and other family members to fit needs and capacity of all.
- Coping with family care requires a sense of humor, a strong faith or value system, creativity, practical problem-solving skills, and support from friends and family.
- Successful family caregivers gather information, take direct action when possible, and often reframe in more positive terms things they cannot change.

Challenges

- Underreporting of burden and underuse of services is common among caregivers.
- A family caregiver's knowledge of, need for, and access to an available service do not necessarily lead to appropriate timely use of services.
- No bad defense mechanisms exist. Some people need to deny the inevitable outcome (i.e., loss of a loved relative) to provide hopeful, consistent care.
- No perfect control exists in a care situation. Families are better off if they work on their reactions to stress or lack of control. Even in ideal situations, contingency plans are necessary.

UNDERSTANDING THE CAREGIVER CONTEXT

Caregiver situations vary, and different situations require different interventions. To support caregivers effectively with the right services at the "servable moment," the network must understand and appropriately respond to the unique caregiving situation.[29] The network must be prepared to address savvy caregivers as well as caregivers who harbor misconceptions about service coordination. Caregiving circumstances can affect the quality of information exchange and ultimate service delivery.

Exhibit V1.1 depicts the following elements, which circumscribe the major dimensions of the caregiving context to consider when working with caregivers.

Contextual Dimension

- Relationship of the caregiver and care recipient (spouse, adult child, in-law, grandparent, grandchild, friend)
- Location of the caregiver relative to the care recipient (co-residence, nearby, long-distance)
- Family values and beliefs (cultural background)
- Health of the caregiver (physical, mental, social)
- Nature of previous family relationships (conflicted, distant, estranged, nurturing, supportive)

Care Task Dimension

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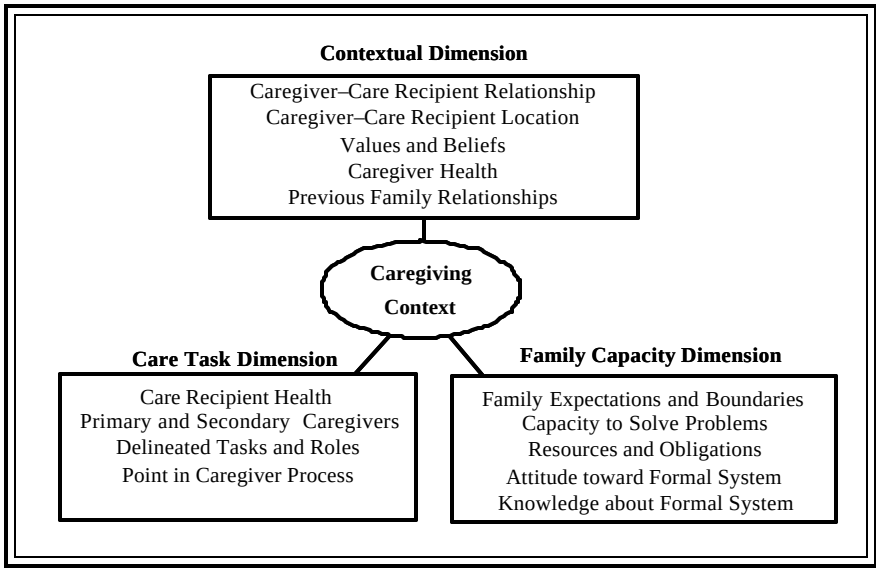
[29] Montgomery, R.J.V. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

- Health of the care recipient (conditions, cognitive, functional, and behavioral strengths and deficits)
- Existence of both primary and secondary caregivers (decision-making and perception of who is in charge)
- Sharing of caregiving tasks and delineation of roles (structure to accomplish caregiving tasks)
- Point in the caregiving process and the caregiver's receptivity to support (see discussion of Montgomery's "marker framework" in ***Chapter III.***

Family Capacity Dimension

- Underlying family expectations and boundaries (inclusion and exclusion of family members)
- Family capacity to solve problems (ability to identify and discuss problems, explore alternative solutions, and resolve problems)
- Available resources and caregiver obligations (work, caring for others, income, informal resources)
- Family attitude toward the formal service delivery system (factors include culture, ethnicity, religion, socioeconomic status, geography, past experience, and others)
- Caregiver's knowledge about the formal service delivery system (how it operates, service coordination)

Exhibit VI.1
Dimensions of the Caregiving Context



CAREGIVER ASSESSMENT

Conducting a caregiver assessment formally captures information on the caregiving context and institutionalizes the acts of listening to and directly supporting caregivers. It reinforces the program goal to expand the network focus on caregivers and families. Caregiver assessments "clarify the nature of the caregiving situation both in terms of the caregiver's characteristics and competing demands, and the care recipient's characteristics that influence the caregiving experience."[30] Using an assessment instrument might support collection of demographic data on caregivers served by the program, help to ensure uniform procedures are followed, and assist agencies in making fair decisions about resource allocation when the demand for services exceeds the supply. Furthermore, assessments aid in evaluating service effectiveness and continuous quality improvement.

Some of the common reasons given for not pursuing caregiver assessments include: 1) burden in the amount of time needed to complete the assessment (service provider and caregiver burden), 2) hampered ability to develop trust and rapport with caregivers and care recipients (probing questions before reaching a level of comfort), and 3) interference with the natural flow of the clinical process (available interventions cannot address caregivers' concerns, or issues are raised prematurely).[31] ***Exhibit VI.4*** at the end of this chapter offers tips that can help minimize these concerns. Regardless of whether an agency decides to adopt a caregiver assessment instrument, an inevitable challenge will arise in working with frustrated or skeptical caregivers who might have completed assessments in the past as part of the care recipient's care but received no intervention addressing their own expressed concerns, expectations, or preferences.

Agencies considering the use of caregiver assessments will have to: 1) establish the constructs to be included in the assessment, 2) design the instrument, and 3) develop implementation procedures.[32]

Constructs of Existing Assessment Instruments

The major domains of caregiver assessments often include:

- Caregiver well-being and health;
- Health, functional status, preferences, and behaviors of care recipients;
- Level of care, skills, supervision, or tasks required to care for recipient;
- Negative caregiving consequences;

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[30] Guberman, N., Keefe, J., Fancey, P., Nahmiash, D., and Barylak, L. (2001). *Assessment Tools Serving the Needs of Caregivers: A Document to Better Understand the Importance of Assessing Caregivers' Needs.* Project funded by the Health Transition Fund of Health, Canada.

[31] Bass, D. (2002). *Content and Implementation of a Caregiver Assessment.* Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

[32] Bass, D. (2002). *Content and Implementation of a Caregiver Assessment.* Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

- Caregiver strengths; and
- Informal and formal network of support for care recipients and caregivers.

Many researchers and practitioners also include the construct of caregiver burden in caregiver assessments. Most measures of caregiver burden recognize that burden is multidimensional and includes both subjective and objective dimensions. Steven Zarit's caregiver burden scale focuses on the intra- and interpersonal experiences of the caregiver. Most multidimensional scales have two drawbacks: 1) they tend to be lengthy (possibly causing respondent fatigue and aversion to seeking further assistance) and 2) they are unvalidated for use with culturally and ethnically diverse caregiver populations.[33]

Assessing the functioning of families as caregiving systems is another possible component of a caregiver assessment. In this case, the focus is on family processes around caregiving and the perception of family support. Gathering information about the network of family and friends is critical for interventions designed to support and mobilize the informal care network.[34]

Exhibit VI.2 showcases several instruments for assessing caregivers. A helpful resource for the network, scheduled for release in July 2002, is a "promising practices" monograph on caregiver assessment prepared by the Family Caregiver Alliance's National Center on Caregiving. The monograph will discuss caregiver assessment issues from a practice perspective. It will include a brief history of caregiver assessment, cover the importance of assessing the needs and situation of the family or informal caregiver, summarize existing caregiver measures, identify "best practice" criteria for cargiver assessment tools, and discuss how caregiver assessments can be used to inform policy and practice. Information about its release will be posted on the Family Caregiver Alliance Web site at http://www.caregiver.org/.

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[33] Gupta, R. (1999). The Revised Caregiver Burden Scale: A Preliminary Evaluation. In *Research on Social Work Practice*. 9(4): 508–520. Sage Publications, Inc.

[34] Bass, D. (2002). *Content and Implementation of a Caregiver Assessment.* Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

Exhibit VI.2
Caregiver Assessment Instruments

California Caregiver Assessment Tool and Instruction Manual

These assessment materials were developed by the Family Caregiver Alliance (FCA) and are used by the state's Caregiver Resource Centers to examine the needs of families caring for adults who suffer from chronic brain disorders. FCA conducts thorough training for all staff who administer the assessment. Direct requests for the instrument and instruction manual to Lana Sheridan, Family Caregiver Alliance, National Center on Caregiving, 690 Market Street, Suite 600, San Francisco, CA 94104. Your request should include a check for $25 to cover the cost of printing, handling, and shipping.

Pennsylvania Department on Aging Caregiver Assessment

The caregiver assessment is part of Pennsylvania's Comprehensive Options Assessment Instrument used for home- and community-based programs for older adult care recipients. A practical, user-friendly assessment, it captures information about the informal support network and more detailed information about the primary caregiver. It includes a modified version of Steven Zarit's Caregiver Stress Interview along with scoring instructions. Forms and instructions are provided on AoA's Web site at http://www.aoa.gov/carenetwork/Tools.html.

Caregiver Risk Screen and Caregiver Assessment Tool

Nancy Guberman and colleagues developed these tools and presented them at the 2001 GSA conference. The screen is a simple, validated instrument that can be used by the aging network, medical clinics, and others. It is designed to: 1) rapidly and systematically give a concise picture of the caregiver's situation; 2) evaluate the level of risk to the caregiver's mental and physical health as a result of caregiving; and 3) evaluate whether the care is adequate. The assessment tool is a longer, validated, multidimensional instrument designed to evaluate the conditions and needs of caregivers by gathering information from the caregiver's perspective and allowing the assessor to add his or her own comments. The tool is intended to be adapted to the specific situation of the caregiver, and therefore it depends on what sections the caregiver wants to cover. It need not be completed in one session. A user guide appears on the facing pages of the tool to provide further context and examples. For more information, contact Nancy Guberman at guberman.nancy@uquam.ca or Janice Keefe at janice.keefe@msvu.ca.

AMA Caregiver Self-Assessment Questionnaire

The caregivers self-assessment tool, with instructions for use, was developed and tested for distribution to physician offices by Dr. Joanne Schwartzberg. It contains 16 Yes/No items and two global scale items designed to measure indices of emotional and physical distress. English and Spanish versions of the instrument are available on the AMA's Web site at: http://www.ama-assn.org/ama/pub/category/4642.html.

University of Wisconsin Family Assessment Caregiver Scale

This 21-item scale looks at the functioning of the family as a caregiving unit. It consists of five dimensions of family functioning relevant to caregiving: validation, family of origin, problem-solving, roles, and boundaries. The tool was developed to assess family processes around caregiving and should be viewed only as one component of a total caregiver assessment. This information appeared in Greenberg, J.R., Monson, T., and Gesino, J. (1993). Development of the University of Wisconsin Family Assessment Caregiver Scale: A New Measure to Assess Families Caring for Frail Elderly Members. *Journal of Gerontological Social Work.* 19(3/4): 49–68.

Assessment Design

The major factors to consider when designing and using a caregiver assessment are as follows:

- Is the tool for one primary caregiver with one primary adult care recipient?

- Is the tool for more than one primary caregiver?
- Is the tool adaptable for unique caregiver situations?
- Is the tool multidimensional?
- Does the tool take into account the caregiver's perspective?
- Is the tool appropriate for ethnically and culturally diverse caregivers?
- How long is the tool, and how much time does it take to administer it?
- How can the tool be integrated with existing tools?[35,36]

Building on available measures and existing tools and modifying them to align with specific program goals is more practical than starting from scratch. In designing an assessment, the network should consider involving clinical and direct service staff. Caregiver assessments may be derived from multiple sources, such as direct questioning of caregivers and care recipients, observation, performance testing, and self-administered questionnaires. Caregiver strain, for example, can be measured during an interview or in a self-administered form. Information on informal support can be collected through picture drawings. Assessment experts recommend including an assessment feature that can capture the source of information (e.g., direct observation versus caregiver responses) and the collection method (e.g., self-administered versus clinical interview) in the instance when multiple collection procedures are adopted.[37]

Assessment Implementation

David Bass notes in his issue brief that although many sources can be used to construct an assessment, less is known about successful implementation. The network should consider approaches that minimize burden and create realistic expectations about the level of support that could be provided. He offered the following tips for the network in designing and implementing a useful assessment.

Flexibility in Timing and Methods

- Allow some flexibility in the timing of when the information is collected.
- Allow flexibility in the method used to collect the information (e.g., structured questions, observation, extracted from clinical interview, provided by an informant).
- Decide if certain parts of the assessment can be self-administered by caregivers.

Striving for Short and Simple

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[35] Guberman, N., Keefe, J., Fancey, P., Nahmiash, D., and Barylak, L. (2001). *Assessment Tools Serving the Needs of Caregivers: A Document to Better Understand the Importance of Assessing Caregivers' Needs.* Project funded by the Health Transition Fund of Health, Canada.

[36] Bass, D. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

[37] Bass, D. (2002). *Content and Implementation of a Caregiver Assessment.* Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

- Eliminate redundant information, avoiding overlap with care recipient assessment. However, some subjective information that is redundant between the caregiver and the care recipient is helpful to reflect important differences.
- Simplify answer categories, and use only items essential for a valid and reliable measure of each characteristic.
- Control the length of the assessment by using a filter question and dividing the assessment into sections—some parts for all caregivers and other parts for caregivers with certain characteristics (e.g., spouse caregivers, working caregivers).

Utility of the Information

- Analyze assessment information, and provide the results to those completing the information.
- Directly link the assessment, care plan, and reassessment so assessment information is used to guide service delivery.
- Consider use of information technology that can help streamline the process.[38]

The longer the assessment, the more difficult and time consuming it will be to use. Practical assessments should be developed that are limited to the essential items for designing a care plan, delivering interventions, and evaluating outcomes. Items most likely to inform outcomes are those that change over time from the baseline assessment to reassessments (e.g., caregiver strain, caregiving mastery, family members' involvement in caregiving, social isolation). Improvements in outcomes are more likely when: 1) the initial assessment indicates some type of problem, 2) appropriate timing and dosing of the intervention occurs after the initial assessment, and 3) the expected outcomes and goals of the intervention are closely aligned.

In addition, the network is encouraged to consider adopting a statewide assessment that is implemented in a standardized fashion for all caregivers. This kind of assessment allows similar information to be collected and analyzed across programs so evaluators can draw meaningful conclusions about overall program effectiveness. (See ***Chapter V*** for further information about evaluating program effectiveness.) The development of a statewide assessment does not preclude acknowledging local innovation because it could require certain common elements and then permit Area Agencies on Aging (AAA) to add their own items that match local program goals.

Lastly, a direct link between the assessment, care plan, and reassessment is important to guide service delivery. Done effectively, care planning helps clarify roles, sources of care, financial limitations, need for care, service priorities, and expectations.[39] Care planning should be a collaborative process among caregivers, care recipients, and service coordinators.

CARE MANAGEMENT-SUPPORT COORDINATION FOR CAREGIVERS

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[38] Bass, D. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

[39] Bass, D. (2002). *Content and Implementation of a Caregiver Assessment.* Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html

Roles and Skill Sets

Supporting caregivers and families requires a shift in how the care management system currently operates. Although our current system often acknowledges the caregiver as an important customer, it has not treated them as clients in need of formal services. Even the term "care manager" might need replacing with more appropriate terminology of support coordination.[40] For example, some of the existing caregiver programs use the terms "caregiver consultant" or "support specialist," emphasizing the caregivers' decision-making role. This section uses the term "support coordinator" to reflect the NFCSP's ideals of caregiver empowerment.

Support coordinators can play an important role in supporting caregivers under the NFCSP in the following ways:[41]

- Teacher – providing timely, appropriate, dosed, and relevant information specific to the caregiving situation
- Networker – linking families to needed formal and informal resources for both the caregiver and the care recipient
- Counselor, Validator, and Advocate – supporting caregivers through acknowledgment, absolution, encouragement, and decisional support
- Family Guide – navigating families through the maze of eligibility requirements, service definitions, and funding

Linda Noelker notes that the extent to which the caregiver is capable of and willing to access, coordinate, and monitor services largely affects the role of the support coordinator.[42] When caregivers are capable of assuming all of these functions, the support coordinator acts as a *family/caregiver consultant*. When the caregiver's ability is limited by disability or family conflict, the support coordinator takes on a more active *coordinator* role. Lastly, when the caregiver cannot take responsibility for any of these tasks, the support coordinator assumes the role of a *manager*.

In interacting with caregivers, support coordinators must be particularly skilled at empathetic listening, engaging family caregivers in the service coordination process, and integrating caregivers into the care system. Family participation in the decision-making process constitutes a critical piece to realizing the goals of a caregiver-focused program. Experience shows that responding to caregivers' preferences and setting clear expectations are the key determinants of caregiver satisfaction. The support coordinator must, therefore, be a skilled objective and subjective listener and be able to suggest appropriate resources to enhance what the family is considering based on the family's unique preferences. Furthermore, support coordinators

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[40] The disability community has adopted more contemporary terminology, and collaboration between the networks would be beneficial in enhancing support coordination strategies.

[41] Gwyther, L. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

[42] Noelker, L. (2002). *Case Management for Caregivers.* Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html .

assume responsibility for consulting with service providers to improve service quality based on feedback from caregivers and care recipients.[43]

Support coordinators should be able to assess family dynamics and assist caregivers with: 1) maintaining family communication and the exchange of information, 2) balancing the needs of the care recipient with the needs of other family members, 3) managing feelings toward family members who fail to help, 4) maintaining the family as an effective decision-making group over the long term, and 5) asking for help from other family members when necessary.[44]

A great tension exists between two goals of our long-term care system: to reduce caregiver burden and stress and to maximize the length of stay of seniors in the community. The goal of maximizing length of stay in the community is often achieved at the expense of the caregivers' quality of life. A significant proportion of families experience family conflict associated with caregiving, particularly around the issue of timing of formal service use or institutional placement. Therefore, providing caregiver support services early in the caregiver's career and being able to identify and respond at the servable moment is critical. If caregivers come in contact with the system only after they have exhausted all their physical and emotional reserves and institutional placement is the only option they are willing to consider, this conflict between the two values in our system emerges. The NFCSP provides an opportunity for the network to play an important role in helping minimize the conflict through the provision of timely and accurate information and caregiver support. In doing so, support coordinators must be able to help families make decisions that consider both the care recipients' and caregivers' needs and preferences.

Working with caregivers of persons with dementia requires additional skills. Support coordinators often can establish effective communication with these caregivers through continued reiteration and processing over time.[45] Support coordinators should be prepared to assess both the primary caregiver and other family members for their ability to accept recent diagnoses and other changes to come. Assisting the caregiver and care recipient with care decisions becomes a particularly delicate issue when the care recipient with cognitive impairments might be unable to make decisions and voice his or her preferences. The research suggests that it might be useful for families and support coordinators to incorporate a structured values assessment around the issues of

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[43] Noelker, L. (2002). *Case Management for Caregivers.* Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html .

[44] Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/ issuebriefs.html.

[45] Cummings, S.M. (1996). Spousal Caregivers of Early State Alzheimer's Patients: A Psychoeducational Support Group Model. *Journal of Gerontology.* 55B(3): 163–172.

daily care preferences at home to improve understanding and enhance communication between the caregiver and the care recipient.[46]

Zarit, Whitlatch, and Femia are designing and evaluating an intervention to help families in the early stages of dementia or other cognitive impairments.[47] The goals of this intervention study, funded by the NFCSP, are to: 1) develop positive communication patterns between the caregiver and the care recipient; 2) increase knowledge and understanding of available services, preferences for care, and care values; and 3) increase the care recipient's active participation in his or her care plan. Anticipated outcomes of this intervention are that caregivers and care recipients experience improved well-being and self-esteem and an increased sense of self-efficacy in managing the consequences of cognitive impairments.

Care Management - Support Coordination Infrastructure

If formal support coordination of caregivers is pursued, care management systems for caregivers must depart from the traditional caseload model and move toward a model that supports families coming in and out of the system of care over many years, based on their strengths, needs, and resources, which change over time. Considerations of the aging network in implementing support coordination for caregivers include:

Structure

Agencies must decide which is more beneficial: merging support coordination systems (support coordinators assisting both caregivers and care recipients) or keeping those roles separate (caregiver support coordinator and care recipient support coordinator) and the level of integration between information and assistance (I&A) and care coordination. Some members of the network argue that a separate structure might allow the caregiver to receive more focused and specialized attention. Others assert that the relationship between the caregiver and care recipient is intimately intertwined and that separating the two could undermine the goal of an integrated care plan with support coordinators at cross purposes. A combined approach might be more practical in pursuing coordinated assessment, care planning, and service monitoring activities through understood priorities, goals, and desired interventions for the family.[48] ***Exhibit VI.3*** presents several examples of a combined approach.

Standards

Organizational culture, governance, and caregiver input likely will drive standards for caregiver support coordination. For example, the New Jersey Easy Access, Single Entry

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[46] Whitlatch, C.J. (2001). *Consumer Direction for Family Caregivers and Care Recipients: Challenges and Opportunities.* Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

[47] Zarit, S.H., Whitlatch, C.J., and Femia, E. (2001). Early Diagnosis of Dementia: Dyadic Counseling for Family Caregivers and Patients. Research grant in progress funded by the U.S. Administration on Aging's National Family Caregiver Support Program.

[48] See Noelker's issue brief, Case Management for Caregivers, at http://www.aoa.gov/ carenetwork/issuebriefs.html for a more detailed discussion of this matter.

system (see ***Chapter VII, Exhibit VII.10***) includes both county service coordination protocols and state performance standards (organizational, process, outcome, reliability, and validity testing). Key components of support coordination standards include the definition, eligibility/closure criteria, support coordination volume, and caregiver rights and responsibilities.

Recipient of Support Coordination

Agencies must examine their program objectives (e.g., serve as many caregivers as possible, prevent health problems/negative effects by targeting caregivers most at risk, delay/prevent institutionalization of care recipients) and decide which caregivers formal support coordination will support. Gwyther recommended that the aging network target support coordination for the most vulnerable caregivers ("high-risk family care"). Possible target populations include frail, older spouse caregiver; existence of caregiver stress, ignorance, or apathy; presumed unintentional neglect or other abuse; history of conflict or estranged relationships; family financial situation; and combative, disruptive care recipient.[49]

Caregiver Outcomes

Agencies must consider what outcomes they hope to achieve through support coordination. Possible outcomes include caregiver health; appropriate, timely use of help; reduction of passive neglect, abuse, stress; increased effectiveness of care and coping; increased satisfaction with preferred level of involvement; decreased negative consequences on family; and minimized family conflict.[50] Support coordinators play a role in monitoring outcomes of support coordination itself as well as the quality of outcomes of other services used by the caregiver and care recipient.[51]

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[49] Gwyther, L. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

[50] Gwyther, L. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

[51] Noelker, L. (2002). *Case Management for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html .

Technology Applications

Agencies might want to assess technology options that could facilitate efficiencies in support coordination. Some applications might include technology that assists in capturing data, improves communication between support coordinators and caregivers as well as with service providers, and enables real-time access to service information and available resources. The use of laptop computers at home visits could be beneficial for capturing information from the assessment.

Exhibit VI.3
Combined Support Coordination at the Local Level

Combining the Components of Information with Assistance

Pierce County Aging and Long Term Care (AAA in Washington) established a new fulltime Family Caregiver Support Specialist position within the existing agency Case Management In-House Team. This position provides information and outreach to caregivers and the community and assists caregivers in accessing available services.

Combining Caregiver and Care Recipient Coordination

Eastern Agency on Aging (AAA in Maine) plans to establish "care teams" comprising a Community Service Consultant and a Family Caregiver Specialist to provide a holistic approach to serve both the caregiver and the care recipient.

In Pennsylvania's experience, the Family Caregiver Support Program demonstration included a separate system of both assessment and care management for caregivers. When the program went statewide, the integration of these systems was thought to be much more practical. Officials in Pennsylvania noted that this approach vastly improved caregivers' portability throughout the system as their needs changed.

CAREGIVERS' USE OF FORMAL SERVICES

> We must learn how to better integrate our formal services into family caregiving so that we can maximize the effect of both. This shift in approach focuses on helping families decide how best to integrate supportive services to complement and supplement their informal caregiving, rather than determining when and how to intervene when families can no longer care for their own. With this perspective, the family caregiver is the "key provider" [partner], not just a service recipient or client. [52]

Services should be designed and implemented in a way that meets the needs and preferences of different types of caregivers. The services must be marketed to the appropriate groups at the point that the groups are receptive to using the services. If caregivers are too frail themselves to attend programs outside the home, for example, the system must offer alternative options and communicate them effectively to caregivers.

How caregivers perceive access, red tape, expectations, and benefits greatly influences their willingness to seek formal assistance. Past experience, particularly for long-term caregivers,

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[52] Taken from the North Carolina Division on Aging slide presentation, *North Carolina Moves Forward for Caregiver Information and Support.* Slide 10.

likely will influence caregivers' receptivity to new interventions.[53] A common attitudinal barrier in many rural communities is the reluctance to seek community-based services because they are seen as welfare or handouts as well as a perceived stigma associated with the use of mental health or counseling services. Some common program-related barriers for the network to alter include poorly publicized programs, programs perceived as involving too much red tape, and programs with restrictions such as those that are means tested.

Culture also influences how families interact with the formal system. In many African American families, for example, when some members want to receive paid help but elders refuse it, the family members generally respect their wishes, unless the care burden becomes so great that a nursing home is the next choice.[54] As another example, some Indians and Pakistanis seem reluctant to talk about personal issues outside the family because they consider it shameful to do so.[55] Certainly caregivers' racial and ethnic backgrounds can affect the caregiving situation and are factors to consider in assessing and addressing their needs. However, these cultural factors must be considered along with the caregiving context (e.g., adjustment levels, family functioning, availability of extended family support) to fully address the unique needs for a particular family.[56] (See ***Chapter VIII*** for further information about planning and implementing programs that support ethnically and culturally diverse caregivers).

Gwyther notes family caregivers want the formal system to provide relevant information, acknowledgement, reminders or tips, absolution, and decisional support.[57] The aging network has a role in assisting caregivers in identifying personal and community resources, formal and informal supports. ***Exhibit VI.4*** presents tips for encouraging families to accept assistance.

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[53] Bass, D. (2002). *Content and Implementation of a Caregiver Assessment.* Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

[54] Taken from Metropolitan AAA/Minnesota Minority Service issue brief, August 9, 2001.

[55] Gupta, R., (1999). The Revised Caregiver Burden Scale: A Preliminary Evaluation. In *Research on Social Work Practice*. 9(4): 508–520. Sage Publications, Inc.

[56] Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov /carenetwork/issuebriefs.html.

[57] Gwyther, L. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

Exhibit VI.4
Tips for Encouraging Families to Accept Assistance

Offer Emotional Support

- Acknowledge what is working in the family caregiver's plan.
- Normalize initial reluctance (fears, stigma) to seek help. Allow time for the family to express fears and talk about barriers.

Realistically Educate

- Suggest to the caregiver how proposed services might benefit the elder (personal relevance and timing).
- Do not oversell the services or outcomes.
- Correct misconceptions about service use and eligibility.

Seek Outside Reinforcement

- Suggest that the family talk to a current family caregiver user of the service.
- Have physician, clergy, or trusted family friend reinforce service use.

Tailor Services to Family Circumstances

- Recognize the family's comfort level and seek informal, volunteer, low-cost, subsidized, or alternative payment services before more formal assistance.
- Offer only one change in service use at a time.
- Match providers with the consumers carefully, and offer an alternate if the match fails to work.
- Use culturally sensitive and jargon-free service descriptions.

Source: Adapted from Gwyther, L. Caregiver Counseling, Education and Support Groups, October 15, 2001.

VII. NFCSP SERVICE COMPONENTS

The National Family Caregiver Support Program (NFCSP) calls for the aging network to develop and coordinate a range of high-quality caregiver services linked through a system to enable caregivers easy access to the right service at the appropriate time. Building a strong system infrastructure, as described in ***Chapter IV***, is the foundation to implementing services that are truly integrated, flexible, responsive to caregivers' needs, and sustainable. Though many programs and services provided in home- and community-based settings benefit caregivers, many of the benefits are incidental to services received by the older or disabled adult. The NFCSP provides the network with an opportunity to consider caregivers' unique values and needs and to create a service system that better meets the family's needs and preferences.

This chapter addresses the major service components of the NFCSP:

- **Information** for caregivers about available services;
- **Assistance** for caregivers in gaining access to these services;
- **Individual counseling, support groups, and training** to help caregivers make decisions and solve problems relating to their caregiving roles;
- **Respite care** to temporarily relieve caregivers from their caregiving responsibilities; and
- **Supplemental services**, on a limited basis, to complement care provided by caregivers.

Within this chapter are service descriptions and program examples of these five components, and a discussion of implementation issues. Based on current service activities that network agencies are pursuing as well as the interim guidelines that the Administration on Aging (AoA) issued on October 31, 2001 (see ***Appendix A***), the service descriptions reflect a broad range of options for the network. The service definitions for Title III-E are expected to evolve over the next year as part of the Title III information system refinement process, spearheaded by AoA with the assistance of aging network representatives.

Program examples are provided to illustrate a range of strategies for designing and implementing caregiver services. Some of the program examples represent multi-component approaches that might reside in more than a single service category. Such approaches manifest the flexibility the NFCSP affords. Just as the needs, experiences, and preferences of caregivers vary, caregiver support interventions differ and must be designed to account for the heterogeneity of both caregivers and localities.

Under the NFCSP, the care recipient must have two or more activities of daily living (ADL) limitations or a cognitive impairment for the caregiver to be eligible for respite or supplemental services. (See Section 373(c)(1)(B) and its footnote to the "Frail Elderly" Section 102(26)(A)(i) or (B) of the NFCSP Act in ***Appendix A.***) Some of the respite care and supplemental service examples described later in this chapter have been supported by state or other non-Title III-E sources and therefore are not bound by this eligibility restriction.

The chapter emphasizes several overarching principles for designing and implementing caregiver support services:

- Seek flexible approaches to service design and delivery to meet caregivers' diverse needs and preferences.
- Monitor, evaluate, and modify services on an ongoing basis.
- Leverage resources through service integration and the use of partners and volunteers.
- Invest in personnel skills and training to reach caregivers at the "servable moment."
- Coordinate services so program delineation is invisible to the caregiver and so the services enhance, not duplicate, the caregiver program.

INFORMATION

Service Description

Information refers to individual and group services, including public education, provision of information at health fairs and other similar designations as determined by the state, that inform caregivers of available services. Information is inclusive of outreach activities—interventions initiated by an agency or organization for the purpose of identifying potential clients and encouraging their use of existing services and benefits. Information can include both group and individual contacts but, for reporting purposes, service units for information signify individual, one-on-one contacts between an information provider and a caregiver.

The aging network can pursue a broad range of activities in local communities to reach individuals of diverse caregiver populations. ***Exhibit VII.1*** presents a spectrum of information activities for caregivers planned by the aging network or under way.

Exhibit VII.1
Strategies to Provide Information to Caregivers

▪ Conduct outreach through caregiver fairs. ▪ Target working caregivers through employee assistance programs (EAP) and Human Resources departments. ▪ Contract with the publisher of a local senior newspaper to include "Caregiver Corner" columns. ▪ Purchase computers with large-screen monitors to place in senior centers for caregiver access to the Internet. ▪ Enhance Web sites with links to caregiver information. ▪ Develop "caregiver survivor kits". ▪ Develop resource guides for caregivers.	▪ Provide a caregiver information bookmobile or resources-mobile. ▪ Subcontract with an ethnic community organization for outreach. ▪ Provide one-on-one contact and counseling to targeted caregiver populations. ▪ Develop a media campaign and community outreach effort in collaboration with providers, such as congregate meal sites, legal aid or insurance counselors, and senior centers. ▪ Create an interactive Web page: *Caregiver Journal Exchange.* ▪ Hire caregiver resource specialists. ▪ Make caregiver resources available on video.

Strategies and Program Examples

Align Information Activities with Caregiver Program and System Development Goals to Facilitate Desired Outcomes. Strategies to provide caregivers with information about available resources should reflect programmatic goals in terms of the type of information needed, target audience, methods to circulate information, and desired message. In conceiving information strategies, the network should process the knowledge gained from needs assessment, focus group, advisory council, and other activities. ***Exhibit VII.2*** presents the Minnesota Board on Aging's (SUA) approach to reach caregivers with service information as it relates to the goals of the wider system change activities taking place in the state.

Exhibit VII.2
Communication for Caregiving in Minnesota

Overall Goals of the Project	Goals of Caregiving Communications	Potential Audiences
▪ Improvement in quality and duration of care provided by informal caregivers ▪ Reduction of long-term care expenditures ▪ Strengthening of the caregiving network in Minnesota, both formal and informal	▪ Raising of public awareness of caregiving ▪ Education of caregivers about services that could assist them as a caregiver, with special targets. ▪ Education of businesses about the impact of caregiving on workers and enlistment of their support in educating employees about caregiving resources in their communities ▪ Raising of public awareness of individual responsibility for long-term care planning and preparedness.	▪ Spouses who provide care ▪ Adult children who provide care ▪ African American and Hispanic women, Hmong caregivers ▪ Businesses and other employers ▪ General public

Explore Traditional Settings, as well as New Locales, Through Which the Aging Network Can Distribute Information to Caregivers. The aging network will want to reach caregivers at health fairs, senior centers, and other traditional venues. The NFCSP encourages agencies to expand their efforts to other locales exhibiting potential to tap into the caregiver market (e.g., businesses, schools, community clinics, churches, and hospice organizations). ***Exhibit VII.3*** details examples of network strategies to reach caregivers through the military, medical, and faith communities.

Exhibit VII.3
Expanding Outreach to Caregivers

Title: Information and Outreach with the Military

Affiliation: Mid-Carolina AAA in Fayetteville, NC

Status: Operational

Target Population: Individuals in the military, veterans, and their families

Approach: The caregiver specialist at the AAA contacted the Veteran's Administration (VA), the VA nursing home, Family Services (social workers for the military), the Family Readiness Programs, and insurance carriers to discuss caregiver support and open channels to reach these individuals. This process involves a coordinated effort between the military and civilian communities to provide information, education, and services available to all military affiliated caregivers at the community level. Outreach information is provided through many venues such as newsletters; the Moral, Welfare and Recreation (MWR) division; hospitals; and grocery stores.

Contact Information: Kristina Dice, Family Caregiver Resource Specialist, Region M, Mid Carolina AAA, at kdice@fayetteville.net or (910) 323-4191 ext. 28.

Exhibit VII.3
Expanding Outreach to Caregivers, continued

Title: Information and Outreach through Physician Offices

Affiliation: New Mexico State Agency on Aging

Status: Developmental (Suggestion for outreach under the NFCSP being considered)

Target Population: Office nurses that provide information to caregivers

Approach: The SUA is considering options for outreach to caregivers under the NFCSP including an adaptation of a successful program used elsewhere with Pediatric nurses. In the model program, flyers were sent to physicians' offices to offer education for office nurses on what is available for caregivers. The training explained how to access services so nurses can provide caregivers with necessary information and connect them to services. The training was held once a month during lunch or on a day that the clinic closed early.

Contact Information: Barbara Owens, Program Manager, New Mexico State Agency on Aging, at Barbara.Price-Owens@state.nm.us or (505) 255-0971 ext. 104.

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Title: Outreach through Collaboration with the Faith Community

Affiliation: Northwest Regional Council, AAA (Washington) and Community of Faith Outreach

Status: Operational

Target Population: Caregivers known to faith communities

Approach: Northwest Regional Council, AAA contracted with an individual to liaison with the Community of Faith Outreach program to reach "hidden" caregivers in faith communities. The program raises awareness of caregivers' issues and provides recommendations on how to support caregivers and refer individuals to resource specialists. Through this collaboration, over 100 faith communities have been contacted and more than 50 presentations conducted.

Contact Information: Kim Boone, Northwest Regional Council, AAA at boonkb@dshs.wa.gov or (360) 676-6749.

Provide Information about Available Resources in a Targeted and Timely Fashion. Non-specialized and limited availability of information might contribute to a lack of awareness of existing services and, even when caregivers are aware of resources, an inability to apply them to their own needs.[58] Information about services must be tailored to different caregiver needs in terms of the type of information (e.g., disease related) and the strategy employed. ***Exhibit VII.4*** lists effective outreach strategies to different ethnic populations, emerging from the seven-year Alzheimer's Demonstration program that ran in Washington State from 1993–2000. The outreach materials and strategies developed for Chinese, Korean, Hispanic, and Native American communities under the demonstration might be a helpful resource for the aging network in enhancing outreach methods and targeting previously underserved populations. (See http://www.aoa.gov/alz for more information.)

[58] Coyne, A. (1991). Information and Referral Service Usage Among Caregivers for Dementia Patients. *The Gerontologist*. 31(3): 384–388.

Exhibit VII.4
Effective Outreach Strategies to Ethnic Communities

- Use face-to-face contact and an informal one-on-one approach that is slow paced, allowing time to build trust.
- Partner with existing community organizations such as family associations, women's groups, and professional associations to spread the word. Request that your program be part of their meeting agendas.
- Make your services visible in the targeted community through local businesses, local media, and community events. Ask ethnic-based business owners to distribute brochures.
- Ask organizations to let you host a "resource table" at a community event.
- Cast a broad net and consider making presentations focusing on broad issues of aging, caregiving, and long-term care.
- Form collaborations with community health providers to bring referrals to the program.
- Help an individual or family with an immediate need rather than expect them to discuss sensitive issues surrounding dementia or other long-term services.

Source: AASA, 2000. Pamphlet, Description of Effective Washington State Alzheimer's Disease Demonstration strategies.

Marketing to caregivers requires new strategies, materials, and techniques. In providing information about services, the network must use language that seems responsive to caregivers. The term "caregiver" is unfamiliar to many people—caregivers identify themselves as wife, husband, daughter, son, partner, or friend. Similarly, "respite care" and "support group" might fail to resonate with caregivers who desire "a break" and "peers to talk to." The National Family Caregivers Association (NFCA) and the National Alliance for Caregiving (NAC) have joined together to conduct the first phase of a two-phase intervention, The Family Caregiver Self-Awareness Project. The goal is to produce a comprehensive communication campaign aimed at family caregivers that incorporates specific tested messages and recommended interventions to change how family caregivers perceive themselves and behave in their role. The project team will apply social marketing principles, focusing on the perceptions and needs of family caregivers. In addition to developing effective messages for caregivers, the team will explore a range of message delivery options based on research. Further information about this project can be obtained through NFCA's Web site at http://www.ncfacares.org/.

In addition to receiving information intended for them, caregivers need timely information. When information is not received in a timely manner and when questions or concerns go unanswered, caregivers tend to give up and make the best of their situation. This circumstance leads caregivers to access the system at points of crisis. Likewise, outreach efforts must accommodate differences in caregivers' receptivity (using Montgomery's "marker framework") and be tailored to caregivers' specific needs. Some examples of planning and service activities to aim caregiver outreach at different career markers include:

- Sponsoring an annual "Rake the Town" community event to help identify caregivers. (contact: Linda Giersdorf, Director, Region Nine AAA in Mankato, Minnesota, at lindag@rndc.mankato.mn.us)

- Conducting outreach to caregiver support group attendees to inform caregivers about additional services as well as learn from them ways to connect with caregivers who might fail to identify with that role. (contact: David Hanson, Program Specialist, Pierce County Aging and Long Term Care, AAA in Lakewood, Washington, at dhanson@co.pierce.wa.us)
- Establishing an advisory council of caregivers and interested professionals to offer advice about reaching individuals who care for others but might fail to identify as caregivers. (contact: David Hanson, information same as above)
- Targeting family caregivers of older persons who have been placed in or are transitioning back to the community after receiving care in skilled nursing facilities and offering them assistance, support, education, and empowerment. (contact: Robert Sessler, Director, Contra Costa County Aging and Adult Services Bureau in Martinez, California, at [925] 313-1605)

Disseminate Information in Various Formats Responsive to Different Caregivers' Preferences. Findings from the 1998 NAC survey and other empirical evidence suggest that more caregivers would like to receive information about caregiving in written form than another information channel.[59] Agencies might want to develop resource guides for caregivers in partnership with other entities (e.g., the local Alzheimer's Association chapter). The guides could then be distributed to other community entities such as social service agencies, major employers, hospitals, and home health agencies.

Still, caregivers desire information through a variety of channels, which the aging network should consider in meeting their diverse needs. ***Exhibit VII.5*** showcases two individual face-to-face outreach strategies. A segment of the caregiver population is growing accustomed to seeking information via the Internet. Supporting caregivers' information needs might involve, for example, producing materials that list Web resources for caregivers or developing or enhancing agency Web sites that contain specific information for caregivers, including hypertext links when appropriate. Sites could offer caregiver calendar events, access to one-on-one dialogue, and other means of information dissemination. To gain a better sense of the utility and response to the site, agencies can track hits (i.e., visits to the Web site). Also, because caregivers often seek information through the medical community, the aging network should consider bridging with local medical Web sites (e.g., community hospital, home health care, hospice, disease associations, outpatient clinics, nursing facilities, academic medical centers / Institutes on Aging). Regardless of its design and features, a Web site is only as good as its information. Therefore, a critical, albeit time-consuming, activity, content should be maintained on a regular basis. For further information about Internet applications for caregivers and the aging network, see ***Chapter IX***.

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[59] National Alliance for Caregiving. (September, 1988). *The Caregiving Boom: Baby Boomer Women Giving Care*. Prepared by the National Alliance for Caregiving, Bethesda, MD.

Exhibit VII.5
Individual Face-to-Face Outreach Examples

Title: Mobile to Immobile Caregiver Outreach Program

Affiliation: Southwest Missouri Office on Aging (AAA)

Status: Operational

Target Population: Geographically-isolated caregivers

Approach: The AAA launched a two-year outreach program in June 2001 in which a staff member and a specially equipped van with caregiver information are assigned to an isolated geographic area. The program targets older individuals in the especially rural areas of Oregon and Shannon counties. The program has been successful largely because the mobile outreach coordinator has been an employee of the AAA for 20 years and has the trust of the communities' residents. Since the program's start, 68 caregivers have been assisted with accessing benefits and service coordination. Referrals generate from other AAA-sponsored activities in the communities.

Cost/Funding: The program is funded through a grant. Expenses include a fulltime employee's salary and fringe benefits, a used van, and van supplies (i.e., fax, cell phone, and laptop).

Contact Information: Dana Cain, Project Coordinator for Technology Education and Assistance for Missouri Seniors (T.E.A.M.S.) Project, Southwest Missouri Office on Aging, at dana@swmoa.com or (417) 862-0762 or (800) 497-0822.

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Title: Caregiver Resources and Book Mobile Program

Affiliation: Piedmont Triad Council of Governments Area Agency on Aging, North Carolina

Status: Developmental

Target Population: Caregivers of elders known to the service system, grandparents raising grandchildren, caregivers of adult children with MR/DD, and caregivers who have not self-identified as such

Approach: The AAA is pursuing a regional library initiative to collaborate with public libraries in providing caregiver resources in their seven-county service area. The majority of counties in the region have a book mobile that extends to seniors' homes, senior centers, and nursing homes. Using the reputation of a library, the program seeks to reach an otherwise isolated population through a non-threatening and credible institution. The AAA is building on this effort to ensure that caregiver literature is available with the book mobile program. Each county's planning committee, comprising service providers, community members, and county commissioners, developed partnerships with the local public library by sharing caregiver resources with the library administrators during committee meetings. The book mobile drivers will now serve as a distribution source and depository of caregiving information (i.e., video or audio materials, books, information on seminars and community events). Plans include educating the drivers to identify caregivers and helpful resources.

Cost/Funding: Because it has built an existing infrastructure, the program has minimal costs beyond developing marketing materials for the caregiver program. Service providers supply service information materials for distribution. NFCSP dollars might be used in the future to fund the driver education piece.

Contact Information: Blair Barton-Percival, Aging Program Specialist, Piedmont Triad Council of Governments, at bbpercival@ptcog.org or (336) 294-4950.

ASSISTANCE

Service Description

Assistance refers to a service that assists caregivers in obtaining access to the services and resources available within their community. The major form of assistance this chapter discusses

is information and assistance (I&A).[60] I&A is a service that provides current information on available opportunities and services; assesses the problems and capacities of the individuals; links the individuals to the opportunities and services; and ensures, to the maximum extent practicable and by establishing follow-up procedures, that the individuals are aware of the opportunities and receive the services needed. I&A represents a key component of a multifaceted system that supports caregivers. The NFCSP gives the network an opportunity to review their existing I&A system to evaluate how it can better serve caregivers and minimize the confusion and frustration of families seeking information, services, or both.

Care management (support coordination) is another method of assistance, either in the form of access or care coordination, in circumstances where the older person or his or her caregivers are experiencing diminished functioning capacities, personal conditions, or other characteristics which require the provision of services from formal service providers. Activities of care management include assessing needs, developing care plans, authorizing and arranging services, coordinating the provision of services among providers, and conducting follow-up and reassessment, as required. The network varies in how it organizes care management. Some agencies tie it closely to I&A functions, while others operate relatively freestanding care management systems. State Units on Aging (SUAs) and Area Agencies on Aging (AAAs) can pay for care management out of Title III funds. ***Chapter VI*** gives a full description of care management for caregivers and the related activities of assessment and care planning.

Strategies and Program Examples

Adjust I&A Systems to Respond to Caregivers' Needs. Any I&A system should recognize that caregivers are customers in their own right. They have needs related to the care recipient's needs, and they have needs distinct from the care recipient. If caregivers' needs are met at the right time, they more likely will seek assistance again. Also, because people can use only the information they are prepared to grasp, I&A systems function more effectively when they avoid overloading caregivers with materials. In recognizing caregiver diversity, I&A systems should be equipped to address the needs of different types of caregivers and account for caregiver career variation and other unique circumstances. For example, some of the caregivers in contact with an I&A system are "information seekers" and some are "service seekers," requiring staff to detect the difference and assist appropriately.[61]

Although many caregivers will continue to use the telephone to connect with the system, a segment of the population will take advantage of the Internet as their first resource. Agencies will want to consider designing online I&A databases that allow caregivers to "self serve," a particularly convenient format for workforce participants and long-distance caregivers. When designing an online resource, then, agencies must ensure that information available via the Internet is compatible with the information dispensed to caregivers by telephone. ***Exhibit VII.6*** offers a snapshot of Eldercare Solutions, an I&A-based resource referral product for working caregivers.

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[60] The term information and assistance (I&A) used in this Resource Guide refers to what some call Information and Referral (I&R) or (I&R/A).

[61] Montgomery, R.J.V. Presentation at the AoA Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

Exhibit VII.6
Self-Serve I&A for Working Caregivers

Title: Elder Solutions

Affiliation: CICOA the Access Network (Indiana AAA)

Status: Operational

Target Population: Working caregivers

Approach: CICOA developed Elder Solutions, an I&A-based resource referral product for working caregivers, on the premise that with easy access to information and services, the loss of work time will decrease while company productivity and, consequently, revenue will increase. In addition to I&A, Elder Solutions distributes a quarterly newsletter; maintains a dedicated phone line and an email address for a broad array of questions; and conducts onsite events, including staff training, employee consultation, resource kiosks, and seminars on specific caregiving topics. The AAA targets companies with 100 to 500 employees. Companies' receptivity to this product has led Elder Solutions to now include an assessment for the caregiver and care recipient. CICOA marketed Elder Solutions through the use of paid advertisements, articles, brochures, and results from an Eldercare survey completed by employees of five companies. The results of this survey, which clearly show the need for employer support, have proven the most effective marketing tool because they negate employer beliefs that caregiver issues represent no problem. The AAA has found that employers respond more positively when they are experiencing their own eldercare issues.

Cost/Funding: Pricing for Elder Solutions is based on the number of employees. CICOA used philanthropic funds to develop and market the service.

Contact Information: Thomas Otto, Executive Vice President and COO, CICOA, the Access Network, at totto@cicoa.org.

Build I&A Capacity to Achieve Overall Systems Development Goals. Personnel, training, standards, requirements, information technology, protocols, and linkages must be addressed to ensure that systems are flexible to meet the I&A needs of caregivers. Agencies will want to consider several options, such as extending hours of I&A telephone staff, purchasing computers and database software, exploring opportunities to coordinate with other I&A providers, and creating positions to provide assistance specifically for caregivers. As *Exhibit VII.7* shows, several movements at the national level are helping shape systems across the country, offering guidance to the network in building capacity.

Exhibit VII.7
National Information and Assistance Movements

The **Alliance for Information and Referral Systems** (AIRS) has developed a set of standards for effective I&R and a classification of I&R terminology. AIRS also offers an accreditation program as well as a certification program for I&R providers. See http://www.airs.org/.

Eldercare Locator and the **National Aging I&R Support Center** were introduced in 1991. Beginning as a telephone line (1 [800] 677-1116), Eldercare Locator connects elders and their caregivers with information providers nationwide. It is administered by the National Association of Area Agencies on Aging (N4A) in cooperation with the National Association of State Units on Aging (NASUA). Now Eldercare Locator is available online, as well, allowing caregivers 24-hour access. The Support Center has assisted many SUAs and AAAs with I&A system redesign, developed and operationalized standards, conducted training and certification, and tracked emerging technologies. The Support Center has been working with AIRS to develop an aging I&R specialist certification and examination, expecting to launch in spring 2002. See http://www.eldercare.gov/ and http://aoa.gov/naic/.

Aging Connection Plus was created by the Atlanta Regional Commission, stemming from the commission's development of the CONNECT database—the foundation of Georgia's entire aging and long-term care information system. The software (developed by CyberPath, Inc.) used for this system, Elderly Services Program (ESP), includes categories and services for traditional and nontraditional services. Businesses and community organizations can subscribe to the fully automated, comprehensive, and maintained Aging Connection Plus database of more than 4,000 providers and 8,000 services for an annual fee of $5,000 to $10,000. CyberPath now makes the software database packages available for AAAs outside the state of Georgia. See http://www.agingatlanta.com/agingconnectionplusindex.html

The **211 Movement** first started in Atlanta, Georgia, and now more than 15 states have adopted it. The movement refers to the designation of 2-1-1 by the Federal Communications Commission as the abbreviated dialing code for human services information. See http://www.211.org/.

NASUA Vision 2010: Toward a Comprehensive Information Resource System for the Next Century is a framework established to guide I&A systems in coordination, comprehensiveness, technology, personnel, marketing and outreach, responsiveness, knowledge building, and leadership. As it relates to caregivers, Vision 2010 aims to develop a caregiver information and assistance system that is broad based, empowers caregivers, supports caregiver choice, uses appropriate technology to provide timely assistance, and includes evaluative and caregiver satisfaction components for setting direction and assessing value. See http://www.nasua.org/.

In building capacity, the need for information and assistance is great for people who fail to qualify for public assistance. The aging network will have to consider provisions to treat I&A as a distinct service and method of reaching the general public and not just for individuals seeking publicly funded services. In Wisconsin, for example, counties operate Aging and Disability Resource Centers offering information and assistance to older adults and their families of all ages and incomes. It has been argued that by receiving help with making effective long-term care choices, middle- and upper-income older adults and their families will use their private resources more efficiently, thereby reducing the chances of exhausting all their resources and relying on more costly publicly-funded services.[62]

[62] Reinhard, S.C. and Scala, M.A. (2001). Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States. Prepared for the Public Policy Institute, AARP.

Develop Strong Leadership at the State and Local Levels. Theresa Lambert of NASUA suggests that the network provide leadership to address the I&A needs of caregivers through the following:[63]

- Creating the vision for I&A in the NFCSP;
- Establishing organizational structure and internal leadership to initiate and sustain caregiver focus (e.g., advisory committee, caregiver champion, caregiver advocacy);
- Promoting the strengths of the current I&A system, identifying its weaknesses, and developing plans to meet those challenges;
- Ensuring continuous quality assurance and improvement of I&A systems to adequately respond to caregivers while empowering caregivers to recognize their own role and needs;
- Developing new partnerships that increase coordination and decrease duplication;
- Securing additional resources as might be required to achieve the vision (agencies should investigate the extent to which the state is willing to supplement OAA funding for I&A); and
- Designing data collection systems that capture meaningful information and can inform the systems change process, service development, advocacy, etc.

Pursue Internal and External Coordination. Reinhard and Scala reported that more than 3,500 OAA-funded I&A programs exist across the country that greatly differ in their effectiveness in reaching older adults and families with I&A.[64] In developing or enhancing I&A support for caregivers, states should review their current systems for possible ways to streamline their efforts both internally and externally with other I&A providers. Cheryll Schramm suggests focusing on the following coordination activities:[65]

- Internal. An essential step of systems development is the coordination between the I&A service and other aging programs with an information and assistance component (i.e., Long Term Care Ombudsman, SHIP [Senior Health Insurance Information Program], APS, legal hotlines, pension counseling, and care management). Staff from other programs must be educated about the role and function of the I&A service under the NFCSP and be able to link caregivers to that service. For many states that have no statewide databases, the NFCSP presents an opportunity to evaluate the prospect of developing a centralized database and a classification of service terms.
- External. In building multifaceted systems of support, coordination with external statewide and regional I&A providers—both nonprofit and for-profit—must occur. The NFCSP legislation calls for the aging network to address the needs of other caregiver populations (i.e., grandparents raising grandchildren and older persons caring for children with developmental disabilities), which requires coordination with external

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[63] Lambert, T.N. (2001). *Information and Assistance*. Comments on Cheryll Schramm's issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/ issuebriefs.html .

[64] Reinhard, S.C. and Scala, M.A. (2001). Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States. Prepared for the Public Policy Institute, AARP.

[65] Schramm, C. (2001). *Information and Assistance: Where We Are . . . Where We Can and Should Be*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/ carenetwork/issuebriefs.html.

agencies that have their own I&A systems. Such coordination offers the network an opportunity to: 1) educate others about the aging I&A system and the NFCSP; 2) receive education and training surrounding grandparent issues, kincare, communicating with caregivers caring for individuals with development disabilities, etc.; and 3) develop integrated resource databases that are population-specific and can be tailored to individual user needs. In addition to coordination with disability, children, and youth I&A services, SUAs, AAAs, and ITOs should coordinate with 211 for human services information, whether pursuing formal integration or simply ensuring proper referral mechanisms.

Different strategies exist for building I&A systems that support caregivers. When considering a strategy, two primary concerns should be whether to combine aging and caregiver I&A or create a designated I&A system for caregivers and whether to develop a statewide system or a regional one. Further, agencies must ask themselves if the I&A will be in house and which staff will assume responsibility for assisting caregivers.

The AAA in Pierce County, Washington, for example, contracts with the city of Tacoma to deliver I&A. The AAA maintains an in-house team of five, with one position dedicated to the Family Caregiver Support Program (FCSP). They decided to structure the FCSP I&A in house to better connect caregivers to available resources. The AAA educated providers to refer caregivers to the in-house I&A number; if a caregiver calls the city of Tacoma I&A, automatically he or she is referred to the in-house system. The AAA is also considering the creation of a caregiver telephone hotline in collaboration with the crisis and information line and with the Tacoma YWCA. The hotline would enable caregivers who either have insufficient time to attend a support group or have no one else to help care for the care recipient to receive the support they need. Trained providers and volunteers would staff the hotline.

Exhibit VII.8 showcases an I&A approach at the local level in Ohio that involves coordination with Catholic Social Services and the Alzheimer's Association.

Exhibit VII.8
Local Level I&A Coordination

Title: Caregiver Help Lines

Affiliation: Council on Aging of Southwestern Ohio (AAA in Cincinnati, Ohio), Alzheimer's Association, and Catholic Social Services

Status: Developmental

Target Population: Caregivers of older adults with and without dementia

Approach: The AAA is arranging I&A lines specifically for caregivers. One help line operated by Catholic Social Services through its Caregiver Assistance Network uses trained current or former caregivers to provide counseling, information, and support over the telephone. The Caregiver Assistance Network also works with area community organizations and senior centers to reach caregivers. The other help line will be run through the local Alzheimer's Association to provide similar support for caregivers of seniors with Alzheimer's Disease or related dementia (ADRD). This design is based on its finding that caregivers of individuals with ADRD need professional education about disease process, suggestions about behavioral management, and specific safety issues. Typically, non-dementia caregivers need someone to talk with, and they respond well to empathic people who have "walked in their shoes."

Cost/Funding: The program costs approximately $160,000, and most funding comes from Title III-E funds. The funding supports: 1) the network of support groups linked to the information lines, including staff to train volunteer facilitators, advertising, and occasionally professional speakers; 2) staff and volunteers for the help lines; and 3) workshops for caregivers in the community sponsored by both agencies.

Contact Information: Gene McClory, Caregiver Assistance Network, Catholic Social Services, at (513) 241-7745; Clarissa Rentz, Alzheimer's Association, at (513) 721-4284.

Establish Uniform and Consistent Messages for Single Point-of-Entry Systems, While Maintaining Local Flavor. A number of states (e.g., New Jersey, Indiana, Wisconsin, Minnesota, Georgia, Iowa, and New Mexico) are further developing their I&A service by pursuing single-point-of-entry systems. They are attempting to establish uniformity and consistency of information for consumers, while maintaining the individuality of the local organizations (particularly a strong county-based system which requires negotiation and adaptation).

Georgia's Aging Connection I&A system and CONNECT database resulted from a long process that began at the local level before statewide expansion. In the development phase, the Atlanta Regional Commission chose to manage the system at the regional AAA for the 10-county area. The commission convened a steering committee to advise the development and formulate a vision and goal for the system. ***Exhibit VII.9*** describes this development process in further detail, while ***Exhibit VII.10*** describes New Jersey's experience in pursuing comprehensive statewide I&A reform with the Easy Access, Single Entry (EASE) program.

Exhibit VII.9
Development of Aging Connection and CONNECT Database

Atlanta Regional Commission (AAA in Atlanta, Georgia)

- Maintained an inventory of internal resources—costs, available funding sources, potential funding sources, staffing requirements, adequacy of the agency structure for development.
- Continually analyzed the geographic area—how the health and human service infrastructure affects the implementation or expansion of I&A, political considerations, involvement of the business community, how special needs populations should be included, and how demographics influence development and expansion.
- Identified the potential users.
- Named the system and developed a tag line that will speak to the audience (caregivers).
- Decided what information to collect, the collection method, and the use of the data.
- Developed a follow-up system to measure client satisfaction.
- Developed a provider database along with a classification of aging and LTC services. (The Atlanta Regional Commission selected ESP software developed by CyberPath, Inc.)
- Developed Aging Connection Plus, a fully automated and comprehensive database of more than 4,000 providers and 8,000 services marketed to business and community organizations, with an annual subscription cost of $5,000 to $10,000.
- Purchased additional software that interfaces with the ESP software allowing a client screen that measures need through activities of daily living (ADLs) and instrumental activities of daily living (IADLs), care recipient assessment instrument and care plan linked to the provider database, and a brief caregiver assessment tool.
- Expanded the database for uniformity and accessibility throughout the state of Georgia.
- Integrated the database with other LTC programs to support the Medicaid Waiver programs, SHIP, the Corporate Eldercare program, and the Aging Information Network and the Senior Employment Referral program.
- Provided ongoing training and required AIRS certification of I&A specialists in Georgia. (The training involves the requirement to explore the unique needs of the caregiver in addition to the needs of the older adult.)
- Created a Web site, http://www.agingatlanta.com/, that links to the CONNECT database and allows users to search for information and services and correspond with staff via email.
- Developed an ongoing collaborative effort with community organizations to further enhance the I&A system (e.g., Greater Georgia Alzheimer's Association, Jewish Family and Career Services, and United Way 211).

Exhibit VII.10
Comprehensive Statewide I&A Reform in New Jersey

Title: NJ EASE (Easy Access, Single Entry)

Affiliation: New Jersey Division of Senior Affairs (SUA)

Status: Developmental

Target Population: Older adults and their caregivers

Approach: NJ EASE is a statewide initiative led by the New Jersey Department of Health and Senior Services in partnership with county governments and local agencies. A unit of the SUA works with each county on system design to provide core services (i.e., information and referral, assistance and outreach, screening, comprehensive assessment, care planning, and care management) through the use of standardized assessment instruments, service coordination protocols, care management standards, and staff training. In addition, the program established a single nationwide toll-free number for consumers to learn about and access services that address financial, medical, and social needs; created a uniform resource directory; and launched a public awareness campaign to encourage consumer use of NJ EASE services. The SUA allowed counties the flexibility to adapt the program to best meet their local needs. The I&A staff must attend a mandatory three-day training session (NASUA based), and care managers must attend a four-day training, with an optional seven-day advanced training. Current plans are to incorporate caregiver components into NJ EASE, including caregiver assessment tools, staff training about caregivers, caregiver service coordination policies and protocols, and a caregiver resource Web site.

Cost/Funding: The state of New Jersey, under the auspices of the governor's office, received a $238,251 grant from the Robert Wood Johnson (RWJ) Foundation in December 1994. Together with $400,592 in matching state monies, the grant supports NJ EASE planning. The state currently has a Title III-E National Innovation Grant from AoA to help develop the caregiver components of NJ EASE.

Contact Information: Barbara Fuller, Program Manager, New Jersey Division of Senior Affairs, at barbara.fuller@doh.state.nj.us or (609) 943-4060.

For further information about building a comprehensive I&A system, see Reinhard and Scala's 2001 manuscript for AARP.[66] (See ***Appendix B*** for a self-assessment chart for states considering comprehensive statewide reform [adapted from the framework used in the AARP manuscript]).

Invest in Personnel Because They Are Vital to Effective I&A Service Delivery. The success of an I&A system relies on the staff's capacity to respond to an increasingly diverse caregiver and care recipient population—their ability to interpret, ask the right questions, make the proper referrals, and conduct adequate follow-up. I&A staff should be viewed as "knowledge brokers" skilled at analyzing, synthesizing, and creative problem-solving.[67] Investment in personnel involves retraining of existing I&A staff about the NFCSP goals, the philosophy of treating caregivers as consumers, caregiver diversity, operations, and reporting requirements.

Agencies might want to consider requiring certification of I&A staff, developing protocols (e.g., decision trees), and hiring specialized I&A staff experienced with caregiver issues. This

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[66] Reinhard, S.C. and Scala, M.A. (2001). Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States. Prepared for the Public Policy Institute, AARP.

[67] Lambert, T.N. (2001). *Information and Assistance*. Comments on Cheryll Schramm's issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/ issuebriefs.html .

suggestion applies both to staff who work on the telephone lines and those who take responsibility for online information or service requests. ***Exhibit VII.11*** describes the Caregiver Resource Specialist position created by the AAAs in North Carolina. The network might consider the addition of a caregiver consultant to the I&A staff who can address behavior management, scheduling, medication management, and other specific caregiver issues. In Atlanta, for example, the AAA hired a registered nurse (RN) to fill this role due to the health issues surrounding caregiving. The state of Indiana implemented standardized training through a contract with the Indiana Association of AAAs. Training components include basic orientation to the in-home services system and Medicaid waivers, customer service skills like dealing with difficult people, techniques for asking questions, use of the Internet and the I&A software, and time management.[68]

Exhibit VII.11
I&A Staff for Caregivers

Title: Family Caregiver Resource Specialist Position

Affiliation: AAAs in North Carolina

Status: Operational

Target Population: Caregivers

Approach: Each AAA created a fulltime position for a Family Caregiver Resource Specialist. This individual is responsible for: 1) developing, implementing, and tracking the AAA's work plan for family caregiving support (subsumed in the Area Plan) in consultation with state-identified contacts; 2) leading program and resource development efforts (e.g., networking, grant writing, volunteer recruitment and training); 3) providing or arranging for direct services (e.g., public information activities, outreach, I&A, counseling, caregiver training); 4) establishing an adequate system for recordkeeping of individuals served, expenditures, and unmet needs; 5) developing an area publicity campaign for the NFCSP; 6) advocating for the interests of family caregivers; and 7) participating with AAA peers, the Division Specialist, and other staff members in support of program implementation and evaluation. The AAAs were encouraged to hire individuals for the Specialist position who had personal or professional experience in caregiving, or both. The SUA hired a Family Caregiver Program Specialist to work closely with the AAAs and oversee and support statewide development of the FCSP.

Contact Information: Chis Urso, Family Caregiver Program Specialist, Division of Aging, at chris.urso@ncmail.net or (919) 733-3983.

[68] Reinhard, S.C. and Scala, M.A. (2001). Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States. Prepared for the Public Policy Institute, AARP.

Structure the I&A Data Collection Process So It Captures Relevant Caregiver Information That Will Enhance Intake, Assistance, Follow-up, and Program Assessment Activities. Well-designed I&A systems with mechanisms for capturing key information can be used to inform service planning, outreach activities, capacity assessment, caregiver needs, training needs, advocacy, and other program operations related to supporting caregivers. The network will want to:

- Examine current software and assess its ability to integrate existing databases (including caregiver-specific data);
- Evaluate data collection needs beyond looking at "ease of burden" and toward how data collection can produce important evaluative information at the caregiver, local program, and overall program levels;
- Consider screening caregivers through the use of a structured interview; and
- Decide what information must be captured (basic information and beyond basic information) and when (what information is valuable to capture at initial intake and what information can and should be captured in future).

Washington's FCSP uses one caregiver screening form for both "contact" and "screening" purposes. A contact is any call about or request for the FCSP, FCSP services, or family caregiving. Basic information is collected on all callers in two sections of the form. Additional information is collected from those callers who need something beyond basic information.

The program intake form used in the Alzheimer's Demonstration is part of a one-time intake to gather basic demographic and functional abilities information on the person with Alzheimer's Disease and on his or her caregiver, if one exists. Visit AoA's Web site at http://www.aoa.gov/alz for information about the program intake form used by several states participating in the Alzheimer's Disease Demonstration.

COUNSELING, SUPPORT GROUPS, AND TRAINING

Service Description

Counseling, support groups, and training refer to a range of individual and group services that assist caregivers in making decisions, solving problems, and gaining knowledge related to their caregiving role. ***Exhibit VII.12*** presents a sample of activities for the network to consider.

Exhibit VII.12
Caregiver Counseling, Support Group, and Training

- Family conflict resolution
- Cognitive behavioral therapy
- Behavioral management skills training
- Problem-solving skills training
- Personal care skills training
- Counseling to caregivers of hospice recipients (pre-mortem and postmortem)
- Peer counseling
- Caregiver mentors
- Family counseling for grandparents
- Support group counselors
- Grief counseling
- Support group for former caregivers
- Education through caregiver camps
- Single session community workshops and education forums
- Lecture series followed by a discussion
- Short-term support groups (structured to educate about resources and caregiving skills)
- Long-term support groups (mutual information sharing, self-help among members)
- Psycho-educational and skills-building groups
- LTC planning
- Telephone-mediated groups
- Computer-mediated groups
- Videoconference training and education
- Education via Internet radio

Strategies and Program Examples

Focus on Program Goals, Targeting Variables, and Type of Intervention in Determining the Design and Implementation of These Services. Toseland and Smith recommended that the network follow these steps:[69]

1. Carefully consider the characteristics of caregivers the program intends to serve (i.e., need for support; education; problem-solving, coping skills and personal care skills training; unique needs; and personal characteristics [of both the caregiver and care recipient]).
2. Define the goals of the educational or training program (i.e., the program should focus on prevention or remediation).
3. Define the target population, based on the program goals (i.e., cast a broad net over all caregivers or target caregiver subgroups).

Exhibit VI1.13 presents a caregiver training and education program modeled on defined goals.

[69] Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/ issuebriefs.html.

Exhibit VII.13
Training and Education for Dementia Caregivers

Title: The Savvy Caregiver: An Education Program for Family Caregivers

Affiliation: Alzheimer's Disease Resource Agency of Alaska and the University of Minnesota (School of Medicine, Department of Family Practice and Community Health)

Status: Operational

Target Population: Primary caregivers of persons with dementia currently receiving services and caregivers yet to be involved with the service system

Approach: The Savvy Caregiver is a formal educational program that focuses on improving informal caregivers' practice of providing care. The program seeks to: 1) increase the knowledge, skills, and outlook needed for caregiving; 2) reduce the stress and adverse effects associated with caring for an individual with dementia; and 3) improve the quality of life of family caregivers and their family members. The program consists of six didactic two-hour sessions that employ a combination of teaching methods, such as lectures, group exercises, role-playing, readings, and homework assignments.

Cost/Funding: The Alaska Commission on Aging (SUA) provided a $64,037 grant for this two-year project.

Contact Information: Dulce Nobre at dnorbe@alz.alaska.com or (907) 561-3313.

Avoid a "One Size Fits All" Approach to Service Design and Implementation That Fails to Account for Different Types of Interventions Caregivers Both Need and Prefer. As Montgomery and Kosloski noted, adult children experience different needs than spouses. The former more likely will raise issues concerning sibling rivalry, family conflict, work-related conflict, and the effects of caregiving on their relationship with their spouse and children. Educational programs for this population could cover the disease process, community-based services, and legal and financial information. Support groups could address extending the support network and knowledge of community services. The latter more likely will broach issues about changes in their marital relationship, behavioral management concerns, and problems with their own health. In this case, education programs that cover coping skills, behavior management, and in-home supports might be a better fit. Support groups could cover changing relationship with a spouse, seeking and using supports, options for respite care, and how-to self care.[70]

Clearly, a flexible program design will prove critical to meeting the needs of diverse caregivers who have different preferences and schedules. Some people might prefer and benefit more from individual interventions, while others might be better suited to group training. Toseland and Smith report that the empirical evidence on effectiveness shows the following:[71]

- Both individual and group interventions can be effective in reducing caregiver stress and should be considered.
- Caregivers with emotional problems might be better suited for individual training.

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[70] Montgomery, R.J.V. and Kosloski, K.D. (1999). *Family Caregiving: Change, Continuity and Diversity*. In P. Lawton and R. Rubenstein (Eds.) Alzheimer's Disease and Related Dementias: Strategies in Care and Research. New York, NY: Springer Publishing Company.

[71] Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

- Dementia caregivers benefit from interventions that are comprehensive, intensive, and individually tailored to caregivers' needs.
- Caregivers needing specialized information might be better served in smaller group settings.
- Group training could be more effective for caregivers in relation to building social support and overcoming isolation.
- With group interventions, structured psycho-educational programs containing a combination of education, problem-solving and coping skills training, and support might be more effective than single component support group programs.

In terms of support groups, one singular format usually proves ineffective because many people will be left out. Some caregivers might desire a support group early in the day (e.g., older spouse caregivers), while some prefer evenings (e.g., adult children). Some caregivers might want to participate in online support groups. Others will want to attend support groups at businesses during the employee lunch hour. Most support groups are just for caregivers, although some combine caregivers and care recipients (e.g., individuals with early-stage dementia simultaneously with their caregivers).

Providers have reported that support groups do not follow the mantra, "If you build it, they will come." Instead, to some people, support groups represent a weakness and admission of failure, especially for spouses. They can also represent a stigma or issue of pride in some communities. The term, itself, can be derogatory for certain minority groups. Montgomery recommended that support groups be held in familiar settings such as churches, giving them "legitimacy."[72] Senior Spectrum AAA in Maine is attempting to rejuvenate poorly attended support groups by collaborating with existing groups to determine what needs exist and creating additional groups based on that need. Staff are presenting at existing support groups and gaining a better sense of group style so they can better inform caregivers of the groups that might best match their needs. Effectiveness of support groups depends on the type, scheduling, and content of the support group as well as on the interpersonal dynamics. Therefore, the leader of a support group should be appropriately trained to deal with small group interactions.

Many caregivers are unable to receive support outside the home or prefer not to do so. For this population, the network will want to consider in-home counseling, education, and support options. In addition, technology-based interventions might be convenient for rural communities, special populations dispersed over a large area, and caregivers who are unable to or wish not to leave the care recipient alone to attend an out-of-home group. Colantonio and colleagues reported that telephone support has proven effective as part of combination interventions and has been used as an alternative to support groups to increase satisfaction with social supports and disseminate information about dementia. They recommended that the support staff (professional or caregiver) receive adequate training in screening for depression and knowledge of appropriate follow-up. Also, the network should remain flexible when determining timing of telephone support to meet caregivers' schedules. Online support options include CD-ROM information series, email, distance education courses, caregiver chat, etc.

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[72] Montgomery, R.J.V. AoACarenet Listserv, January 30, 2001.

Research suggests that caregivers using computer support tend to be younger and seek additional means of support (e.g., telephone, newsletter).[73]

Act Creatively to Leverage Resources. First, the network should evaluate what *partnerships* can enhance their support of caregivers' counseling, support groups, and training needs. Toseland and Smith recommend affiliating with local chapters of organizations (e.g., Alzheimer's Association, the American Cancer Society, and AARP) to develop educational and training programs for caregivers of specific disorders,[74] like the example of in-home support and education in ***Exhibit VII.14***. Agencies will want to consider partnerships with organizations that have expertise in caregiver education and training such as Cooperative Extensions and hospice/end-of-life organizations to provide caregiver educational programs. Also, a local college, public library, hospital, or other health and human service organizations might offer the resources for interactive videoconferencing. This format could be particularly useful for experts and caregivers to engage in dialogue from remote sites.

Second, the network will want to look at *building on existing services*. Many service providers who currently support care recipients are in the position to expand their focus to caregivers. ***Exhibit VII.15*** presents a multi-component program for caregivers offered by a local homemaker provider.

As a third means of leveraging resources, the network will want to explore *economies of scale*, through cost-effective options to educate or train a large number of caregivers concurrently. ***Exhibit VII.16*** offers an example of statewide and local caregiver training conferences held in Washington, funded by the state unit and corporate support.

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[73] Colantonio, A., Cohen, C., and Pon, M. (2001, June). Assessing Support Needs of Caregivers of Persons with Dementia: Who Wants What? *Community Mental Health Journal*. 37(3): 231–243.

[74] Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

Exhibit VII.14
In-Home Support and Education

Title: Caregiver In-Home Education and Support Demonstration

Affiliation: Council on Aging of Southwestern Ohio and the Alzeimer's Association

Status: Developmental

Target Population: Homebound high-risk, high-stress caregivers of persons with dementia

Approach: Care managers from the AAA identify caregivers at high risk who exhibit significant levels of stress resulting from demanding caregiving situations and alert the local Alzheimer's Association chapter. Professionals from the Alzheimer's Association then consult with the caregiver in the home. The program assumes that caregiving responsibilities would likely prohibit these caregivers from attending support group. The program teaches behavioral management techniques to curb problem behaviors that instigate caregiver stress. Educational issues addressed include eating, wandering, arguing, and communicating. After a few visits from the Alzheimer's Association professional, the caregiver receives a help line number for future use. Caregivers in this pilot program reported decreased levels of stress, high levels of satisfaction with the program services, and increased use in behavioral interventions.

Cost/Funding: Total annual program costs are $15,000. Although the pilot began before Title III-E funds became available, the AAA will pursue continued implementation with the new NFCSP funds. The AAA reimburses the Alzheimer's Association by the hour. The cost per client ranges from $55 to $400, and 64 clients have been served.

Contact Information: Ken Wilson, Council on Aging of Southwestern Ohio, at wilson@help4seniors.org or (513) 345-8612.

Exhibit VII.15
Leveraging Existing Service Providers

Title: In-Home Caregiver Support

Affiliation: Visiting Nurse and Homemaker Services; the Division of Senior Affairs (SUA), New Jersey Department of Health and Senior Services

Status: Operational

Target Population: Any unpaid primary caregiver (must live with care recipient or visit regularly to assist with managing life activities)

Approach: Visiting Nurse and Homemaker Services, under contract with the state of New Jersey SUA, provides an in-home caregiver education and support program to caregivers at all income levels. The program was established in response to unmet caregiver needs resulting from services not covered under Medicare. Program services include home visits by a nurse to help with education about personal care, nutrition, disease specific information, community resources, and stress management. The program also employs a licensed clinical social worker and an advanced practice psychiatric nurse to provide short-term counseling. Referrals for caregivers in need come from hospitals, social services, and caregivers themselves. The program allows five educational and supportive visits per caregiver, serving approximately 16 to 20 families yearly.

Cost/Funding: An $8,000 grant supports this program. Funding for the program is the same for each county.

Contact Information: Bonnie Mangle, Director of Special Programs, Visiting Nurse and Homemaker Services, at bonnie_mangle@toadmail.com or (609) 267-7417.

Exhibit VII.16
Caregiver Conferences to Train Caregivers

Title: Challenges in Caregiving: Giving Care, Taking Care

Affiliation: Washington Aging and Adult Services Administration (AASA is the SUA in Washington)

Status: Operational

Approach: The Aging and Adult Services Administration (AASA) holds an annual "Challenges in Caregiving: Giving Care, Taking Care" conference that offers caregivers practical, up-to-date information on resources and services available to help them in their caregiving role. The one-day event renders a chance to train and recognize a large number of caregivers at once. Assistance in arranging for respite services is available, making it a good opportunity for caregivers to receive the information they need. Additionally, AASA provides funding and technical assistance to AAAs to hold local caregiver training conferences for teaching caregivers practical skills they can use daily, providing current information on supportive services and resources, offering emotional support, and raising community awareness of caregiver issues. Between 1997 and 2000, AASA contracted with seven AAAs to hold conferences in 14 areas. The large AASA conference usually attracts between 350 and 400 attendees, while local AAA conference attendance usually ranges from 50 to 100 people, with the larger AAAs reporting attendance of up to 300.

Cost/Funding: AASA's "Challenges in Caregiving: Giving Care, Taking Care" conference typically costs about $15,000, with some free speakers. AASA contributes to almost half of that cost. Corporate support, resource exhibitor fees, and low registration fees for caregivers cover the rest. The AAA conference budgets for Fiscal Year 2001 were under $1,500.

Contact Information: Hilari Hauptman, Program Manager, Aging and Adult Services Administration, at haupthp@dshs.wa.gov or (360) 725-2556.

Emulating *train-the-trainer models* represent a fourth strategy to leverage resources. "Powerful Tools for Caregiving," detailed in ***Exhibit VII.17***, is a popular train-the-trainer course that members of the network across the country have used. The course, modeled on the highly successful Chronic Disease Self-Management Program developed by Dr. Kate Lorig and adapted for caregivers by Dr. Vicki Schmall, is used extensively in Oregon and is shown to reduce caregiver guilt and anger while increasing caregiver self-care behavior and confidence. SUAs and AAAs should consider several options to cover the cost. In North Carolina, for example, AAAs interested in providing "Powerful Tools for Caregiving" were encouraged to consider co-sponsorship with other AAAs and with organizations such as AARP that might subsidize persons to attend the training.

Exhibit VII.17
Train-the-Trainer Approach to Family Caregiver Education Program

Title: Take Care of You: Powerful Tools for Caregiving

Affiliation: Legacy Health System, Portland, Oregon

Status: Operational

Target Population: Trains pairs of Class Leaders and Co-Leaders (Class Leaders should be professionals in the fields of aging, social work, health or human services with professional and/or personal experience in family caregiving; Co-Leaders should be community volunteers currently or recently engaged in caring for an older adult relative). Teams will then train caregivers of an older adult with a chronic condition.

Approach: Master trainers are trained by Legacy and then conduct training for Class Leaders and Co-Leaders. In Washington, six teams sent by AAAs attended an intensive four-day training session and committed to leading two training sessions in the 12 months following their attendance. In North Carolina, teams received half-day intensive training over a two-day period. The Class Leaders and Co-Leaders then conduct a six-week class series for caregivers (sessions of two and one-half hours). Caregivers learn a variety of strategies to ease their burden, including how to reduce personal stress, communicate their needs to family members and professionals, effectively deal with challenging situations, and make difficult caregiving decisions. The recommended class size of caregivers is between 12 and 15. The course was originally designed for caregivers of patients with Parkinson's Disease, AD, or stroke, but is has been deemed useful, as well, for caregivers of people with other chronic health problems and disabilities. Legacy Caregiver Services recently received a three-year grant from the Robert Wood Johnson (RWJ) Foundation to expand the program throughout Oregon and to rural and diverse communities, including translating materials into Spanish.

Cost/Funding: In North Carolina, the cost of the two and one–half-day intensive course includes instructor fees, curricular materials, and supplies. Additional costs, depending on class location, might include travel and per diem for instructors and participants and costs associated with classroom rental or refreshments. Estimated cost for an area assumed to be located away from a central location is $4,800 (amounts to $320 to $400 per attendee). This includes in-kind contributions on one Master Trainer's time (two percent match) and indirect costs (26 percent) to North Carolina State University. Not included in this price are the additional costs as described above. The North Carolina SUA funded the Legacy training of Master Trainers. In Washington, the SUA funded the initial training of trainers at the cost of $500 per attendee.

Contact Information: (for information about Washington's experience with this program) Hilari Hauptman, Program Manager, Aging and Adult Administration, at haupthp@dshs.wa.gov or (360) 725-2556 and Lynne Korte at kortelm@dshs.wa.gov or (360) 725-2545; (for North Carolina's experience with this program) Dr. Luci Bearon, Master Trainer, at luci_bearon@ncsu.edu or (919) 515-9146; (for more information from Legacy Caregiver Services) Alison Burrell at (503) 413-6578 or Sue L. Frymark at (503) 413-7430 and visit http://www.legacyhealth.org/healthcare/caregiver/default.ssi.

Lastly, *peer support and caregiver mentors* have proven successful in supporting caregivers and appear to increase the likelihood of their receiving further assistance. In Wisconsin, one of the AAAs developed a peer counselor system in which a psychiatric social worker from the mental health system trains and supervises caregivers to provide in-home caregiver support.

Montgomery notes that one of the most successful aspects of a support group often is the ability to connect two caregivers who then interact more informally, as "supportive friends."[75]

Enlist Service Providers to Serve Caregivers at the "Reachable Moment." A common issue that providers report is the difficulty with establishing and sustaining caregiver support groups. In addition to designing flexible services, providers must be able to recognize how appropriate the intervention is for an individual caregiver (identify the "caregiver marker"). And, once caregivers are involved in an intervention, the provider must understand that caregivers' needs change. Service providers have a key responsibility to educate caregivers who are outgrowing their programs about other community resources so caregivers receive the right services at the right time. When a caregiver leaves a support group, for example, follow-up should ensure that he or she receives support in other ways. In effect, providers "become the conduit of moving the caregiver through the system."[76]

Build In Training and Supervision for Individuals Implementing the Services, and Monitor Implementation. Toseland and Smith noted that consistent feedback to staff and trainers is essential to improving the design of education, training, and support workshops.[77] Even seasoned clinicians can benefit from close supervision, as ***Exhibit VII.18*** demonstrates. Audiotaping or videotaping of group sessions helps trainers improve their program implementation skills. And, as an ongoing activity, providers and administrators should compare program goals with what is actually delivered and the impact of these sessions. ***Exhibit V.4*** in ***Chapter V*** suggests the value of caregiver surveys, for example. Evaluations can include assessments of the effect of a particular program on members' knowledge and skills, their ability to cope with or solve pressing problems, or their well-being. However, the goals of the program should guide the choice of outcome measures.

In addition, Toseland and Smith suggested that, at a minimum, caregivers should be asked about:[78]

- Instructor evaluation,
- Program usefulness,
- Features that were most and least helpful, and
- Issues that should be included in future programs.

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[75] Montgomery, R.J.V. AoACarenet Listserv, January 30, 2001.

[76] Montgomery, R.J.V. AoACarenet Listserv, February 1, 2001.

[77] Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork /issuebriefs.html.

[78] Toseland, R.W. and Smith, T. (2001). *Supporting Caregivers Through Education and Training*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork /issuebriefs.html.

Exhibit VII.18
Responsive Trainers and Evaluative Issues of Caregiver Workshops

Title: Caregiver Workshops Demonstration

Affiliation: Central Ohio Area Agency on Aging (COAAA)

Status: Developmental

Target Population: Broad caregiver population

Approach: The AAA is designing and implementing, in each of its eight counties, four different workshops that address a range of caregivers' needs. The program consists of four two-hour sessions covering: 1) practical, financial, and emotional issues related to caregiving, including the caregiver's role and relationship to the care recipient; 2) moving, lifting, and transferring an older family member; 3) accessing a full range of services; and 4) preventing caregiver burnout. Participants can attend some or all of the workshops free of charge. The evaluative component to this program includes phone follow-up by another staff member to evaluate the workshop, regular meetings with all the trainers to make necessary adjustments to the workshops, and an ongoing literature review. Attendee response to the workshops has been positive, particularly at the rural sites. The program's success has been attributed to effective recruiting and marketing, flexible scheduling, highly skilled and responsive trainers, and well-developed written materials. An innovative feature of COAAA's marketing approach is free, four-hour workshops for aging services professionals, which are offered quarterly. To raise awareness and reach aging services professionals as a referral source, the professional workshop affords an overview of all the workshops. Additionally, the professionals are offered continuing education units (CEUs). The AAA plans to partner with counties to provide respite care so that more caregivers can attend.

Cost/Funding: The AAA received a two-year Demonstration grant funded by the Ohio Department of Aging and is currently funded through the NFCSP.

Contact Information: Lisa Durham, Community Education and Outreach Director, Central Ohio AAA, at durham@coaaa.org or (614) 645-7250.

RESPITE CARE

Service Description

Respite care is considered to be temporary, substitute supports or living arrangements to provide a brief period of relief or rest for caregivers. Under the NFCSP, respite is *caregiver focused*. It can take the form of in-home respite, adult day services respite, or institutional respite. "Respite should be regarded as an outcome, not a specific service."[79] ***Exhibit VII.19*** offers examples of respite care.

[79] Montgomery, R.J.V. Presentation at the AoA Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

Exhibit VII.19
Respite Care

- Supervision
- Personal care
- Telephone reassurance (reminding care recipient to take medications; telephone companionship with the dementia care recipient while caregiver prepares dinner)
- Socialization (friendly visitor, intergenerational program)
- Accompanying a care recipient to appointments
- Elder sitting (allowing caregiver to attend training and support groups)
- Homemaking services
- Expanding respite care beyond dementia caregivers
- Adult day services
- Respite camps
- Caregiver retreats
- Social, recreational, educational, leisure, or other activities for the caregiver
- Overnight placement of a care recipient in a licensed foster care or long-term care facility
- Overnight placement of a care recipient in a non-licensed care setting (neighbor, companion)
- Errand running

Strategies and Program Examples

Coordinate Multiple Respite Programs to Expand Eligibility, Facilitate Access, and Avoid Duplication, While Making Program Differences Invisible to Caregivers. The number of state respite programs has grown considerably through state-funded, single-purpose programs and as a specific benefit under Medicaid Waiver programs. The type, eligibility criteria, and funding mechanisms vary considerably across states and at the local level, requiring the network to examine what respite options are currently available and for whom and what gaps exist. States might want to pursue intra-agency collaboration around respite standards and definitions. Although many respite services have been built around the needs of caregivers of relatives with dementia, the NFCSP offers an opportunity to extend respite support beyond the traditional focus of serving the Alzheimer's Disease population. ***Exhibit VII.20*** presents an AAA approach in Maine to supplement the state's dementia respite program.

Exhibit VII.20
Expanding Eligibility for Respite Care

Title: Family Caregiver Respite Program

Affiliation: Senior Spectrum, AAA (Maine)

Status: Developmental

Target Population: Caregivers of care recipients receiving no assistance from another state subsidized program

Approach: Based on community needs assessment and focus groups, the AAA will expand eligibility for respite beyond dementia caregivers receiving assistance from the State's Partners in Caring Respite Program. Caregivers eligible for funding are caring for an individual who: 1) receives no assistance from another state subsidized program; 2) completes a confidential interview with a caregiver consultant, including taking the Utah Caregiver Burden Scale; and 3) after completing the Caregiver Burden Scale within 48 hours of the initial interview, scores 39 or higher. The caregiver is assessed twice to ensure that the stress derives from more than just a situation (e.g., having a bad day). The Family Caregiver Respite Program will pay up to a $500 annual limit for any provider the caregiver chooses among in-home, adult day service, or short-term overnight placement options. The caregiver receives a bill for services rendered and then sends the AAA (Senior Spectrum, in this case) a copy of that bill attached to a copy of an AAA request for reimbursement form. The caregiver then receives a reimbursement check.

Cost/Funding: The estimated annual funding amount is $10,000.

Contact Information: Debra Halm, Senior Director, Senior Spectrum, at dhalm@seniorspectrum.com or (800) 639-1553 ext.119; Leslie Shaffer, Senior Spectrum, at lshaffer@seniorspectrum.com or (800) 639-1553 ext. 106.

To minimize confusion for caregivers and providers in accessing the full range of available support, coordination between caregiver respite programs and other home- and community-based programs that offer respite care should also be pursued.

Offer a Range of Respite Care to Meet Individual Caregivers' Needs and Preferences, Including In-Home and Out-of-Home and Single-Component and Multi-component Respite Programs. Family caregivers prefer and use in-home respite care more than any other respite type. In Washington's experience, nearly two-thirds of respite hours in the state respite program are expended in the home. Overall findings from the Alzheimer's Disease Demonstration Grants to States (ADDGS) program revealed that families using in-home respite instead of adult day services tended to be middle-income (i.e., ineligible for Medicaid), had higher activities of daily living (ADL) impairments, and had spouse caregivers. Still, other caregivers (e.g., those who work, desire time by themselves at home, require hospitalization, or plan a vacation) might prefer out-of-home respite care. ***Exhibit VII.21*** presents two examples of out-of-home respite. Programs that leverage family, friends, and volunteer systems (e.g., Faith in Action) to deliver respite care might be in a better position to offer a full range of respite options.

Exhibit VII.21
Out-of-Home Respite Care

Title: Georgia Mobile Day Care Program

Affiliation: Greater Georgia Chapter Alzheimer's Association, Augusta Area Chapter Alzheimer's Association, and Central River Savannah Area AAA.

Status: Operational

Target Population: Caregivers of older persons in rural or metropolitan areas (originally developed for caregivers of persons with Alzheimer's Disease)

Approach: With materials and supplies needed for the day, staff travel to a designated site (e.g., church, senior center). Depending on the needs of the community, each site is open five or six hours per day, one to three days each week. Staff return to a central location in the evening. They worked hard to build trust and credibility by using well-known community sites, partnering with local agencies, and hiring a local employee. Though staffing for each program differs, most programs employ up to two paid fulltime equivalents (FTEs). In addition, volunteers assist staff with program activities, such as providing stories and poems from the past.

Cost/Funding: The program costs are spread between two sites. Primary cost components comprise salaries, fringe benefits, travel, rent, and day center meals. In Fiscal Year 2001, the mobile adult day care program budget of Athens Community Council on Aging was $68,616.

Contact Information: Cliff Burt, Alzheimer's Program Director, Georgia Division on Aging Services, at gcburt@dhr.state.ga.us or (404) 657-5336.

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Title: Senior Respite Guest-House Program

Affiliation: Metropolitan Family Services-DuPage County (Illinois private, nonprofit provider)

Target Population: Families caring for individuals age 60 and older in need of 24-hour supervision

Approach: The agency operates two respite guest houses, each with a five-bed capacity, providing respite services from 1 to 30 days. The facility environment is home-like and does not offer nursing care. The houses arrange for personal care assistant service and provide 24-hour supervision, socialization, home-cooked meals served family style, activities, and outings staffed by volunteers. On referral, the family meets with the agency social worker who conducts an assessment, followed by a tour of the house so the care recipient can become acclimated to the surroundings. The program serves approximately 150 unduplicated families per year, with an average stay of six days. Repeat visits are encouraged and are opted by nearly three-quarters of the families. Caregiver counseling and consultation are integrated into the service components.

Cost/Funding: Annual program costs are $350,000 to operate two guest houses with a fulltime social worker and two house managers. Although some families are subsidized, others pay according to a sliding scale. Sources of funding include the NFCSP, fundraising, United Way, and several grants. NFCSP funding for the program is provided through billing the AAA case coordination units.

Contact Information: Janet Driscoll, Director of Senior Services, Metropolitan Family Services, at driscolj@metrofamily.org or (630) 784-4840.

Varying circumstances of the caregiver and care recipient call for caregivers to be able to choose from a range of options. By the time caregivers seek or use respite care, they often have many other support and care needs. Respite care, by itself, is insufficient to produce positive caregiver outcomes. Therefore, the network will want to consider combining respite care with other forms of caregiver support. The Asian-Pacific Adult Day Services Program in Washington (an Alzheimer's Disease demonstration) offers adult days services, family education, family counseling, one-on-one counseling for caregivers, and linkage with other services such as

transportation and home care. ***Exhibit VII.22*** presents an example of a local multi-component program.

Exhibit VII.22
Multi-component Program

Title: Caregiver Camp

Affiliation: Cabarrus County Department of Aging and Centralina Area Agency on Aging, North Carolina

Status: Developmental (Planned for June 2002)

Target Population: Adult caregivers caring for someone over the age of 60 or a grandparent caring for a grandchild 18 and under.

Approach: The county is holding a five-day (9am to 3pm) caregiver camp at the Cabarrus County Senior Center focusing on educational information and training for the caregivers. Fun activities to reduce stress will also be part of the program by introducing the caregivers to activities at the center. In addition, group or in-home respite will be provided to care recipients when their caregivers attend camp. Transportation will be provided, if needed.

Cost/Funding: The camp is offered at no cost to caregivers. Funding is provided by the NFCSP and other sponsors as contacted.

Contact Information: Chasity Stoker, Aging Services Coordinator, Cabarrus County Department of Aging, at clstoker@co.cabarrus.nc.us or (704) 920-3484; Cyndi Smart, Caregiver Resource Specialist, Cabarrus County Department of Aging, at cmsmart@co.cabarrus.nc.us or (704) 920-3484.

Seek Different Approaches to Improve Respite Care Use. Research indicates that services providing respite care to caregivers prove more effective when delivered in adequate amounts (frequency and duration) and at the appropriate time. Brief users of respite reflect those situations in which the service fails to meet their need. Brief use raises costs for both the family and the provider (i.e., turnover, increased need for marketing, increased staff time, filling spaces from which others could benefit).[80]

Furthermore, respite care more likely succeeds when it avoids increasing perceived burden by the caregiver. Caregivers experience no relief, for example, when a care recipient refuses help or creates difficulties for caregivers for arranging help.[81] If the cost of respite services exceeds the benefit, (e.g., transportation or personal care needs for the care recipient overwhelm a caregiver trying to prepare his or her loved one for adult day services), respite care is perceived as unhelpful.[82]

Caregivers exhibit different patterns of use by respite type. The characteristics associated with in-home respite are: spouse caregiver, married, co-residence, high disability-level of care recipient, and White. Characteristics of those who tend to use adult day services are: adult child,

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[80] Montgomery, R.J.V. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

[81] Zarit, S.H. *Respite Services for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

[82] Montgomery, R.J.V. Presentation at the U.S. Administration on Aging Conference, *National Family Caregiver Support Program: From Enactment to Action*, September 6, 2001.

single elder, younger, lower disability-level of care recipient, Hispanic, African American, and urban. Spouse caregivers tend to use less respite overall than all other caregivers.[83]

The following strategies aim to gain caregivers' acceptance and appropriate use of respite services:

- **Identify structural and process barriers to respite care use.** The network should re-examine existing policies around respite provision, particularly rules that might encourage caregivers to delay respite care with the concern that they could need it more in the future. Likewise, more generous and flexible financial incentives might influence service use more than using more conventional care management means to link caregivers.[84]

  It is clear that the appropriate type and level of respite care differs among caregivers. Arbitrary caps on respite care could impede effective resource allocation among consumers with different levels of need, resulting in ineffective or inefficient service use.[85] By developing mechanisms for the caregiver consumer to gain more control over the process, the network realizes a greater chance of meeting the caregiver's respite needs.

- **Provide respite care through properly trained, reliable, and accommodating support staff.** Consumer satisfaction levels with respite care are more affected by things that providers do than by client characteristics. With in-home respite care, provider reliability is likely to reduce care-related strain, improve caregiver well-being, and ultimately result in more effective use.[86] Providers can be educated to demonstrate sensitivity to the needs of caregivers and the tendency for caregivers to feel that they are imposing. Caregivers, in turn, can be educated about: 1) how to communicate important caregiving routines to respite care staff; 2) how to determine the best times of day for respite and communicate that knowledge to respite staff; and 3) how to communicate with the care recipient before and after the respite care experience.[87] Caregivers more often perceive providers they know as the most reliable.

  Choice of provider is one element of control that programs can offer caregivers. A trend has emerged for state respite care programs to become laboratories for consumer-directed programs for the elderly and their caregivers. Findings from the Family Caregiver Alliance (FCA)–funded multi-state study of in-home respite delivery models showed that the majority of consumers preferred a "direct pay" model to an "agency based" model.[88] This conclusion suggests that states should seriously consider developing and instituting

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[83] Montgomery, R.J.V. and Kosloski, K.D. (2001). *Change, Continuity and Diversity Among Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

[84] Zarit, S.H. (2001). *Respite Services for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

[85] Montgomery, R.J.V., Marquis, Schaefer, J., and Kosloski, K.D. Profiles of Respite Use. (Forthcoming 2002). *Home Health Care Services Quarterly*. 20(3/4).

[86] Zarit, S.H. (2001). *Respite Services for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

[87] Worchester, M. And Hedrick, S. (1997). Dilemmas in Using Respite for Family Caregivers for Frail Elders. (Vulnerable Populations Part I). *Family and Community Health*. 19(4): 31(18).

[88] Feinberg, L.F. and Whitlatch, C.J. (1996). *Family Caregivers and Consumer Choice: Options for In-Home Respite Care* (Final Report). San Francisco, CA: Family Caregiver Alliance.

consumer-directed programs. ***Chapter IX*** offers further information about consumer-directed services for caregivers.

- **Change caregivers' perception of respite to a beneficial support service by communicating the *value* of respite.** Awareness of a program and the availability of other secondary caregivers account for family decisions about seeking respite (e.g., a more extended network of caregivers actually keeps families from seeking help). Also, if a caregiver perceives a service as a poor match for his or her needs in terms of availability or disability level of the elder, the caregiver will reject the service.[89,90]
- The value, rather than the price, becomes the key issue for most caregivers considering respite care. Translating program features into benefits to the caregiver to communicate value is a potentially helpful practice. For example, in the case of adult day service, Henry advises letting the caregiver know that the center's providing the care recipient a nutritious lunch relieves the caregiver of cooking and worry about the participant's getting enough to eat. Moreover, she says that exercise programs seem to help participants sleep better at night. Henry suggests a marketing exercise for respite staff: list all program features and convert them into benefits to the caregiver. This practice helps the staff "sell" the program as well as indicates areas of the program that can be enhanced to benefit caregivers.[91] Some considerations for adult day service providers in enhancing support for caregivers include:[92]

- Working caregiver convenience,
- Sandwich generation needs,
- Spouse and adult children needs,
- Health problems of the caregiver,
- Providing support groups,
- Communicating benefits, and Physiological fear (e.g., concerns about quality of life, feelings of guilt, concerns for safety).

A Caregiver's Reflection

"As we observed the staff's caring watchfulness and attentiveness to her, we knew her days were safe and that the place retained familiarity to her. The staff's watchfulness extended to me as Katherine's caregiver. They answered all my questions (many before I asked them) and each day brought a gentle smile, a special moment recalled, a hearty laugh, or, sometimes, a fear. All in the intimate understanding of the woman we cared for together."

Katryna Gould

Communicating the value of respite for caregivers should also be directed to individuals and organizations that represent major referral sources: health care professionals (e.g., physician office personnel, discharge planners), community providers, and employers.

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[89] Kosloski, K., Montgomery, R., and Youngbauer, J. (2001). Utilization of Respite Services: A Comparison of Users, Seekers, and Non-Seekers. *Journal of Applied Gerontology*. 20: 111-132.

[90] Brooks, G. Executive Director, Western Illinois AAA, in Rock Island, Illinois AoACarenet Listserv, February, 2001.

[91] Henry, R.S. (1993). *Customers Need to See Value of Services*. Winston-Salem, N.C.: Bowman Gray School of Medicine of Wake Forest University.

[92] Nestler, J. Executive Director, Eastside Adult Day Services. Telephone interview. October 22, 2001.

- **Respond to "information seekers" and "service seekers" with different strategies.** Newton and Henry developed a caregiver targeting framework that can assist network staff and respite providers in identifying how best to serve different types of caregivers.[93]

  Information seekers are individuals who might be caring for someone with early-stage Alzheimer's Disease or minimal impairment who is in denial about the diagnosis or the fact that he or she needs help. The adult day service could focus on offering caregiver education to this caregiver population rather than attempting to enroll the care recipients in the program. Providers could supply information about future service options and support in dealing with the psychological aspects of caregiving. Because information seekers are potential users, staying in touch is valuable. When the caregivers reach the servable moment, then, they will consider the benefit of adult day service.

  Respite seekers need an occasional break from caregiving but have no desire for daily adult day service. This segment encompasses two subgroups: *givers* are individuals who want to provide maximum care but are physically and emotionally unable to do so, and *responsibles* are individuals who provide care out of a sense of duty but who might find little satisfaction in caregiving tasks. Respite seekers are moderate users for whom providers might consider offering support groups and education about additional services.

  Care seekers desire all the assistance they can get and are ready for more fulltime and regular adult day service. This segment also contains two subgroups: *delegator*s are individuals who want their caregiving problem fixed and might go for the first service available, and *balancers* are individuals who would like to provide the care themselves but, because of other responsibilities, are unable to do so. Particular about the kind of care, this group tends to remain closely involved. Care seekers are heavy users for whom providers could offer extended hours, ancillary services, and counseling services.

Examine Program Goals, and Determine Caregiver Outcomes and Quality Standards for Respite Care Use. Currently, evaluation of respite care services and identification of measurable outcomes are at an early stage of development. Zarit noted the unlikelihood that any intervention will affect all aspects of the stress process (primary stressors, secondary stressors, and outcomes) for caregivers; rather, a respite intervention is likely to affect some areas directly and others, indirectly, or it might exert no effect at all.[94] ***Chapter V*** offers further information about outcomes for respite care. The network might contemplate partnering with a researcher to assist in developing caregiver outcomes and indicators for single respite services and multi-component programs to inform respite program outreach, design, and delivery.

National accreditation for adult day service has been available to providers since 1999 through the Commission on Accreditation for Rehabilitation Facilities (CARF).[95] Because many states have no regulations, certification, or licensure for adult day service, accreditation is a valuable option. Through CARF, accreditation becomes a:

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[93] Newton, G. and Henry, R.S. (1992). *Marketing Adult Day Programs: Targeting Caregivers to Reach Participants*. Winston-Salem, N.C.: Bowman Gray School of Medicine of Wake Forest University.

[94] Zarit, S.H. (2001). *Respite Services for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html .

[95] As of March 2001, 39 Adult Day Service programs, located in 18 states, were accredited.

- Management tool that sets direction for consumer satisfaction and program success according to each center's mission, purpose, and core values.
- Business strategy used in establishing goals and objectives with performance measures and measurable outcomes.
- Quality enhancement strategy used in defining priorities for action through strategic planning and for directing resources through budget considerations, monitoring, and forecasting.
- Marketing strategy that allows development of a market focus through identifying consumer needs and expectations.
- Quality assessment tool that can be recognized as a seal of approval for providers, regulators, caregivers, and care recipients.[96] [97]

SUPPLEMENTAL SERVICES

Service Description

Supplemental services are other services to support the needs of caregivers, as defined by the state. The category of supplemental services has a funding cap under the NFCSP (no more than 20 percent of the federal funding should be dedicated to this category). By definition, supplemental services are meant to be flexible enhancements to caregiver support programs and are for the benefit of *caregivers*. ***Exhibit VII.23*** presents examples of supplemental services.

Exhibit VII.23
Supplemental Services

- "Caregiver survivor kits"
- Purchase of caregiver training materials for lending libraries
- Loan Closet with adaptive equipment
- Home modifications that benefit the caregiver
- Registered nurse to conduct in-home assessments
- Homemaker services for money management
- Emergency respite care
- Emergency alarm response system
- Professional consultation (RN, OT, PT, MH, RD, JD)
- In-home nutrition and diet counseling
- Limited adult day service transportation
- Home safety interventions
- Assistive technology
- Chore services and errand running by volunteers
- Legal assistance
- Telephone reassurance

[96] Nestler, J. (December, 2001). Accreditation for Adult Day Services: The Choice and What is CARF? Unpublished issue brief prepared for the U.S. Administration on Aging.

[97] See http://www.carf.org/ for further information.

Strategies and Program Examples

Limit Restrictions through More Flexible, Cost-Effective Methods. Because caregivers best know their own needs and each caregiver is different, the network should think about financing methods that allocate services to caregivers who need enhanced support. The process would take into account their needs for service type, timing, and amount. Some potential strategies include aggregate caps on supplemental services, individual caps on supplemental services, and integration of supplemental services with other services.

Consider Use of Professional Consultation for Assisting Caregivers with Financial and Legal Issues. Caregiver focus groups and surveys have commonly found that caregivers need guidance on financial and legal matters. The network could use supplemental services funding to go beyond what might be offered in a support group setting by contracting with professional consultants. Pierce County Aging and Long Term Care, Washington AAA, for example, is developing a service contract to provide professional consultation and legal assistance by an attorney. The elder law/legal assistance program will help caregivers with durable power-of-attorney matters and health care directives. An annual $500 cap per caregiver exists for supplemental services.

Implement Simplified Categorization and Accounting of Supplemental Services to Allow for Greater Flexibility. One area of confusion rests with how to categorize and account for supplemental services, particularly if a voucher system is in place. As described by Cliff Burt of Georgia Division of Aging Services, Legacy Express is a self-directed care model in which voucher books in the amount up to $500 are issued.[98] For Title III reporting purposes, each voucher is counted as a unit of service. In the database, some services are identified by whether the service was purchased with a voucher.

Remain Open to the Unusual. In thinking about what is an acceptable supplemental service, allow for the caregiver's circumstance to dictate the "solution." McGuire recommended that the network, instead of making a list all of the possible services a program will allow, should consider just those items or circumstances that would be unacceptable.[99]

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[98] Burt, C. Presentation at the AoA Conference, National Family Caregiver Support Program: From Enactment to Action, September 7, 2001.

[99] McGuire, D. AoACarenet Listserv, April 30, 2001.

VIII. DESIGNING THE NFCSP IN THE CONTEXT OF DIVERSE CAREGIVER POPULATIONS

This chapter aims to guide administrators and program planners of State Units on Aging (SUAs), Area Agencies on Aging (AAAs), Service Providers (SPs) and Indian Tribal Organizations (ITOs) in designing services to meet the needs of individual caregiver subpopulations. The following general strategies for reaching and serving specific caregiver subpopulations are reflected throughout this chapter:

- Establish implementation goals based on needs and resources in particular regions and local communities.
- Involve caregiver stakeholders in the implementation process at the state, regional, local and tribal levels.
- Educate and train staff on the most effective approaches for reaching and serving specific subpopulations.
- Employ culturally competent communication tactics that ensure outreach, assistance, education, and referral efforts are communicated through methods proven effective in reaching particular subpopulations (e.g., targeting ethnic groups in locations where they are likely to live).
- Maximize resources by forming partnerships with existing advocacy organizations and health, social service, and other community entities already specializing in advocacy efforts or services relevant to a specific subpopulation.
- Build flexibility in the program so it can respond to individual characteristics, preferences, and needs.

Caregivers represent a heterogeneous group of subpopulations, each with different demographic, circumstantial, and environmental factors influencing the caregiver experience. This chapter presents the type of NFCSP services needed by particular caregiver subpopulations within the following three domains.

1. Demographic Factors
   - Ethnicity, race, and culture
   - Sexual orientation
2. Special Caregiver Circumstances
   - Grandparents and other relatives raising children
   - Older caregivers of children and young adults with developmental disabilities

3. Environmental and Other Conditions
   - Working caregivers
   - Rural caregivers
   - Long-distance caregivers

Presenting service needs by subpopulation in this chapter highlights the relevance of designing programs in the context of specific demographic factors and other caregiver circumstances. The subpopulations represented, however, overlap with one another (e.g., rural caregivers include minority groups). Also, significant overlap exists in the types of challenges caregivers face across subpopulations (e.g., rural and long-distance caregivers both face geographic obstacles in coordinating services for care recipients).

In discussing each subpopulation, the chapter incorporates the available evidence in the literature and provides program examples and strategies used by states experienced in designing program models for diverse caregiver populations. The lessons learned in states can inform the network's efforts to address both the subtle and palpable needs of caregivers.

DEMOGRAPHIC FACTORS

Designing an effective National Family Caregiver Support Program (NFCSP) calls for consideration of demographic factors influencing the needs of caregivers, including ethnicity, race, culture, socioeconomic status, and sexual orientation. These factors affect the type of support that a caregiver needs, how or whether he or she seeks and receives services, and the duration of services required. Some caregivers need information, some seek emotional support, and others require assistance with direct care tasks. Caregiver interventions might be intensive initially, until the family's situation stabilizes, and then intermittent, as new challenges arise.[100]

Ethnicity, Race, and Culture

Ethnic and racial minorities age 65 and over are increasing faster than other segments of the population, and by 2030, minority groups are projected to comprise 25 percent of the older population.[101] This trend holds significant implications for the aging network's role in responding to the needs of caregivers supporting the aging minority population.

The U.S. Census Bureau broadly categorizes ethnic and racial populations into four groups (African American, Asian American and Pacific Islander, Hispanic American, and American Indian/Alaska Native); however, many other racial or ethnic minorities and considerable diversity exist within each group. National data indicate that 28 percent of African Americans,

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[100] Montgomery, R.J.V. and Kosloski, K. (2001). *Change, Continuity and Diversity Among Caregivers.* Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/ carenetwork/issuebriefs.html.

[101] Angel, J.L. and Hogan, D.P. (1994). The Demography of Minority Aging Populations. Minority Elders: Five Goals Toward Building a Public Policy Base. Washington, DC: The Gerontological Society of America.

42 percent of Asian/Pacific Islander Americans, and 34 percent of Hispanic Americans provide care to their aging parents, in-laws, or other relatives.[102]

Recognition of cultural differences in racial and ethnic populations from the larger caregiver population is an important component of implementing the NFCSP. "The term 'culture' connotes a common heritage and set of beliefs, norms and values. Within any given group, an individual's cultural identity involves multiple layers, including language, country of origin, gender, age, class, religious/spiritual beliefs, acculturation,[103] sexual orientation, and physical disabilities." [104]

The literature documents numerous barriers to treatment by racial and ethnic minorities, including cultural, organizational, poverty, and income limitations. Similar to other health care service recipients, caregivers' cultural identities can influence practices that affect their willingness to seek, and ability to respond to, health and social services. Significant culture-related barriers to care exist for racial and ethnic minorities in part because the health and social service systems historically have ignored the unique needs of these groups.

Until recently, research on caregivers has focused almost exclusively on non-minority caregivers.[105] [106] Despite limited research in this area, lessons learned from national research studies such as the Alzheimer's Disease Demonstration Grants to States (ADDGS)[107] program and the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program, identify several mechanisms for state and local agencies to respond to the needs of minority groups.[108]

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[102] Gallagher-Thompson, D., Haley, W., Guy, D., Rubert, M., Tennstedt, S., and Ory, M. (2002). Tailoring Psychosocial Interventions for Ethnically Diverse Dementia Caregivers. Unpublished manuscript.

[103] Acculturation refers to the "social distance" separating members of an ethnic or racial group from the wider society in areas of beliefs and values and primary group relations (work, social clubs, family, friends). Thus, greater acculturation reflects greater adoption of mainstream beliefs and practices and entry into primary group relations. Taken from Gordon, M.F. (1964). *Assimilation in American Life*. New York, NY: Oxford University Press.

[104] Lu, F.G., Lim, R.F., and Mezzich, J.E. (1995). Issues in the Assessment and Diagnosis of Culturally Diverse Individuals. *Review of Psychiatry*. Washington, DC: American Psychiatric Press.

[105] Connell, C.M. and Gibson, G.D. (1997). Racial, Ethnic, and Cultural Differences in Dementia Caregiving: Review and Analysis. *The Gerontologist*. Vol. 37.

[106] Aranda, M.P. and Knight, B.G. (1997). The Influence of Ethnicity and Culture on the Caregiver Stress and Coping Process: A Sociocultural Review and Analysis. *The Gerontologist*. Vol. 37.

[107] The ADDGS program is authorized in Section 398 of the Public Health Service Act (42 U.S.C. 398 et seq.), as amended by Public Law 101-157 and by 105-379, the Health Professions Education Partnership Act of 1998.

[108] REACH is a five-year, multi-site study funded by the National Institutes of Health (NIH), the National Institute on Aging (NIA), and the National Institute on Nursing Research (NINR). The project measures effectiveness of various interventions for family caregivers and maintains six intervention sites throughout the United States.

Strategies and Program Examples

The NFCSP provides the network with an opportunity to build on prior efforts to design caregiver and care recipient services that are culturally competent. Cultural competence is defined as "a set of cultural behaviors and attitudes integrated into the practice methods of a system, agency, or its professionals."[109] Cultural competence has proven effective in increasing utilization and improving services for minority populations across a range of health care sectors.[110]

Employing strategies to achieve cultural competence ensures that The aging network can work effectively in cross-cultural situations. The following section presents some of the key approaches for moving toward a culturally competent system:

- Demonstrating a commitment to responding to cultural diversity.
- Providing population-based service delivery to maximize cultural strengths and minimize barriers to care.
- Partnering with community organizations already dedicated to addressing the needs of specific minority groups.
- Tailoring communication style to the target population.

Demonstrate Commitment to Responding to Cultural Diversity. The aging network can demonstrate its commitment to placing a high priority on recognizing and responding to culturally diverse populations through a range of approaches, including:

- Creating mission statements that articulate principles, rationale, and values for culturally and linguistically competent service delivery;
- Developing mechanisms to assure diverse caregiver participation in the state- and local-level planning, delivery, and evaluation of services;
- Employing policies and practice standards around staff recruitment, hiring, and retention that will achieve a goal of a diverse and culturally competent workforce; and
- Dedicating resources to support training and staff development, as well as outreach, translation, and interpretation services.

An important initial step in identifying and conducting outreach to minority populations involves using data, such as the Census, to identify counties and neighborhoods with high concentrations of minority groups. Other aggregate data might be obtained from community planning agencies, social service departments, and services for new immigrants. ***Chapter III*** addresses detailed methods and sources for identifying prevalence estimates of the caregiver population.

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[109] Lavizzo-Mourey, R. and Mackenzie, E. (1995). Cultural Competence – An Essential Hybrid for Delivering High Quality Care in the 1990's and Beyond. *Transactions of the American Clinical and Climatological Assoc.* Vol. 107.

[110] Cross, T., Bazron, B., Dennis, K., and Isaacs, M. (1989). Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed. Washington, DC: Georgetown University Child Development Center.

Employing bilingual individuals who reflect the ethnic backgrounds of the local caregiver community is also a key strategy for outreach and service provision to caregivers. Some states, such as California, require all caregiver resource centers to employ bilingual staff and provide basic information and educational materials in languages other than English.[111] In addition to recruiting and hiring bilingual staff, training and professional development efforts should ensure that all staff members, regardless of background, understand cultural differences and their impact on attitudes and behaviors. Staff members must be sensitive, understanding, and respectful in dealing with people whose culture differs from their own. Training should also focus on making sure staff members remain flexible and skillful in responding and adapting to different cultural contexts and circumstances.

Aging network agencies can create an advisory committee represented by individuals serving in leadership roles in ethnic communities to offer guidance on how to serve different populations effectively. To enhance minority outreach efforts, network agencies can seek bilingual and minority volunteers from established volunteer organizations, as well, such as AmeriCorps and Retired Seniors Volunteer Program (RSVP).

Decorating network offices with culturally and linguistically friendly pictures, posters, and artwork makes facilities more welcoming and attractive to minority caregivers, thereby enhancing program participation.

Provide Population-Based Service Delivery to Maximize Cultural Strengths and Minimize Cultural Barriers to Care. Knowing and understanding the characteristics of the population being served and delivering population-based services are important methods for developing effective caregiver support programs. An essential step in delivering population-based services is creating or using model burden assessments tailored to evaluate the needs of specific minority groups. ***Chapter IV*** addresses in detail strategies for developing burden assessments.

This section presents frequently identified strategies in the literature for addressing some of the cultural differences among specific minority groups. African American caregivers, in general, consider aging as a transitional phase of life, and therefore, view family caregiving as a normal expectation, rather than a disruption of the life course.[112] These positive perceptions about aging and caregiving contribute to lower levels of stress, such as fewer symptoms of depression and greater satisfaction with the caregiving role.[113] [114] [115] [116]

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[111] Administration on Aging (2001). *Achieving Cultural Competence, A Guidebook for Providers of Services to Older Americans and their Families*. Washington, DC: AoA.

[112] Haley, W.E., Roth, D.L., Coleton, M.I., Ford, G.R., West, C.A.C., Collins, R.P., and Isobe, T.L. (1996). Appraisal, Coping, and Social Support as Mediators of Well-Being in Black and White Family Caregivers of Patients with Alzheimer's Disease. *Journal of Consulting and Clinical Psychology*. Vol. 64.

[113] Hinrichsen, G.A. and Ramirez, M. (1992). Black and White Dementia Caregivers: A Comparison of Their Adaptation, Adjustment and Services Utilization. *The Gerontologist*. Vol. 32.

[114] Haley, W.E., West, C.A.C., Wadley, V.G., Ford, G.R., White, F.A., Barrett, J.J., Harrell L.E. and Roth, D.L. (1995). Psychological, Social and Health Impact of Caregiving: A Comparison of Black and White Dementia Family Caregivers and Noncaregivers. *Psychology and Aging*. Vol.10.

[115] Lawton, M.P., Rajagopal, D., Brody, E., and Kleban, M. (1992). The Dynamics of Caregiving for a Demented Elder Among Black and White Families. *Journal of Gerontology: Social Sciences*. Vol. 47.

African Americans' acceptance of the role of caregiver coupled with support from both family and community members, however, might explain why individuals often wait to obtain caregiver services in the late stages of the caregiving process. Compared with non-minority caregivers, African American caregivers are more likely to provide higher-intensity level of care yet also report having lack of access to caregiver support services. Despite these trends, African American caregivers report limited use of formal support systems.[117]

Also important for the aging network is focusing on initiatives that capitalize on the cultural strengths of African Americans and other minority groups. For example, ties to family and community are especially strong in many African American, Hispanic, and Asian communities. As such, program administrators must shift interventions from working with caregivers individually to involving the whole family. When faced with personal difficulties, African Americans have often been known to seek guidance from religious institutions.[118] Services for African Americans that involve family members and churches often prove more effective than other initiatives.[119] ***Exhibit VIII.1*** highlights program examples that target African Americans, as well as other minorities, in community settings familiar to them.

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[116] Mui, A. (1992). Caregiver Strain among Black and White Daughter Caregivers: A Role Theory Perspective. *The Gerontologist*. Vol. 32.

[117] Navaie-Waliser, M., Feldman, P., Gould, D., Levine, C., Kuerbis, A., and Donelan, K. (2001). The Experiences and Challenges of Informal Caregivers: Common Themes and Differences Among Whites, Blacks, and Hispanics. *The Gerontologist*. Vol. 41

[118] Broman, C.L. (1996). Coping with Personal Problems. In H.W. Neighbors and J.S. Jackson (Eds.), *Mental Health in Black America*. Thousand Oaks, CA: Sage.

[119] Lockery, S.A. (1991). Caregiving Among Racial and Ethnic Minority Elders. *Generations.* Vol. 15.

Exhibit VIII.1
Skills Training for African Americans

Title: Alabama REACH Project

Affiliation: University of Alabama in Birmingham, Alabama

Status: Operational

Target Population: African American and non-minority caregivers of individuals with dementia

Approach: The Alabama REACH Project employs several strategies to eliminate observed cultural and socioeconomic barriers to care for African American caregivers. This program involves African American and non-minority staff presenting three-hour skills training workshops in centers known to the African American community (e.g., churches). The key objectives of the workshop are to provide caregivers with accurate information about dementia and to teach behavior management skills to address care recipients' problematic behavior. Another objective involves encouraging caregivers to increase positive health behaviors (e.g., exercise) for themselves. Selecting sites familiar to the community has proven fundamental to reducing workshop absenteeism. Staff members are trained to adapt their teaching strategies to the educational level and learning styles of participants. In follow-up to the workshop, one-on-one in-home training takes place over a three-month period to provide caregivers with ongoing coping skills for potentially stressful circumstances.

Contact Information: Louis D. Burgio, Ph.D., Principal Investigator, Director, Applied Gerontology Program, The University of Alabama at Uscaloosa, at jburgio@sw.ua.edu or (205) 348-7518.

Asian Americans commonly assume more responsibilities for both children and living parents in comparison to other minority groups because many have postponed having children, according to findings from a national survey of African American, Hispanic American, and Asian American caregivers aged 45 to 55. Yet, this group often reports experiencing feelings of guilt for failing to do more. Asian Americans also are apt to express that caring for family members creates stress. In some respects, older Asian Americans in the U.S. have fewer family caregivers available in comparison to other minority groups. They generally have fewer and younger children, or no children at all, to help care for them.[120]

Under use of services among Asian Americans represents a key challenge for providers. Asian Americans refrain from requesting services for a number of reasons, including cultural stigma associated with seeking assistance, limited English proficiency among some Asian immigrants, different cultural explanations for the problems, and the inability to find culturally competent services.[121] ***Exhibit VIII.2*** presents an example of a program in Ohio that has proven effective in reaching Asian Americans.

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[120] AARP (2001). In the Middle: A Report on Multicultural Boomers Coping with Family and Aging Issues. A National Survey Conducted for AARP.

[121] Sue, S., Zane, N., and Young, K. (1994). Research on Psychotherapy with Culturally Diverse Populations. In A.E. Bergin and S.L. Garfield (Eds.), *Handbook of Psychotherapy and Behavior Change.* New York, NY: Wiley.

Exhibit VIII.2
Outreach to Asian Americans and African Americans

Title: Central Ohio Area Agency on Aging (COAAA) Outreach Project

Affiliation: Central Ohio AAA

Status: Operational

Target Population: Asian American and African American caregivers

Approach: COAAA is collaborating with several community groups in Columbus, Ohio, to organize effective outreach to Asian American and African American caregivers. Community groups include the Black Church Network and the Asian American Community Services. The agency is conducting workshops to educate caregivers about aging-related disorders, the impact on the entire family, and challenging situations and behaviors. Staff and interpreters go to individuals' homes and communities to inform caregivers about the educational workshops. COAAA uses a range of incentives, such as gift certificates, to encourage minority populations to attend the seminars.

Contract Information: Lisa Durham, Community Education and Outreach Director, COAAA, at durham@coaa.org or (614) 645-7250.

For many Hispanic American caregivers, the combination of high expectations and effort create a heavier caregiver load. Much of this care entails such substantial tasks as supporting older parents financially, giving them personal care, and helping them obtain medical attention.[122]

Recognizing that variation exists among caregiver perceptions and preferences within different Hispanic communities (e.g., Mexican, Puerto Rican, Cuban, Central and South American, or Spanish origin) as well as other minorities is important. However, several studies indicate that, in general, Hispanic caregivers experience higher levels of depression, burden, and stress compared with their non-minority or African American counterparts.[123] [124] [125] [126] Hispanic caregivers also report more dissatisfaction with family support, in part because they tend to internalize stress. Despite Hispanic caregivers' need for assistance, they do not necessarily seek services. Cultural values that place importance on enduring and not complaining publicly about stress contribute to the difficulties associated with the Hispanic population's reluctance to

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[122] AARP (2001). In the Middle: A Report on Multicultural Boomers Coping with Family and Aging Issues. A National Survey Conducted for AARP.

[123] Cox, C. and Monk, A. (1993). Black and Hispanic Caregivers of Dementia Victims: Their Needs and Implications for Services. In C.M. Barresi and D.E. Stull (Eds.), E*thnic Elderly and Long Term Care*. New York, NY: Springer.

[124] Kemp, B. and Adams, B. (1996). The Role of Caregiver Appraisal, Coping Method and Social Support in the Stress of Dementia Caregivers of Four Different Ethnic Groups: Final Report. Downey, CA: Alzheimer's Disease Diagnostic and Treatment Center, Rancho Los Amigos Hospital.

[125] Mintzer, J.E., Rubert, M.P., and Lowenstein, D. (1992). Daughters' Caregiving for Hispanic and Non-Hispanic Alzheimer's Patients: Does Ethnicity Make a Difference? *Community Mental Health Journal*.

[126] Polich, T. and Gallagher-Thompson, D. (1997). Preliminary Study Investigating Psychological Distress among Female Hispanic Caregivers. *Journal of Clinical Geropsychology*. Vol. 3.

receive services.[127] ***Exhibit VIII.3*** highlights a program in California that attempts to reduce stress for Mexican American caregivers.

Exhibit VIII.3
Stress Management for Mexican Americans

Title: California REACH Project

Affiliation: VA Palo Alto Health Care System and Stanford University School of Medicine

Status: Operational

Target Population: Mexican American caregivers

Approach: This program seeks to provide Mexican American caregivers with the resources to address depression and other forms of psychological distress associated with caregiving through a small group (no more than 6 to 10 participants per group) workshop format. During the workshops, well-trained bilingual staff members help caregivers identify negative thoughts and provide them with specific skills to challenge those thoughts. Staff members encourage caregivers to find more adaptive ways to view the situation. To ensure maximum participation, the workshops are always held in community locations near where a majority of the caregivers live. Before implementation, consultation was sought from numerous community leaders primarily representing local Mexican American groups as well as from Hispanic caregiver focus group meetings. Based on clinical observations of staff, the interventions described above appear effective in decreasing the prevalence of caregiver depression and enhancing sense of self-efficacy for continuing in their role.

Cost/Funding: Services are free of charge to caregivers, and financial assistance is available as needed for transportation and elder care costs incurred while participating in REACH activities.

Contact Information: Dolores Gallagher-Thompson, Veteran Affairs Medical Center, at dolorest@standford.edu or (650) 493-5000.

Knowledge of issues affecting American Indian caregivers is far less developed then similar research on other minority groups. However, the limited literature underscores some important considerations for ITOs in implementing caregiver support programs. Respect for elders is regarded as a strong central value by American Indians. Unlike their non-minority counterparts, American Indians express less guilt and anger toward their dependent elders. Cultural values tend to encourage acceptance of present-day circumstances, including caregiving. Additionally, American Indians are generally described as "group oriented with individual goals." Therefore, emphasizing benefits to the community first is important, followed by addressing personal benefits.[128]

Compared to other communities, many American Indian communities lack core community-based services, such as adult day services and home health, hospice, support group, and other community services.[129] A dearth of core services requires that ITOs conduct an assessment of

[127] Valle, R. (1998). Caregiving across Cultures: Working with Dementing Illness and Ethnically Diverse Populations. Washington, DC: Taylor & Francis.

[128] John, R., Hennessy, C., Dyeson, T., and Garrett, M. (2001). Toward Conceptualization and Measurement of Caregiver Burden among Pueblo Indian Family Caregivers. *The Gerontologist*. 41(2): 210–219.

[129] U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), LTG Associates, Inc. (2001). Geriatric Training Initiative, Cultural Diversity: American Indians.

available services and providers and identify opportunities for tribes to pool regional resources for meeting the needs of caregivers. ITOs should consider developing relationships with the providers and assist in making the services culturally appropriate.

In addition to recognizing perceptions and general patterns of care among minority groups, understanding particular groups within minorities is imperative. With more than 550 federally recognized tribes and an additional 365 state-recognized tribes and bands, many differences exist in coping mechanisms for caregivers from tribe to tribe. For example, one study on Pueblo Indian family caregivers found that this population experiences guilt more intensely than other types of caregiver burden. With this knowledge, service providers can initially determine whether the level of guilt is warranted. If the elder is being cared for inadequately, then additional caregiving support services can be procured for the family. If the elder is adequately cared for, but the guilt feelings of the caregiver are based on faulty perceptions, then services of the caregiver should be tailored to provide education and affirmation to the caregiver.[130] ITOs can conduct focus groups to gather information on caregiver perceptions within various tribes that can inform the service approach under the NFCSP. ***Exhibit VIII.4*** presents a range of approaches tribes use to implement the NFCSP.

Exhibit VIII.4
Caregiver Programs for Native Americans

Title: Care Coordination Program

Affiliation: Sitka Tribe of Alaska

Status: Developmental

Target Population: Caregivers in Sitka tribes

Approach: The main components of this caregiver support program are care coordination and paraprofessional rural care advocacy services. The care coordination system consists of professional care coordinators in Juneau, the hub community. The care coordinators travel to Sitka to meet with individual caregivers, assess their needs, create a plan of care, and arrange for services and benefits. Care coordinators work closely with the Sitka rural care advocate who provides ongoing support to the caregiver. The rural care advocate also provides ongoing outreach in the community to locate caregivers. Counseling services are available to help families cope with the emotional demands of caregiving.

Contact Information: Lawrence Widmark, Tribal Chairman, Sitka Tribes of Alaska, at widmarkw@mail.ssd.kiz.ak.us or (907) 747-3207.

[130] John, R., Hennessy, C., Dyeson, T., and Garrett, M. (2001). Toward Conceptualization and Measurement of Caregiver Burden among Pueblo Indian Family Caregivers. *The Gerontologist.* 41(2):210–219.

Exhibit VIII.4
Caregiver Programs for Native Americans, continued

Title: Warm Spring Caregiver Support Program

Affiliation: Confederated Tribes of Warm Springs (Oregon)

Status: Developmental

Target Population: Caregivers in confederated tribes

Approach: This caregiver support program assists individuals caring for frail elderly or individuals with disabilities in their homes. By receiving support, the caregiver becomes less prone to "burn-out." A coordinated effort is made with the Indian Health Service and state and local social services agencies to identify individuals with the greatest need. Information on the program is available through the Title VI site, one-on-one contract with senior program and social services staff, and the local radio station and newspaper. The program staff also assists in providing advocacy, transportation, coordination of care, and direct services.

Contact Information: Olney Patt, Jr., Chairman of the Tribal Council, or Gayle Rodgers, Confederated Tribes of Warm Springs, at (541) 553-3491.

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Title: Family Caregiver Support Program

Affiliation: Red Cliff Band of Lake Superior Chippewas (Bayfield, Wisconsin)

Status: Developmental

Target Population: Native American caregivers

Approach: Among the activities planned are the development of brochures, flyers, and other materials publicizing the availability of caregiver respite services, caregiver support group meetings, and resources available from other agencies. In addition to providing public information, the Red Cliff Band will provide direct assistance to caregivers through the Elder Program administration. The Elder Program administration will act as caseworker and provide referral and assistance services to the caregivers. Respite services will be established within the community to allow for temporary respite for the caregiver.

Contact Information: Kim Gordon, Administrator of Social Services, Red Cliff Band of Lake Superior Chippewas, at (715) 779-3706.

Exhibit VIII.5 summarizes frequently identified strategies described above for addressing some of the cultural differences among minority groups.

Exhibit VIII.5
Strategies for Addressing Cultural Differences

Minority Population	Cultural Differences among Minority Groups	Strategies for Responding to Cultural Differences
African American	▪ Employ coping mechanisms such as reliance on religious faith or prayer. ▪ Share caregiving responsibilities among a number of households and family members, including parents, adult children, siblings, and other relatives. ▪ Use cognitive strategies often, such as re-framing the situation and positive self-statements, consequently experiencing lower levels of stress.	▪ Use approaches designed to meet the needs of the family, rather than solely the individual. ▪ Include spiritual themes and reference prayer as a form of coping, and hold educational workshops in a church setting.
Asian/Pacific Islander	▪ Experience feelings of guilt often and believe they should be doing more, despite significant level of engagement in caregiving. ▪ Experience high levels of stress associated with caregiving due partly to the high value placed on emotional control. ▪ Possess limited English proficiency (many Asian immigrants).	▪ Conduct focus groups to determine if guilt is an issue in the local community, and if so, understand reasons for guilt and design appropriate services. ▪ Design programs that focus on strategies for reducing stress levels for caregivers. ▪ Translate all program materials to reflect the meaning of the content, rather than literal translation, and ensure appropriateness of materials by seeking input from the Asian / Pacific Islander community.
Hispanic American	▪ Place high value on interpersonal and social interactions in which individuals deal with one another in a compassionate manner. ▪ Experience high levels of depression and dissatisfaction with family support network in relation to the caregiving experience. ▪ Feel bound by cultural values to endure stress and not complain about it publicly.	▪ Incorporate a socialization component to engage caregivers in conversation because an interactive and personal approach is crucial for working with this population. ▪ Design programs that focus on strategies for reducing stress levels for caregivers, such as helping caregivers identify negative thoughts and providing them with skills to find more adaptive ways to view the situation. ▪ Focus on intensive outreach efforts, such as using community-based media outlets (e.g., minority newspapers and magazines, minority college campus newsletters, local minority radio and cable television programs).

Exhibit VIII.5
Strategies for Addressing Cultural Differences, continued

Minority Population	Cultural Differences among Minority Groups	Strategies for Responding to Cultural Differences
American Indian / Alaska Native	▪ Place less emphasis on having control over the caregiving situation, and focus more on the positives of managing the needs of a dependent elder. ▪ Place greater priority on the effects of caregiving on the group (i.e., family and tribe), rather than on a caregiver's individual needs. ▪ Value verbal non-assertiveness, and believe verbalizing a problem makes the problem become reality. ▪ Perceive time as a sense of being rather than doing (e.g., find rushing a social or professional encounter disrespectful).	▪ Define intervention strategies in relationship to the family and community, rather than to the individual, such as emphasizing the impact of caregiving on the entire family or tribe. ▪ Seek tribal members to assist in the development of communication strategies that reflect the values of the culture. Focus areas should include orientation to the present, orientation to a past that honors tradition (e.g., storytelling), oral transmission of knowledge, and discrete communication respecting the individual. ▪ Educate providers on how to alter communication style to respond to different perception of time and allot an adequate amount of time to communicate effectively with individuals during encounters.

Although cultural differences are important considerations, recognizing the heterogeneity within ethnic and racial groups is essential. The aging network should continue to place a high priority on considering individual-level differences (e.g., age, education, length of time spent in the United States, literacy, income, gender, and geographic location) and preferences.

Partner with Community Organizations Dedicated to Addressing the Needs of Minority Groups. The literature clearly establishes the need for formal support services but also indicates that minority caregivers often fail to receive services early in the caregiving process. Lessons learned from the REACH and the ADDGS projects reveal that to effectively reach minority caregivers, establishing partnerships and relationships with key minority leaders and institutions in the community is critical during program implementation. Although initial development of relationships with ethnic minority clients requires a significant amount of staff resources, acceptance of new services rests on gaining trust and support from respected members of the community. Potential groups for collaboration might include:

- Neighborhood government advisory groups,
- Community colleges and universities,
- Church committee chairs,

- Local business owners, and
- Disease-specific groups that focus on minority health risk factors.

An evaluation conducted by The Gerontology Center Research Team at the University of Kansas indicates that the ADDGS[131] program has proven effective in its outreach efforts to the caregivers of minority persons with Alzheimer's Disease. About 50 percent of the total families (including care recipients and caregivers) served in the program represent ethnic minorities.

Under the ADDGS, new service programs have been developed for: Hispanic populations in California, Florida, California, and Washington; Native Americans in Montana and Washington; Korean and Chinese communities in Washington; and Asian Pacific Islander groups in Hawaii. ***Exhibit VIII.6*** presents the Washington Aging and Adult Services Administration Alzheimer's Demonstration Project. Washington has been successful in developing culturally sound services for caregivers through collaborating with experts in delivering minority services.

Tailor Communication Style to the Target Population. Communication approaches must capture the attention of the target audience, employ the dialect and language of the people served, and involve communication styles and vehicles proven meaningful for and accessible by the target audience. Although knowing all of the nuances of a particular culture might be difficult, health care agencies and providers should remain alert to subtle differences. For example, the literature indicates that in contrast to non-minority populations, American Indians might find rushing a social or professional encounter disrespectful because they place no priority on time being rigidly structured. In the American Indian culture, time is more closely related to a sense of being than of doing, and events begin when all expected participants are present. Additionally, in many American Indian cultures, taking time to answer a question posed to an individual is a sign of respect to the questioner and should not be rushed. Asking too many questions could also give the impression of being disrespectful to the speaker.[132]

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[131] See http://www.aoa.gov/alz/profprov/pp_r_eval.asp for evaluation data.

[132] U.S. Department of Health & Human Services, Health Resources and Services Administration (HRSA), LTG Associates, Inc. Crain (2001), Geriatric Training Initiative, Cultural Diversity: American Indians.

Exhibit VIII.6
Partnerships with Ethnic Organizations

Title: Alzheimer's Disease Demonstration Grants to States Program

Affiliation: Washington Aging and Adult Services Administration (AASA)

Status: Operational

Target Population: Chinese, Korean, Hispanic, and Native American caregivers of individuals with Alzheimer's Disease

Approach: This project aims to increase the number of ethnic and culturally diverse persons with Alzheimer's Disease and their families who receive respite and support services. Four local agencies partnered with various ethnic organizations to gain a better understanding of cultural perceptions related to Alzheimer's Disease and to develop culturally sensitive programs. Through these partnerships, the agencies developed culturally appropriate outreach materials and tactics that led to increased service use. The partnerships also provided multilingual Alzheimer's education/training materials, in-home multilingual dementia diagnosis, multilingual outreach programs, caregiver support groups, client advocacy, and interpretation/translation. Ethnic specific project features include an Asian social day care program, adult day services and client advocacy for Spanish-speakers, a Native American outreach coordinator and caregiver support group, and an Alzheimer's/Dementia Support Center for the Chinese community. All of the programs developed through the Demonstration operate today and serve as useful resources as the State continues efforts to support ethnically and culturally diverse caregivers. For more information on these projects, please visit: http://www.aoa.gov/alz

Cost/Funding: The program was originally funded through HRSA grants. In 1998, AoA began administering the grants.

Contact Information: Hilari Hauptman, Program Manager, Aging and Adult Services Administration, at haupthp@dshs.wa.gov or (360) 725-2556; Lynne Korte, at kortelm@dshs.wa.gov or (360) 725-2545.

Keeping some general points in mind is useful when developing and using communication vehicles for minority populations:

- Explore the use of community-based media outlets (e.g., minority newspapers and magazines, minority college campus newsletters, local minority radio, cable television programs), and use prepared public service announcements, flyers, and posters as mechanisms for providing service information to minority caregivers.
- Translate program materials to reflect the meaning of the content, rather than literal translation, of existing material, and ensure materials are multi-validated by seeking input from multiple reviewers.
- Develop and widely distribute materials presenting basic service definitions that have comparability in other languages and other cultures.
- Consider and respect language preferences without making assumptions (e.g., many non-native English-speaking individuals are bilingual but prefer to converse in English for certain matters).
- Organize conferences and workshops tailored for a particular minority audience and presented by minority staff.

- Be cognizant of varying levels of technological sophistication and access among minority caregivers, particularly when providing services over the telephone or via the Internet. Some people need more instruction than others, in formats and educational levels meaningful to that sub-population.

All of these communication issues must be considered in relationship to the design and use of burden scale instruments and other caregiver tools. (See ***Chapter VI*** for more information.)

Sexual Orientation

The following section borrows from David Coon's article "Caregiving for Families We Choose: Intervention Issues with LGBT Caregivers." The Lesbian, Gay, Bisexual, and Transgender (LGBT) caregiving experience cuts across age groups and cultural and experiential lines. Prevalence rates reported in studies on the LGBT caregiver population range from 2 percent and 3 percent to upwards of 18 percent to 20 percent.[133] [134] The number is hard to determine because respondents fear social stigma and discrimination associated with LGBT self-identification as well as complexities associated with defining LGBT status.

LGBT adults experience a range of individual-, community-, and organizational-level barriers to accessing appropriate caregiver services. The LGBT population often faces discrimination in the health care system. Research indicates that LGBT people have legitimate concerns about negative views held by medical professionals and the impact these views can have on their health care. Older LGBT caregivers, in particular, have experienced multiple years of discrimination and intolerance. As a result, many LGBT caregivers harbor extremely mixed feelings about openly seeking help and often need to research whether services and organizations will support them, ignore them, or even condemn them.[135] ***Exhibit VIII.7*** presents some of the key barriers this population faces.

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[133] Tanfer, K. (1993). National Survey of Men: Design and Execution. *Family Planning Perspectives*, Vol. 25.

[134] Sell, R.L., Wells, J.A., and Wypij, D. (1995). The Prevalence of Homosexual Behavior and Attraction in the United States, the United Kingdom and France: Results of a National Population-Based Sample. *Archives of Sexual Behavior*. Vol. 24.

[135] Kauth, M.R., Hartwig, M.J., and Kalichman, S.C. (2000). Health Behavior Relevant to Psychotherapy with Lesbian, Gay, and Bisexual Clients. In R. Perez, K.A. DeBord, and Bieschke (Eds.), *Handbook of Counseling and Psychotherapy with Lesbian, Gay, and Bisexual Clients*. Washington, DC: American Psychological Association.

Exhibit VIII.7
Barriers to Care for LGBT Caregivers

Individual Barriers	Community Barriers	Institutional Barriers
▪ Some LGBT individuals might be reluctant to seek services because of their internalized beliefs about sexuality. ▪ Some LGBT individuals might believe their sexuality is a private matter, inappropriate for public discussion, and therefore might resist service providers who either self-identify as LGBT or tailor their services to clients on the basis of sexual orientation and identity.	▪ Formal support systems for older gays and lesbians, let alone for caregivers, are rarely in place, even among larger and more urban LGBT communities. ▪ LGBT persons of color might confront racial or ethnic discriminations from within the LGBT community, as well. ▪ The reality of limited resources and greater isolation might exacerbate obstacles and issues LGBG caregivers in rural areas and small cities face.	▪ LGBT caregivers and care recipients might be reluctant to reveal their sexual orientations and behaviors to health care professionals for fear of discrimination. ▪ Health care systems often defer decision-making to biological relatives rather than to long-time partners, and extended-care settings frequently refuse to allow LGBT partners to visit care recipients.

Source: Coon, D. "Caregiving for Families We Choose: Intervention Issues with LGBT Caregivers." Presented at the American Psychological Association Annual Conference. San Francisco, CA. August, 2001.

Strategies and Program Examples

Provide a Safe Place for LGBT Caregivers. The aging network can incorporate a range of approaches to demonstrate a commitment to serving LGBT caregivers. Network agencies are encouraged to adopt a zero tolerance policy for subtle or overt discrimination and to review employee and client policies to ensure that employment practices are inclusive and that training dollars are allocated for diversity training that encompasses LGBT concerns. A simple "safe place symbol" that is easily identifiable and known to the LGBT community can be chosen to appear in aging network offices, newsletters, and intake forms. This symbol indicates that the organization's staff and service providers have received specific training in working with LGBT issues.

Create LGBT Caregiver Support Groups. Support groups can also be tailored to meet the needs of the LGBT population. ***Exhibit VIII.8*** serves as a good example of a support program that blends the basic elements of grassroots support groups with basic cognitive and behavioral techniques that address specific issues affecting LGBT caregivers.

Exhibit VIII.8
Support Groups for LGBT Caregivers

Title: LGBT Caregiver Support Group

Affiliation: Greater San Francisco Bay Area Chapter of the Alzheimer's Association – San Francisco, California

Status: Operational

Target Population: LGBT caregivers

Approach: Participants in this support group share their feelings about caregiving and its impact on their lives. This project is grounded on the SURE 2 Framework (Sharing and Support, Unhelpful Thinking and Understanding, Reframes and Referrals, and Education and Exploration). Caregivers often discuss the stressors that bring them to the group, whether they be conflict between themselves and significant others, including the care recipients, or conflicts with health care systems. Fellow group members and the facilitator encourage one another to identify what is not working and to share their understanding of how easy it is to get caught up in negative thinking about themselves and their thinking. Caregivers are also encouraged to reframe their thinking and their situations through basic cognitive and behavioral techniques (e.g., basic problem-solving, cost/benefit analyses, avoiding black and white thinking, and positive reframing) and to illicit ideas or perspectives from the group. These ideas include recognition of the obstacles LGBT people face as a result of their sexual orientation or identity, such as difficulty finding LBGT-sensitive in-home health services, day care services, or appropriate placement situations, and the sharing of referrals when competent professionals and organizations are identified. The groups regularly include education about the course of caregiving and upcoming educational seminars sponsored by local groups. Each session reviews explorations of alternative coping strategies, recent referrals tried, and feedback to one another about those referrals. The group closes with at least one strategy or referral for each group member to try to help himself or herself in the caregiving process.

Contract Information: Dr. David Coon, Support Group Leader, at dcoon@ioaging.org. or (415) 750-4180; Toni Morley, ATR, MFT, Alzheimer's Association Support Group Coordinator, at (650) 962-8111.

Train Providers. To communicate a safe environment, the aging network can become skilled in helping LGBT caregivers tell their own stories and describe their relationships with caregiving situations in their own terms. Provider competence requires ongoing training through a variety of vehicles, including workshops and presentations at professional meetings and consultation with groups specializing in LGBT topics.

Sharing ones sexual orientation or "coming out" is an extremely personal choice, and depending on the individual caregiver, might be perceived as a benefit or an additional burden. The coming out process involves balancing a complex set of issues, such as redefinition of self and the management of parents, siblings, and friends. Caregivers, similar to all LGBT individuals, vary in their levels of outness. For example, some individuals are out of the closest with friends but not work colleagues, or vice versa.

Providers can watch for signs of distress and help LGBT caregivers determine if they possess adequate amounts of social support services to effectively manage the process. The provider can accept responsibility for respecting the caregiver's level of outness; however, he or she takes on no responsibility for pulling the person out. As with all populations, listening to the nuances of language providers' use and their level of experience and training is fundamental for determining their suitability to work with the LGBT population. One strategy for determining

provider competence with LGBT clients involves asking employees about their experiences with LGBT people. Additionally, it is extremely helpful if providers are comfortable referring caregivers to local LGBT resources; LGBT clients often consider service providers' knowledge of LGBT community resources a deciding factor when choosing a provider.[136] [137]

Build on Strengths of the LGBT Community. For some caregivers, the LGBT response to the AIDS crisis has created advanced networks of family and friends experienced with caregiving, end-of-life issues, and AIDS-related dementia. However, for other caregivers, the impact of the AIDS epidemic is profound, and the isolation of dementia care is painful. As emphasized throughout this guide, the aging network will need to re-conceptualize social support beyond the family unit—not just by creating and relying on chosen "families," but by extending support contacts beyond the immediate group to a larger community with services sensitive to the needs of LGBT caregivers.

SPECIAL CAREGIVER CIRCUMSTANCES

Although the term "caregiver" frequently is associated with spouses and adults caring for elderly parents, circumstances involving caregivers other than adults and spouses, as well as care recipients other than the elderly, are common. Sometimes grandparents and other relatives serve as caregivers, and older persons care for adult children or other relatives with developmental disabilities.

Grandparents and Other Relatives Raising Children

Chapter III summarizes the special challenges of grandparents and other relatives caring for grandchildren. Dr. Meredith Minkler's issue brief *Grandparents and Other Relatives Raising Children*, found at www.aoa.gov/carenetwork/IssueBriefs.html, elaborates on the same topic.

The majority of kinship care families comprise grandparents raising their grandchildren; however, many other relatives, including aunts, uncles, older siblings, tribal members, and godparents, are also raising children. By the late 1990s, 5.4 million children were living in grandparent- or other relative-headed households. In almost 40 percent of these cases, the children's parents were absent.[138] The tremendous increase in kinship care families is attributable to many factors, including substance abuse, the rise in single-headed households, death, incarceration of the child's parent, child abuse, neglect, teen pregnancy, divorce and health issues.[139] The typical relative caregiver is a married woman living on modest means but

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[136] Liddle, B. (1997). Gay and Lesbian Clients? Selection of Therapists and Utlization of Therapy. *Psychotherapy*, Vol. 34.

[137] Matteson, D. (1996). Counseling and Psychotherapy with Bisexual and Exploring Clients. In B. Firestein (Ed.), *Bisexuality: The Psychology and Politics of an Invisible Minority* (pp. 185–213). Newbury Park, CA: Sage Publications.

[138] Casper, L.M. and Bryson, K. (1998). Co-resident Grandparents and Their Grandchildren: Grandparent Maintained Families. Washington, DC: Bureau of the Census.

[139] Minkler, M., Deurr-Berrick, J., and Needell, B. (1999). *The Impact of Welfare Reform on California Grandparents Raising Grandchildren*. Berkeley, CA: Center for Social Services Research, School of Social Welfare, U.C. Berkeley.

above the poverty line. Single women, African Americans, and the poor, however, have a greatly increased likelihood of taking on this role.[140]

Strategies and Program Examples

A number of implications for practice can be drawn from the experiences of the aging network and health and social service providers, through a rapidly burgeoning research base, and through the voices of grandparent caregivers and their families. The following principles and approaches can establish the framework for meeting the needs of grandparent caregivers and their families.

Establish Implementation Goals Based on Needs Identified by Grandparents and Other Relative Caregivers. Grandparent caregivers make articulate spokespersons for their own needs and concerns and those of their families and fellow caregivers. New programs that begin with the agenda of grandparent caregivers are far more likely to achieve success. Relative caregiver town halls and forums, focus groups, and surveys and other data collection methods help determine the needs of grandparent caregivers in a given geographic area.

Develop, Publish, and Disseminate Information. Many states take advantage of grants awarded by the Brookdale Foundation, which sponsors the Relative as Parents Program (RAPP) to facilitate information dissemination through a variety of vehicles, including comprehensive resource guides for relatives raising children. The guides typically use a question-and-answer format and cover topics such as childcare, education, custody, other legal issues, and contact information for a range of programs and resources. Washington State partnered with the state's AARP and Casey Family programs to develop its RAPP initiative. A key element of the initiative involved the development of *Relatives as Parents: A Resource Guide for Relatives Raising Children in Washington State.* ***Exhibit VIII.9*** offers a summary of Washington's RAPP initiative.

Seek and Develop Creative Partnerships. A major factor in the success of the Brookdale Foundation's RAPP is the requirement that funded entities work collaboratively with other agencies and organizations, including those outside the aging network. By partnering with voluntary children's and youth organizations, faith-based entities, public sector programs such as Head Start and Section 8 Housing, and local hospitals and schools, SUAs, AAAs, and ITOs can vastly increase the resource base, visibility, and effectiveness of their NFCSP efforts. Partnering with agencies or programs without limits for client age might enable the programs developed to better meet the needs of the many relative caregivers below age 60.

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[140] Minkler, M. (2001). Grandparents and Other Relatives Raising Children: Characteristics, Needs, Best Practices and Implications for the Aging Network. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

Exhibit VIII.9
Information Dissemination

Title: Washington Relatives as Parents Program (RAPP) State Initiative

Affiliation: Washington Aging and Adult Services Administration (AASA)

Status: Operational

Target Population: Grandparents and other older adults raising children

Approach: The RAPP state initiative serves grandparents and relatives raising children by providing informational resources and services through a range of mechanisms, including a free resource guide. *Relatives as Parents: A Resource Guide for Relatives Raising Children in Washington State* describes available services and provides general information on raising children. To date, more than 23,000 copies of this 44-page guide have been distributed to caregivers and professionals. AASA sponsors regional workshops co-facilitated by experts, such as attorneys and paralegals, social service providers, and legislative staff. AASA also co-sponsored a national Grandparents Raising Grandchildren satellite teleconferences (linked to 19 sites) for caregivers and professionals who serve them. The state maintains a RAPP resource library containing videos, books, and other material for caregivers and professionals working with this population. In collaboration with the state's University Cooperative Extension Program, the state has also established a Web site that contains a statewide database of support groups, legal services, and links to other relevant resources and special events that might interest relative caregivers and their families. Other initiatives include creating an interagency, public/private, statewide RAPP coalition (comprised of more than 40 agencies) to provide means for networking and support; development, advocacy, and maintenance of kinship caregiver support groups; and legal advocacy and education for kinship caregivers.

Cost/Funding: AASA, as well as several local partnering organizations, received grants from the Brookdale Foundation's RAPP.

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Maintain Open Communication with Advocacy Organizations. Achieving substantive improvements in the well-being of relative caregivers and their families frequently requires new legislative and policy changes, framed in an intergenerational context that support, rather than penalize, these families. Although SUAs, AAAs, and ITOs generally cannot directly advocate legislative changes, they are in an excellent position to help document the need for new policy directions. Members of the aging network can help create the knowledge base vital to organizations like AARP, Generations United (GU), the Child Welfare League of America (CWLA), and the Children's Defense Fund (CDF), as they work to promote needed policy change.

Assist Caregivers in Gaining Access to Needed Programs. Several SUAs have developed creative methods to assist grandparent caregivers in gaining access to programs and services for themselves and the children in their care. Ohio's Department of Aging funded a kinship care "navigator" program to help caregivers in both negotiating the legal system and accessing benefits. Ohio's creation of a toll-free hotline for kinship caregivers and Kentucky's Senior Health Insurance Information Program (SHIP) 1-800 hotline represent other creative approaches that SUAs might emulate.

Provide Respite Services. Although respite from the demands of caregiving has proven among the most desired services for grandparent caregivers, few existing programs address the respite needs of relative caregivers. A notable exception on the state level involves the Oklahoma Respite Resource Network (ORRN), created in part through the Aging Services Division of Oklahoma's Department of Human Services. For more than a decade, the ORRN has provided respite to grandparents and other caregivers with low to moderate incomes. Caregivers enjoy wide discretion in the choice of respite care providers.

Facilitate Support Groups. Aided by a seed grant from the Brookdale Foundation Group and contracting with a statewide nonprofit family service agency, Children and Families First, the intergenerational program of Delaware's SUA began the Family Circles education and support group program for relative caregivers in 1997. Operating six support groups throughout the state, the program provides a significant model partly because of its success in insuring the sustainability of these groups. Children and Families First has been able to maintain support groups after the termination of state funding.

Caregivers of Children and Young Adults with Developmental Disabilities

The following section borrows from Dr. Matthew P. Janicki's issue brief *Coordinating Systems Servicing Caregivers of Children and Adults with Developmental Disabilities,* found at http://www.aoa.gov/carenetwork/IssueBriefs.html. Approximately 1.9 million children and adults with developmental disabilities live with their parents. Approximately 25 percent of these caregivers are age 60 and older. Many older caregivers are mothers who have provided care throughout the life of their adult son or daughter.[141] While the NFCSP is effectively restricted to older caregivers of children with MR/DD, it is useful, particularly from a coordination standpoint, to look at this broader range of caregivers.

In the past, state developmental disabilities' agencies designed family support services primarily with the needs of younger parents of children with developmental disabilities in mind, while support services for older caregivers were extremely limited. This situation is now changing, however, because current belief holds that most individuals with an intellectual disability enjoy life expectancy typical of other people and continue to rely on some level of support from their parents. Additionally, there continues to be an increasing number of older caregivers each year with younger generations of older people remaining healthier and less impaired longer than previous generations. Each of these factors makes it critical to provide support for elder individuals caring for both children and adults with developmental disabilities.

Many challenges confront older parents as they provide care to *young children* with developmental disabilities, including a range of system issues such as shortages of special education teachers, inappropriate level of services, and inadequacies in special education programs. Other challenges include deficiencies in responsiveness to Individual Education

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[141] Janicki, M. (2001). *Coordinating Systems Servicing Caregivers of Children and Adults with Developmental Disabilities*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carnetwork/issuebriefs.html .

Programs (IEP)[142] and abuse and neglect in the school system. Elderly parents are typically the very parents who have failed to benefit from recent policies promoting mainstreaming, equal education, supported employment, and independent living options for children and adults with developmental disabilities. Therefore, these caregivers might feel less comfortable receiving assistance or less familiar with the system to know where to turn for support.

As children with developmental disabilities become *young adults*, older parents worry about what will happen to their family member if they become incapable of caring for him or her, and they identify this concern as an ever-present source of stress and anxiety. Some want to have a plan for the future but often feel too overwhelmed by their day-to-day responsibilities as caregivers to focus on the problem. In addition to facing problems associated with the caring they have provided all of their lives, older caregivers are faced with issues related to their own aging and changing life situation, such as changes in physical health and financial resources.

Clearly, a need exists to locate, inform, and draw older caregivers of children and adults with developmental disabilities into the aging network and to establish mechanisms that link them to family support networks often available through aging, social services, or disability agencies. The majority of caregivers providing in-home support for people with a developmental disability experience the same needs as other families in caring situations, the main difference being that they are lifelong caregivers. As they age, they want:

- Services that meet their immediate needs (e.g., respite, housekeeping assistance, transportation, and emotional supports),
- Assistance with obtaining financial planning information (e.g., information on entitlements, guardianship, and trusts) and financial supports or determinations of eligibility,
- Help with negotiating the health and social service systems and advocacy for obtaining services for which they qualify, and
- Help with making decisions about their life or the life of the person for whom they are caring.

Strategies and Program Examples

Challenges for the aging network responding to the mandates of the NFCSP include developing mechanisms for effective outreach to the older parents of the developmentally disabled, enhancing their information and assistance (I&A) processes, providing support coordination and general assistance, and, when appropriate, linking these families to the local developmental disabilities providers.

Determine Existing Needs. In undertaking an initiative to serve older caregivers of individuals with a developmental disability under the NFCSP, first determining the number and nature of such families in the catchment area is helpful. In addition, the following questions should be investigated:

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[142] The Individuals with Disabilities Act (IDEA, Public Law 105-17) is the federal law mandating that all children with disabilities have available to them a free, appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living. Part B of IDEA requires that schools provide an individualized education program (IEP) to all children with disabilities.

- What are the local needs of this population, and which are most immediate?
- What resources currently exist in the community to help these families?
- What are the disability and social services networks doing to help these families and caregivers?
- How can the aging network interface with existing efforts or spearhead the initiation of a new effort?

Another key consideration is whether to undertake this type of initiative within the aging agency or to contract it out. Whether the aging agency does direct work, normally contracts out, or works through other agencies might govern this decision.

Continue to Partner with Developmental Disability State Agencies. The aging network can build on their substantial experience in creating effective partnerships with developmental disability agencies to help implement local or regional disability-related activities under the NFCSP. Developing such partnerships can involve a number of approaches, including:

- Inviting representatives of aging and developmental disability agencies to serve on a planning committee or task group or to speak to a provider/consumer group or at an interagency conference;
- Formalizing a relationship between the aging service agencies, developmental disabilities agencies, and the state's developmental disabilities planning council through mutually agreed roles and responsibilities and sharing of directives that stem from an interagency memorandum of understanding (MOU) or agreement;
- Fostering interagency cooperation with budgetary submissions and allocations and regulatory reviews; and
- Establishing an interagency task group that examines a particular long-term care problem (e.g., housing, adult day care, family assistance) that involves both dependent elderly and older disabled populations.

Working within the greater disability system to build the NFCSP initiative can allow the aging network to rely on providers as resources they can call on when the caregivers or care recipient needs assistance. The disability system can also share financial resources and stretch the available funds under the NFCSP, preventing duplication of effort or waste of scarce resources. ***Exhibit VIII.10*** summarizes a Texas Department of Aging initiative that represents a good example of an effective collaboration with the network and community developmental disability agencies.

Exhibit VIII.10
Outreach and Linkages with Developmental Disability Agencies

Title: Support for Aging Individuals with Developmental Disabilities

Affiliation: Texas Department for Aging (SUA), Texas Council for Developmental Disabilities

Status: This demonstration project ended in 2001; however, the participating AAAs are continuing to build on this effort under a new statewide program (Regional Access Plan).

Target Population: Aging individuals with developmental disabilities and caregivers of individuals with developmental disabilities

Approach: This five-year project has allowed nine Texas AAAs to develop collaborative work groups with local developmental disability service providers and family caregivers to explore ways to increase their collective capacity and to meet the needs of people growing older with developmental disabilities. The findings from this project were compiled into a report entitled "Aging with Developmental Disabilities: The Texas Project." The report includes individual AAA case studies, as well as findings related to best practices for building capacity and collaboration across providers, and lessons learned and outcomes achieved. This report is available through the Texas Department of Aging.

Cost/Funding: The state's Developmental Disabilities Council funded this project.

Contact Information: Linda Fulmer, Texas Department of Aging Contractor, at abana@falsh.net or (817) 451-8740; Gary Jessee, Director of AAA Support and Operations, at gary.jessee@tdoa.state.tx.us. or (512) 424-6857.

ENVIRONMENTAL CONDITIONS

A number of environmental conditions play a role in defining the needs of particular caregiver groups, including individuals faced with balancing the dual roles of working part-time or fulltime and serving as caregivers. Caregivers living in rural areas also experience unique barriers to receiving appropriate services. And, long-distance caregivers experience obstacles specifically associated with being geographically removed from the care recipient.

Working Caregivers

> Based on workplace surveys, individuals with current elder care responsibilities have been estimated at 13 percent of the workforce, and those involved in caregiving at some point during the past 12 months at 25 percent. Regardless of the actual prevalence rate among U.S. workers, we can expect to see higher numbers, perhaps double the numbers, involved in providing care in the future due to the aging of our population and the increased number of women in the workforce.[143]

Although little systematic research has been conducted explicitly on the needs of working caregivers, existing research and anecdotal reports from working caregivers indicate the perceptions, priorities, and preferences of working caregivers. Flexibility in the work place, particularly in the scheduling of work hours, constitutes one need. A second set of needs centers on I&A—an area in which the aging network exhibits considerable expertise. A third area of need involves emotional support and a fourth, other tangible assistance, such as assisting caregivers with health insurance paperwork.

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[143] Neal, M.B. and Wagner, D. (2001). *Working Caregivers: Issues, Challenges and Opportunities for the Aging Network*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

Strategies and Program Examples

Working caregivers require a way to access information, referrals, advice, case management assistance, emotional support, and tangible assistance that minimizes interruptions to their work, supports involvement in caregiving, and maximizes time efficiency. Following are strategies the aging network can use to respond to the needs of this population.

Facilitate Access to Information, Assistance, and Referral. Most working caregivers need information on the community services available to support the needs of elders because they possess little or no previous experience with negotiating the aging services system. Working caregivers also need help with legal, financial, and health insurance matters and the paperwork associated with these responsibilities (e.g., securing and completing the legal forms for durable power of attorney, wills, and reverse mortgages). The aging network can play an important role in providing useful information to working caregivers about caregiving, health conditions, and where to turn for help. The aging network can also provide assessment and case management services to evaluate the elder's needs, determine eligibility and payment options, and package the required services.

To provide resources for caregivers, the aging network can partner with employers. Offering I&A—notifying working caregivers about specific services available to them and their elders and helping them locate these services—represents the most common form of direct services employers provide. Generally, the service is performed by an in-house employee assistance program, or by a private for-profit organization. The aging network can link to caregivers directly by publicizing their existing information lines. Also, the aging network can tailor specific services for some employers on a contractual basis. Using the network as a vendor might prove especially attractive to small employers for whom in-house programs are unfeasible and contracted services are too expensive.

Educate Caregivers. A variety of educational programs and written materials assist employees with caregiving demands. The aging network and contract agencies can reach working caregivers either directly or through their employers. An effective way to inform a large number of employees about caregiving issues and resources is through newsletters and inserts in paycheck envelopes. Single articles can be prepared or entire newsletters can focus on caregiving concerns. Some businesses have implemented caregiving fairs, along the lines of health fairs, where employees can obtain information from a variety of different agencies and organizations at one time. Employees can stop at booths, talk to service providers, and obtain written information about specific community resources. The network can organize such fairs for the employees of one large employer or several smaller employers.

Inform Employers about Working Caregivers' Need for Flexibility as well as Benefits of Supporting Caregivers. Most network agencies operate only during the regular business hours. As a result, many working caregivers have to either use work time for making telephone calls or take time off to gain access to services for their elders or themselves. Working caregivers routinely note the importance of both flexible work hours and being able to take unscheduled time off when needed to handle caregiving responsibilities. A recent study found that lower levels of family-related supervisor support were associated with higher levels of work-family conflict. Similarly, a less supportive workplace culture was associated with work-family

conflict.[144] Network agencies can play an important role in facilitating workplace flexibility by educating employers and providing evidence of benefits to employers.

Enhance Internet Services. A tremendous amount of information on work-family issues is available on the Internet. Providing employees with access to a computer and printer to obtain the information they need is an economical method for employers to support their employees with elder care responsibilities. Multnomah County, Oregon's local AAA developed the idea of facilitating access to Web resources by creating and distributing a desktop icon for installation on employees' computer screens that would link them to the agency's Web site and also provide links to other useful Web sites. A compact disk (CD) containing Web site information is made available to employees without access to the Internet.

Negotiate with Employers to Provide Direct Services for Elderly Care Recipients. Some companies help employees deal with their dependent care needs directly by providing subsidies, vouchers, or discounts for particular services, such as adult day services and respite programs or by sponsoring onsite or near-site day care facilities. AAA contract agencies can make arrangements with employers for working caregivers to use their adult day services or respite services at a discount or through subsidies or vouchers. Network agencies can also assist in establishing registries of respite care workers. For the purpose of facilitating other needed services, the network can help employers set up cooperatives among employers. AAAs, however, must consider the state's policies on such arrangements. ***Exhibit VIII.11*** presents examples of efforts under way in Texas and Washington, DC, to improve access to information and quality services and providers for working caregivers.

[144] Barrah, J.L. and Shultz, K.S. (2001). Elder Care Based Work-Family Conflict: Antecedents and Consequences. Paper presented at annual meeting of the Gerontological Society of America, Chicago, IL.

Exhibit VIII.11
Public/Private Partnerships

Title: Elder Service Network

Affiliation: Dallas, North Central, and Tarrant County AAAs; AT&T Communications; Workers of America; and International Brotherhood of Electrical Workers

Status: Developmental

Target Population: Working caregivers

Approach: AAAs partnered to respond to a request for proposal (RFP) issued by AT&T to develop the Elder Service Network, an initiative to provide more convenient access to services for working caregivers. The program will involve a study of working caregivers' needs in the participating AAA service areas. The study will also examine the costs and quality of available services and credential providers to develop a preferred provider network. Care management serves as a significant component of the Elder Service Network program because care managers will provide a one-stop shop in assessment, service arrangement, and unified billing for network services.

Cost/Funding: The estimated project cost is $80,000 per year. Funding is provided as follows: 1) a $40,000 grant from AT&T Family Care Development Fund, a joint project of AT&T, the Communications Workers of America, and the International Brotherhood of Electrical Workers; 2) $40,000 per year from NFCSP funds; and 3) client revenues. Grant funds will be used to employ a part-time program coordinator. NFCSP funds will be used for the research, market survey, quality indicator development and implementation, and development of an expanded resource database, including for-profit providers. After two years, planners intend the program to sustain itself through private pay revenue.

Contact Information: Donnie Van Ryswyk, Dallas AAA, at doni@winfo.com or (817) 695-9193.

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Title: FannieMae Eldercare Initiative

Status: Operational

Affiliation: IONA Senior Services, Washington, DC; FannieMae Corporation

Target Population: Working caregivers

Approach: IONA Senior Services is under contract with FannieMae to provide a clinical gerontological social worker, "Eldercare Consultant," to FannieMae employees seeking assistance with financial, medical, and legal issues surrounding caregiving. The Eldercare Consultant also provides educational seminars related to aging and caregiving. IONA assisted Fannie Mae in developing an Eldercare Kit, including caregiving related resources and brochures, to distribute to employees. The program has served about 10 percent of the company's 4,000 employees.

Contact Information: Daniel Wilson, Director of Social Services, IONA Senior Services, at dwilson@iona.org or (202) 895-9436. For more information, please visit http://www.iona.org.

Make Support Coordination Service Available. Support coordination for working caregivers who need help in assessing, addressing, and monitoring an elder's multiple needs is more intensive and individualized. Some employers offer it via their internal employee assistance program or, more typically, through an external vendor. Network agencies can provide this service to employers for their employees, ideally at the workplace, the agency, or both, with expanded evening and weekend hours.

Facilitate Workplace Support Groups. Aging network staff can assist in organizing or conducting support groups or both. Such groups typically provide information, as well as emotional support, to members and may be facilitated by professionals or peers. Based on

evaluations of demonstration projects, caregivers prefer that some support groups be held after work, as opposed to on the lunch hour; that separate groups for management and non-management be held to enhance willingness to discuss problems; and that groups be promoted as "informational" to overcome discomfort with the stigma overtones of a "support group."

Rural Caregivers

> The overall rural population has increased significantly over the last fifty years and has been aging rapidly as a result of: the desire to "age-in-place," out-migration of youth from agricultural and mining areas, and the immigration of elders from urban areas. Caregivers provide more than 70 percent of both direct and indirect care services for poor, socially isolated, underserved, frail and chronically ill elders in rural communities and the need to support these informal caregivers is a crucial rural health care program planning issue.[145]

Both attitudinal and structural barriers exist for caregivers living in rural communities. Community norms and cultural attitudes serve as key factors influencing service acceptability in rural communities. Research studies highlight several attitudinal barriers for rural caregivers. Barriers include: 1) stigma and guilt about seeking help and receiving services, 2) value of self-reliance, 3) belief that family members should assume responsibility for care, 4) reluctance to seek services until a crisis occurs; 5) denial of symptoms, and 6) ageism. These values and beliefs, and the stigma particularly associated with the use of mental health or counseling services, often contribute to the low use of formal services in rural populations.[146]

Several structural barriers also affect help-seeking behavior and the experience of being a caregiver. Most rural communities possess limited fiscal resources and infrastructure (e.g., program planners, trained workers, transportation) necessary to develop their own community-based programs. Key barriers include:

- Lack of coordination in the service delivery system;
- Cost of services;
- Service agencies that are overburdened, understaffed, or unavailable;
- Distance and lack of access to transportation;
- Restrictive reimbursement policies for services;
- Lack of access to comprehensive diagnostic and assessment services; and
- Family physicians who sometimes make no referrals for services.[147]

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[145] Buckwalter, K. and Lindsey Davis, L. (2001). *Elder Caregiving in Rural Areas.* Issue Brief prepared for the U.S. Administration on Aging. Available at http:// www.aoa.gov/carenetwork/issuebriefs.html .

[146] Connell, C.M., Kole, S.L., Avey, H., Benedict, C.J., and Gillman, S. (May/June 1996). Attitudes about Alzheimer's Disease and the Dementia Service Delivery Network Among Family Caregivers and Service Providers in Rural Michigan. *American Journal of Alzheimer's Disease*.

[147] Connell, C.M., Kole, S.L., Avey, H., Benedict, C.J., and Gillman, S. (May/June 1996). Attitudes about Alzheimer's Disease and the Dementia Service Delivery Network Among Family Caregivers and Service Providers in Rural Michigan. *American Journal of Alzheimer's Disease*.

Rural caregivers also frequently report frustrations related to use of needed services, such as being put on a waiting list for services that are needed immediately and difficulty understanding complex reimbursement policies.

Strategies and Program Examples

Collaborate with Rural Caregivers, Community Leader, and Staff Reflecting the Values of the Community. Demonstration projects in rural communities across a variety of states indicate that successful rural caregiver assistance programs are developed in collaboration with rural caregivers, endorsed by community leaders, and staffed by persons familiar with the cultural and social values of the community. Many communities also partner with, or refer caregivers to, entities in the community that have traditionally provided important support systems to rural families. For example, many network agencies take advantage of educational programs provided by county cooperative extension centers under the land grant system. Cooperative extension centers have a long history of providing educational services to families. The North Carolina Cooperative Extension Service provides a how-to educational approach for caregivers (e.g., seminars related to managing stress associated with caregiving and addressing caregiving issues at the end of life). ***Exhibit VIII.12*** presents program characteristics and persons to involve for planning successful rural caregiver assistance programs.

Exhibit VIII.12
RURAL Caregiver Program Planning Model

	Desired Program Characteristic	**Program planners must ensure rural caregiver assistance programs.**
R	**R**elevance	Involve caregivers in identifying program service needs and program relevance.
U	**U**nity	Integrate new program offerings with existing community services to ensure the new program does not compete with or duplicate existing programs.
R	**R**esponsiveness	Respond to the ethnic and cultural identity and traditions of elders, caregivers, and residents in the community.
A	**A**ccess	Enhance program access for caregivers through timing, location, transportation, and publicizing new services.
L	**L**ocal leadership	Include local leadership (e.g., nurses, social workers, physicians, ministers, church groups, civic leaders, other community service workers) in supporting and publicizing the program.

Source: Buckwalter, K. and Lindsey Davis, L. (2001). *Elder Caregiving in Rural Areas.* Issue Brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

Train Caregivers. Similar to other caregivers, caregivers of elders in rural communities need assistance with acquiring a core set of skills that will enable them to accurately monitor and interpret symptoms, successfully manage medical regimens, provide hands-on care, find and use appropriate resources, and make sound caregiving decisions, all while providing affective support and encouragement to the chronically ill or disabled. Thus, rural caregiver assistance programs traditionally combine information on aging and chronic illness with skills training on

providing home care as well as affective support, counseling, and periodic respite for the caregiver.

Employ Innovative Information Technologies. Information technologies might answer access challenges for both rural communities and long-distance caregivers. Promising are communication and information technologies to expand the reach of case managers and improve the coordination, access to, and quality of care in rural communities. Because of increasing pressures on service infrastructures, case managers face constant challenges in finding, getting, and monitoring services for clients and educating caregivers to improve their care decisions. Several potential benefits of telehealth technologies exist for support coordinators:

- Reductions in travel time to adequately assess and monitor clients
- Increases in numbers of clients who can be effectively monitored
- Opportunities to more frequently conduct educational sessions and provide technical and emotional support to homebound clients and their caregivers
- Ability to readily access through the Internet client records, educational and informational materials, communications with colleagues, and other activities that decease isolation

Benefits for caregivers include the following:

- Closer contact with case managers
- Opportunities for interaction with others in similar circumstances
- Timely access to face-to-face contact when needed for assistance or support
- Reductions in time and energy needed to travel for health monitoring
- Assistance with the supervision and monitoring of in-home workers

Form Partnerships. Forming creative partnerships might involve encouraging local high schools and nearby community colleges to offer credit courses in visiting and working with frail elders and their caregivers, encouraging urban health profession schools to include rural family caregiving courses in the curricula, and creating articulated models of caregiver assistance programs between urban and rural health care centers. The Seamless Delivery System Project, illustrated in ***Exhibit VIII.13***, serves as a good example of a collaborative program model designed specifically to meet the needs of rural caregivers.

Exhibit VIII.13
Building a Seamless Dementia-Specific Service Delivery System in Rural Iowa

Title: Seamless Dementia-Specific Service Delivery System Project (ADDGS Project)

Affiliation: Collaboration among the Iowa Department of Elder Affairs, the University of Iowa's College of Nursing and Center on Aging, the AAAs, Alzheimer's Association chapters, and Resource Link of Iowa

Status: Operational

Target Population: Rural Caregivers

Approach: This AoA funded project provides expanded in-home services to rural Iowans and their caregivers who are affected by Alzheimer's Disease and related disorders (ADRD). The project uses a community organization model, developed by the Big Sioux chapter of the Alzheimer's Association, to help rural communities create care systems that meet their unique needs in eight rural counties. Two assumptions underlie the approach: 1) if services are to be accepted within rural communities, the services must be designed by the community; 2) if the community values the services, it will refer neighbors to them. This program designates nurse care managers (NCMs) trained to provide in-home services, education, and support, to caregivers of ADRD. The NCMs work with the local case management system to coordinate available services, refer clients to funding sources, assist with community development programs, and report to the AAAs.

Cost/Funding: This program is funded through a three-year AoA ADDGS grant from 2000–2003.

Contact Information: Ann Bossen, Project Director, University of Iowa's College of Nursing and Center on Aging, at ann-bossen@uniowa.edu or (319) 335-7136; Mary Ann Young, Iowa Department of Elder Affairs, at mary.ann.young@dea.state.is.us or (515) 242-3312.

Provide Services that Compensate for Geographic Isolation of Rural Areas. Programs that compensate for geographic isolation through the combination of periodic home visits and innovative information technologies and telecommunications (e.g., peer caregiver telephone networks, telemedicine and telenursing contact systems) are critical to helping rural caregivers. Individuals also need to have access to preventive counseling and supportive mental health services for distressed and depressed caregivers, transportation to access community-based programs offerings, and caregiver "health promotion" programs in community centers (e.g., blood pressure checks, mammograms) during weekday and daytime hours. Caregivers can combine their self-care activities with a doctor appointment for the elder during a trip into town.

Long-Distance Caregivers

The complexities of providing support to care recipients are compounded for long- distance caregivers, who often must make decisions and implement actions without face-to-face assistance. Most long-distance caregivers are unable to visit frequently and cannot provide care in the home. Adult children, as well as other long distance relatives, often experience guilt

associated with spending less time with their parents and feelings of being overwhelmed by the challenges of arranging services long distance.[148]

Long-distance caregivers have numerous concerns, including lack of knowledge about where to begin obtaining information about accessing services to meet their needs and care-recipient needs. Rather than contacting an AAA, many of these caregivers turn to neighbors, friends, and doctors for information. These individuals are less likely to be as informed as the AAA, and thus, the long-distance caregiver continues to experience difficulty in accessing services. Common needs of long-distance caregivers include the following:

- Assistance with determining what services are needed for the care recipient and how to coordinate the range of needed services
- Knowing when to visit the care recipient and how to monitor care recipient activities
- Learning how to identify and rely on other formal and informal caregivers for assistance
- Receiving ongoing information on the care recipient's physical, emotional, and mental health status from clinicians and supporting agencies
- Making the most of visits to the care recipient's home (e.g., making appointments with physicians, lawyers, and financial advisers to facilitate decision-making; meeting with the care recipient's local support system to hear observations about how the care recipient is doing; understanding whether behavioral changes, health problems, or safety issues have occurred; taking time to reconnect with the care recipient)
- Moving a care recipient into a nursing home and monitoring care for a loved one in a home
- Resolving family conflicts

Strategies and Program Examples

Link Long-Distance Caregivers to Community Resources (e.g., toll-free telephone numbers and Web sites). Long-distance caregivers must be made aware of Eldercare Locator, a national directory assistance designed for seniors and caregivers providing local support services. Eldercare Locator is piloting a program that involves transferring callers from Eldercare Locator directly to the AAA, thereby eliminating the cost of a long-distance telephone call. In addition to Eldercare Locator, long-distance caregivers should be made aware of other resources, including the following:

- National Alzheimer's Association
- American Association of Home and Services for the Aging
- National Adult Day Services Association
- National Association for Home Care
- National Council on Aging Benefits
- National Association of Professional Geriatric Care

All of these resources can help long-distance caregivers identify services in local communities.

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[148] AARP, Long-Distance Caregiving http://www.aarp.org/confacts/caregive/londistance.html .

Provide Mechanisms for Long-Distance Caregivers to Receive Regular Updates on Care Recipient's Health Status from Clinicians and Other Providers. The Los Angeles Alzheimer's Association operates a program, highlighted in ***Exhibit VIII.14***, that makes it possible for long-distance caregivers supporting individuals with Alzheimer's Disease living in Los Angeles to regularly receive information on the health of their relative. The aging network can play an important role in easing the burden of long-distance caregiving by establishing case management systems that ensure ongoing and frequent flow of information from the aging network to the caregiver.

Exhibit VIII.14
Information Exchange with Long-Distance Caregivers

Title: Long-Distance Caregivers Project

Affiliation: Alzheimer's Association of Los Angeles, California

Status: Operational

Target Population: Long distance caregivers of individuals with Alzheimer's Disease

Approach: This program provides staff with the resources to contact and share information with long-distance caregivers (individuals living outside the Los Angeles area) of individuals with Alzheimer's Disease living in Los Angeles area. The project provides caregivers with a professional consultant to assist in caregiving tasks and access to legal services, a Web site, support groups, safe return registration, and a resource guide and workbook. Caregivers report increased comfort levels regarding the well-being of their loved ones because the information is coming directly from professionals, rather than solely through the care recipient.

Cost/Funding: The Archstone Foundation of Long Beach, California, funds this project.

Contact Information: Judith Delaney, Clinical Coordinator, Alzheimer's Association of Los Angeles, at judith.delaney@alz.org or (323) 938-3379.

IX. NONTRADITIONAL APPROACHES

Assistant Secretary, Josefina G. Carbonell, elaborated her vision for the National Family Caregiver Support Program (NFCSP) at the national Administration on Aging (AoA) conference, calling for the aging network to learn from other programs and, at the same time, recognize that every state, community, and family is different. Carbonell also emphasized the need under the NFCSP to create optimum flexibility, maximize consumer choice, and communicate directly with caregivers. This chapter highlights several innovative strategies and approaches the network can consider to enhance support to caregivers through: 1) consumer direction for caregivers, 2) caregiver self-advocacy, 3) volunteer models, and 4) technology applications.

CONSUMER DIRECTION

Parts of the following section are drawn from Carol Whitlatch's issue brief *Consumer Direction for Family Caregivers and Care Recipients: Challenges and Opportunities*.[149]

The notion that individual preferences and freedoms should drive health care delivery has become commonly characterized as consumer direction. In the broadest sense, consumer direction provides opportunities for persons to make meaningful choices regarding their care or the care they are providing.[150] It is also based on the premise that "individuals with long-term care needs should be empowered to make decisions about the care they receive, including having primary control over the nature of the services and who, when, and how the services are delivered."[151]

Consumer-directed services were originally developed to meet the needs of younger people with disabilities. The consumer direction movement emerged from the push by the younger physically disabled population for alternatives to institutionalization and evolved during the 1990s to imply greater consumer control and decision-making around care. The National Institute of Consumer-Directed Long Term Care Services has established several key principles of consumer direction, as illustrated in ***Exhibit IX.1.***

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[149] Whitlatch, C. (2001). *Consumer Direction for Family Caregivers and Care Recipients: Challenges and Opportunities*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

[150] Sciegaj, M. (2001). *Elder Preferences for Consumer Direction*. Paper presented at *Consumer Voice and Choice*, Scripps Gerontology Center, Fourth Conference on Long-Term Care. October 18, 2001, Columbus, OH.

[151] Stone, R.I. (2001). *Long Term Care Workforce Shortages: Impact on Families* (Executive Summary No. 3). San Francisco, CA: Family Caregiver Alliance.

Exhibit IX.1
Principles of Consumer Direction

- Systems should be based on the presumption that consumers are the experts of their service needs.
- Different types of services warrant different levels of professional involvement.
- Choice and control can be introduced into all service delivery environments.
- Consumer-directed service systems support the dignity of people requiring assistance as well as cost less when properly designed.
- Consumer direction should be available regardless of payer.

Source: The National Institute of Consumer-Directed Long Term Care Services.

The services that constitute "consumer-directed care" represent a range of delivery and financing models that support varying degrees of individual choice, autonomy, and self-determination. For example, on the more conservative end of the spectrum are consumer-directed models that allow caregivers to choose between a variety of agency-selected home health or chore service providers rather than appointing a specific provider or worker. On the more flexible end of the spectrum are consumer-directed programs that provide direct payments to consumers so individuals can determine how they would like to use the funding allocation. Area Agencies on Aging (AAAs) should keep in mind that the spirit of consumer-directed care lies in the practice of assuring that the consumer retains choice and control. ***Exhibit IX.2*** presents the range of service approaches for providing consumer-directed care.

Exhibit IX.2
Range of Consumer-Directed Approaches

Consumer Directed Models			
Choice of service type *or* service provider	Choice of *both* service type or service provider	Direct management of service and providers	Direct payment to consumer

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Level of Consumer Direction

Many federally and state-funded consumer-directed models have been established for the *care recipient,* but few states have developed consumer-directed programs that focus on the *caregiver.* Some consumer-directed programs designed for care recipients, however, have also benefited caregivers. For example, under the Cash and Counseling Model, funded by the Robert Wood Johnson (RWJ) Foundation and the Office of the Assistant Secretary of Health and Human Services, *care recipients* are offered a choice between receiving traditional agency-delivered personal assistance services listed in their care plans or managing cash allowances to obtain these services themselves. Medicaid Home and Community-Based Waivers (HCBW) approved by the federal Centers for Medicare and Medicaid Services permit direct cash payments to Medicaid consumers receiving personal assistance services. Payments are available to care recipients to pay for nontraditional services and *to employ family members as caregivers.*

Although this model benefits both care recipients and caregivers, it is important to distinguish that the care recipient, rather than the caregiver, is the individual with ultimate decision-making power. The aging network must recognize the interdependence of the caregiver and the care recipient in designing and delivering consumer-directed services, but the network also should make a deliberate effort to move beyond consumer-directed program options that address the needs of caregivers solely in the context of care recipients. For example, a program that makes direct payments to caregivers to obtain a needed service, such as respite care, is clearly a consumer-directed caregiver program.

The NFCSP presents an opportunity for the aging network to create consumer-directed models specifically aimed at offering caregivers the flexibility to select services that will benefit them directly. Well-designed consumer-directed programs for caregivers should:

- Empower the caregiver to serve as the decision-maker;
- Provide multiple approaches for caregivers and their families to obtain services, training opportunities (e.g., information on how to hire, train, and manage service providers), and peer and advocacy support programs; and
- Incorporate flexible designs to ensure individual needs and preferences are met.

STRATEGIES AND PROGRAM EXAMPLES

This section presents concepts and approaches drawn from consumer-directed models for both care recipients and caregivers. Program examples, however, strictly reflect models that have been specifically designed for caregivers and allow the caregiver to be the key decision-maker.

Provide Staff Education and Training on Consumer Direction for Caregivers. Because intake and eligibility staff across a range of aging and non-aging providers are likely the first representatives caregivers encounter, training on caregiver consumer direction for these people is essential. The information that intake and eligibility staff routinely give consumers about aging network services could include a description of the ways either the SUA or specific AAAs accommodate consumers' individual needs and preferences. AAA staff must understand and support principles of consumer direction, incorporate consumer direction principles into service planning, and support consumers who want to exercise varying degrees of choice and control.[152]

Provide Flexibility and Maximize Caregivers' Opportunities to Make Choices. No single consumer direction model will be useful in all settings; thus, flexible designs in consumer direction are crucial and more apt to meet the individual needs of caregivers. A consumer-directed NFCSP offers more than one consumer-directed option, giving caregivers numerous choices, ranging from traditional service models to programs that offer consumers cash or vouchers to purchase services for themselves. At a minimum, a caregiver program should be flexible enough to:

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[152] National Institute on Consumer-Directed Long-Term Services. 1996. Principles of Consumer-Directed Home- and Community-Based Services. Washington, DC: National Council on Aging.

- Give consumers a range of choices regarding service types, providers, service delivery models, and financing mechanisms, etc.;
- Consider development of services and options identified by consumers as important;
- Allow consumers to choose the level of responsibility they will assume in making decisions about services; and
- Offer an acceptable reimbursement rate for services to attract a variety of providers from which consumers can choose.

Whitlatch also emphasizes the importance of recognizing that some consumers do not want to use consumer-directed service options. The program example in ***Exhibit IX.3*** highlights Michigan's effort to allow caregivers to select respite services from a menu of service options identified by Michigan's Adult Well-Being Service agency.

Exhibit IX.3
Respite Care Self-Determination Model

Title: Respite Care Self-Determination Model

Affiliation: Adult Well-Being Service (AWBS) and Detroit AAA, Detroit, Michigan

Status: Operational

Target Population: Family caregivers

Approach: AWBS, a community-based, nonprofit organization, has launched an initiative to offer respite services to caregivers unlikely to seek services on their own. Respite services for caregivers are being advertised and promoted through the news media (e.g., newspaper articles, radio talk shows). When a caregiver contacts or is referred to AWBS, a social worker conducts an assessment at the caregiver's home. Based on the assessment, the social worker presents several appropriate options for receiving respite services. AWBS has developed working agreements with multiple respite agencies so caregivers can choose the type of respite they would like to receive, including: 1) in-home one-on-one respite offered during non-traditional hours, 2) adult day services for the care recipient, and 3) overnight respite or 4) use of an independent respite worker chosen by the caregiver (family member not living in care recipient's home, friend, or neighbor). Caregivers can receive up to 80 hours of respite per year. Approximately 100 families per year are served.

Costs/Funds: The program's funding sources and approximate amount include: 1) $75,000 from the NFCSP, 2) $50,000 from tobacco settlement dollars, 3) $50,000 from a federal program earmarking dollars to serve low-income neighborhoods, and 4) United Way funds.

Contact Information: Darlene Racz, Director of Aging, Adult Well-Being Service, at dracz@awbs.org or (313) 825-2505.

Direct Payment Options to Caregivers. Concepts of consumer direction for care recipients have been tested under the Cash and Counseling Model in several states, including Arkansas, Florida, and New Jersey. This concept has also been applied to caregiver programs in California, Georgia, and Pennsylvania, which offer caregivers the option of receiving direct payment to purchase and select needed services. Georgia and Pennsylvania require the caregiver to choose a formal provider; however, California allows consumers to hire and manage their own respite workers, including family or friends. In Georgia, caregivers enjoy the option of using funds to receive direct services (e.g., respite) from a list of providers that contract with the AAA or to receive services for care recipients. In Pennsylvania, caregivers can receive any type of service from a formal provider that will help "prolong, improve, or enhance

their relationship with the care recipient." ***Exhibit IX.4*** highlights the California, Georgia, and Pennsylvania consumer-directed caregiver program examples.

Exhibit IX.4
Direct Payments to Caregivers for Needed Services

Title: Caregiver Resource Center System

Affiliation: Caregiver Resource Center, California Department of Mental Health

Status: Operational

Target Population: Caregivers of persons with adult-onset brain diseases and disorders

Approach: This model system of 11 Caregiver Resource Centers (CRCs) serves families and caregivers of persons with adult-onset brain diseases and disorders (e.g., Alzheimer's Disease, Parkinson's Disease, stroke, traumatic brain injury). CRCs provide a range of support services, including specialized information and assistance (I&A), family consultation and care planning, support groups, legal and financial consultations with attorneys, education, training, and subsidized respite care. In-home respite, the most sought after service within the CRC system, is delivered through two mechanisms: 1) the vendor in-home respite (agency based) in which caregivers are offered vouchers to purchase service hours from home care agencies subcontracting with a CRC and 2) the direct pay or consumer-directed program whereby family caregivers are offered vouchers to hire and manage their own respite workers, including family or friends.

Costs/Funds: A sliding scale copayment schedule, uniform for all CRCs, is used for respite services and takes into account both family income and household size.

Contact Information: Wailing Rosello, Associate Mental Health Specialist, Caregiver Resource Center, at wrosello@dmhhq.state.ca or (916) 654-2629.

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Title: Legacy Express

Affiliation: Legacy Link AAA, Gainesville, Georgia

Status: Operational

Target Population: Family caregivers

Approach: Legacy Express promotes caregiver participation in the planning and management of services they receive. Caregivers receive vouchers totaling $500 (the AAA has varied the amount available) and can elect to spend the money on either: 1) services that will directly benefit the caregiver (e.g., respite) or 2) services for that might reduce some of the burden on the caregiver (e.g., prescriptions, day care services, homemakers services, home modifications, emergency response systems). The program issues to caregivers a handbook of approved providers willing to accept voucher payments.

Contact Information: Cliff Burt, Alzheimer's Program Director, Georgia Division of Aging Services, at gcburt@dhr.state.ga.us or (404) 657-5336.

Exhibit IX.4
Direct Payments to Caregivers for Needed Services, continued

Title: Pennsylvania Family Caregiver Support Program in Bucks County

Affiliation: Bucks County AAA, Pennsylvania

Status: Operational

Target Population: Family caregivers

Approach: Under the "voucher system," the AAA supplies the caregiver in need of service with a list of contracted providers. The caregiver contacts a contracted AAA provider and the provider verifies authorization with the AAA ficsal department. After the service is provided, the provider bills the AAA for the authorized AAA percentage and bills the caregiver for the caregiver percentage, if any. Under the "reimbursement system," if a caregiver purchases from a noncontracted provider (e.g., neighbor or drugstore), the caregiver pays the entire cost and sends the receipt to the AAA, who then reimburses the caregiver for their percentage. Unused amounts from the previous six months are automatically "banked," but caregivers must recieve prior approval in order to use funds from this "savings."

Cost/Funding: Caregivers eligible for the FCSP can receive reimbursement for their percentage of the first $200 per month that they spend on necessary care expenses for the older relative. Caregivers eligible for the NFCSP can receive reimbursement for their percentage of up to $500 per month in some instances.

Contact Information: JoLynn Mokos, FCSP Program Supervisor, Bucks County AAA, at jlmokos@co.bucks.pa.us or (215) 348-0510.

Balance the Needs of the Caregiver with the Needs of the Care Recipient. Whitlatch emphasizes that one of the key challenges for the aging network in building caregiver consumer-directed models is balancing the needs and preferences of caregivers with those of the care recipients.[153] For example, a care recipient with impaired capacity for planning and judgment might perceive adult day services as a threat to his or her level of independence. In contrast, a caregiver might view adult day services as an opportunity to receive respite from the day-to-day responsibilities of caregiving. Increased understanding of the preferences of the person with cognitive or physical impairments and the needs of the family caregiver will improve the decision-making process, lead to more informed decisions, and reduce the strain on family caregivers and associated health costs.

Support Caregivers Who Choose Consumer Direction. To make a caregiver consumer-directed program work, caregivers must have more than decision-making authority—they must also receive necessary support and information to enable them to decide whether they need staff support and how to manage their service providers. Although individual caregivers will vary in the amount of information and support they need, NFCSPs should make training and counseling available to all caregivers.

The range and scope of consumer-directed programs vary greatly according to funding source and amount, population served, and organizational capacity. As more consumer-directed

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[153] Whitlatch, C. (2001). *Consumer Direction for Family Caregivers and Care Recipients: Challenges and Opportunities*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

programs are developed and implemented specifically for caregivers, Whitlatch notes the importance of remembering several critical issues:[154]

- Only some caregivers will use consumer-directed models.
- Caregivers must be presented with tools to explore and understand what the care recipient's preferences are.
- In systems of care, provider agencies' focus shifts from providing services to supporting provision of services.
- Contrary to myths about consumer-directed services, states with experience in this arena have found little or no abuse of program funds; however, they included mechanisms to ensure appropriate use of program funding.
- Consumer-directed programs must be thoroughly evaluated, modified, and re-evaluated if they are to be efficient and effective.
- The results of program evaluations must be disseminated widely to ensure the continuation and replication of effective consumer-directed programs.

SELF-ADVOCACY

One of the most effective methods for promoting consumer preference can be through AAA support of caregivers interested in serving in advocacy roles. With resources and innovation under the NFCSP, caregivers can play an integral role in advocating supports for themselves at the individual, program, and state levels. Similar to the niche that other consumers (e.g., individuals with developmental disabilities and individuals with behavioral health problems) have created in various segments of the health care system, SUAs and AAAs have the opportunity to help caregivers make an imprint on the evolving system of care for this population. ***Exhibit IX.5*** presents specific mechanisms caregivers might use to advocate change at the individual, program, and system levels.

Exhibit IX.5
Multiple Levels of Self-Advocacy

Individual Level	Program Level	System Level
▪ Self-identify as a caregiver. ▪ Determine and communicate needs through consumer-directed models. ▪ Establish an individual sense of empowerment.	▪ Help AAAs conduct outreach to caregivers who have yet to self-identify. ▪ Establish self-help/peer groups, and educate and train other caregivers.	▪ Participate in planning, implementation, and evaluation efforts.

[154] Whitlatch, C. (2001). *Consumer Direction for Family Caregivers and Care Recipients: Challenges and Opportunities*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html.

Strategies and Program Examples at the Program Level

Several key approaches can help AAAs with successful mobilization of caregivers interested in serving as advocates. However, involving caregivers in a way that minimizes disruption to caregiving is critical for AAAs.

Use Caregivers as Resources for Reaching Other Caregivers. A major challenge in implementing the NFCSP is overcoming barriers to reaching the caregiver population. Individuals who have yet to self-identify as caregivers often fall through the cracks and either receive no needed services at all or receive inappropriate services. The term "caregiver" is unfamiliar to many people—caregivers identify themselves as wife, husband, daughter, son, or friend. Many individuals also have concerns with the term caregiver redefining the relationship with the person to whom they provide care. Some caregivers are also less apt to respond to outreach efforts that emphasize change is needed to help them, primarily because caregivers believe the focus should be on the care recipient. The aging network must solicit advice from caregivers on how best to help others self-identify as caregivers**.** Caregivers can help AAAs create outreach strategies by identifying areas of "hidden" caregivers, or those who have yet to self-identify, and crafting messages that will attract the attention of this difficult-to-reach population.

Encourage Caregivers to Provide Peer-to-Peer Assistance. The use of caregivers to reach, educate, train, and support other caregivers represents an important strategy for AAAs. Peer support and caregiver mentors have been shown to be effective methods in supporting caregivers and appear to increase the likelihood of their receiving additional assistance. Some AAAs face challenges in piquing interest about support groups for caregivers; however, using caregivers to facilitate discussions provides an entirely different perspective to the group. Support groups can cover a range of topics, including changing relationships with a spouse, navigating the support system, options for respite care, and how to provide self-care. Recognizing that "support group" might fail to resonate with caregivers who desire "a break" and "peers to talk to" is important.

Create Volunteer or Paid Caregiver Specialist Positions in AAA Offices. As mentioned throughout this guide, SUAs and AAAs must re-conceptualize how services are delivered for the caregiver population. Some agencies are planning to or have already created caregiver specialist positions to support and advocate, rather than directly provide or manage, services for caregivers. Many states, such as North Carolina, are placing a priority on recruiting caregivers to serve in this capacity, as ***Exhibit IX.6*** explains.

Exhibit IX.6
Caregivers Serving as Caregiver Specialists

Title: North Carolina Regional Caregiver Specialists

Affiliation: North Carolina Department of Aging and AAA

Status: Operational

Target Population: Caregivers

Approach: Seventeen of the State's AAAs hired a regional caregiver specialist (RCS) responsible for building program and community relations and functioning in an advocacy role as a primary spokesperson in the region on the FCSP and the needs of family caregivers. The RCS collaborates with a wide array of individuals and groups to develop community resources and coordinate care for the caregiver population.

Contact Information: Program information and job descriptions are available upon request from North Carolina. Chris Urso, Family Caregiver Specialists, North Carolina Department of Health and Human Services, Division on Aging, at chris.urso@ncmail.net or (919) 733-8400. For more information on the credentials of the specialists, please visit: http://www.dhhs.state.nc.us.aging/ fcaregr/fcjobs.htm

Strategies and Program Examples at the System Level

Invite Caregivers to Participate in the Program Design Process. A fundamental step in employing caregivers to serve as advoctes is ensuring that they are given many opportunities to play an active role in guiding system design. Barriers that prevent or discourage caregiver involvement should be identified to facilitate increased consumer participation in developing, designing, administrating, and evaluating caregiver programs. Both formal (e.g., public hearings) and informal opportunities (e.g., community forums, public meetings) to provide input should be made available to consumers. Caregivers can also play an ongoing advisory role in delivery and evaluation of caregiver services.

Recruit and Train Caregivers to Serve on Planning Counsels in States. As the goals of providing long-term care have evolved, an increasing number of care recipients and caregivers have assumed advocacy functions. The Oklahoma AAA initiative provides valuable examples of involving caregivers in advocacy roles. ***Exhibit IX.7*** showcases Oklahoma Aging Services Division efforts to establish a program for training and developing volunteers, including caregivers, to become informed leaders on issues affecting caregivers and care recipients.

Exhibit IX.7
Development of Advocates

Title: Oklahoma Aging Advocacy Leadership Academy

Affiliation: Oklahoma Aging Services Division (SUA)

Status: Operational

Target Population: Volunteers persons of all ages, including caregiver volunteers, interested in aging issues

Approach: The Oklahoma Aging Advocacy Leadership Academy (OAALA) identifies and trains volunteer persons interested in becoming leaders and advocates on issues related to aging. Selected applicants participate in the OAALA, a 10-month program convening one weekend per month that prepares individuals for serving on local and state boards and councils assisting the aging in Oklahoma. Strategies focus on issues related to aging. Topics addressed during the course of the training include: caregiver issues; demographics of aging; aging issues in society, legislative advocacy, mental health and aging, organizing social change, diversity of the aging population, self-protection in negotiations, and medical relations. Participants in the OAALA represent business, nonprofit organizations, communities, and individuals.

Cost/Funding: The Department of Human Services, Aging Services Division, sponsors the Academy, which was developed through a grant from the Oklahoma Developmental Disabilities Council. Southwestern Bell Telephone, Oklahoma Gas and Electric, and Sooner Management Consultants have joined as corporate sponsors, as well, and further corporate sponsorship is being sought throughout the state.

Contact Information: Judy Leitner, Director of Community Relations, Oklahoma Aging Services Division, at judy.leitner@okdhs.org

VOLUNTEER MODELS

Volunteers serve as critical partners to the aging network through a range of administrative and direct service activities. Despite the large number of people who share their time and talents, however, the needs of local communities and the nation as a whole continue to outpace the number of volunteers. AAAs will have to create effective strategies to recruit additional volunteers to provide support to caregivers.

SUA and AAAs can employ a number of strategies to use volunteers as a resource for supporting caregivers, such as conducting outreach campaigns targeting volunteers, establishing volunteer databases, creating non-financial incentives for volunteers (e.g., having volunteers provide respite to one another), and training new and existing volunteers. Several programs across the country, including programs in Minnesota, North Carolina and Kentucky, have efforts under way to recruit and train volunteers for providing respite and other services to caregivers, as ***Exhibit IX.8*** illustrates.

Exhibit IX.8
Recruitment and Training of Volunteers Providing Respite

Title: Project ROSE (Reaching Out to Support Elders)

Affiliation: Serving as the Project ROSE Coordinator in Mankata, Minnesota, Region Nine partners with eight nonprofit agencies: Interfaith Volunteer Caregivers, CARE Project, Chippewa County Interfaith Caregiver Program, Waseca Faith in Action Program, Community Response Effort Service Team, Volunteer Interfaith Network Effort, Mid Minnesota AAA, and Upper Minnesota Valley AAA.

Status: Operational

Target Population: Family caregivers

Approach: Project ROSE provides community-based volunteer respite care and informal caregiver support services for caregivers. The program comprises nine nonprofit entities in the south central region of the state that provide respite services to a 20-county area. Volunteers provide respite for caregivers so they can spend time accomplishing other tasks, such as attending medical and dental appointments, running errands and shopping, meeting friends, and enjoying relaxation time. Respite volunteers receive professional training and commit to a regular schedule (usually 2 to 4 hours per week). Caregivers also receive information and assistance services, have access to lending libraries of books and video tapes specific to caregiving issues, and can attend caregiver education and support group activities.

Costs/Funding: A Minnesota Department of Human Services grant, and Robert Wood Johnson Foundation grants have provided funding for these services. NFCSP funds will be utilized to expand these services into additional counties.

Contact Information: Elaine Spain, Project ROSE Coordinator, Region Nine AAA, at (507) 389-8860.

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Title: Volunteer Respite Services

Affiliation: Region J AAA, including seven county area, in North Carolina

Status: Operational

Target Population: Family caregivers

Approach: The region's seven counties recruit volunteers to provide respite services for caregivers. Several counties served by the AAA have seed volunteer respite programs newly in place. One of the longest-standing county programs has 400 volunteers serving 300 families. The counties are working with United Way, RSVP, and other volunteer organizations to expand their volunteer base.

Costs/Funding: The funding for the services for the last six months of Fiscal Year 2001-2002 totals $204,217. Costs include: outreach, staff time, recruitment, screening and supervision of volunteers, assessment of caregiver family situations, matching of clients with volunteers, and program promotion. The program is funded primarily through the NFCSP.

Contact Information: Ellison Jones, Family Caregiver Specialist, Region J AAA, at ejones@tjcog.org or (919) 558-9391.

Exhibit IX.8
Recruitment and Training of Volunteers Providing Respite, continued

Title: Dementia-specific Volunteer Caregivers Program (VCP)

Affiliation: University of Louisville School of Nursing, Alzheimer's Disease Chapter

Status: Operational

Approach: This program is an outgrowth of the Volunteer Interfaith Caregivers of Kentucky. The idea for this support program began when representatives from various religious congregations and a local Alzheimer's Disease chapter joined together and developed a vision to train volunteers to provide in-home respite to keep caregivers connected to their support groups. Since 1994, the VCP has provided support services to more than 100 caregivers at no charge. Program services include assessment, care planning, education, evaluation, information and assistance, and volunteer support. The VCP also provides free public services such as memory screening and community education programs.

Contact: Karen Robinson, RN, Ph.D., FAAN, University of Louisville School of Nursing, at kmrobi01@louisville.edu or (502) 852-8512.

Other AAAs have established service banks to encourage volunteers to provide in-home services and respite care for homebound people with disabilities and their caregivers. When a volunteer or family member needs similar services, he or she may draw on, at no cost, services credits earned for time volunteered.

Under the Retired and Senior Volunteer Program (RSVP), volunteers serve from a few to more than forty hours a week in a range of organizations. RSVP involves individuals age 55 and older who volunteer to provide services that typically match their personal interest and make use of their skills and lifelong experiences. Some states, including Washington, partner with RSVP to provide specialized training to volunteers interested in serving as peer counselors to caregivers. Caregiver peer counseling differs from professional counseling in several ways, such as allowing for a more equal relationship and less intimidation. ***Exhibit IX.9*** highlights Washington's Olympic Area Agency on Aging's initiative to provide specialized training for RSVP volunteers to serve as peer counselors.

Exhibit IX.9
Building on RSVP Activities to Support Caregivers

Title: RSVP Caregiver Peer Counseling Program

Affiliation: Olympic Area Agency on Aging, Washington

Status: Operational

Target Population: Volunteers

Approach: Olympic AAA is building on its relationship with RSVP to train volunteers to work with caregivers. RSVP trains individuals to serve as caregiver peer counselors who offer emotional support, guidance and empathy to peers who are providing ongoing caregiving. Peer counselors make visits to caregiver homes to assess needs, assist in accessing supportive services, and provide informal counseling/problem-solving assistance. Training includes instruction, role-playing, group discussions, and training materials.

Cost/Funding: One training session for 10 volunteers is budgeted at $2,000. Additional costs are minimal because volunteers staff the program.

Contact Information: Sheryl Lowe, Senior Planner, Olympic AAA, at loweshj@dshs.wa.gov or 360-452-3221 ex.103.

TECHNOLOGY APPLICATIONS FOR CAREGIVERS

The following section draws on Frank Worts' issue brief *Technology and Applications for Caregivers*.[155] Individuals in the age range 50 to 64 and older, a group extremely apt to represent caregivers, are three time more likely to access the Internet than the 65 and older population, according to a study conducted by the Pew Internet and American Life Project in 2000. This section presents strategies for SUAs and AAAs to share information with caregivers and to support caregiver efforts to obtain information through technology applications, including Web sites, email, listservs, and real-time communication.

Strategies and Program Examples

Establish and Maintain AAA Web Sites That Include Caregiver-Specific Information and Links to Other Critical Caregiver Web Sites. Many AAAs are creating and designing information for their Web sites that specifically targets the caregiver population. The Web provides caregivers with the opportunity to efficiently find and contact needed resources such as a list of services provided under the NFCSP or approaches for providing services selected by consumers; a list of statewide resources (e.g., information and available services) for caregivers; agendas and materials for upcoming caregiver seminars, conferences, or both; and links to other caregiver-related Web sites and online caregiver support groups. Providing current and accurate information on AAA Web sites can prove extremely valuable to caregivers as well as to staff assisting caregivers in community organizations across the state.

Provide Training to Caregivers in Using Technology-Based Resources and Educate Caregivers on the Benefits of Using Different Applications. The Web can serve as a valuable information source for caregivers and care recipients; however, because of the variability in the quality of

[155] Worts, F. (2001). *Technology and Applications for Caregivers*. Issue brief prepared for the U.S. Administration on Aging. Available at http://www.aoa.gov/carenetwork/issuebriefs.html .

information, SUAs and AAAs should provide guidance (e.g., providing linkages on the AAA Web site) and training to caregivers on how to find useful, reliable, and authoritative sources. Often, individuals are directed to a specific Web site for information. In other cases, finding specific information can be a formidable task. The following list includes key types of information that might be useful to caregivers and are easily accessible on the Web.

- Health services and resources
- Social service resources
- University services and resources
- Virtual libraries
- Online support groups
- Newspaper clipping services
- Full-text reports and articles from experts
- Government reports
- Expert advise
- Medication availability, uses, and side effects
- Stress reduction strategies
- Assisted technology equipment

Email can facilitate communication among: 1) caregivers and care recipients, 2) caregivers in different locations and households providing care to the same care recipient, and 3) caregivers and service providers. At times, the primary caregiver has to make important decisions concerning the family member, and the caregiver feels that all family members should take part in the decision-making process. Email can enhance this process by providing an opportunity for sharing information with all significant family members to reach a consensus.

Caregivers can connect with service providers working with their relative to communicate about shifts in care recipient need, resources available, and suggestions for care. They can remain informed about the elder's status and issues. Email can also help in planning caregiving tasks. Caregivers can send themselves email reminders about appointments and activities needing attention at specific intervals.

Real-time communication, also referred to as *chat*, is an extension and refinement of email. The advantage of chat is that individuals communicate in real time, so the information shared, the questions asked, the opinions given are addressed immediately. No waiting occurs, and in most cases, the interaction is much more personal. Chat takes place in three formats: text, audio, and audio/video. When audio and video are used, the communication approaches in-person communication.

People providing distance caregiving have difficulty communicating with service providers as well as other caregivers and their family members. Caregivers using real-time communications can participate in care planning conferences for their family member in a creative way. This technology offers the opportunity for the family member to present his or her preferences, share medical and other information, and be involved in the decision making process.

Costs, except for equipment purchase, are contained in the monthly Internet service provider fees. The most difficult issue with real-time chat relates to software set up. AAAs can help caregivers locate the appropriate support to configure the software and hardware. When adding equipment to an existing computer, individuals would benefit, in most instances, from professional installation.

Typically, *discussion forums* are organized by topic. The forums are real-time text-oriented mechanisms that give individuals a chance to communicate around a certain topic in real time. Many Web sites offer support for people with similar problems or situations. Caregivers can communicate with other caregivers to support each other. They can also invite professionals to log on to their site to provide advice and information for assisting their caregiving efforts. Professionals working with specific client types can communicate with each other about best professional practices.

Listservs enable caregivers to participate in discussion forums. Subscribers to a listserv usually receive information that addresses state-of-the-art and recent developments in a specific topic area. Because they provide an easy way to keep up with a given field and provide information that is forwarded frequently and automatically, listservs are useful and convenient. Caregivers can post questions to the list, receive helpful responses, and join and leave a listserv at any time. A number of listservs cover a range of topics on aging, health, social service, government funding, and other issues of interest to the aging network. For a comprehensive directory of listservs, visit http://www.list.com. ***Exhibit IX.10*** provides an example of an SUA that employs a Web page and listserv to facilitate information sharing for caregiver specialists.

Exhibit IX.10
Caregiver Specialist Listserv and Web Page

Title: Family Caregiver Specialist Listserv and Webpage

Affiliation: North Carolina Department of Aging (SUA)

Status: Operational

Target Population: Family caregivers and staff supporting family caregivers

Approach: The state created a Yahoo Web site for caregiver specialists and a listserv for staff at the SUA and AAAs involved in the NFCSP initiative. The Web site provides: 1) NFCSP development information, 2) a list of statewide resources for caregivers, 3) a list of AAA caregiver specialists and their credentials, 4) summaries of issues addressed during AAA caregiver listserv discussions, and 5) a snapshot of support services available for caregivers in North Carolina. Furthermore, the North Carolina SUA is developing a common list of keywords that will be used across the State to ensure that each AAA is using common terms in categorizing their services. The listserv provides a mechanism for staff to exchange information across the state regarding available resources for caregivers. In addition to information exchange opportunities, it also allows staff to provide support to one another in addressing questions and concerns related to the NFCSP.

Contact Information: Chris Urso, Family Caregiver Specialist, North Carolina Department of Health and Human Services Division on Aging, at chris.urso@ncmail.net or (919) 733-8400.

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Title: TeleCare Connections

Affiliation: The Office of Aging (AAA), New Jersey

Status: Developmental (implementation expected May 2002)

Target Population: Long-distance caregivers

Approach: The Office of Aging (OOA) is in the final stages of developing a program that allows caregivers and care recipients to use interactive Web-based television for communication between care recipient and caregivers. The AAA, a local hospital, and the local Visiting Nurses Association are working together to locate individuals interested in participating in the program. The program also involves the use of outcome measurements.

Costs/Funding: Funding sources include grants from the NFCSP, the New Jersey Department of Health and Senior Services, the Administration on Aging, and Verizon.

Contact Information: Jill Smith, Program Coordinator, The Office of Aging, at jcsmith@shore.co.monmouth.jn.us or (732) 431-7450.

Facilitate Online Support Groups or Refer Caregivers to Support Group Web Sites. AAAs should consider hosting online support groups for caregivers or referring individuals to known caregiver support groups. Caregiver support groups, which currently are available 24 hours a day, provide the information needed to cope with day-to-day caregiving situations. The groups offer support in that participants recognize immediately that their situation is far from unique. Logging on to a discussion group could be one way to relieve tension and gain support and advice. Participants can use discussion groups in the following ways:

- Receive information on almost any topic.
- Pose questions and receive answers from people with varying information and experience.
- Follow trends and state-of-the-art development in any area of interest.
- Become part of a network where their experience and expertise could help others.
- Discuss their situation and receive support and feedback.

This chapter presented strategies, including the use of models that emphasize individual consumer needs and preferences as the focal point, and state program examples familiar to the aging network. Challenges for the aging network in this venue are twofold. First, no single, universally applicable model exists that constitutes self-determination for either care recipients or caregivers. Models in each state are shaped by unique political, geographic, demographic, and systemic characteristics as well as differing levels of available resources. Second, although self-determination models have been used for many developmentally disabled individuals and can be adapted for adults caring for children with developmental disabilities under the NFCSP, self-determination models for older individuals likely will require different types of approaches (e.g., more intense support from staff to help elders manage the service system). Regardless of the age of the individual served through the NFCSP, a clear consensus exists that program planners must strive to promote choice and foster independence among caregivers. SUAs and AAAs must remain informed about consumer-directed programs that have been evaluated and respond to lessons learned from evaluations by being willing to modify programs as needed.

The network also is especially aware of the need to maximize important resources, such as volunteers and technology. Recruiting and training volunteers and supporting caregivers in their efforts to access relevant information through technological applications requires SUAs and AAAs to look beyond the initial investment of staff resources. Rather, the network must recognize and envision the potential long-term value of establishing informative AAA Web sites and other Internet resources.

APPENDIX A

NFCSP Policy Information

OLDER AMERICANS ACT, as amended in November, 2001

(Based on Unofficial Compilation by the Center for Social Gerontology)

TITLE III–GRANTS FOR STATE AND COMMUNITY PROGRAMS ON AGING

I. PART E--NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

SECTION 371 SHORT TITLE .

This part may be cited as the "National Family Caregiver Support Act".

Subpart 1--Caregiver Support Program

SECTION 372. DEFINITIONS.

In this subpart:

(1)CHILD-The term "child" means an individual who is not more than 18 years of age.

(2)FAMILY CAREGIVER-The term "family caregiver" means an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual.

(3)GRANDPARENT OR OLDER INDIVIDUAL WHO IS A RELATIVE CAREGIVER-The term "grandparent or older individual who is a relative caregiver" means a grandparent or step grandparent of a child, or a relative of a child by blood or marriage, who is 60 years of age or older and--

(A)lives with the child;

(B) is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and

(C) has a legal relationship to the child, as such legal custody or guardianship, or is raising the child informally.

SECTION 373.PROGRAM AUTHORIZED.

(a)IN GENERAL-The Assistant Secretary shall carry out a program for making grants to States with State plans approved under section 307,to pay for the Federal share of the cost of carrying out State programs, to enable area agencies on aging, or entities that such area agencies on aging contract with, to provide multifaceted systems of support services—

(1) for family caregivers; and

(2) for grandparents or older individuals who are relative caregivers.

(b)SUPPORT SERVICES-The services provided, in a State program under subsection

(a), by an area agency on aging, or entity that such agency has contracted with, shall include—

(1) information to caregivers about available services;

(2) assistance to caregivers in gaining access to the services;

(3) individual counseling, organization of support groups, and caregiver training to caregivers to assist the caregivers in making decisions and solving problems relating to their caregiving roles;

(4) respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and

(5) supplemental services, on a limited basis, to complement the care provided by caregivers.

(c)POPULATION SERVED; PRIORITY.--

(1)POPULATION SERVED-Services under a State program under this subpart shall be provided to family caregivers, and grandparents and older individuals who are relative caregivers, and who—

(A) are described in paragraph (1) or (2) of subsection (a); and

(B) with regard to the services specified in paragraphs (4) and (5) of subsection (b), in the case of a caregiver described in paragraph (1), is providing care to an older individual who meets the condition specified in subparagraph (A)(i) or (B) of section 102(26).*

(2)PRIORITY-In providing services under this subpart, the State shall give priority for services to older individuals with greatest social and economic need, (with particular attention to low-income older individuals) and older individuals providing care and support to persons with mental retardation and related developmental disabilities (as defined in section 102 of the Developmental Disabilities Assistance and Bill of Rights Act (42 U.S.C.6001))(referred to in this subpart as “developmental disabilities”).

(d)COORDINATION WITH SERVICE PROVIDERS-In carrying out this subpart, each area agency on aging shall coordinate the activities of the agency, or entity that such agency has contracted with, the activities of other community agencies and voluntary organizations providing the types of services described in subsection (b).

(e)QUALITY STANDARDS AND MECHANISMS AND ACCOUNTABILITY-

(1)QUALITY STANDARDS AND MECHANISMS-The State shall establish standards and mechanisms designed to assure the quality of services provided with assistance made available under this subpart.

(2)DATA AND RECORDS-The State shall collect data and maintain records relating to the State program in a standardized format specified by the Assistant Secretary. The State shall furnish the records to the Assistant Secretary, at such time as the Assistant Secretary may require, in order to enable the Assistant Secretary to monitor State program administration and compliance, and to evaluate and compare the effectiveness of the State programs.

(3)REPORTS-The State shall prepare and submit to the Assistant Secretary reports on the data and records required under paragraph (2), including information on the services funded under this subpart, and standards and mechanisms by which the quality of the services shall be assured.

(f)CAREGIVER ALLOTMENT-

(1)IN GENERAL.—

(A)From the sums appropriated under subsection 303(e) for fiscal years 2001 through 2005,the Assistant Secretary shall allot amounts among the States proportionately based on the population of individuals 70 years of age or older in the States.

(B)In determining the amounts allotted to States from the sums appropriated under section 303 for a fiscal year, the Assistant Secretary shall first determine the amount allotted to each State under subparagraph (A) and then proportionately adjust such amounts, if necessary, to meet the requirements of paragraph (2).

(C)The number of individuals 70 years of age or older in any State and in all States shall be determined by the Assistant Secretary on the basis of the most recent data available form the Bureau of the Census and other reliable demographic data satisfactory to the Assistant Secretary.

(2)MINIMUM ALLOTMENT.—

(A)The amounts allotted under paragraph (1)shall be reduced proportionately to the extent necessary to increase other allotments under such paragraph to achieve the amounts described in subparagraph (B).

(B)(i)Each State shall be allotted 1/2 of 1 percent of the amount appropriated for the fiscal year for which the determination is made.

(ii)Guam and the Virgin Islands of the United States shall each be allotted 1/4 of 1 percent of the amount appropriated for the fiscal year for which the determination is made.

(iii)American Samoa and the Commonwealth of the Northern Mariana Islands shall each be allotted 1/16 of 1 percent of the amount appropriated for the fiscal year for which the determination is made.

(C)For the purposes of subparagraph (B)(i), the term "State" does not include Guam, American Samoa, the Virgin Islands of the United States, and the Commonwealth of the Northern Mariana Islands.

(g)AVAILABILITY OF FUNDS-

(1)USE OF FUNDS FOR ADMINISTRATION OF AREA PLANS-Amounts made available to a State to carry out the State program under this subpart may be used, in addition to amounts available in accordance with section 303(c)(1), for costs of administration of area plans.

(2) FEDERAL SHARE-

(A) IN GENERAL-Notwithstanding section 304(d)(1)(D), the Federal share of the cost of carrying out a State program under this subpart shall be 75 percent.
(B)NON-FEDERAL SHARE-The non-Federal share of the cost shall be provided from State and local sources.
(C)LIMITATION-A State may use not more than 10 percent of the total Federal and non-Federal share available to the State to provide support services to grandparents and older individuals who are relative caregivers.

SECTION 374.MAINTENANCE OF EFFORT.

Funds made available under this subpart shall supplement, and not supplant, any Federal, State, or local funds expended by a State or unit of general purpose local government (including an area agency on aging) to provide services described in section 373.

Subpart 2--National Innovation Programs

SECTION 375.INNOVATION GRANT PROGRAM.

(a)IN GENERAL-The Assistant Secretary shall carry out a program for making grants on a competitive basis to foster the development and testing of new approaches to sustaining the efforts of families and other informal caregivers of older individuals, and to serving particular groups of caregivers of older individuals, including minority caregivers and distant caregivers and linking family support programs with the State entity or agency that administers or funds programs for persons with mental retardation or related developmental disabilities and their families.

(b)EVALUATION AND DISSEMINATION OF RESULTS-The Assistant Secretary shall provide for evaluation of the effectiveness of programs and activities funded with grants made under this section, and for dissemination to States of descriptions and evaluations of such programs

and activities, to enable States to incorporate successful approaches into their programs carried out under this part.

(c)SUNSET PROVISION-This section shall be effective for 3 fiscal years after the date of enactment of the Older Americans Act Amendments of 2000.

SEC.376.ACTIVITIES OF NATIONAL SIGNIFICANCE.

(a)IN GENERAL-The Assistant Secretary shall, directly or by grant or contract, carry out activities of national significance to promote quality and continuous improvement in the support provided to family and other informal caregivers of older individuals through program evaluation, training, technical assistance, and research.

(b)SUNSET PROVISION-This section shall be effective for 3 fiscal years after the date of enactment of the Older Americans Act Amendments of 2000.

* **Excerpt from OAA, Title I, Section 102:**

(*26*) The term "frail" means, with respect to an older individual in a State, that the older individual is determined to be functionally impaired because the individual—

(A)(i)is unable to perform at least two activities of daily living without substantial human assistance, including verbal reminding, physical cueing, or supervision; or (ii)at the option of the State, is unable to perform at least three such activities without such assistance; or

(B) due to a cognitive or other mental impairment, requires substantial supervision because the individual behaves in a manner that poses a serious health or safety hazard to the individual or to another individual.

TITLE VI-GRANTS TO INDIAN TRIBES

II. PART C--NATIVE AMERICAN CAREGIVER SUPPORT PROGRAM

SEC. 631. PROGRAM.

(a) IN GENERAL- The Assistant Secretary shall carry out a program for making grants to tribal organizations with applications approved under parts A and B, to pay for the Federal share of carrying out tribal programs, to enable the tribal organizations to provide multifaceted systems of the support services described in section 373 for caregivers described in section 373.

(b) REQUIREMENTS- In providing services under subsection (a), a tribal organization shall meet the requirements specified for an area agency on aging and for a State in the provisions of subsections (c), (d), and (e) of section 373 and of section 374. For purposes of this subsection, references in such provisions to a State program shall be considered to be references to a tribal program under this part.

SEC. 643. AUTHORIZATION OF APPROPRIATIONS.

There are authorized to be appropriated to carry out this title--

(1) for parts A and B, such sums as may be necessary for fiscal year 2001, and such sums as may be necessary for subsequent fiscal years; and

(2) for part C, $5,000,000 for fiscal year 2001, and such sums as may be necessary for subsequent fiscal years.

Program Instruction

AoA-PI-01-02
January 8, 2001

TO: State Agencies on Aging Administering Plans Under Title III of The Older Americans Act of 1965, as Amended

SUBJECT: State Guidance to Implement Title III, Part E -- NFCSP

III. LEGAL AND RELATED

IV. REFERENCES: Sections 371, 372, 373, and 374 of the Older Americans Act of 1965, as amended (p.l. 106-501), grants for state and community programs on aging.

This Program Instruction provides guidance to states for use in implementing the provisions of the newly authorized National Family Caregiver Support Program under Title III, Part E of the Older Americans Act, as amended in 2000 (P.L. 106-501). The legislative authority and provisions of the National Family Caregiver Support Program became effective upon the signing of the Older Americans Act Amendments of 2000 by President Clinton on November 13, 2000. This new program provides an opportunity for the aging network to develop a service delivery system to respond to the needs of our Nation's caregivers.

Use of Title III-E Funds for State and Area Plan Administration

Title III-E funds may be used to compute the total amount of funds which are available for administration of the State plan and also may be used to pay for administration of the State plan. Section 308(b) allows the State agency to use five percent of the total Title III allotment or $500,000 to pay for not more than seventy-five percent of the cost for administration of the State plan. Therefore, Title III-E funds may be used for State administrative costs in the same manner as other Title III funds and are subject to the same limitations.

Title III-E funds may be used to compute the total amount of funds which are available for area plan administration and also may be used to pay for administration of area plans. Section 304(d) of the Act provides that, after the application of Section 308(b), the State may use up to ten percent of the State's remaining total Title III allotment to pay for not more than seventy-five percent of the cost for administration of area plans. Section 303(c) indicates that funds under Title III-B and C may be used for paying part of the cost of area plan administration. Section 373(g) authorizes the State agency to use Title III-E funds for the cost of administration of area plans. Therefore, Title III-E funds may be used for area plan administrative costs in the same manner as Title III-B and C funds and are subject to the same limitations. The cost of administration of area plans can be taken from any or all of these three sources.

Maintenance of Effort

The intent of the Title III-E maintenance of effort provision in Section 374 is that States use the funds made available under Title III-E to supplement existing services. Further, those funds must be spent in addition to, and shall not supplant, any Federal, State, or local funds expended by a State or unit of general purpose local government (including area agencies on aging) to fund services described in Section 373 provided prior to the date of enactment of Part E. In other words, a State or unit of general purpose local government (including area agencies on aging) may not use Federal Part E funds to supplant, replace, or in substitution for, any other Federal, State, or local funding expended pursuant to Federal, State, or local laws that were in effect on or before November 12, 2000, which was one day before the date of enactment of Title III-E.

To implement this requirement, the State must provide, in its State plan, an assurance that it will use funds made available under Title III-E to implement a National Family Caregiver Support Program and will not supplant with Title III-E funds any funds that were expended under any Federal, State, or local program in existence on or before November 12, 2000. For your convenience, an optional form is attached which can be used to fulfill this requirement.

Federal Share Limitation

Section 373(g)(2)(C) permits a State to use up to ten percent of the total Federal and non-Federal share available to the State under Title III-E to provide support services to grandparents and older individuals who are relative caregivers.

The term "grandparent or older individual who is a relative caregiver" means a grandparent or stepgrandparent of a child, or a relative of a child by blood or marriage, who is 60 years of age or older and: (A) lives with the child; (B) is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and (C) has a legal relationship to the child, as such legal custody or guardianship, or is raising the child informally. The term "child" means an individual who is not more than 18 years of age.

The ten percent limitation applies to the State as a whole. As a result, the state has the flexibility to vary among area agencies on aging the expenditures to provide support services to grandparents and older individuals who are relative caregivers.

SUA Distribution of Title III-E

Section 305(a)(2)(C) requires a State to develop and publish for review and comment a formula for distribution within the State of funds received under Title III. Funds available to States under the newly authorized Title III-E are subject to this provision and must be allocated to area agencies on aging.

There is no specific requirement to amend the Intrastate Funding Formula (IFF) in order to distribute Title III-E funds. States may use their current IFF for the allocation of funds under Part E. However, if a State chooses to amend its IFF, it shall submit the revised formula to the Assistant Secretary for Aging for review and approval.

Title III-E Reporting

Sections 373(e)(2) and (3) require the State to maintain and report information relating to the Title III-E program. In addition, basic grant fiscal reporting requires the inclusion of Title III-E

expenditures into the SF-269 Supplemental Report. To this end, an amended SF-269 Supplemental Report and instructions will be published in the *Federal Register* for comment. It will be designed to provide States with the necessary information and specific format requirements for initial reporting of performance under Title III-E. Concurrently, an effort will commence to review amending the State Performance Report as a component of the National Aging Program Information System. This effort will be aimed at producing outcome measures for Title III-E to fulfill the requirements of the Government Performance and Results Act.

Title III-E Match Requirements

Sections 373(g)(2)(A) and (B) require that the Federal share be 75% of the cost of carrying out a State program under this subpart. The non-Federal share (25%) of the cost of carrying out a State program under this Part must be provided from State and local sources and may be met with cash or in-kind expenditures. Expenditures used to satisfy the non-Federal share requirement must be related to the purpose of Title III-E and may not be used to meet maintenance of effort or non-Federal share requirements in other Federal programs, including other sections of Title III.

However, expenditures previously used to "over match" other programs may be used to satisfy the non-Federal share requirement in Title III-E provided that those expenditures no longer are counted toward meeting the non-Federal share requirement of such other programs and those expenditures are related to the purpose of Title III-E.

Expenditures previously used to satisfy maintenance of effort requirements in other Federal programs, e.g., Titles III-B and C, may be used to satisfy the maintenance of effort and/or non-Federal share requirements for Title III-E, provided those expenditures are related to the purpose of Title III-E and are no longer counted toward satisfying the maintenance of effort requirements for those other programs. States are reminded that they must continue to meet the maintenance of effort requirements in those other programs, e.g., section 309(c).

Reallotment of Title III-E Grant Funds

Section 304(b) provides that whenever the Assistant Secretary determines that any amount allotted under Title III-E will not be used by a State, the Assistant Secretary shall make such funds available for use through a reallotment to other States. States will be requested to notify the AoA of the amount, if any, of Title III-E funds the state will not use by the end of the Fiscal Year. These funds will be released for reallotment to other states.

Technical Assistance

The AoA will provide ongoing technical assistance to States to assist in implementing the National Family Caregiver Support Program. Currently, the agency maintains a "Caregiving Resources for the Aging Network" website at *http://www.aoa.gov/ carenetwork/* This website is being upgraded and expanded to add additional research on caregiving and evidence-based materials developed by the network. Also, shortly we will initiate a moderated listserv with aging network representatives to discuss caregiver issues of concern to the network. Finally, a national symposium on caregiving is being planned to provie a forum for the exchange of knowledge and information about various caregiver program models and methods of delivering services to address better the diverse needs of caregivers throughout the nation.

EFFECTIVE DATE: Immediately, State Assurance Due February 15, 2001

ATTACHMENTS: Certification of Maintenance of Effort

INQUIRIES: Address inquiries to Regional Administrators on Aging, DHHS Regional Offices.

_____

Jeanette C. Takamura
Assistant Secretary for Aging

Certification of Maintenance of Effort

TITLE III, PART E

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

I, the undersigned, affirm, certify and give the assurance that funds made available under Title III, Part E shall supplement, and not supplant, any Federal, State, or local funds expended by the State or unit of general purpose local government (including area agencies on aging) to provide services described in section 373 of the Older Americans Act, as amended in 2000 (P.L. 106-501).

_____

Signature Of Authorized State Official

_____

Typed Name Of Authorized State Official

_____

Title of Authorized State Official

_____

Date

Frequently Asked Questions about the National Family Caregiver Support Program

1. Are most of the National Family Caregiver Support Program funds earmarked for respite services?

2. Who is eligible to apply for the competitive innovative grants?

3. If a state already funds a caregiver support program, can funds from such a program be used to match the new federal program? If so, how does this affect the "maintenance of effort" requirements?

4. Are direct payments to family caregivers allowed with the new National Family Caregiver Support Program?

5. Do the grandchildren who are cared for by grandparents need to have a disability or chronic illness (including those with mental retardation and developmental disabilities) in order to receive services?

6. Does the child with MR/DD have to be under the chronological age of 19?

7. Are States required to reserve 10% of the funding for services to grandparents?

8. Can States reserve funds to conduct a caregiver demonstration in one geographic area of the state?

9. Can the needs of other caregivers be addressed through the National Family Caregiver Support Program?

1. Are most of the National Family Caregiver Support Program funds earmarked for respite services?

Funds under the National Family Caregiver Support Program (NFCSP) are not earmarked. Funds may be used to provide the five categories of services authorized: 1) information about services; 2) assistance with access to services; 3) individual counseling, organization of support groups, and caregiver training; 4) respite care; and 5) supplemental services, on a limited basis. States and area agencies have the flexibility to determine the funding allocated to these services. The category of supplemental services is designed to be on a limited basis. As a result, no more than twenty percent of the federal funding should be dedicated to this category.

Five percent of the total program allocation is reserved at the national level for competitive innovation grants, and activities of national significance such as program evaluation, training, technical assistance, and research.

2. Who is eligible to apply for the competitive innovative grants?

As with the discretionary authorization in Title IV, AoA will provide guidance regarding who is eligible to apply for the competitive innovative grants. Since the purpose of these grants is to assist in the development of multifaceted systems of caregiver support, states are likely to be one of the preferred grantees with incentives to include area agencies and others as partners.

3. If a state already funds a caregiver support program, can funds from such a program be used to match the new federal program? If so, how does this affect the "maintenance of effort" requirements?

A state may use other funds currently used for related programs to match the federal NFCSP so long as such monies are not from other federal sources, e.g., Medicaid, and are not used to match other programs. The maintenance of effort requirements are met if the overall amount of state and local funding remains at or above what was previously allocated to existing caregiver programs.

4. Are direct payments to family caregivers allowed with the new National Family Caregiver Support Program?

Direct payments to family caregivers is neither specifically included in, nor precluded by, the statute. As such, payments may be possible for certain services if so defined by the state.

5. Do the grandchildren who are cared for by grandparents need to have a disability or chronic illness (including those with mental retardation and developmental disabilities) in order to receive services?

No, there is no requirement that the grandchildren have a disability. Under the NFCSP, states may design services for grandparents or older individuals who are relative caregivers. In these instances, the grandparent or relative caregiver must be an older individual (60+), who lives with the child, is the primary caregiver of the child, and has a legal relationship to the child or is raising the child informally. The child must be no more than 18 years old.

As a state determines how to target its services under the caregiver program, it shall give priority to older individuals in greatest social and economic need and older individuals caring for persons with mental retardation and developmental disabilities.

6. Does the child with MR/DD have to be under the chronological age of 19?

Yes, the statute does not provide any distinctions other than the child must be no more than 18 years of age.

7. Are States required to reserve 10% of the funding for services to grandparents?

No. States have the flexibility to determine the expenditures up to a maximum of 10%, to provide support services to grandparents and older individuals who are relative caregivers of children age 18 and under. States may design intrastate funding formula allocations that vary the proportion of funding among area agencies. It is conceivable that such a formula could be designed that would allocate the majority of funding to certain area agencies within the state.

8. Can States reserve funds to conduct a caregiver demonstration in one geographic area of the state?

No. Funds under Title III-E must be allocated via an intrastate funding formula to area agencies on aging.

9. Can the needs of other caregivers be addressed through the National Family Caregiver Support Program?

The NFCSP was developed as an initial effort to meet the needs of a segment of the caregiver population. For FY 2001, it is funded at $125 million and is designed to begin to address the needs of caregivers. As part of the program's original design, we identified options for expanding the population of caregivers to be covered. As the program matures, and outcomes are generated, and most importantly, as additional resources become available, we will consider expanding the program to other groups of persons requiring and providing care.

Interim Reporting Guidelines

ISSUED OCTOBER 31, 2001

Dear State Agency on Aging Director:

The Office of Management and Budget has approved the Administration on Aging request for a stand-alone data collection instrument for the National Family Caregiver Support Program (NFCSP). The purpose of this letter is to provide instructions for your submission of the Fiscal Year (FY) 2002 NFCSP information to the Administration on Aging (AoA). The FY 2002 NFCSP data are due to AoA on January 31, 2003.

State agencies on aging are required to report expenditure data, units of service and number of people served for the five categories of service (information, assistance, counseling, support groups and training, respite and supplemental services) as a temporary separate stand-alone report. Reports may be based on partial year data and estimated for the remainder of the year. NFCSP data may be submitted on the attached form in hard copy or electronically via E-mail.

As you know AoA and a workgroup of aging network representatives are reviewing our data collection requirements including how to incorporate Title III-E reporting into the on-going data collection system. States were asked to share with their regional office any data that was voluntarily collected for FY2001 when they submitted their FY 2001 program performance data. We suggest that you use the attached form for FY2001 as well. Information provided voluntarily for FY 2001 and data reported for FY 2002 provide a snapshot of services and resources used to implement the NFCSP. We look forward to the integration of the NFCSP data requirements into a streamlined data collection system.

Sincerely,

Carol Crecy

Director
Office of State and Community Programs

Frank Burns

Director
Planning and Evaluation

Reporting Requirement Attachment

- States are encouraged to use NAPIS definitions and units of service where appropriate;
- Multiple services can be reported in each category;
- Services to the *caregiver* are the *only* services to be reported; and
- Only Older Americans Act Title III- E funds should be reported under expenditures.

Examples of services that States could report in the five statutory service categories:

INFORMATION: Group services, including public education, provision of information at health fairs and other similar designations as determined by the state.

Outreach: Interventions for the purpose of identifying potential caregivers and encouraging their use of existing services and benefits.

ASSISTANCE: individual one-on-one contact.
information and assistance: a service that provides current information on opportunities and services available; assesses the problems and capacities of the individuals; links the individuals to the opportunities and services available; to the maximum extent practicable, ensures that the individuals receive the services needed, and are aware of the opportunities available to the individuals by establishing adequate follow-up procedures.

Case management: Assistance either in the form of access or care coordination in circumstances where the older person or their caregivers are experiencing diminished functioning capacities, personal conditions or other characteristics which require the provision of services by formal service providers. Activities of case management include assessing needs, developing care plans, authorizing services, arranging services, coordinating the provision of services among providers, follow-up and reassessment, as required.

Individual Counseling/ Support Groups/Training:
Provision of advice, guidance, and instruction about options and methods for providing support to caregivers in an individual or group setting.

Respite: Temporary, substitute supports or living arrangements to provide a brief period of relief or rest for caregivers. It can be in the form of In-home respite, adult day care respite, or institutional respite for an overnight stay on an intermittent, occasional, or emergency basis.

Supplemental Services: Other services to support the needs of caregivers, as defined by the state.

Submission of SPR Data

Option 1: Mailing NFCSP Form to the AoA Central Office

Send the Form, accompanied by a cover letter signed by the Director, State Unit on Aging, directly to the AoA Central Office at the following address:

U.S. Department of Health and Human Services
Administration on Aging
Office of Planning and Evaluation
330 Independence Avenue, S .W.,
Washington, D. C. 20201
Attn: NFCSP 2002

Option 2: Sending Files via Internet Mail

Send a message to: http://www.william.ellis@aoa.gov from the State Agency on Aging Director or a designee.

Attach the data files to the internet mail message. Specify that the message be sent certified, if possible. This will return a message that the mail has been received at AoA. In the body of the E-mail message, please identify:

- State and Fiscal Year of the data being sent; and
- Name, address, and phone number of the point of contact.

FINANCIAL STATUS REPORT

AOA SUPPLEMENTAL FORM TO SF-269 – TITLE III

The Administration on Aging plans to publish for comment in the *Federal Register* a revision to the Supplemental Form to the SF-269. This publication will be the first step in the process of obtaining OMB clearance for the collection of data about expenditures under Title III, Part E, the National Family Caregiver Support Program. The form that follows reflects the preliminary type of information that is necessary to collect on an interim basis in order to document the need for a comprehensive caregiver service delivery system.

The need to collect data about service expenditures and to begin to gather data about older individuals needing care and those persons who are providing care is well recognized. We are aware however, that without modification, many data collection systems are not equipped to provide information about caregivers. As a result, we have proposed to collect minimal data about older persons served consistent with your systems' current capacity. Concurrently, we will engage the aging network in discussions about any possible revisions to the National Aging Program Information System as a means of collecting data on a permanent basis. Further, we will explore options for gathering data about the characteristics of older individuals needing care and the caregivers who provide that care through other means such as sampling, surveys, research projects and our performance outcomes measures project.

The form that follows is provided for your information and in advance of its publication in the *Federal Register*. We look forward to working with you to reflect the needs of older individuals in need of care and their caregivers. This information will be essential to the ongoing support and expansion of the National Family Caregiver Support Program.

FINANCIAL STATUS REPORT

AOA SUPPLEMENTAL FORM TO SF-269-TITLE III

(*Note: Readers should refer to Title III-E sections)

STATE_____ **FY**_____

DATE SUBMITTED_____ **REPORTING PERIOD ENDED**_____

Item 10 i **Column III, Total Recipient Share of Outlays which consist of outlays from:**

	State	AAAs
ADMIN	$_____	$_____
Title III		
Part B	$_____	$_____
LTCO (Part B)	$_____	$_____
Part C-1	$_____	$_____
Part C-2	$_____	$_____
Part D	$_____	$_____
Part E	$_____	$_____
TOTAL	$_____	$_____

Item 10 j **Column III, Federal Share of Net Outlays:**

	State	AAAs
ADMIN	$_____	$_____
Title III		
Part B	$_____	$_____
LTCO (Part B)	$_____	$_____
Part C-1	$_____	$_____
Part C-2	$_____	$_____
Part D	$_____	$_____
Part E	$_____	$_____
TOTAL	$_____	$_____

<u>Item 10 o</u> Column III Total Federal Funds Authorized by AOA for the Federal FY _____ have been allocated by the State as follows (as applicable):

1. State administrative activities which consists of funds in the amount of $_____ from the following:

Part B $_____
Part C-1 $_____
Part C-2 $_____
Part D $_____
Part E $_____

2. Part B, Supportive Services $_____
3. Part B, Long Term Care Ombudsman $_____ FY=2000 $_____
4. Part C-1, Congregate Meals $_____
5. Part C-2, Home Delivered Meals $_____
6. Part D, Preventive Health $_____
7. Part E, Caregivers $_____
Area Plan Administration $_____
which consists of funds from:

Part B $_____
Part C-1 $_____
Part C-2 $_____
Part E $_____

<u>Item 10 p</u> Column III, Unobligated Funds:

Part B $_____
Part C-1 $_____
Part C-2 $_____
Part D $_____
Part E $_____

<u>Item 10 r</u> Column III, Disbursed Program Income using the additional alternative (cumulative amount):

Part B $_____
Part C-1 $_____
Part C-2 $_____
Part D $_____
Part E $_____

PART E (STATEWIDE EXPENDITURES)

	EXPENDITURES	UNITS	PEOPLE SERVED
INFORMATION	$_____	_____	_____
ASSISTANCE	$_____	_____	_____
COUNSELING SUPPORT GROUPS TRAINING	$_____	_____	_____
RESPITE	$_____	_____	_____
SUPPLEMENTAL SERVICES	$_____	_____	_____
Total	$_____		

APPENDIX B

NFCSP Program Resources

Special Thanks to the Following Contributors

David Coon, Ph.D., Project Director, Goldman Institute on Aging

Daniel Murphy, *Chief, Aging and Adult Services Administration (WA)*

Hilari Hauptman, *Program Manager, Aging and Adult Services Administration (WA)*

Lynne Korte, *Program Manager, Aging and Adult Services Administration (WA)*

Debbie Cool, *Coordinator, Family Caregiver Support Program, Olympic Area Agency on Aging (AAA in WA)*

Sue Estes, *Coordinator, Family Caregiver Support Program, Olympic Area Agency on Aging (AAA in WA)*

David Hanson, *Program Specialist, Pierce County Aging and Long Term Care (AAA in WA)*

Daniel McGuire, *Chief, Division of Managed Care, Pennsylvania Department of Aging*

Joan Dougherty, *Caregiver Specialist, Pennsylvania Department of Aging*

Lois Tobin, *Program Director, FCSP, Bucks County Area Agency on Aging (PA)*

Bill Orzechowski, *Executive Director, Office of Human Service, Inc. (AAA in PA)*

Dennis Streets, *Planning, Budget and Systems Support Section Chief, North Carolina Division on Aging*

Yoko Crume, Human Services Planner, North Carolina Division on Aging

Chris Urso, Family Caregiver Program Specialist, North Carolina Division on Aging

Jean Wood, Deputy Director, Minnesota Board on Aging

Linda Giersdorf, Director, Region Nine Area Agency on Aging (AAA in MN)

Mary Walsh, Manager of Community Programs, Maine Bureau of Elder and Adult Services

Debra Halm, Senior Director, Senior Spectrum Area Agency on Aging (AAA in ME)

Jayne Paprowicz, formerly Family Caregiving Coordinator, Senior Spectrum (AAA in ME)

Innovation Grants To Support Family Caregivers, Fiscal Year 2001

Approximately $6 million was awarded for 34 projects to develop innovative approaches to assist families and informal caregivers of older persons as well as grandparents and older relatives who are caregivers of children. These innovative grants are one component of the new National Family Caregiver Support Program established as part of the Older Americans Act. Following is a list of grantees and their awards, listed alphabetically by state:

Pima Council on Aging, Tucson, AZ - will develop, test and implement a culturally proficient model of family caregiver support to meet the needs of Mexican-American caregivers and elders.

Pima Council on Aging
5055 East Broadway Blvd., Ste C104
Tucson, AZ 85711
Contact: Marian Lupu
520-790-7262

United Cerebral Palsy of Southern Arizona, Tucson, AZ - will increase services to grandparents and older caregivers who are raising children with mental retardation or developmental disabilities. The project will identify barriers to access and implement a voucher system to access services.

United Cerebral Palsy of Southern Arizona
3914 E. 29th St, Ste. 603
Tucson, AZ 85711
Contact: Dr. Ellie Ward
520-795-3108

Contra Costa County Aging and Adult Services Bureau, Martinez, CA - will provide assistance, support, educate and empower family caregivers of older persons who have been placed in or are transitioning back to the community after receiving care in skilled nursing facilities.

Contra Costa County
Employment and Human Services Dept.
40 Douglas Dr.
Martinez, CA 94553
Contact: Robert Sessler
925-313-1605

Asian Community Center, Sacramento, CA - will sustain and support Asian American and Pacific Islanders family caregiver efforts through a community-based wellness, lifelong learning and information program.

Asian Community Center
7801 Rush River Dr
Sacramento, CA 95831
Contact: Dr. Donna Yee
916-393-9026

Family Caregiver Alliance, San Francisco, CA, - will examine the growth and enhance the development of caregiver programs nationwide. The project will analyze family support services and identify model caregiver programs that could be replicated in other areas.

Family Caregiver Alliance
690 Market St. Ste. 600
San Francisco, CA 94104
Contact: Lynn Friss Feinberg
415-434-3388, ext 324

American Society on Aging, San Francisco, CA - will collaborate with the American Nurses Association, the National Association of Social Workers, and the American Occupational Therapy Association to increase the skill and knowledge of their members who provide professional services to family caregivers and to link these groups with the aging network.

American Society on Aging
833 Market St., Ste. 511
San Francisco, CA 94103
Contact: Jim Emerman
415-974-9628

University of Denver, Institute of Gerontology, Denver, CO - will demonstrate an empowerment-oriented intervention that increases the value of older care-receivers in self-care, use of services and support networks, communications skills and other aspects of care-receiving that assists their caregivers and improves the quality of the overall care process.

University of Denver
Graduate School of Social Work
2199 S. University Blvd.
Denver, CO 80208
Contact: Enid Cox
303-871-4018

Generations United, Washington, D.C. - will establish the "*National Center on Grandparent and Other Relatives Raising Children*" which will develop and coordinate groups of experts who will provide technical assistance and training to the aging network and enhance the growth of caregiver intergenerational programs nationwide.

Generations United
122 C St., Ste. 820
Washington, DC 20001
Contact: Donna Butts
202-638-1263

National Association of State Units on Aging, Washington, D.C. - will identify barriers, challenges, opportunities and recommend potential approaches to link caregivers with existing state home and community-based services. The project will also convene a series of national teleconferences and develop a series of educational materials to assist states.

National Association of State Units on Aging
1201 M St., Ste. 350
Washington, DC 20005
Contact: Virginia Dize
202-898-2578

Alliance for Aging, Miami, FL - will demonstrate a 24-hour crisis respite and referral system for caregivers of elders and adults with disabilities. This will increase flexibility and convenience of current services; provide crisis respite for elder caregivers of children and adults with disabilities; recommend ways to reduce stress, and minimize or prevent future crisis events.

Alliance for Aging, Inc.
9500 S. Dadeland Blvd., Ste. 400
Miami, FL 33156
Contact: Michael Weston
305-670-6500

Hospice Institute of the Florida Suncoast, Largo, FL - will establish and evaluate a multifaceted national project on end-of-life issues providing hospice, palliative care professionals, and family caregivers with in-depth training on caregiver concerns.

Hospice Institute of the Florida Suncoast
300 East Bay Dr.
Largo, FL 33770
Contact: Kathleen Egan
727-586-4432, ext. 2771

Georgia Department of Human Resources, Division of Aging Services, Atlanta, GA - will increase service options available to caregivers by developing five self-directed voucher care projects in rural areas that can be duplicated in other states.

Georgia Department of Human Resources
Division of Aging Services
Two Peachtree St., NW, Ste. 36.385
Contact: Cliff Burt
404-657-5336

Georgia Southwestern State University, Americus, GA - the Rosalynn Carter Institute for Human Development will establish a statewide network of caregiving communities, and a caregiver capacity index that will allow communities to assess their caregiving strengths and needs, and then develop action plans for a coordinated response to improve services.

Georgia Southwestern State University
800 Wheatley St
Americus, GA 31709
Contact: Dr. Ronda Talley
229-928-1234

University of Hawaii Center on Aging, Honolulu, HI - will work with community partners to explore the impact of group-targeted messages and individually tailored support on end-of-life planning by multi-ethnic caregivers of elders receiving long-term care services.

University of Hawaii at Manoa
Center on Aging, John A. Burns School of Medicine
2530 Dole St., SAG D200
Honolulu, HI 96822
Contact: Kathryn Braun
808-956-5768

The Healthcare Consortium of Illinois, Dolton, IL - will establish a caregivers assistance registry that will improve identification and support of caregivers and expand access to in-home respite services by enhancing coordination among service providers in four predominantly African-American communities on Chicago's south side.

Healthcare Consortium of Illinois
1350 E. Sibley Blvd.
Dolton, IL 60419
Contact: Salem Al Nurridin
708-841-9515

Mather Lifeways, Evanston, IL - will implement a regional family caregiver education project to deliver a cadre of experienced trainers who will work with a coalition of local aging service providers to improve caregiver outreach, service referrals and follow-up.

Mather LifeWays
1603 Orrington Ave., Ste. 1080
Evanston, IL 60201
Contact: Dr. David Lindeman
847-492-6810

Illinois Department on Aging, **Springfield, IL -** will provide supportive services to frail older caregivers and their adult children with developmental disabilities to maximize independence, through using a holistic family approach and through the use of joint waivers and shared resources with the potential of cost cutting.

Illinois Department on Aging
421 East Capitol Ave., Ste. 100
Springfield, IL 62701
Contact: Jean Blaser
217-785-3393

Easter Seals, Chicago, IL - will produce a transportation-solutions package that the aging network can use to address caregivers concerns about transporting relatives with behavioral problems; use of assistive technology; best practices of volunteer supported transportation; use of escorts; and the Americans With Disabilities Act.

Easter Seals
230 W. Monroe St., Ste. 1800
Chicago, IL 60606
Contact: Jed Johnson
1-800-221-6827

Ten County Aging Board, Inc. Arkansas City, KS - will support a statewide caregiver marketing and media campaign to increase public awareness of caregiving, provide caregiving tips, and inform people of available resources.

Ten County Aging Board, Inc.
P.O. Box 1122
Arkansas City, KS 67005
Contact: Stacey Boothe
316-681-2144

Commonwealth of Massachusetts, Boston, MA - will develop regional training centers for caregivers of deaf older adults. The project will consist of a multi-curriculum caregiver training program and a respite care center for the deaf.

Commonwealth of Massachusetts
Elder Affairs
One Ashburton Pl.
Boston, MA 02108
Contact: Eliza Lake
617-222-7481

The ARC of the USA, Silver Springs, MD – will provide training and technical assistance to enhance the capacity of the aging network and disability provider organizations to plan, coordinate and provide supportive services to older caregivers of children and adults with intellectual and developmental disabilities.

The ARC of the USA
1010 Wayne Ave., Ste. 650
Silver Spring, MD 20910
Contact: Dr. Sharon Davis
301-565-5478

Eastern Area Agency On Aging, Bangor, ME- will demonstrate that primary health care is an effective and efficient point of caregiver intervention in a rural setting because caregivers will more likely use information, support and training when a need is validated by a trusted healthcare provider and assistance is personally tailored to their needs.

Eastern Area Agency on Aging
420 Essex St.
Bangor, ME 04401
Contact: Roberta Downey
207-941-2865

The Center for Social Gerontology, Inc., Ann Arbor, MI - will use mediation to help resolve problems and disputes that occur when families face the physical, emotional and financial demands of providing long-term care to an older family member.

The Center for Social Gerontology, Inc.
2307 Shelby Ave.
Ann Arbor, MI 48103
Contact: Penelope Hommel
734-665-1126

Normandale Ministry for Healing and Wholeness, Edina, MN - will develop model volunteer care teams who will provide training, respite and resource counseling and tools to help caregivers arrange for other community services as needed.

Normandale Ministry for Healing and Wholeness
6100 Normandale Rd.
Edina, MN 55436
Contact: Jean Sigford
952-929-1697

St. Andrew's Resources For Seniors, St. Louis, MO - will develop cost-effective eldercare management services that allows employed caregivers to provide quality care and continue working. The program will establish a business advisory council and a pilot project to evaluate alternative eldercare approaches and provide assessments and services to caregivers.

St. Andrew's Resources For Seniors
6633 Delmar Blvd.
St. Louis, MO 63130
Contact: Ann Bannes
314-802-2192

New Jersey Department of Health and Social Services, Division of Senior Affairs, Trenton, NJ - will expand the *NJ EASE (Easy Access Single Entry) Caregivers* program with caregiver assessment and care planning tools; pilot staff caregiver training; critical pathways for caregiver decision making and service protocols to guide worker actions.

New Jersey Department of Health and Social Services
Division of Senior Affairs
P.O. Box 807
Trenton, NJ 08625
Contact: Barbara Fuller
609-943-3463

Senior Service Centers of the Albany Area, Inc., Albany, NY - will assess the effectiveness of telephone support groups for caregivers of frail elders. This multi-component group program includes emotion-focused and problem-focused coping strategies and support.

Senior Service Centers of the Albany Area, Inc.
25 Delaware Ave.
Albany, NY 12210
Contact: Ann DiSarro
518-465-3322

Catholic Charities of the Diocese of Rochester, NY - will collaborate with 15 national and local organizations to create an integrated care management approach to support relative caregivers of grandchildren and adult children with developmental disabilities.

Catholic Charities of the Diocese of Rochester
25 Franklin St.
Rochester, NY 14604
Contact: Irene Coveny
716-262-7053

Ohio Department of Aging, Columbus, OH - will design and test an outcome-based system for enhancing the quality of caregiver support services. Recommendations of caregivers, older adults, the aging network and service providers will be used to develop a guide to improve the quality of caregiver support services delivered through the aging network.

Ohio Department of Aging
50 W. Broad St., 9th Floor
Columbus, OH 43215
Contact: Richard LeBlanc
614-644-7967

Mid-County Senior Services, Newtown Square, PA - will evaluate the addition of caregiver care management to its adult day services, and evaluate outcomes that reflect positive and negative aspects of caregiving including caregiving strain, self-efficacy, perceived rewards of caregiving, depression, health, and the length of stay of the care receiver.

Mid-County Senior Services, Inc.
22 Media Line Rd.
Newtown Square, PA 19073
Contact: Karen Reever
610-353-6642

Philadelphia Corporation For Aging, Philadelphia, PA - will develop a model health care and training intervention that targets African American daughters who serve as caregivers. The intervention will focus on identifying the health related issues and caregiver challenges specific to the target population. Anticipated outcomes include improved quality of life, health status, and caregiving skills. A clinical pathway protocol will be developed to assist other organizations in replicating the intervention for African American or other minority family caregivers.

Philadelphia Corporation For Aging
642 N. Broad St.
Philadelphia, PA 19130
Contact: Joan Klein
215-765-9000

Pennsylvania Department of Aging, Harrisburg, PA - will implement a support system for older caregivers of adult children with mental retardation or developmental disabilities. The program will be individually tailored and will reimburse consumers for expenditures related to caregiving and given resources for all caregiving needs.

Pennsylvania Department of Aging
555 Walnut St., 5th Floor
Harrisburg, PA 17101
Contact: Joan Dougherty
717-783-6207

Pennsylvania State University, Gerontology Center, University Park, PA - will provide a structured, time-limited program of counseling to family caregivers and patients in the early stages of dementia. Through positive communications and active participation in their care, care recipients and their family caregivers will have a better understanding and knowledge about available services and preferences for care.

Pennsylvania State University
Gerontology Center
110 Technology Center Bldg.
University Park, PA 16802
Contact: Steven Zarit
814-863-9980

Virginia Department for the Aging, Richmond, VA - will provide specialized services for male caregivers, particularly retired military personnel and men who live in rural and farming communities, who are less likely to share their concerns and challenges as a care provider, or to seek services that can provide them with respite.

Virginia Department for the Aging
1600 Forest Ave., Ste. 102
Richmond, VA 23229
Contact: Bill Peterson
804-662-9325

Native American Caregiver Support Program Grants, Fiscal Year 2001

Grants were awarded to 110 tribal organizations to provide families of Native American and Native Hawaiian elders with access to information, respite care, counseling, training, and supplemental services to help them meet their real-life caregiving challenges. In addition, nine tribal organizations each received $100,000 demonstration grants in the following areas:

- ***"Starting at the Beginning"*** grants were awarded to the Central Council, Tlingit and Haida Indian Tribes of Alaska; the Jamestown S'Klallam Tribal Center in Washington; and the Blackfeet Tribe of Montana. These grants will be used to identify and prioritize the most critical needs of family caregivers, and then develop and demonstrate the benefits of services that address those needs.
- ***"Coordination and Leverage"*** grants were awarded to four tribal organizations: the Oneida Tribe of Wisconsin; the Confederated Salish and Kootenai Tribes of Montana; the South Puget Intertribal Planning Agency for Chehalis and Nisqually in Washington; and the Hana Community Health Center in Hawaii. These grants will be used to demonstrate the benefits of coordinating and leveraging all the family caregiver support programs and services in these four tribal areas.
- ***"Quality Standards and Mechanisms of Accountability"*** grants were awarded to Alu Like, Incorporated in Hawaii and the Rosebud Sioux Tribe of South Dakota to design and test quality standards and assurance mechanisms for multifaceted systems of supportive services for family caregivers.

The 110 tribal organizations receiving the formula grants and each award amount

Organization	State	Amount
Association of Village Council Presidents	AK	$63,020
Cook Inlet Tribal Council	AK	$63,020
Hoonah Indian Association	AK	$18,010
Metlakatla Indian Community	AK	$27,010
Fairbanks Native Association	AK	$45,020
Maniilag Association	AK	$63,020
Chugachmiut	AK	$18,010
Klawock, I.R.A.	AK	$18,010
Kootznoowoo inc.	AK	$18,010
Native Village Of Fort Yukon, I.R.A.	AK	$18,010
Craig Community Association	AK	$18,010
Sitka Tribes Of Alaska	AK	$36,010
Yakutat Native Association	AK	$18,010
Ketchikan Indian Corporation	AK	$36,010
Gila River Indian Community	AZ	$72,030
Hopi Tribal Council	AZ	$63,020
Hualapai Tribal Council	AZ	$18,010
Navajo Nation	AZ	$63,020
Pascua Yaqui Association	AZ	$36,010
Salt River Pima-Maricopa Community	AZ	$36,010
White Mountain Apache Tribe	AZ	$45,020
AK-Chin Indian Community	AZ	$18,010
Havasupai Tribal Council	AZ	$18,010
Inter-Tribal Council Of Arizona	AZ	$18,010
Bishop Indian Tribal Council	CA	$27,010
Karuk Tribe Of California	CA	$63,020
Pit River Health Services	CA	$18,010
Southern Indian Health Council-Area I	CA	$27,010
Southern Indian Health Council-Area Ii	CA	$27,010

United Indian Health Services (For Resighini)	CA	$18,010
United Indian Health Services (For Smith River)	CA	$36,010
California Indian Manpower Consortium	CA	$18,010
California Indian Manpower Consortium -- Lajolla And Susanville Rancheria	CA	$18,010
California Indian Manpower Consortium -- Ysabel, Pasual	CA	$18,010
Redding Rancheria Indian Health Services	CA	$63,020
Nez Perce Tribe Of Idaho	ID	$54,020
Kickapoo Nation In Kansas	KS	$18,010
Aroostook Band Of Micmac Indians	ME	$18,010
Grand Traverse Band Of Ottawa And Chippewa Indians	MI	$27,010
Inter-Tribal Council Of Michigan	MI	$27,010
Keweenaw Bay Indian Community	MI	$27,010
Leech Lake Reservation Business Committee	MN	$45,020
Minnesota Chippewa Resource Development	MN	$36,010
White Earth Reservation Tribal Council	MN	$27,010
Assiniboine And Sioux Tribes	MT	$54,020
Chippewa-Cree Tribe	MT	$36,010
Fort Belknap Community Council	MT	$36,010
Northern Cheyenne Tribe	MT	$36,010
Crow Tribal Elders Program	MT	$54,020
Spirit Lake Nation	ND	$36,010
Standing Rock Sioux Tribe	ND	$63,020
Trenton Indian Service Area	ND	$36,010
Turtle Mountain Band Of Chippewa Tribe	ND	$63,020
Omaha Tribe Of Nebraska	NE	$27,010
Laguna Rainbow Corporation	NM	$54,020
Pueblo De Cochiti	NM	$27,010
Pueblo Of Acoma	NM	$54,020

Pueblo Of Isleta	NM	$63,020
Pueblo Of San Felipe	NM	$36,010
Pueblo Of Zuni	NM	$63,020
San Juan Pueblo	NM	$63,020
Inter-tribal Council of Nevada, Inc. (Duckwater)	NV	$18,010
Inter-Tribal Council of Nevada, Inc. (South Fork)	NV	$18,010
Inter-tribal Council of Nevada, Inc. (MOAPA)	NV	$18,010
Shoshone-Paiute Tribes	NV	$27,010
Pyramid Lake Paiute Tribe	NV	$27,010
Elko Band Council	NV	$18,010
St. Regis Mohawk	NY	$63,020
Seneca Nation Of Indians	NY	$45,020
Cherokee Nation Of Oklahoma	OK	$72,188
Chickasaw Nation	OK	$72,030
Choctaw Nation Of Oklahoma	OK	$72,030
Citizen Band Potawatomi Of Oklahoma	OK	$72,030
Iowa Tribe Of Oklahoma	OK	$63,020
Muscogee (Creek) Nation	OK	$72,030
Pawnee Tribe Of Oklahoma	OK	$63,020
Quapaw Tribe Of Oklahoma	OK	$45,020
Wyandotte Tribe Of Oklahoma	OK	$63,020
Fort Sill Apache Tribe	OK	$27,010
Confederated Tribes Of Siletz Indians Of Oregon	OR	$27,010
Confederated Tribes Of The Umatilla Indian Reservation	OR	$45,020
Confederated Tribes Of Warm Springs	Or	$36,010
Confederated Tribes Of Grand Ronde	OR	$27,010
Klamath Tribe	OR	$36,010
Confederated Tribes Of Coos, Lower Umpqua & Siuslaw Indian	OR	$27,010
Lower Brule Sioux Tribe	SD	$18,010

Uintah And Ouray Business Committee	UT	$27,010
Lummi Indian Business Council	WA	$45,020
Makah Indian Tribal Council	WA	$18,010
Muckleshoot Indian Tribe	WA	$36,010
Nooksack Indian Tribe	WA	$27,010
Puyallup Tribal Health Authority	WA	$63,020
Quinault Indian Nation	WA	$36,010
South Puget Intertribal Planning Agency For Skokomish & Squazin	WA	$45,020
Swinomish Indian Tribal Community	WA	$18,010
Spokane Tribe Of Indians	WA	$27,010
Yakama Indian Nation	WA	$18,010
Tulalip Tribes	WA	$63,020
Quileute Tribal Council	WA	$18,010
South Puget Intertribal Planning Agency – Shoalwater Bay	WA	$27,010
Stillaguamish Tribe Of Indians	WA	$27,010
Sauk-Suiattle Indian Tribe	WA	$18,010
The Suquamish Indian Tribe	WA	$18,010
Port Gamble S'klallam Tribe	WA	$18,010
Bad River Band Of Lake Superior Chippewa	WI	$36,010
Forest County Potawatomi Community	WI	$18,010
Lac Du Flambeau Band Of Lake Superior Chippewa Indians	WI	$27,010
Menominee Indian Tribe Of Wisconsin	WI	$63,020
Red Cliff Band Of Lake Superior Chippewa	WI	$18,010
Ho-Chunk Nation Committee	WI	$45,020
TOTAL		**$4,087,708**

Instructions for Using the U.S. Census Bureau American FactFinder Tool

The American FactFinder tool is available on the U.S. Census Bureau Web site at http://factfinder.census.gov. In order to retrieve the needed data, first select "Advanced National Summary File 1" (middle of page), as shown in ***Exhibit 1***.

EXHIBIT 1

Then, the page shown in ***Exhibit 2*** will appear. In the bottom paragraph, click "detailed tables."

EXHIBIT 2

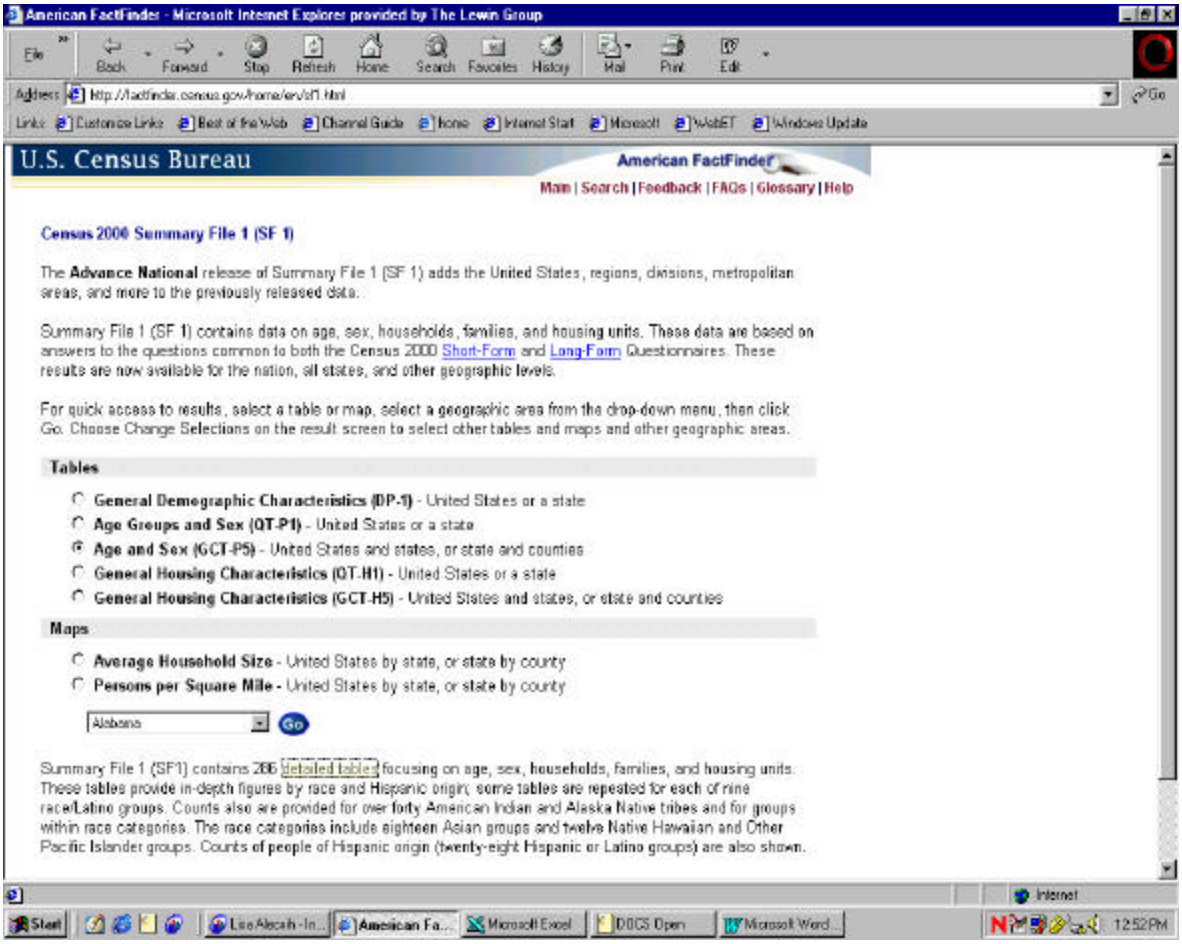
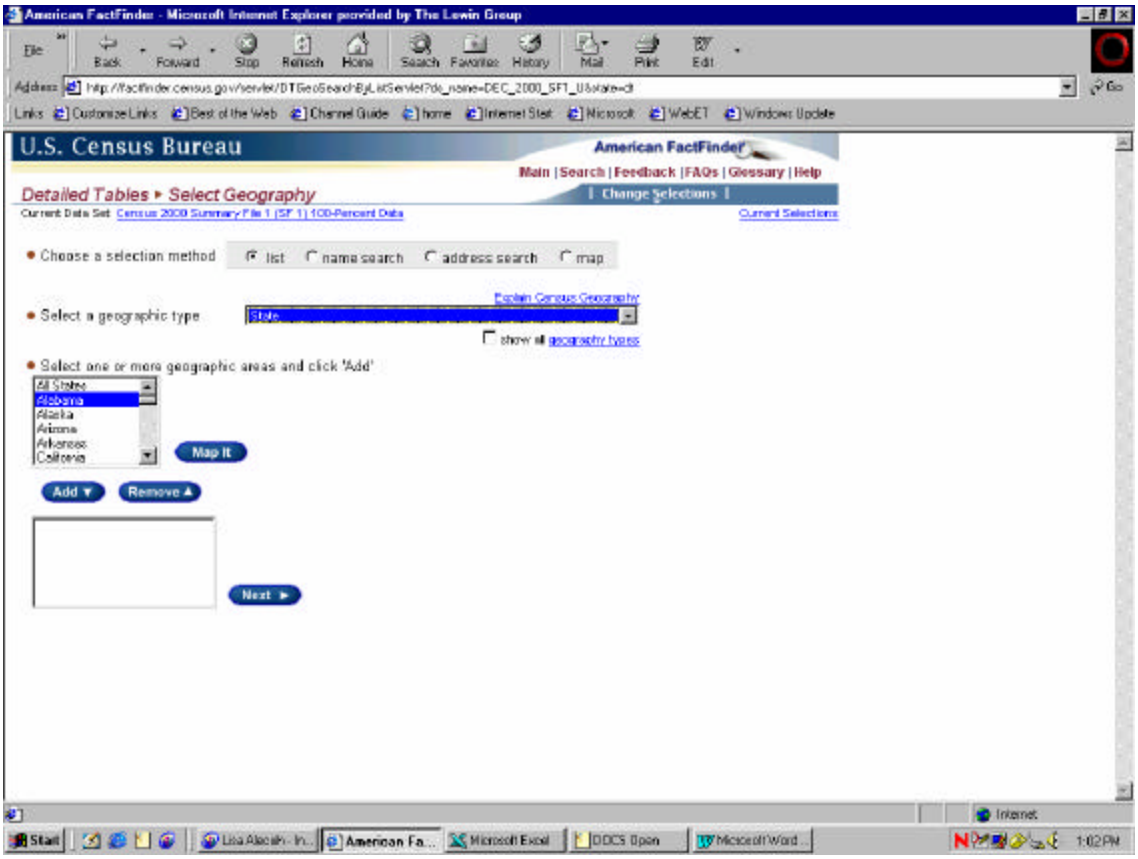


Exhibit 3 displays the resulting page. On this page, choose "list" as the selection method and choose "state" as the geographic type. Next, select the state for which you want data and click "Add." Then click "Next." [156]

EXHIBIT 3



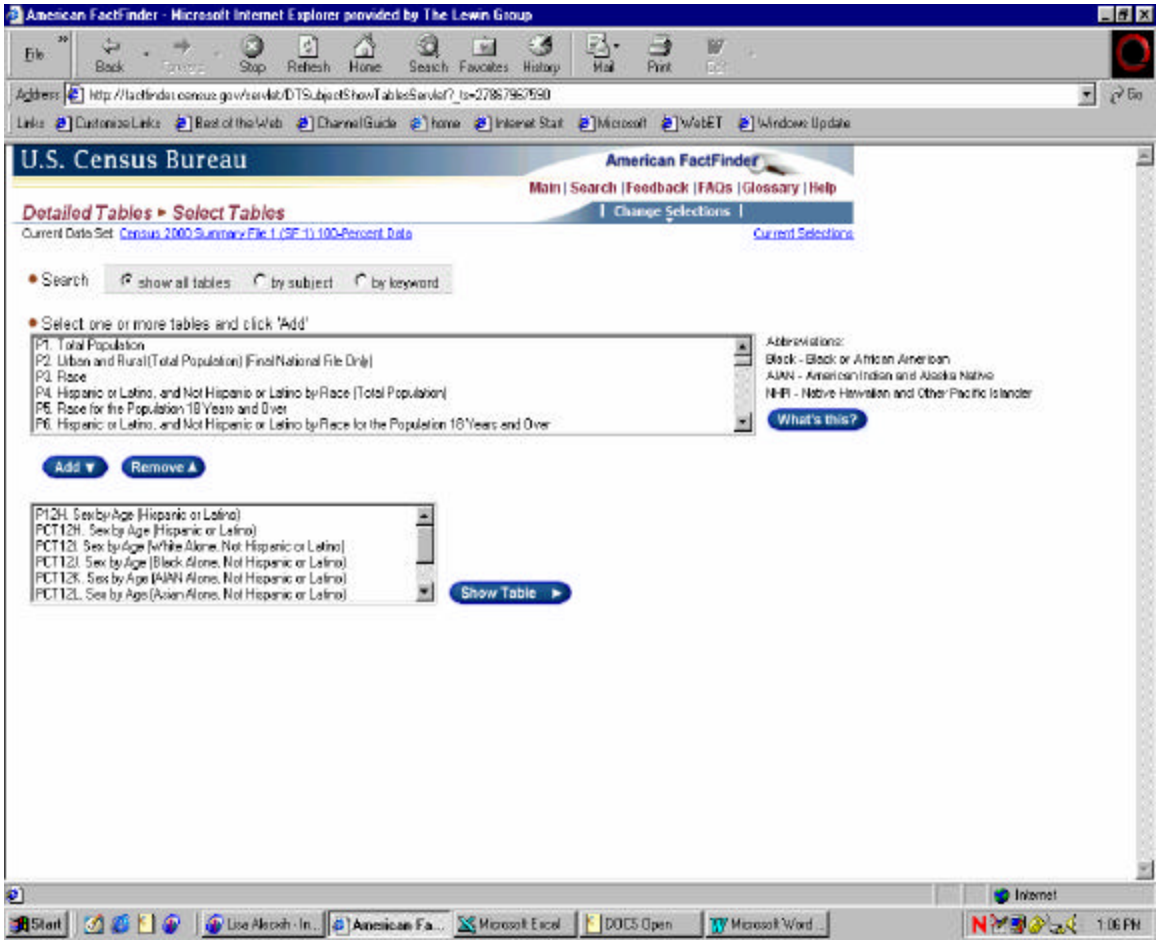
[156] Similarly, data can be obtained at the county level by selecting "county" as the geographic type. Then, a new, very similar page will appear. Select the state for which you want data. Again, a new page will appear to add the county/counties for which you want data. Select the county/counties and click "Add." Then click "Next."

The page shown in ***Exhibit 4*** will appear. Select "show all tables" as the search. Then select the following tables (they will be highlighted once selected):

- PCT12 -Sex by Age (Total Population)
- PCT12I-Sex by Age (White Alone, Not Hispanic or Latino)
- PCT12J-Sex by Age (Black Alone, Not Hispanic or Latino)

Click "Add" and then click "Show Table."

EXHIBIT 4



Copy the tables into Excel. To calculate "Other," subtract Hispanic, White Alone, and Black Alone from Total. To calculate non-White and Hispanics, subtract White Alone from Total. For the White, Black, Hispanic, and Other race categories, sum the ages into the same age groups provided in the matrix depicted in ***Exhibit III.5***.

Sample request for collaboration

Issued by senior spectrum

Family caregiver support program
Request for collaborations

V. INTRODUCTION AND GOALS

Senior Spectrum, an agency that provides an array of options for vital and independent living, announces a Request for Collaborations (RFC) to initiate the Family Caregiver Support Program. On November 13, 2000, President Clinton signed the Reauthorization of the Older Americans Act. As part of the reauthorization, additional Title 111, Part E funds have been appropriated for the National Family Caregiver Support Program. Area Agencies on Aging, or agencies that contract with AAA'S, will provide multifaceted systems of support services for family caregivers and for grandparents or older individuals who are relative caregivers. These Caregiver Funds are designated to provide services along the following guidelines:

- Information about services
- Assistance with access to services
- Individual counseling, organization of support groups and' caregiver training Respite care
- Supplemental services on a limited basis

In Maine, we are committed to specifically applying the funds to:

- Support newly identified caregivers
- Organize and fund Caregiver Support Groups
- Work with employers to identify caregivers
- Provide community education and resources
- Provide counseling, information and referrals
- Partner with community organizations

This RFC addresses the last item listed above - Partner with community organizations. Senior Spectrum has created a fund for seed money to support collaborations between community organizations or businesses and Senior Spectrum to effectively identify and provide resources to caregivers in our communities.

The Older Americans Act defines caregiver as an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual. Caregivers are also grandparents taking care of grandchildren under age 18 or parents caring for disabled adult children.

Examples of caregivers include a 42-year old mother of teenagers who works full-time and helps her 75-year old father get to doctor's appointments and the grocery store, or a 65-year old mother caring for her 40-year daughter with Down's Syndrome who lives with her. Caregivers are a diverse group of people.

Eligibility Criteria

Applicants may be nonprofit or for profit organizations or businesses that can successfully form a collaborative relationship with Senior Spectrum to identify and support caregivers. Senior Spectrum Community and Resource Centers, Housing Plus and Bridges are not eligible for this RFC.

Funding Available

The awards will provide seed money of between $500-$2,500 for an organization or business to institute the collaboration and/or pay for necessary supplies and overhead. The funds should cover a 9-month collaboration, with the goal of identifying internal organizational resources that will maintain the relationship in subsequent years. There will be between two and ten awards distributed.

Selection Criteria

Senior Spectrum seeks RFC applications that: [a] address one or more of the guidelines listed in the Introduction and Goals, [b] demonstrate and document how caregivers will be reached through this collaborative relationship, [c] identify and describe who will complete tasks outlined in the RFC, (d] describe how reporting documentation will be completed in a clear and timely manner*, [e] outline the benefits to both the applicant organization or business and Senior Spectrum, and [fl build capacity to sustain the collaborative relationship beyond the seed money.

* Seed money recipients will be required to submit a I -page progress report by January 22, 2002 and a 2-page final report by June 25, 2002 describing [1] progress toward outlined goals and objectives, [2] number of caregivers reached to date through collaborative efforts (please provide a clear definition of how caregivers are reached and in what capacity they are being "reached" - number taking literature at a health fair; 1:1 contact repeatedly through counseling sessions; estimated readership of a newsletter or listening area of a radio station; etc), and [3] any challenges confronted in completing the goals and objectives of this collaborative project.

How to Apply

Please send seven copies of the application to:

Senior Spectrum
Family Caregiver Specialist
One Weston Court
Augusta, ME 04330
(207) 622-9212

Applicants are encouraged to contact Senior Spectrum with any questions regarding this RFC. Proposals may be up to four pages in length (single space, 12-point font and one inch margins). Applications should include the following:

- Cover Letter (include name/address of applicant; name/title of contact person; requested amount of seed money)
- Narrative - up to four pages
  - Describe how collaborative relationship will satisfy [a-fl from Selection Criteria
  - Outline goals and measurable objectives associated with the collaboration
  - Provide definitions for reporting documentation of how caregiver contacts will be counted and what it means to "reach" or "make contact with" caregivers
  - Create a plan for sustaining the collaboration beyond the seed money
- Budget (see attached sample worksheet)

Timeline

Application Due Date	September 14, 2001
Seed Money Awards	October 1, 2001
Mid-point Progress Report	January 22, 2002
Final Report	June 25, 2002

Request for Collaboration
Sample Budget Worksheet

Senior Spectrum

Family Caregiver Support Program

	Seed Money Request	In-kind Other Sources
Personnel		
Consultants		
Travel		
Equipment		
Supplies		
Postage		
Printing & Copying		
Telephone & Fax		
Rent & Utilities		
Other		
Total		

Notes/Description of Line Items:

Request for Collaboration
Sample Layout for Goals & Objectives

Senior Spectrum
Family Caregiver Support Program

Please note, this worksheet provides a guideline for applicants and is not required. The following is an example:

Goal:	To contact previously unidentified caregivers among the workforce of TWRF Company.
Objective I:	By January 2, 2002, the Employee Assistance Program contracted by TWRF Company will be offering sessions on Eldercare Planning for employees.
Responsible Party(ies):	Abe Fiction, Personnel Manager and the Employee Satisfaction Committee of TWRF Company
Action Item: Action Item: Action Item:	Mr. Fiction and the Employee Satisfaction Committee will work with the EAP to identify current employee needs. Mr. Fiction and the Employee Satisfaction Committee will work with the EAP and Senior Spectrum to identify meaningful resources and educate employees about the rollout of this new benefit. The Employee Satisfaction Committee will use paycheck stuffers and notices in internal monthly newsletters to inform employees of the added benefit to their EAP.
Goal:	
Objective: Objective:	
Responsible Party(ies):	
Action Item: Action Item: Action Item:	

Family Caregiver Program

Request For Collaboration Application Review

September 2001

Score Sheet

Name of Applicant (organization):
Name / Title of Contact Person:
Amount Requested:

Please score the application based on each of the selection criteria using a scale of I to 5; 1 = not addressed; 2 = inadequately addressed; 3 = addressed and adequate; 4 = better than adequately addressed; 5 = addressed and proposed plan is excellent. (Total scores will range between 6-30).

[a]	Application addresses one of more of the guidelines listed in the Introduction & Goals. [Information about services; Assistance with Access to services; Provides individual counseling, organizing support groups and caregiver training; Provides respite services; Provides supplemental services on a limited basis; Work with employers to identify caregivers; Provide community education & resources; provide counseling, information & referrals]	Score _____

Comments:

[b]	Application demonstrates and documents how caregivers will be reached through this collaborative relationship between applying agency and Senior Spectrum.	Score _____

Comments:

[c] Application identifies and describes who will complete the tasks outlined in this RFC application. Score

Comments:

[d] Application describes how reporting documentation will be completed in a clear and timely manner. Score

Comments:

[el Application outlines the benefits to both the applicant organization/business and Senior Spectrum. Score

Comments:

[f]	Application describes how capacity will be built or maintained to sustain the collaborative relationship beyond the terms of this seed money.	Score

Comments:

_____

Total Score of a + b + c + d+ e + f

_____

Additional Comments / Suggestions:

Reviewer: _____ Date: _____

NORTH CAROLINA DATA COLLECTION

Family Caregiver Support Program

Note: The following is a report generated from the current North Carolina Division on Aging data collection spreadsheet. The Division plans to convert this into a database product.

Region:		Date Submitted:	

A. TOTAL CAREGIVERS SERVED

1	**Total Category 1**	**19**
2	**Total Category 2**	**9**
3	**Total Category 3**	**3**
4	**Total Category 4**	**5**
5	**Total Category 5**	**2**
6	**Total – Grand**	**38**

B. SERVICES DELIVERED:

4	**# Activities**	**# Participants**	**# Caregivers**	**# Professionals**
1. Publicity Campaigns	0	0	0	0
2. Information/Educational Programs	0	0	0	0
3. Outreach Programs	6	34	20	20
4. Public Information	4	24	8	17
5. Relations & Advocacy	0	0	0	0
6. Program assessment, planning	9	60	25	50
7. Participate in Community Events	0	0	0	0
8. Program Promotion	0	0	0	0
TOTAL	**19**	**118**	**19**	**87**
Information About Services	Printed Media Count	0	Broadcast Media Count	**0**

Access to Services	**# Caregivers**	**Access to Services**	**# Caregivers**
Total Caregiver Served-Category 2	9	Total Economically Needy	0
Total Males	4	Total Spouse Caregivers	2
Total Females	9	Total Children Caregivers	9
Total Whites	12	Total Grandparent Caregivers	0
Total Blacks	0	Total Grandparents - DD Children	0
Total Hispanic	0	Total Other Caregivers	1
Total American Indian	1	Lives with Care Recipient	4
Total Asian Pacific	0	Total Rural Caregivers	13
Total Multi-racial	0	Total Handicapped Caregivers	0

Access to Services	# Caregivers	Access to Services	Caregivers
Enter # I&A Calls from Log			
Care Management	0	**Age:**	
In-Home Assessment-Caregiver	0	Under 59	0
Care Planning	1	60 - 64	3
Benefits Screening/assessment	0	65 - 69	0
Develop caregiver emergency plan	0	70 - 74	3
Program Coordn./resource Devlp.	8	75 and Over	0
Other:	11	**Total**	**6**
Total	**1**		
Individual Counseling, Organization of Support Groups and Caregiver Training	**# Caregivers**	**Individual Counseling, Organization of Support Groups and Caregiver Training**	**# Caregivers**
Total Caregiver Served-Category 3	3	Total Economically Needy	1
Total Males	0	Total Spouse Caregivers	0
Total Females	2	Total Children Caregivers	2
Total Whites	3	Total Grandparent Caregivers	0
Total Blacks	0	Total Grandparent-DD children	1
Total Hispanic	0	Total Other Caregivers	0
Total American Indian	0	Lives with Care Recipient	2
Total Asian Pacific	0	Total Rural Caregivers	3
Total Multi-Racial	0	Total Handicapped Caregivers	0
Individual Counseling, Organization of Support Groups and Caregiver Training	**# Caregivers**	**Individual Counseling, Organization of Support Groups and Caregiver Training**	**Caregivers**
Counseling (Legal, Grief, Financial, End of Life)	0	**Age:** Under 59	1
Support Groups (caregiver, widows, peer, geriatric, etc)	3	60 – 64	1
Home Based Education/counseling	0	65 – 69	1
Caregiver Training	0	70 – 74	0
Workplace Caregiver Support/training	0	75 and Over	0
Legal Services	0	**Total**	**3**
Other:	0		
Total	**3**		
Respite Care	**# Caregivers**	*a. Respite Care*	**# Caregivers**
Total Caregiver Served-Category 4	5	Total Economically Needy	2
Total Males	2	Total Spouse Caregivers	1
Total Females	3	Total Children Caregivers	3
Total Whites	4	Total Grandparent Caregivers	0
Total Blacks	0	Total Grandparent-DD Children	0
Total Hispanic	0	Total Other Caregivers	0
Total American Indian	1	Lives with Care Recipient	2
Total Asian Pacific	0	Total Rural Caregivers	5
Total Multi-racial	0	Total Handicapped Caregivers	0

Respite Care	# Units	Respite Care	# Units
Adult Day Care/Adult Day Health Care	4	Emergency Respite	0
Group Respite Program	6	Senior Companion/home visitor	4
Institutional Respite program	0	Hospice Care	7
In-Home Respite Care	0	Other short-term Respite	0
Mobile Day Respite	0		
Total	**10**	**Total**	**11**

Respite Care	Caregivers
Age:	
Under 59	0
60 – 64	1
65 – 69	1
70 – 74	2
75 and Over	1
Total	**5**

Supplemental Services	# Caregivers	Supplemental Services	# Caregivers
Total Caregiver Served-Category 5	2	Total Economically Needy	1
Total Males	1	Total Spouse Caregivers	1
Total Females	1	Total Children Caregivers	0
Total Whites	1	Total Grandparent Caregivers	0
Total Blacks	0	Total Grandparents-DD Children	0
Total Hispanics	0	Total Other Caregivers	1
Total American Indian	1	Lives with Care Recipient	1
Total Asian Pacific	0	Total Rural Caregivers	2
Multi-Racial	0	Total Handicapped Caregivers	1

Supplemental Services	# Caregivers	Supplemental Services	# Units
Home Safety interventions	1	Nutritional Supplements	0
Home Modifications	0	Home Delivered Meals	10
Assistive Technology	0	Medical Transportation	0
Emergency Alarm response system	0	In-Home Services	0
Handy man, yard, household, etc	1	No of Other Services Provided	0
Incontinence Supplies/other	1		
Lgal Assistance	1		
Telephone Reassurance	1		
Equipment Loans	0		
Total	**5**		

Supplemental Services	Caregivers
Age:	
Under 59	0
60 - 64	0
65 - 69	1
70 - 74	0
75 and Over	1
Total	**2**

***Total Information and Assistance and Hotline Assisted Caregivers not included in the demographic totals.**

Statewide I&A Reform: A Self Assessment

	Leadership
	Which governmental, private, and consumer organizations will help push for reform to create statewide systems for long-term care I&A?
	Is there a clear vision and strong enough leadership to effect and sustain reform?
	Is State legislation needed or will voluntary movements by local agencies suffice?
	How much local variation can be supported?
	Will staff in county / local agencies embrace the change?
	What is the extent of consumer advocacy and involvement?
	System Design/Coordination and Data Collection
	How can the local agency that establishes Medicaid financial eligibility be better linked to the information, assistance, and care management agency?
	Which organizations will pay for what?
	Is the National Eldercare Locator effort well integrated into this effort?
	How will the emerging 211 system affect these efforts?
	Will there be duplication of effort?
	What data are needed for tracking and monitoring purposes?
	How can the State develop a centralized system that meets these data needs without overburdening local staff?
	Do older adults and families get the I&A they need to make long-term care choices that suit their needs, preferences, and resources?
	How satisfied are consumers (caregivers and care recipients) who use the system?
	What systems can be put in place that can effectively answer these questions?
	Funding
	How should a State department establish an adequate level of funding for I&A (particularly in the absence of data about unmet need for this service) ?
	What is needed in terms of level of staffing, technology, outreach and promotion, development of standards and protocols, training, data collection, evaluation, database assembly and maintenance?
	How should a State garner the political support they need to obtain that funding?
	What are the implications for designing an I&A system that increases demand for a LTC system that may already have a long waiting list and limited funds for services?
	Personnel and Staffing
	Are the I&A staff properly trained and sufficient in number to meet the level of requests by caregivers for assistance?
	What degree of variance in credentials and experience of staff is acceptable?
	What local government rules govern the hiring process?
	Is certification (e.g. AIRS) desired?
	Is the staff culturally competent? Do they meet the language needs of I&A seekers?

	Outreach and Promotion
	What mission do local staff embrace? If the State desires to reach out to all income levels, do local staff endorse this?
	To what extent are current State and local methods to reach caregivers of different incomes and cultures effective (e.g., TV, radio spots, supermarket bags, Internet)?
	To what extent to middle-income persons want to turn to government agencies for information and assistance?
	What are possible entities to market information to (e.g., faith-based, businesses)?

Adapted from Reinhard and Scala (2001). *Navigating the Long-Term Care Maze: New Approaches to Information and Assistance in Three States.* Prepared for the Public Policy Institute, AARP.