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THE BOOMERS ARE COMING: THE CHALLENGE OF FAMILY CAREGIVING

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BEFORE THE

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CONTENTS

PANEL I

PANEL II

APPENDIX

THE BOOMERS ARE COMING: THE CHALLENGE OF FAMILY CAREGIVING

MONDAY, OCTOBER 11, 1999

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
MONROE, LA

The Committee met at 1:30 p.m., in the Conference Room, Seventh floor of the Library, University of Louisiana at Monroe, Monroe, LA, the Honorable John Breaux presiding.

OPENING STATEMENT OF SENATOR JOHN BREAUX

Senator BREAUX. Good afternoon. Our U.S. Senate Aging Committee will please come to order. I'd like to start off by thanking our host here at the ULM hosting our Aging Committee Hearing in Monroe. We are delighted to be here. I am delighted to have such a well attended hearing. Sometimes in the U.S. Senate, we have these hearings and there are two or three people sitting out in the audience watching us. Although, I guess there are a lot more that watch through C SPAN. Today we're delighted that the media is covering this event, to let a lot of people know about what we're attempting to do. All of you who represent so many of the organizations that are dealing with senior care and older American programs we thank you for being with us as well. We thank our elected officials for their support and their turn out. I know they have things that they need to do, so if they do have to leave early, we'll certainly understand and thank them for showing their support for what we are attempting to do. Let me just tell you just a little bit about why we're here. The Aging Committee in the United States is a Special Committee what we call a non-legislative committee that doesn't write legislation, but makes recommendations to other Members of Congress about things that are of great importance. We do oversight hearings which are very important for Congress. We take the time to look at different programs and analyze what they're doing right and what they're doing wrong, so that we can report to our colleagues in the Senate about what improvements need to be made. We have had hearings, for instance, on looking at nursing homes, and how they treat people and problems that they have experienced, as well as the cutbacks that they have had. We have looked at how the balanced budget amendments have curtailed the money that suppliers and providers of health care to medicare beneficiaries, the problems that they are experiencing in not having sufficient funds to keep up the quality of care that people have come to expect—and, rightfully so—in this country. Our

Committee is divided, of course, between Democrats and Republicans.

In this Congress, the distinguished Chairman of the Committee is Senator Chuck Grassley, who is a United States Senator and my colleague from the State of Iowa. He and I have leadership responsibilities for making the Aging Committee work, and I have a good working relationship with him. He is very committed to doing what is right, and seeing to it that senior Americans are being cared for properly and are getting what they have come to expect in terms of health care and making their lives easier in their senior years. So, our Committee is here today to continue that work. I suggested that we come to ULM, which when I made that commitment was still named NLU. We are delighted to be at the new and improved university. We're here because this school has a great reputation in the area of Gerontology, the study of the aging process. The university here is doing outstanding work in this area and I wanted to make sure that those who read our reports and listen to what we do are mindful of the fact that ULM has this outstanding Gerontology program. They are helping to educate our citizens about what is happening in this particular field. So, that is why we're here. We will make our report to our colleagues in the Senate after we hear from our witnesses today. And I want to continue this relationship between the U.S. Senate and the ULM, learning about what you all are doing here at the University, as well as in the Ouachita, Northeast Louisiana community, which has some outstanding organizations working with our senior population.

Let me just point out that what all of us know is that we now have more and more Americans who are living longer and longer. I like to use the good news/bad news analogy. The good news is that we are all living a lot longer. The bad news is that we are all living a lot longer, because a number a problems which we need to have addressed arise when people live longer. So, it is important that they just not live longer, but that they also live quality lives. And, while we in medical science can extend people's lives for longer and longer each year, it is also important that we don't forget that it is necessary to also improve the quality of those years. We all know the numbers and they really are fascinating. Information shows us that the 85 year and older population rose 274 percent between 1960 and 1994 and is the fastest growing group among those over the age of 65. That is wonderful and yet it also presents real challenges as to how we deal with people who have special needs and need special attention in that category. Those people who find themselves in the so-called baby boom generation, of which I see a number in the audience—those Americans born between the year 1946 and 1964—comprise about 77 million American citizens and they are starting to look at what is going to be available to them when they become senior citizens.

They are also experiencing what is the subject matter of the hearing this afternoon, and that is these families in that age category are experiencing what it means to provide care to their parents, either their mother or their father or if they're fortunate enough to be caring for both of them. Most people don't realize and don't think about it until it is time for them to need that type care, and there is insufficient planning as to what happens when we reach that point in our lives when we need that extra care.

Medicare, to the surprise of many people, does not cover long term health care in this country. Unless you are very poor and eligible for Medicaid or very wealthy and don't worry about the cost, you are in a category of people when you need long term care that there is not a great amount of financial assistance.

Therefore families more and more are having to care for their own parents and their own grandparents in some instances. My wife Lois and I, who is here in the audience, are having her mother live with us at our home. That is not an unusual situation. The typical person in this country who is giving care to a parent is about 47 years of age and works about 18 hours a week directly in the care of their parent, in many cases working at a job full time every day and rushing home at lunch or rushing home early in the evening to care for a parent who needs special care. So, we as a nation have a number of challenges. I'll conclude with the fact that we are doing some things. We all work to try and help the so-called sandwich generation who still have young children at home but yet are caring for parents and are sort of sandwiched between the two, to try and make their lives better. I've advocated tax credits to help families who have extra financial burdens while taking care of their parents or to give them some economic assistance and tax deductions in order to make sure that they are able to financially care for their parents.

Senator Grassley and I have introduced legislation together in a bipartisan fashion to establish the National Family Caregivers Support Program, to be part of the Older Americans Act, which we absolutely must re-authorize. Congress has to quit talking about re-authorizing the Older Americans Act and get others committed to actually voting in order to do it. Our legislation would, in fact, be the first step ensuring families that they have the help that they need in order to care for parents or other loved ones in their home. And, we are working on that, to help provide assistance and information and give people really a road map as to where they can go to find out what is available, what help is available in these all important areas.

A lot of people don't have the information they need in caring for parents and selecting a home health care facility helping to select a nursing home or to find out where they can go to find programs that would help them. Sometimes I've said we can find more information about a microwave oven in consumer reports than we can about information on where to go to find out health information, and information on hospitals and on nursing and assisted living facilities for our senior citizens in this country. So, this is what it is all about.

And, to help us today to understand what we are doing and who we are going to help, we have some very special people who I'm going to be introducing as they make comments.

[The prepared statement of Senator Breaux follows:]

PREPARED STATEMENT OF SENATOR JOHN BREAUX

Thank you all for attending this very important hearing today. The topic, family caregiving, is one that touches many of our lives. Whether we realize it or not, many of us give care to chronically ill or disabled family members. There are 22 million family caregivers in the U.S., all struggling daily to provide for their loved ones. Today, we will learn about some of the heroic efforts put forth by these caregivers and discuss how communities in Louisiana, and around the nation, can work together to help these families.

One of the most important activities of the Special Committee on Aging has been educating the public about the challenges that our nation faces in preparing for the aging of the baby boomers. When the 77 million strong baby boom generation begins to retire, not only will our national programs and resources be put to the test, but our families will be as well. The struggles of family caregivers are real and important. And, as our population grows older, the strains felt by families all across the country will only increase. With the average life-span for men and women increasing, many baby boomers will require long term care at some stage in their lives. This means that more seniors than ever before will have long term care needs, and more families will try as best they can to meet those needs.

Currently, there are over 490,000 caregivers in the State of Louisiana. These families spend a grand total of 381 million hours giving care to a loved one in need each year. That number, while staggering, reflects only a portion of the sacrifices that family caregivers make each day. Family caregivers are under tremendous strain. And now is the time to create an infrastructure to assist them in their compassionate work.

In March of this year, Senator Grassley and I, introduced legislation that would establish the National Family Caregiver Support Program. This crucial program would offer assistance to families through the Older Americans Act. Services, support and information would be available to millions of families right in their own communities.

Implicit in the creation of the National Family Caregiver Support Program is the need to reauthorize the Older Americans Act (OAA). The OAA has not been reauthorized since 1992. For 3 years, the issue has been tangled up in debates and differences of opinion. This year we must move forward to reauthorize and modernize the OAA. The National Family Caregiver Support Program will serve a crucial role in meeting the needs of our nation's families and enable our elders to receive the best and most loving care available.

Thank you all for attending today's hearing. And a special thanks to everyone here at the University of Louisiana at Monroe for the use of their beautiful new conference center and for all their hard work.

I want to present the first person to you who has come all the way from California. She is a journalist. She is an author and she has spoken on a number of programs and consulted on the issue of caregiving and also aging issues. Her expertise has grown out of her personal experience caring for her parents who were both terminally ill.

Beth McLeod has written about caregiving for a number of major publications, including the San Francisco Examiner. She has recently written a much acclaimed book, which I have. I'm not selling the book, but I want you to know that this book was one that really I think sort of really summarized what a lot of Americans—what you all were going through yourselves, that you wrote it from a very personal standpoint about what you did. It's called, *Caregiving, the Spiritual Journey of Love and Loss and Renewal*, and was nominated for a Pulitzer Prize. She is going to talk about caregiving from both a national as well as a personal perspective, as well as discussing the baby boomer generation's unique struggle with this very special situation in our country and we would like to introduce Beth to get us started. Then I will introduce the other panelists after Beth makes her presentation. Mrs. McLeod.

STATEMENT OF BETH WITROGEN MCLEOD, AUTHOR

Mrs. MCLEOD. Thank you, Senator Breaux. I am very honored to be here. I thank you all for being here.

It is an honor to talk with you about the subject that has become dearest to my heart, which is how we care for the most vulnerable in our society and how that kind of compassionate attention can inform our nation at the beginning of a new millennium.

I was drifting along in my tidy little life, when out of nowhere I found out that my mother did not in fact have arthritis, but Lou Gehrig's disease, accompanied by Alzheimer's. This was at the same time that my father was losing his battle of 25 years to a very rare form of spinal cancer. So, both of my parents were catastrophically ill and my life as I knew it was completely erased. At that moment, I became a family caregiver, a term that I didn't hear until 6 months after my parents died, 5 weeks apart, bankrupted from long term care expenses in a nursing home. They felt humiliated by diseases they had no control over, and especially by a long term care health delivery system that saw them only as a burden, rather than as whole human beings worthy of dignity and value.

Although I felt isolated and helpless, I was in fact only one of 22.4 million family caregivers in the United States today, and one of 77 million Baby Boomers whose lives are about to change drastically as we enter mid life. I turned 50 last Christmas, a watershed event that is a symbolic as it is real. It marks the turning point of my life from a passenger to an advocate for long-term care issues.

I belong to the largest generation in history in the United States, but it is not our size that matters. It is the mindset with which we have transformed every life passage to date. We were coddled by parents who knew hunger and poverty through the Depression and World War II, and by grandparents who hoped that world wars would put an end to violence and to tribalism.

We were the "me" generation, the youth generation. We grew up with television and now we grow older with computers—and reruns. We had a profound impact on education, and then on the work force. We spent our youth as hippies preaching peace and love, some of us. We are the first generation to address the importance of respecting ethnic diversity and nontraditional family structures. We are the first generation to have two working parents and especially working mothers. We put off marriage and having families and then we had fewer children. We put child care on the map as a work and family issue, and we are about to do the same with elder care. We brought the rights of women to the forefront of the social order, and asked that equality extend to everyone regardless of race, religion, and gender. We also became Perrier-swigging yuppies—not me—and came to exemplify the worst in greed and ambition in business, and we peaked early and wondered, "Is this all there is?"

We who pioneered the sexual revolution and a renaissance in spiritual seeking are now bringing the aging revolution—not the "anti-aging" revolution, but a wholesale turnaround in how we perceive and respect end-of-life issues.

The Baby Boomers are coming of age and we are going to become the elders of the tribe.

Caregiving now is our new mid-life crisis and all of our youthful characteristics are dovetailing into the new demographics. American society is aging because of longer lifespans and falling fertility rates. The Boomer bulge will swell the ranks of those over 65 to some 60 million in the next 30 years—that's one in every five. The era of the United States as a youth-focused nation is ending, and it will not come again in our lifetime. Soon there will be more grandparents than grandchildren. Aging is no longer just about financial and budgetary considerations, however; the social dimension of an aging society demands an equal hearing.

My parents left a double-edged legacy: awareness of both the sorrow and generosity of the human heart. Nowhere perhaps is this paradox more widely played out than on the stage of family caregiving every day, where the unsuspecting can find themselves on a chaotic journey in which the only certainty is the demise of their loved one. These caregivers are on a path seemingly without end, subjected to the stresses and guilts of watching another one's pain without being able to erase it, witnessing a loved one's dying without being able to prevent it. They quietly sacrifice personal agendas to look after those in need, often sandwiched between child care and career, and usually without advanced planning or training. They live a world apart from everyday reality and wonder if they will ever be normal again. They have one goal, to maintain the dignity and well-being of their loved one until the end. The burden is great, the information insufficient, the doubt overpowering. Yet these loyal souls—many of whom do not even recognize themselves as family caregivers—work largely without professional help, feeling they can and must do everything alone. There is no question about taking on this role: They do so compelled not only by the dictates of society, but especially by the mandate of the heart.

Along with global graying, we have entered what geriatric experts call the "third age," the extension of healthy middle age well into what used to be known as the sunset years. Until the Industrial Revolution, only one in ten could expect to live to be 65. Today most people will reach that age and well beyond. Though most elderly are healthier than ever, it is also a time when the ravages of oldest age require the most support services. The rapid growth in the numbers of elderly people who need nursing or home care will be a significant issue in the next century.

The number of family caregivers has exploded by 300 percent in only 9 years. And, this is mostly for personal care. There is only 5 percent of the over 65 population that is in a nursing home at any one time. So, that means 95 percent of family caregiving is done by families—of all caregiving. But this is not, in our sound bite culture, something that is usually over quickly. Caregiving demands an investment for the long term, often an abrogation of dreams and wholesale reconstruction of the future.

Even when families have made preparations for possible disability, it is the unanticipated events—a fall, a stroke, a creeping inability to maintain a checkbook—that define the turning point from a life so familiar to one filled with incalculable unknowns.

It is estimated that a quarter of all North Americans over 65, and half over 85, cannot get through the day without some assistance like bathing or transportation. The typical informal, unpaid family caregiver is an employed 46-year-old woman who spends another 18 hours a week caring for her mother. The typical recipient is a 77-year-old woman who lives nearby but alone and has at least one chronic condition, such as heart disease. Eighty-nine percent of all women over age 18 will be caregivers either of children or of parents, or both; nearly 90 percent will be caregivers for a disabled adult.

Lack of knowledge about how to manage in a fragmented health care system kicks many families into disarray. One caregiver told me there really isn't a long-term care "system" because you have to put all the pieces together yourself. These services must be uncovered and paid for through an overlapping array of providers with different eligibility requirements. Because there is no single entry point into the aging network—medical, housing, social, legal, financial problems can all be doorways. Families may feel pressured to accept the most expedient or high-profile option, such as a nursing home, when the actual solutions may be sound fiscal management, proper hydration and nutrition or home modifications.

In 1991, an Alliance for Aging Research survey found that although many American want to be 100, most are afraid of losing their independence and ending up in a nursing home. In fact, minority populations are facing this more than any other.

They are aging the fastest. They also have the greatest financial stresses in providing this care. Between 1990 and 2030, according to the Census Bureau, the older white population will grow by 92 percent, compared with 160 percent for non-Hispanic blacks, 693 percent for all Native Americans, and 555 percent for Hispanics. Minorities comprised 12 percent of the population in 1992. By the year 2040, it will be 31 percent.

For many minority caregivers, the problems of access and availability of proper medical care are compounded by finances: Poverty may mean improved access to some health services, no access to others. Many minorities lack health insurance and pension benefits, are low-income and suffer from poor health. Most health insurance programs serve the mainstream and aren't culturally competent for ethnic minorities. Care providers may restrict access on the basis of citizenship, immigration status or HMO membership. Minority families may not use the health-care system because of religious beliefs, the pressures of family responsibilities, a history of institutional racism, lack of transportation, lost pay or other employment issues, or ignorance of how to enter the network. Moreover, access to care is not always provided in the patient's own language.

Because of cultural values, tradition dictates that families care for their elders themselves. It is also a tradition born of harsh reality. Minorities historically have lacked access to good medical care, public support and the kinds of jobs that guarantee a secure old age. Because of discrimination, for example, African Americans are quite reluctant to even consider nursing homes or mainstream institutions, even if they need them.

Yet often, they may have no option but to enter a nursing home on Medicaid. They are less likely than whites to have spouses to help with their care. Black caregivers have less money than most white families to care for an elder, and cannot afford to hire help. They are also more likely to be sandwiched with child care. More than half have one or more children under 18 living at home, compared with 39 percent of white caregivers. Many black caregivers are also single working mothers. Yet 34 percent of blacks over 65 live in multigenerational homes, compared with 18 percent of white people.

This is just a background of caregiving and the Baby Boom. What I have found in about 8 years of research and interviewing, and work in my own field, and being on line with thousands of caregiving, I want to present the issues that have come up the most. Number 1 is affordable long-term health care at home. Most people want to live out their days at home; most caregivers want to take care of their loves ones at home. Yet most insurance, and certainly—as Senator Breaux mentioned—Medicare does not respect or reflect this desire. Reimbursement systems are skewed toward expensive institutionalization rather than family care. In my own case, home care ended up costing $15,000 a month, which was 24 hour skilled nursing care for two parents at home. Because my parents were prominent in their home town of Wichita, I was able to do a fund raiser, but that was the only way we could avoid welfare. And, it was a decision that a nursing home would be less humiliating for my parents. My mother never even knew what hit her. She always thought that she was just there for a minute, so it was absolutely devastating. The nursing home was $6,000 a month and we ran out of money 2 days before my father died. Then we sold my mother's piano and that kept her in the nursing home until she died.

Number 2 is Aging and caregiving as women's issues. Because most caregivers are women, and most older people are also women, aging and caregiving are the new women's issues. In a 1998 survey of Boomer women caregivers, half said they felt relatively unprepared for their own possible long-term care needs. Only 6 percent felt very well prepared. Those who experienced financial burdens also suffered a lot of daily caregiver stress and needed more help with in-home assistance. Older women are also chronically more ill. They're usually poorer, they're more often widowed, and more of them live in nursing homes. So, older women's issues are extremely in need of focus today.

Number 3, and probably really Number 1, is Respite care for the caregiver. This means time away from duties, especially when the loved one needs 24-hour care, such as in later stages of Alzheimer's disease. Caregivers say they either cannot afford for someone to come in and watch their loved one for an hour, or they can't find anyone suitable, reliable or affordable, and especially in rural areas. Caregiver burnout is in fact a greater cause for institutionalization than the worsening of a loved one's medical condition. Personally, I lost my health for more than 2 years in a clinical depression. But, I know caregivers who fared much worse in attempted suicide. When caregivers fall apart, then their care for their loved ones also becomes a burden on the formal system. They need support and they especially need validation that what they do matters.

Number 4, Education and awareness of long-term care issues. Too many caregivers do not self-identify and therefore do not realize there are supports and services available to assist them. Most families don't even know there is a professional network of wonderful aging services, even after a crisis hits. Too often families are scrambling—usually in a state of shock and not able to pay full attention—to make decisions about medical care, housing, financial or legal planning, when they really don't know what they're doing. We have not been trained to do this work. And, in an age-and-death denying society, we prefer to ignore it. Socialization in this kind of society robs us of our ability to function fully in a crisis. We need awareness and training for family caregivers.

Number 5 is Work and family issues. A 1997 National Alliance for Caregiving survey estimated the economic value of informal caregiving at $196 billion. Compare that to formal health care at $32 billion and nursing home care at $83 billion and you can see the importance of bringing elder care issues into the work place as a benefit.

No matter how much we fight aging, the end is inevitable. We won't all have healthy deaths. Because birth rates are declining and the lifespan is increasing, there will be fewer family caregivers in 50 years than there are today. Who will care for us, and for the next generation? How much should government become involved? How can government and the private sector become partners in long-term care? And what will happen if we maintain the status quo?

I'd like to quote gerontologist Robert Kastenbaum, who has taken the study of aging into the realm of the spirit. His conclusions extend well beyond tradition, and illuminate the heart of caregiving. He proposes that aging is not about how we grow old, but what life means if our fate is to both age and die—that how we define old age, and what it should be, is one of society's most critical tests of strength.

Ultimately, he believes the well-being of the elderly—and by extension, humanity itself—can be protected only by appreciating the intimate interdependence of life and respect for the whole person. He says, "Limitations and distortions in our core vision of what it means to be a person become starkly evident in old age. If to be an old person is to suffer abandonment, disappointment and humiliation, this is not a geriatric problem. It is the disproof of our whole shaky pudding, technology, science, and all. If our old people are empty, our vision of life is empty."

This is the context in which I hope we will consider long-term care issues, health and social policy. It cannot be ignored if we are to build a system that truly responds to the needs of the aging in their own context, one in which death is not looked at as failure, nor aging as a complex series of disorders to be avoided.

I'm going to skip down and close with this statement. Doomsayers would preach that the world has been overtaken by rage, greed, and resignation. I think that if you look into the back rooms of caregiving families, you will find the true nature of things as they are, beneath the veneer of social conditioning and confusion, stereotype and illusion. There you will find great kindness and devotion, a trust of life that surpasses doubt or pain. There you will find the highest expression of who we are.

If we close our hearts to suffering, we cannot open them to love. Every kind act counts. By surviving these difficulties and holding on to goodness, caregivers inspire others to summon the power of the spirit. Humanity can emerge from violence and carelessness into an enlightened age of caring where the lessons of grief and caregiving will be honored, exemplified by these modern-day heroes who fulfill the age-old mandate—to give.

Thank you all very much.

[The prepared statement of Beth McLeod follows:]

WRITTEN STATEMENT BY BETH WITROGEN McLEOD

Good afternoon, Senators, and thank you especially Senator Breaux for inviting me here today to discuss the subject dearest to my heart: how we care for the most vulnerable in our society, and how that kind of compassionate attention can inform our nation as we enter a new millennium.

I was drifting blithely along in my tidy little life, as naive and immortal as the next fortysomething. Suddenly both my parents at age 70 were catastrophically ill, and my life was abruptly derailed. Everything that had been familiar vanished; what might come was terrifyingly uncertain. The initial severing came the instant my father informed me, at the end of my work day over aching distance, that my mother had Lou Gehrig's disease, not arthritis. She also had a dementia of the Alzheimer's type. His own life was already on the line after a fifth and final surgery to remove a viciously recurring rare form of cancer.

In that moment I became a family caregiver, a term I didn't even hear until six months after both my parents died, five weeks apart in a nursing home, so far from the lives of dignity and service they had known. They felt humiliated by diseases they had no control over -- and especially by a long-term care delivery system that saw them only as a burden rather than as whole human beings worthy of dignity and value.

The Baby Boomers

Although I felt isolated and helpless, I was only one of 22.4 million family caregivers in the United States today, and one of 76 million Baby Boomers -- those born between 1946 and 1964 and whose lives are about to change drastically as we enter the mid-life wave. I turned 50 last Christmas, a watershed event that is as symbolic as it is real. It marks the turning of my life from a passenger to an advocate for long-term care issues. I write extensively for national magazines and newspapers, speak around the country, and have written a new book called CAREGIVING: THE SPIRITUAL JOURNEY OF LOVE, LOSS, AND RENEWAL (John Wiley & Sons, 1999) to help bring awareness to an unprecedented, historic wave that threatens to engulf us if we do not wake up now to the demographics and their implications.

I belong to the largest generation in U.S. history, but it not our size that matters: It is the mindset with which we have transformed every life passage to date. We were coddled by parents who knew hunger and poverty through the Depression and World War II, and by grandparents who hoped that two world wars would put an end to violence and tribalism.

We were the "me" generation, the youth generation, and the protest generation. We grew up with television and grow older with computers -- and reruns. We had a profound impact on education, then on the workforce. We spent our youth as hippies preaching peace and love. We are the first generation to address the importance of respecting ethnic diversity and nontraditional family structures. We are the first generation to have two working parents and especially working mothers. We put off marriage and having families, and then had fewer children. We put child care on the map as a work and family issue, and are beginning to do so with elder care. We fought for civil rights and looked to nonviolent ways of negotiating peace.. We brought the rights of women to the forefront of the social order, and asked that equality extend to everyone regardless of race, religion, and gender. We also became Perrier-swigging yuppies and came to exemplify the worst in greed and ambition in business, peaking early and wondering, "Is that all there is?"

We who pioneered the sexual revolution and a renaissance in spiritual seeking are now bringing the aging revolution -- not, mind you, the "anti-aging" movement, but a wholesale turnaround in how we perceive and respect aging and end-of-life issues. We have always been opinionated and self-involved and we will remain so as we age. Now we will bring these scary issues out of the closet.

Baby Boomers are coming of age; we are becoming the elders of the tribe. The times they are a-changin'.

There is a new mid-life crisis, and it has to do with personal and social values. All of the Boomers' youthful characteristics dovetail into the new demographics. Because of longer lifespans and falling fertility rates, American society is graying. The Boomer bulge will swell the ranks of those over 65 to some 60 million in the next 30 years -- a fifth of the entire population. The era of the United States as a youth-focused nation is ending, and it will not come again in our lifetime. Soon there will be more grandparents than grandchildren. Aging is no longer just about financial and budgetary considerations, however; the social dimension of an aging society demands an equal hearing.

We are becoming responsible, not just for ourselves but for future generations as well. Individualism is giving way to a cry for community. Baby Boomers will change the face of aging and retirement, consumerism and leisure, politics and media, marketing and housing. We are better educated, healthier, more vocal than any generation to date. We will demand the good older life, but this time, with an eye to the greater good of society as a whole. We are bringing the idealism of the flower children into action today, with an eye to service and righting the wrongs of inequality. We are attempting to move society toward compassion and tolerance and an acceptance of the stages and cycles of life. The Boomers are coming, and we are coming to change the social order to make this rite of passage inclusive, supportive, and relevant.

Family Caregiving

My parents left a double-edged legacy: awareness of both the sorrow and the generosity of the human heart. Nowhere perhaps is this paradox more widely played out than on the daily stage of family caregiving, where the unsuspecting can find themselves on a chaotic journey in which the only certainty is the demise of their loved one. These caregivers are on a path seemingly without end, subjected to the stresses and guilts of watching another's pain without being able to erase it, witnessing a loved one's dying without being able to prevent it. They quietly sacrifice personal agendas to look after those in need, often sandwiched between child care and career, and usually without advance planning. They live a world apart from everyday reality and wonder if they will ever be normal again. They have one goal: to maintain the dignity and well-being of their loved one until the end. The burden is great, the information insufficient, the doubt overpowering. Yet these loyal souls -- many of whom do not recognize themselves as caregivers -- work largely without professional help, feeling they can and must do everything alone. There is no question about taking on this role: They do so compelled not only by the dictates of society, but also the mandates of the heart.

Along with global graying, we have entered what geriatric experts call the "third age," the extension of healthy middle age well into what used to be known as the sunset years. Until the Industrial Revolution, only one in 10 could expect to live to 65. Today most will reach that age -- and well beyond. Though most elderly are healthier than ever, it is a time when the ravages of oldest age require the most support services. The rapid growth in the numbers of elderly people who need nursing home care or care at home will be a significant issue in the next century. I thank you for addressing these issues today.

In the United States, the number of family caregivers has exploded by 300 percent in only nine years, reaching into a quarter of all households because most long-term needs of the chronically ill are not skilled nursing but help with daily activities such as grooming or getting out of bed. We become caregivers by choice, default, and obligation; we assume the role because the alternatives are unacceptable. In a culture defined by short attention spans and sound bites, family caregiving demands investment for the long-term, often an abrogation of dreams and a wholesale reconstruction of the future, one slow brick at a time.

Caregiving -- the act of providing assistance to someone ill or frail -- is emerging from the modest recesses of everyday life into one of the most catalytic challenges any of us will face. Even when families have made preparations for possible disability, it is the unanticipated events -- a fall, a stroke, a creeping inability to maintain a checkbook -- that define the turning point from a life so familiar to one filled with incalculable unknowns.

It is estimated that a quarter of all North Americans over 65, and half over 85, cannot get through the day without some assistance like bathing or transportation. The typical informal, unpaid family caregiver is an employed 46-year-old woman who spends another 18 hours a week caring for her mother. The typical recipient is a 77-year-old woman who lives nearby but alone and has at least one chronic condition, such as heart disease or osteoporosis. Eighty-nine percent of all women over age 18 will be caregivers either of children or parents, or both; nearly 90 percent will care for a disabled adult. Three-quarters of caregivers are women, many at mid-life or in retirement themselves, with their own families and health problems to attend to. Most give care seven days a week, many as much as 10 or more hours a day; at least a third work full or part time, and more than half also care for children under age 17. Despite myths to the contrary, families do not abandon their loved ones to institutions when they become disabled or terminally ill. Most are cared for at home, in their communities, at all costs.

Family caregiving is an emotional roller coaster that can leave a person exhausted, bewildered, dislodged, wondering how she or he can feel so helpless in a period so supposedly grown-up. Each stage of an illness presents a succession of hurdles, stretching complacency and hearts more than it seems possible to bear. Yet caregivers abide, because it is human instinct to do so.

America prides itself on rugged individualism, but in caregiving that sense of "independence" can become a handicap. Because most people are reluctant to ask for help or admit they may be in trouble, caregivers can face obstacles merely sorting out what the problems are. Often there is only a sense of something amiss: a hesitant phrase, increased isolation. Adult children suddenly must pry out of secretive or distrustful parents the most private of details about estate matters; spouses who have never made decisions now must make all of them. Parents may have divorced or been unloving; siblings or relatives may have vanished at the first spot of trouble. For young adults who couldn't wait to leave the parental yoke, time and distance now complicate the best intentions, hide the worst scenarios. Few people want to think about death, let alone plan for it. The lucky ones discover that their parents or spouses have already seen to legal documents, health insurance, and funeral arrangements. For others, the discovery phase can be a long ride into purgatory.

Lack of knowledge about how to manage in a fragmented health care delivery system kicks many families into disarray. One caregiver told me there isn't really a long-term care "system" because you have to pull all the parts together yourself. These services must be uncovered and paid for through an overlapping array of providers with different eligibility requirements. An easy solution may become complicated because services are approved based not on need but on funding availability. Because there is no single entry point into the maze of programs -- medical, housing, social, legal, financial problems can all be doorways into caregiving -- families may feel pressured to accept the most expedient or high-profile option, such as a nursing home, when the actual solution may be sound fiscal management, proper hydration and nutrition, or home modifications to accommodate a creeping disability.

There are 100 million Americans with chronic illness today. We can expect the number of people with age-related disabilities will vastly increase, particularly because the fastest-growing segment of the older population is those over 85. By 2050, according to the U.S. Census Bureau, that group will make up nearly a quarter of the elderly population -- the group considered most disabled and in need of long-term care services. Almost 6 million elders receive home health care services today, five times as many as those in nursing homes -- a number likely to double in the next 30 years as Boomers reach their golden years en masse.

Ethnic Minority Caregivers

3

A 1991 Alliance for Aging Research survey found that although many Americans want to live to be 100, most are afraid of losing their independence and ending up in a nursing home. Blacks were less optimistic about living longer yet were less fearful of being in a nursing home.

In fact, minority populations are aging the fastest. They also have the greatest financial stresses in providing that care. According to *A Profile of Older Americans*, 1993 (AARP, from U.S. Census Bureau), between 1990 and 2030 the older white population will grow by 92 percent, compared with 160 percent for non-Hispanic blacks, 693 percent for all Native Americans, and 555 percent for Hispanics. Minorities comprised 12 percent of the population in 1992; by 2010 the percentage will be one-fifth, and by 2040, it will be 31 percent.

For many minority caregivers, the problems of access and availability of proper medical care are compounded by finances: Poverty may mean improved access to some health services, no access to others. Many minorities lack health insurance and pension benefits, are low-income and suffer from poor health. Most health and insurance programs serve the mainstream and aren't culturally competent for ethnic minorities. Care providers may restrict access on the basis of citizenship, immigration status, or HMO membership. Minority families may not use the health-care system because of religious beliefs, the pressure of family responsibilities, institutional racism, lack of transportation, lost pay or other employment issues, or ignorance of how to enter the network. Moreover, access to care isn't always provided to a patient in his or her own language.

Asians and African Americans are more likely than whites to be caring for more than one person, and minority women are more likely to have greater stresses balancing low-paying jobs and caregiving.

Because of cultural values, tradition dictates that families care for their elders themselves . It is also a tradition born of harsh reality: Minorities historically have lacked access to good medical care, public support and the kinds of jobs that guarantee a secure old age. Because of discrimination, African Americans for example are quite reluctant to even consider nursing homes or mainstream institutions, even if they need them.

Yet often, blacks financially may have no option but to enter a nursing home on Medicaid. They are less likely than white people to have spouses to help with their care. Black caregivers also have less money than most white families to care for an elder, and cannot afford to hire help. They are also more likely to be sandwiched with ~~child care:~~ More than have have one or more children under 18 living at home; compared with 39 percent of white caregivers. Many black caregivers are single working mothers. Yet thirty-four percent of blacks over 65 live in multigenerational homes, compared with 18 percent of white people.

Key Caregiving Issues

What are the key issues that caregivers face today? In five years of on-line chats, in interviewing hundreds of caregivers and aging experts for my book, CAREGIVING: THE SPIRITUAL JOURNEY OF LOVE, LOSS, AND RENEWAL, in traveling the country and talking with my peers, these are the areas of greatest concern:

1) **Affordable long-term health care at home**. Most people want to live out their days at home; most caregivers want to take care of their loved ones at home. Yet most insurance, and certainly Medicare, does not respect or reflect this desire to remain at home. Reimbursement systems are skewed toward expensive institutionalization rather than family care. In my own case, home care eventually cost $15,000 a month. Of course we had to move my parents to a nursing home, at $6,000 a month. I'm convinced that "transfer trauma" was partially responsible for their dying only a few weeks later. And all along I thought it was my

fault for being ignorant; I didn't realize there were no safety nets out there for the middle class. Researchers at the Brookings Institution ("Caring for the Disabled Elderly: Who Will Pay?" 1988) estimate the number of elderly using paid home care services during the course of a year will rise from 4 million in 1988 to 6.4 million in 2018, an increase of 60 percent. How viable will reliance on family care be in the future, especially when surveys show that women Boomers are not planning well for their financial future?

2) **Aging and caregiving as women's issues**. Because most caregivers are women, and most older people are also women, aging and caregiving are the new women's issues. In a 1998 National Alliance for Caregiving/Equitable survey of Boomer women caregivers, over half said they felt relatively unprepared for their own possible long-term care needs. Only 6 percent felt very well prepared. Those who experience financial burdens also suffered a lot of daily caregiver stress and needed more help with in-home assistance. Support for older women's issues has never been strong, but to ignore them now is to create a future fiasco in health care financing.

3) **Respite care for the caregiver**. This means time away from duties, especially when the loved one needs 24-hour care, such as in lat er stages of Alzheimer's or any ravaging terminal illness. Caregivers say they either cannot afford someone to come in to watch their loved one even for a few hours, or they can't find anyone suitable, reliable, or affordable, especially in rural areas. Caregiver burnout is a greater cause for institutionalization of a loved one than an exacerbation of the medical condition. I personally lost my health and fell into a clinical depression for two years. I know many caregivers who fared much worse, including several who attempted suicide. When caregivers fall apart, then the care of their loved ones become a burden on the formal system. They need support.

4) **Education and awareness of long-term care issues.** Too many caregivers don't self-identify and therefore don't realize there are supports and services available to assist them. Most families don't even know there is a professional network of aging services, even *after* crisis hits. Too often families are scrambling -- usually in a state of shock and not able to pay full attention -- to make decisions about medical care, housing, financial or legal planning when they really don't know what they're doing. We have not been trained to do this work. And socialization in an age- and death-denying culture rob us of our ability to function fully in a crisis.

5) **Work/family issues**. A 1997 National Alliance for Caregiving and AARP survey estimated the national economic value of informal caregiving at $196 billion. That dwarfs national spending for formal home health care at $32 billion, and nursing home care at $83 billion. To balance work and family roles, many caregivers -- usually women -- reduce their hours or quit altogether to make the pieces fit. The Older Women's League estimates that women spend 11.5 years out of the labor force for child and elder care, which already puts them behind the eight-ball economically when they become elderly. And yet, a 1999 survey for Genesis ElderCare and the National Association of Female Executives revealed that only 19 percent of employers support caregivers "a great deal," despite an environment in which 95 percent of the professional women surveyed said they want defined elder care benefits.

The Future of Caregiving

No matter how much we fight aging, the end is inevitable. We won't all have a healthy death. Because birth rates are declining and the lifespan is increasing, there will be fewer family caregivers in 50 years than there are today. Who will care for us, and for the next generation? How much should government become involved? How can government and the private sector become partners in long-term care? And what will happen if we maintain the status quo?

In his quest to understand the ideas and beliefs that hold a society together, gerontologist Robert Kastenbaum has taken the study of aging into the realm of the spirit. His conclusions extend well beyond tradition, and illuminate the heart of caregiving. He proposes that aging is not about how we grow old, but what life means if our fate is to both age and die -- that how we define old age, and what it should be, is one of society's most critical tests of strength.

Ultimately, he believes, the well-being of the elderly -- and by extension, humanity itself -- can be protected only by appreciating the intimate interdependence of life and respect for the whole person. He writes: "Limitations and distortions in our core vision of what it means to be a person become starkly evident in old age. If to be an old person is to suffer abandonment, disappointment and humiliation, this is not a 'geriatric problem.' It is the disproof of our whole shaky pudding, technology, science, and all. If our old people are empty, our vision of life is empty."

This is the context in which I ask you to consider long-term care issues, health and social policy. It cannot be ignored if we are to build a system that truly responds to the needs of the aging in their own very special context, one in which death is not looked at as failure, and aging as a complex series of disorders to be avoided.

What will be the face of family caregiving in 50 years? Here are some possible scenarios:

* It will be a far more diverse face, as ethnic elders become a majority. If we do not put culturally relevant supports and services in place, the drain on federal programs -- if they are even still in effect -- will be staggering.

* It will be a much older face, as caregivers themselves move from an average age of 47 to the late 50s and 60s. Thirty-five percent of caregivers today are already over age 65, according to OWL; the percentage will be much higher and include people -- mostly women -- who are themselves in need of caregiving.

* It will be a face with smaller families, with fewer siblings to care for longer-living, aging parents. Who will care for these elderly?

* It will be a far more technologically advanced society, so that assistive devices and medical care will provide much greater support than they do today. But that will also mean that even more care will likely be given at home, and families will continue to need support there.

* It may be a world in which Social Security and Medicare are at risk or already bankrupt, depending on courses of action taken in the near future. Because there will be fewer workers paying into entitlement systems, the U.S. will need new, creative systems to pay for public programs. Where finances will come from to pay for expensive long-term care services might involve public/private partnerships and greater incentives for families to save toward these events. Long-term care insurance may be in its flowering.

* It will be a world in which people not only live much longer, but extend their working lives longer as well. They will have greater access to lifelong learning and post-retirement work, which will keep them active and vigorous. So we will see much healthier elders along with more disabled oldest-old people. But with a smaller pool of caregivers, there will need to be more community-based resources and support services.

* It be a world in which geriatrics and elder specialties are sought-after professions because of the rewards in focusing on dignity and compassion. Older women will no longer be dismissed in medical care with a Valium and a pat on the head, but listened to and supported in their special health issues.

* It will be a world in which housing is adapted to the disabled and to extended families, reducing the burden on nursing homes and other expensive institutions. Yet there will still be so many older people, that

the risk of needing skilled nursing care at some point will remain high.

* Lastly, it will be a world in which old age is not a competition or something to be avoided. It will be embraced as wiser cultures view it: as an opportunity to share the wisdom of experience and guide younger generations to living more harmoniously and graciously.

Conclusion

Doomsayers would preach that the world has been overtaken by rage, greed, and resignation. I think that if you look into the back rooms of caregiving families, you will find the true nature of things as they are, beneath the veneer of social conditioning and confusion, stereotype and illusion. There you will find great kindness and devotion, a trust of life that surpasses doubt or pain. There you will find the highest expression of who we are.

If we close our hearts to suffering, we cannot open them to love. Every benevolent act counts. By surviving difficulties and holding onto goodness, caregivers inspire others to summon the power of the spirit. Humanity *can* emerge from violence and carelessness into an enlightened age of caring when the lessons of grief will be honored, exemplified by modern-day heroes who fulfill the age-old mandate: to give.

Senator BREAUX. Thank you very, very much for an excellent statement. I wish I could nominate the statement for the Pulitzer Prize. It was well laid out and I think it's been very helpful. And, we certainly encourage you to continue your efforts in speaking out on this very important problem. This is something that really I think too many people have neglected from a Congressional standpoint. And, I think that is changing and you are going to be part of that reason for the change.

Let me just ask this to try and understand your situation, which I would imagine is probably very typical of others when you were caring for your parents. Were you all in the same city, or were you in a different city from your parents?

Mrs. MCLEOD. No, typically, I left home as a teenager, when I graduated from high school. My parents lived in Kansas and I lived in California. So, I think it's about a third of all caregivers are long distance.

Senator BREAUX. So, in your personal situation, did you have to commute, did you end up moving, or what did you do?

Mrs. MCLEOD. When I offered to move home, my father always said, "We don't want our illnesses to become your lives." Of course, they were. So, I went back home about every 6 to 8 weeks. I had to take unpaid leaves of absence. I lost about 3 months salary and we ended up being bankrupted. We didn't officially file, but my husband and I spent about $30,000 or $40,000 from lost wages and from traveling back and forth and taking care of them.

Senator BREAUX. Were you an only child, or were there other children in the family?

Mrs. MCLEOD. No, but also very typically, I was the sibling who was the closer to my parents.

Senator BREAUX. And, I imagine because of the societal pressures that I guess typically the daughter is much more involved in this actual providing of care than the son or grandson would be.

Mrs. MCLEOD. That is true, but now it is—I think it is 70—it used to be 80 percent are women. Now it is 72 percent in the latest survey, so there are more men becoming involved.

Senator BREAUX. I was wondering whether in your family, had anybody ever looked into the question of long-term care insurance, or is that something like most families, it just wasn't an issue?

Mrs. MCLEOD. My father, because he had battled cancer for 25 years, had about fifteen insurance policies, but he had to keep cashing them out to live on them. My uncle is actually an insurance salesman and I assume that he either advised against it, or my parents could not qualify at that time. That was 1991, there were a lot of restrictions. So, they may not have been able to qualify for long term care insurance. It's very different today.

Senator BREAUX. So, obviously, Medicare did not cover their needs.

Mrs. MCLEOD. No.

Senator BREAUX. They were not in a situation at the beginning that would allow them to qualify for Medicaid.

Mrs. MCLEOD. Right.

Senator BREAUX. And so, all of their care really was through caregiving through the family.

Mrs. McLEOD. That's right. They went through—the entire family went through about $200,000.00, which was all that we had—all of our savings on all sides. My parents spent their retirement income. They spent every penny they had. My father's prescription drugs alone were $700.00 a month. And, their Social Security was $1300.

Senator BREAUX. Again, I would just say to our guests that are here, one of the things that we are trying to do—one of the many things that we are trying to do with Medicare—Medicare, obviously, does not cover prescription drugs for people who are not in the hospital. And, today, prescription drugs are as important as a hospital bed was back in 1965 when we first passed Medicare. Many times, it's even more important to keep people out of hospitals and yet, Medicare does not cover prescription drugs. It doesn't cover long term care. These are two areas that are probably becoming the most important for seniors, prescription drugs and long term care. And yet, just adding them to the program that is already going broke would be something that—unless we find a different way of paying for it, it does not make a great deal of sense. Do you think Beth, do you think that the concept of caregiving, what you went through, and what millions of Americans are also going through—is that concept any different in the 1990's as it was 10 years ago, 50 years ago—have you looked back—did we not always take care of parents, or is it a different focus today than it used to be?

Mrs. McLEOD. Excellent question. It is different and it was one of the things that bothered me the most, that I could not have been the only person who was losing parents. But because—probably because the structure of families is different now. There are more blended families, more long distance families and there are far more women in the work force. There is not someone at home any more. And, it is far more expensive. Medical care has changed. People did not live as long, so we didn't have the kinds of chronic disabilities to care for that we do now. So, it has changed.

Senator BREAUX. The point that she makes is a really good one. Just as an example, when Congress passed the Social Security program in 1935, there were like 16 people working for every one person who was receiving retirement benefits—16 working people for every one person retired. Today, because of the Baby Boom Generation, which is becoming eligible for retirement benefits, this explosion of Americans that was born between 1946 and 1964, there are a lot more of them that are on the retirement side of the equation. And, in addition the people on the retirement side are living a lot longer than they used to live. So, you have got a lot more people over here who live a lot longer. So, instead of having 16 people doing the work every day to pay the bill for the one person who is retired, that number has come down today until it is about three people working for every one person retired, and it is heading down even further, which is of course part of the concerns we are having. Beth, I think that you have made a major contribution. This book, I think, is something everyone should be familiar with and aware of. It really helps you who read it to answer a lot of the questions that I am sure Beth had to find out for herself. And, I may want to get back to Beth with some additional questions.

Senator BREAUX. I would like to present now Dr. Robert John, who is Professor and Chair of our Gerontology program here at ULM and we have asked Dr. John to really discuss the Gerontology program at the University and share some of the findings of the research they are doing here, which shows the problems of minority families in particular, and the problems that we are all experiencing in this area. Also, Dr. David Kerby. David is doing some important research. He is also a Professor here at the University. He will present research that shows that African American caregivers experience greater stress and his findings contradict, actually, some of the findings that we have heard from in other previous studies, so I'm interested in hearing what both Dr. John and Dr. Kerby have to say.

Dr. John, if you would go first, we would appreciate it. Thank you—thank you for letting us be here.

STATEMENT OF DR. ROBERT JOHN, PROFESSOR AND JOSEPH A. BIEDENHARN CHAIR IN GERONTOLOGY, GERONTOLOGY PROGRAM, UNIVERSITY OF LOUISIANA AT MONROE

Dr. JOHN. It's a pleasure to address the U. S. Senate about minority family caregiving. My first insight, however, is that our previous speaker did not leave much uncovered and I hope I get something in here that's new. But second—if you do not have handouts for the next two presentations, the figures will be hard to follow at least at some points, so there are handouts going out right now for the next two presentations.

What I would like to do, at least initially, is to describe the situation of minority family caregivers as briefly as possible. Basically, older members of minority groups are more reliant on family caregiving than non-Hispanic whites are. There is clearly less use of nursing homes among all the minority groups and what this results in has been termed the "bumping down" of care, which means that minority elders are cared for—very highly impaired minority elders are cared for in the home in a community setting, rather than a nursing home. If they were white, they would be in a nursing home. So, there's a "bumping down" of care.

In other words, minority families are the long-term care system for minority elders. But, as you all know, and as was referred to in the previous presentation, all families are changing. This is true of minorities as well as majority families. There are a number of people—I think a third of the Baby Boomers have no children. Clearly, fertility has declined, so there are fewer children. There's a tendency to delay child bearing. As was mentioned, there are more and more women in the labor force. To be successful in the labor force requires you to be mobile. And, there is longer life expectancy. So, there are a number of demographic changes that are going on in our society that really create pretty difficult problems for all families.

One of the stereotypes of minority families is that they follow an extended family model and I have no doubt that extended families might be the normative value that is predominant in all the minority groups. But, for the last decade or so, a number of researchers who study minority families have questioned whether extended family is a proper model to follow for minority families or to promote. And instead, they say maybe it is not extended families, maybe they are "extenuated" families. And, I think that kind of captures what is going on with most families, but in minority families in particular.

Both my colleague and I are going to report some results of some data that we have analyzed that came from the National Alliance for Caregivers and the American Association of Retired Persons. It was a nationwide telephone survey of a representative sample of 1500 self identified caregivers who speak English. There was an oversample of African Americans, Asian Pacific Islanders and Hispanics. But, American Indians were not included in this survey because of the cost. Some colleagues and I have done a study of American Indian caregiving in the Santa Fe, New Mexico Indian Health Service unit and I would like to offer that into the testimony. The lead author of this piece, Dr. Catherine Hennessy from the Centers for Disease Control was awarded the Service to the Public award in 1999, in recognition of her leadership on this project.

In other words, the data that we are looking at today really represents conservative estimates of between-group differences. The participants who did participate in this study were more assimilated and better off economically. The people who were excluded would have been new immigrants, the homeless, transient, non-English speakers, and those without a telephone. In that respect, the Hispanic and Asian Pacific Islander populations are the least well represented in this study, but unfortunately, this is a unique data set, and there's no better data available in the United States.

If you take a look at Table 1, you will see service use by the four groups. Essentially, you will see four tiers of services. In the first tier, there are assistive devices and personal care. Approximately a third to a half of family caregivers access these services, have used these services. In the second tier, you will see three services: house modification, such as a grab bar; medication information by a professional, and caregiver training in how to perform ADL's and approximately a fourth to a third of the caregivers access these types of services. In the third tier is housekeeping assistance, financial information, home delivered meals, respite and transportation. Fewer than one fifth of caregivers obtain any of these services. Then, in the last tier, day care, formal housing assistance, support groups and government financial assistance is really quite rare, less than 10 percent of the caregivers access these services. The other thing I would like to point out from this table is that the pattern of service use by each group is quite different and I think these have important policy implications as well as programming implications.

If you take a look at the next two tables (Tables 2 and 3). Basically, what these two tables do is compare all caregivers in this study versus just the primary caregivers. A couple of points that I would make regarding this is that these caregivers ask for more money, respite care and counseling support groups and the caregiving situations are really quite different and the needs are quite different between the populations. There is a series of recommendations I make in my full testimony and I will post that on my web page and you can get the whole testimony today, since I am not going to have time to really talk about the recommendations. Thank you.

[The prepared statement of Dr. Robert John follows:]

Testimony of Robert John

Joseph A. Biedenharn Chair in Gerontology
University of Louisiana at Monroe

Older members of minority groups are more reliant on family caregiving than older non-Hispanic whites. Research has consistently shown that nursing home use by highly impaired older members of minority groups is significantly less than nursing home use by frail older non-Hispanic whites. This difference between minority and non-Hispanic white elders has been explained by a combination of fewer economic resources and a cultural preference among minorities for care by the family.

The implication of this difference in the level of use of institutional long-term care services for minority family caregivers has been characterized as a "bumping down" of care. In other words, it is well established that family caregivers of minority elders care for more highly impaired individuals. Moreover, these families typically have fewer socioeconomic assets and use fewer formal services (especially in relation to need).

Overall, minority families are the long-term care system for minority elders. However, families are changing in the U.S. among all groups, making family caregiving within a community setting more difficult. There is a common stereotype that minority families are extended families and they are able to meet the care needs of minority elders. This is at least, in part, based upon recognition that an extended family ethic may best represent minority family values. However, for more than a decade attention to the difference between extended family norms and extended family behaviors has raised the possibility that minority families are "extenuated" families, as the needs of older family members stretch family resources beyond the capabilities of the family to provide care. With the U.S. Congress currently considering new initiatives to support family caregiving in community settings, I would like to address my remarks to the key issues of service use and service needs among family caregivers.

The results reported in my testimony come from a data set collected for the National Alliance for Caregivers and the American Association for Retired Persons. I would like to express my thanks to both of these organizations for making this data available for analysis. The research was conducted by telephone on a representative nationwide sample of 1,500 self-identified family caregivers. This data set is unique because it contains an oversample of African American, Asian and Pacific Islander, and Hispanic caregivers. However, American Indian caregivers were not included in the study because of the cost of identifying individual caregivers in a small population. Because the survey was conducted in English by telephone, the caregivers who participated in this study represent individuals who are more assimilated and better off economically. This means that the differences reported between groups are conservative estimates because family caregivers who are marginally integrated into the U.S. economy (i.e., new immigrants, homeless, transient, non-English speakers, those without a telephone) did not participate in this study. This selection process especially disfavored the Hispanic and Asian/Pacific Islander populations. Unfortunately, a better or more inclusive data set on family caregiving does not exist.

Although the data set contains information on a variety of important family caregiving issues, my remarks will concentrate on only two issues. I will compare caregiver's service use and point out important differences in the patterns of service use across the four populations. I will also compare these groups on their self-identified greatest service need. I will attempt to highlight important policy and programming issues in the process.

As seen in the first table, the pattern of service use by each group is quite different. In the first instance, patterns of service use are shaped by the service system. Services must be available, elders or their families must be aware of services, services must be accessible, services must be acceptable, and services must be affordable for all barriers to the receipt of services to be overcome.

A lot of reputable research has shown that older frail elders do not use services unnecessarily. These investigations have shown that the most powerful and consistent predictor of service use (with the exception of senior centers and congregate meals) is impairments of activities of daily living (ADLs and IADLs). Unfortunately, this body of research has also shown that services reach only a portion of the individuals with similarly high levels of functional impairment.

Family Caregiving Service Use by Race and Ethnicity (in percentages)

Service	Non-Hispanic White	African American	Hispanic	Asian/Pacific Islander
Assistive devices	50.0	50.7	46.3	35.6
Personal care	40.3	45.8	33.0	16.4
House modification	35.2	29.4	31.4	25.8
Medication information by professional	27.1	33.8	33.9	22.7
Caregiver training	23.0	32.7	28.7	17.4
Housekeeping assistance	17.1	13.8	15.6	14.8
Financial information	16.0	17.4	22.2	11.7
Home-delivered meals	16.0	18.2	13.9	6.9
Respite	15.4	15.7	10.2	8.5
Transportation service	14.3	22.9	21.7	15.4
Daycare	9.4	14.7	11.2	10.1
Formal housing assistance	8.4	6.2	3.9	3.8
Support group	7.1	6.0	5.8	5.7
Government financial assistance	2.4	5.3	3.6	4.9

Source: NAC & AARP, 1997.

The next two tables reveal the primary service need of all caregivers who participated in the study and those who identified themselves as the primary caregiver. A comparison between primary and other caregivers is important because there has been an ongoing debate within gerontology about the tendency to focus on the primary caregiver, with critics calling for attention to other caregivers in the family system. These two tables (and more detailed evidence not presented) suggest that from a policy and programming perspective deflecting attention from the primary caregiver will greatly dilute any well-targeted intervention efforts that could help family caregivers and the elders for whom they provide care. In short, in comparison to primary caregivers, many secondary or tertiary caregivers are nominal caregivers (i.e., caregivers in name only).

A second insight from this data is the need to fully consider the needs of the different caregiving populations. If the needs of non-Hispanic white caregivers determine the configuration of services, then the needs of minority family caregivers will be less well met, and perhaps poorly met. For instance, several services would be defined out if minority preferences are not considered. In particular, transportation is not as salient for non-Hispanic whites as it is for all of the minority populations. Alternately, meal preparation, which was one of the top service needs among non-Hispanic whites, is not a service of equal importance to any of the minority caregiving populations.

Primary Service Need Among All Caregivers by Race and Ethnicity (in percentages)

Service Need	Non-Hispanic White	African American	Hispanic	Asian/Pacific Islander
Don't Know	39.3	35.0	37.2	51.0
Nothing	20.2	15.2	17.9	14.7
More Money	5.5	8.8	8.3	9.2
Free Time, A Break	5.0	6.4	4.3	3.2
Counseling or Support Group	4.5	4.4	4.7	4.0
Place to Go or Call To Find Help	2.8			
Housekeeping	2.5	1.7	2.7	1.6
Transportation	1.8	4.4	5.3	2.8
Regular Monitoring	1.7	2.4		1.2
Family Help or Support	1.5	1.3	1.7	
Help Pay for Nursing Home	1.5			
Personal Care Assistant	1.3	4.4	1.7	
Companionship/Visitors		1.7	1.3	1.6
Meal Preparation		1.3		
Comprehensive Medical Assistance		1.3	1.7	2.0
Information About Condition			2.7	
Help Selecting Nursing Home				1.6
All Other Services	12.4	11.7	10.5	7.1

Source: NAC & AARP, 1997.

Primary Service Need among Primary Family Caregivers by Race and Ethnicity (in percentages)

Service Need	Non-Hispanic White	African American	Hispanic	Asian/Pacific Islander
Don't know	32.3	25.3	30.0	42.0
Nothing	18.9	13.7	12.9	14.0
Free time, a break	7.9	10.5		2.0
More money	7.1	10.5	14.3	14.0
Counseling/Support group	4.7	2.1	5.7	2.0
Place to go or call for help	3.9			
Personal care assistant	3.1	6.3	2.9	2.0
Housekeeping	3.1	3.2	2.9	2.0
Meal preparation	3.1			
Help pay for nursing home	3.1	3.2		
Regular Monitoring	1.6	3.2		
Companionship/Visitors	1.6	1.1	4.3	2.0
Transportation		5.3	7.1	6.0
Family help or support			4.3	
Medical advice or assistance				6.0
Information about condition			5.7	
Help selecting nursing home				4.0
Legal information			2.9	
All other services	9.6	15.6	7.0	9.4

Source: NAC & AARP, 1997.

Senator BREAUX. Thank you very much. Dr. Kerby.

STATEMENT OF DR. DAVID KERBY, PROFESSOR, UNIVERSITY OF LOUISIANA AT MONROE

Dr. KERBY. I addressed the issue of ethnic differences in caregiving. As Dr. John pointed out, this is a unique data set which gives some information we have not viewed before.

It can be summarized—I think that my information can be summarized by saying that it appears that black caregivers show more caregiver burden. One way that they show more caregiver burden is by the greater amount of activities of daily living in which they assessed. The first table we have here indicates seven activities of daily living in which they report their caring for. Activities of Daily Living called ADL's by Gerontologists. Perhaps they can be described as self care tasks. The self care tasks that we looked at, included helping with toileting, with feeding, dealing with incontinence, getting dressed, giving medicine. When we break this down by ethnic group, what we find are that for every single one of these caregiving tasks, African Americans are more likely to report that they engage in this activity. Most previous researchers just compared people who are already doing caregiving. This data set by having a random sample allows us to make inferences that there is a much greater burden in terms of activities performed by the African Americans. The mean value is about 2.6 for African Americans, and you see that it's much less by the other ethnic groups.

A second way that the greater burden is shown is by a second category—that's on the next page—the instrumental activities of daily living. These are things such as shopping for groceries, housework, preparing meals. In fact, when caregiving begins, they generally begin with these activities. And again, for five out of the six activities, African American caregivers report doing more and again their mean number is higher.

The final page reports another way in which African Americans are more burdened by care. The caregivers were asked how much time per week do you spend in caregiving. I've reported both the mean and the median values. But, African American and Hispanics—on average, using the mean—report 20 hours a week in caregiving. This is greater than the White and the Asian Pacific Islanders. One of the things that is rather contradictory from previous literature, I keep reading—again and again studies seem to suggest that African American caregivers report less stress, the least emotional stress. But on the final line here, there was a measure of self reported stress. They were asked in terms of financial burden, emotional burden and physical burden. And, they were asked to rate them on a scale of 1 to 5—1 being no burden at all, it is rather easy. And 5 being extremely burdensome. African Americans were significantly higher. Their average was 2.2, with quite a large number up at 5. And, this was greater than the other ethnic groups—the Hispanic, the non-Hispanic white, and the Asian Pacific Islanders.

So, in conclusion, data suggests to us that there are significant differences by ethnicity, in terms of caregiver burden. And when we look at activities of daily living, when we look at instrumental activities of daily living, when we look at hours of care and when we look at the amount of stress that they report, African American caregivers report greater burden in all four areas.

Thank you.

[The prepared statement of Dr. Kerby follows:]

Testimony of Dave S. Kerby
Assistant Professor of Psychology
University of Louisiana at Monroe

Thank you for inviting me to testify on family caregiving. I have been studying data from a nationwide random sample of 1,509 family caregivers. The survey oversampled minority caregivers, so it offers good data on minorities and caregiving. Of the 1,509 caregivers surveyed, 736 are baby boomers. I would like to describe some findings about ethnicity and caregiver burden among these boomers.

Briefly put, the evidence here suggests that Black caregivers show greater caregiving burden. This is a surprising result, because there is a common belief that Blacks experience less burden.

Activities of Daily Living

One source of evidence that black caregivers have more burden is that they report doing more tasks that involve self-care; these tasks are known as Activities of Daily Living or ADLs. Caregivers were asked about seven basic ADL tasks. These caregiving tasks are to help their family member do the following:

- Get in and out of beds and chairs.
- Get dressed.
- Get to and from the toilet.
- Bathe or shower.
- Deal with continence or with diapers.
- Feeding.
- Giving medicines, pills, or injections.

The most common response (41%) was to report doing no ADL tasks; 20% said they did only one ADL task. So doing ADLs is fairly uncommon.

The ethnic groups differed in how many ADL tasks they reported doing. Blacks said they did more than the other groups. The means for the four ethnic groups are given below:

Race	Mean
Blacks	2.6 (n=163)
Hispanic	1.8 (n=146)
White	1.6 (n=184)
Asian	1.4 (n=143)

Instrumental Activities of Daily Living

A second source of evidence that black caregivers have more burden is that they report doing more tasks that involve indirect care; these tasks are known as Instrumental Activities of Daily Living or IADLs. Caregivers were asked about six basic IADL tasks. These caregiving tasks are to help their family member do the following:

- Manage finances.
- Shop for groceries.
- Do housework (dishes, laundry, etc.).
- Prepare meals.

12

- Handle transportation.
- Arrange or supervise outside services.

While ADL tasks are uncommon, these IADL tasks are very common for caregivers. The most common response (24%) was to report doing all six IADL tasks. The table below gives the percent doing the IADL tasks:

Six Tasks - 24%
Five Tasks - 22%
Four Tasks - 17%
Three Tasks - 15%
Two Tasks - 11%
One Tasks - 7%
No Tasks - 3%

But again, Black caregivers report doing more IADL tasks. The means for the ethnic groups are given below:

Race	Mean
Black	4.4
Hispanic	4.1
White	3.9
Asian	3.7

Hours of Care

A third source of evidence that Black caregivers have more burden comes from the time spent in caregiving. The caregivers were asked to estimate how much time they spent each week. The baby boomer caregivers reported spending a mean of 17 hours a week in caregiving (standard deviation = 21). Black and Hispanic caregivers reported spending the most time in caregiving. Since a few high values pulled up the value of the mean, I report both the mean and the median below:

Ethnic Group	Mean	Median
Black	20	10
Hispanic	20	10
White	15	6
Asian	16	6

Subjective Strain

A fourth source of evidence that Blacks have more caregiver burden comes from the reports of subjective strain. The caregivers were asked to report their level of strain in three areas: financial, emotional, and physical. The rating went from 1 (not at all stressful) to 5 (very stressful). I computed an average level of strain, using the three ratings. Black caregivers reported the highest level of strain. The average ratings are given below:

Race	Mean
Black	2.2
Hispanic	1.9
White	1.9
Asian	1.8

Summary

In summary, the evidence from a nationwide study shows an interesting pattern of differences in ethnic groups in family caregiving. In particular, the evidence from this data set shows that Black caregivers experience more burden.

Black caregivers report doing more self-care tasks, or ADLs, for their family member. They also report do more indirect care tasks, or IADLs. In addition, Black and Hispanic caregivers report spending more time in caregiving tasks. Finally, Black caregivers report greater subjective feelings of strain from their caregiving.

Senator BREAUX. Dr. John and Dr. Kerby, thank you for your information. And when I hear numbers like you all have presented, I'm probably pretty terrible when it comes to numbers and statistics and everything else. But, what I need to know and I think many in the audience would be interested in knowing, what does all this mean? What does it mean to me as a legislator? What am I supposed to do? What do I get from these numbers that you all have presented to me that we're doing—or, we should be doing because we are not doing, or what problems do these numbers project, what is going to happen if we continue this trend? What do I need to do based on what you have just told me?

Dr. JOHN. I guess I will get a chance to do these policy recommendations after all.

First of all, if the needs of non-Hispanic whites determine service use, what is going to happen is, minority caregivers are going to be either left out or their needs are going to be poorly met. So, clearly, we need to pay attention to what the differences are between these groups, because there are real policy implications for that, you may need to design some specific programs that would address their needs.

The second thing, though, I think is just true of all caregivers, especially listening to the previous presentation to mine. But, there basically does need to be a thorough coordination and combination of programs that in the current situation tend to be defined and administered by separate types of organizations, (i.e. social services and medical care). And, we need to have some combination.

A third point would be that a piecemeal, single-service approach—meals on wheels, or home health aide—would be inadequate and we need to start thinking about services in terms of service packages. One of the things that this data does provide is, it tell us how these things go together for different populations.

A fourth point would be that we need to implement an integrated health and social service model case management system. Now, there are two types of case management, one good—and, as far as I'm concerned—one bad. But, we need to have a case management system that's a facilitator or a broker to services, a case manager that will help or assist the family caregiver or the disabled older adult to find the services that they need, rather than a gatekeeper. I think some case management systems serve that gatekeeper function and it is not very good for a family caregiving situation, because they are very complex situations.

And, the last point that I would make is that we need to design services to meet the needs of the primary family caregiver. One of the things I didn't get a chance to show in any great detail, but if you take a look at the comparison between Tables 2 and 3, is that primary caregivers have a more definite idea of what their needs are. Many secondary or tertiary caregivers are caregivers in name only. They are not really performing those kinds of services. So, where the rubber hits the road in terms of family caregiving, as far as I am concerned—although it's been an issue of debate in the literature of gerontology—is with the primary family caregiver and we need to pay attention to their needs.

Senator BREAUX. Dr. John, you mentioned a point that Baby Boomers have fewer children—and, the answer to this question is probably pretty obvious, but I'd like you to elaborate on it. I mean, it's absolutely true, my wife's father was the 17th of 17 children, which was a huge family. But, his family only had one —my wife is their only child. So, it's a big, big difference. The obvious problem that's out there—tell us what the implication is. I mean, you have all these—used to have a lot of children who were able to be around for a long time to take care of the parents. And now, all the Baby Boomers are having fewer and fewer children. I mean, how bad is this problem going to be in the sense that you have fewer and fewer families—I mean, families with fewer and fewer children available to be around to help take care of Mom or Dad or two sets of parents, for the husband and the wife?

Dr. JOHN. It's going to be a crucial problem. My own family is a case in point. I have two children. Sometimes I wonder about whether it was smart to have two, as one of them reaches age 16. But, I do and I think that in the future, I will receive some care from them. But, my sister, who is only 2 years younger than I am, has no children. I don't know what she's going to do if she can't prepare, lay away enough resources that can guarantee that she will have the kind of care needed as she grows older. One of the things that I think could be explored is a universal system of long term care insurance that might be modeled more upon Medicare or Social Security. If everybody were to buy into it, it seems to me you would realize the thing that you do not under the current system of private, individual insurance plans which is an economy of scale. A universal system would really be able to be a social insurance program that's so necessary in the United States to cover some of these really—in a way, catastrophic—potential life occurrences.

Senator BREAUX. Is it in the interests of Americans to delay as long as possible the entry of a senior person into a nursing care type of facility—I mean, there's a whole industry out there that covers everything from hospital stays to nursing homes, to home health care, to assisted living facilities, communities that are designed for seniors and you add that into the caregivers at home. It seems like there's a lot of options out there as to what is the best way to assist seniors as they need extra care. Can you give me just some general comment on this?

Dr. JOHN. I think we need a full continuum of care and so nursing home care is an option. Assisted living is an option. But, I think that most older family members would prefer to remain in the community. They would prefer to remain being cared for by their family. And so, I think that the programs that are needed are the ones that would support family care giving. This is particularly true of minority families.

Senator BREAUX. Beth, what were your choices—I mean, in deciding how best to care for your parents? Did you look at any of these other things, whether it was a nursing home or an assisted facility or community living facility?

Mrs. MCLEOD. No, I did not get that far. I really never knew what I was doing. We had a social worker who came on the case who always wanted me immediately to put both my parents in the nursing home. And then when hospice came on, that's what they wanted us to do. They never offered us any other options. I didn't know what resources were out there, until a year or two after my parents died and I started researching and talking. I had no idea. So, no, I did not, because I didn't know and I wasn't informed by the people who should have told me. But, my mother was incapable of making a decision. My father did not want to leave his home.

Senator BREAUX. Did you see this coming on gradually, or did it hit you all of a sudden like a ton of bricks?

Mrs. MCLEOD. The ton of bricks.

Senator BREAUX. The two things on Beth's point that I think could be helpful—Senator Grassley and I have introduced this legislation to establish the National Family Caregiver Support Program to work through the Older Americans Act, in order to try and help people know what is available, what the options are, how these options work in helping them to get people the information that is the best information that is available as to what is out there; what are your choices; what are your options; what are the cost ranges between those various options? So, we're going to try and get this thing pushed and I think it will be something that could be very, very helpful. In Louisiana alone, we have half a million, 500 thousand, family caregivers and I bet you a dollar to a doughnut that most of them entered into this job like Beth did, not really knowing where to go. All of a sudden, Mom and Dad are old, yesterday they were OK. Where do I go? Who do I see? What do I do? And, there's a huge lack of information about this, so we are looking at trying to help provide that information. There's a wonderful pamphlet—I would say just in passing—out on the desk, I think in the back—called *Caring Today and Planning for Tomorrow,* which is in the back if you care to pick it up. It really gives some terrific bits of information about the challenge and the difference between Medicaid and Medicare and the legal documents that you are faced with having to deal with and all the various options from aging in your own home to assisted living at nursing homes. All of this, I think, is really valuable information. Just take it with you back to the house and one day it may come in very handy.

Let me thank Beth. This lady has come all the way from California to be with us and we really appreciate her and her testimony. It's making a difference in helping us with this message.

And also, of course, Dr. John and Dr. Kerby for the fine job that ULM Gerontology Program does here in Monroe and look forward to working with them as well in the future. And, thank this panel very much.

Senator BREAUX. Let me invite up our next panel of witnesses to present information and testimony for the Committee. It will be Ms. Barbara Gaulden. Barbara is a caregiver and a high school teacher from Ruston who lives alone, with her 82-year old mother, Helen. Barbara's day begins at 4:30 a.m. ends around 8 p.m. And, I don't want to give you her testimony, but I think it's important to note that she feeds and bathes and dresses her mother and even leaves school sometimes during the lunch period to check with her and prepare her lunch. And, we want to hear about the problems and experiences that she's had in that regard.

Next to Barbara will be Joe Nastasi. Joe is a good friend of this Committee and myself, who is the chief executive officer for the Ouachita Council on Aging. And, he will describe the Council on

Aging's programs and activities that can assist caregivers and give seniors the opportunity to be independent in their own homes.

Next to Joe is Charlotte Moore. Ms. Moore, we are glad to have you. She is the team leader for Senior Services at St. Francis Senior Plaza. And, she will discuss the services for caregivers that are available at the new Senior Plaza, including the Adult Day Care Center.

Next to Charlotte, welcome Joy Huff. Joy, glad to have you with us. She is administrator and also the CEO of Christus St. Joseph's Home. She will describe a joint effort of the Booker T. Washington community and St. Joseph's Home to create a new senior center in a predominantly African American community here in Monroe.

So, welcome, all of you. Ms. Gaulden, we have you scheduled to go first. Thank you for being with us.

STATEMENT OF BARBARA GAULDEN, HIGH SCHOOL SCIENCE TEACHER, GRAMBLING STATE UNIVERSITY LAB SCHOOL, LINCOLN PARISH, LA

Ms. GAULDEN. Thank you, Senator Breaux. Good afternoon, my name is Barbara Gaulden. I am a high school science teacher at Grambling State University Lab School in Lincoln Parish. I also teach in the University's Project Upward Bound Program on Saturdays and during summer school. Before entering the teaching profession 20 years ago, I worked in the medical field as a certified respiratory therapist. I am a caregiver to my lovely and delightful 82 year old mother, a former elementary school teacher and child care center director. I am extremely pleased to be here today and very appreciative that this hearing is dedicated to addressing the crucial issue of family caregiving—an issue that enormously impacts my daily life and on an hourly basis.

I have a strong maternal and paternal family background filled with interesting characters and experiences. I have on sibling, a brother, who is 2 years my senior, lives in Texas, visits about three times a year and calls every Saturday around 3 p.m. I have a daughter who for most of her life has helped me in many ways fulfill my caregiving tasks. I believe this experience is responsible for the deep and abiding interest that she has in elderly affairs. I have been a part of the "sandwich generation", even before the term was coined.

As all encompassing as my present caregiving tasks are, they are minor compared to those of an earlier time in my life. In the early 1980's, my maternal grandmother came to live with my parents in their home. At that time, my caregiving duties included aging parents, grandmother and teenage daughter and son. My grandmother was no longer able to care for herself and maintain her own household. My grandmother died in 1988, at the age of 89. My father, a former high school principal and University Public Relations Director, died in 1996, at the age of 79. They both died at home, my grandmother from a stroke and my father from complications of Parkinson's and Congestive Heart Failure. Both were Medicare and Social Security recipients. Neither were financially well off in life. Both, as the eldest child in large families, had taken their share of responsibilities within those families, until their deaths.

My daily schedule is mind boggling. My mother and I are up at about 4 or 4:30 a.m. daily, except Sundays. Our morning ritual includes supervising her bath, dressing, breakfast and medication.

I leave a snack and lunch in a small cooler by the recliner in which she spends the day. I leave her surrounded by a well placed fortress of necessities; her portable respirator, potty, cooler with food and water, Med-Alert necklace, TV remote control, a basket with reading material, favorite CDs, the telephone and our beautiful little Tibetan Spaniel dog, CoCo, who is the best companion anyone could have.

I am able to come home often during lunch to check on her. I work in a very understanding and compassionate environment, I am happy to say. Many of my coworkers are experiencing similar circumstances, as are many of the parents of the students' that I teach. I manage to work daily and remain upbeat around the very, very active high schoolers that I teach.

My daughter is presently in graduate school and is no longer close enough to help and participate in the "tag team" approach of caregiving we once shared.

My mother is ambulatory with the aid of a walker. She has been asthmatic since infancy. Her medications include those for asthma, diabetes, hypertension and Tomoxifen therapy for the left breast mastectomy she underwent in 1989. I take her to all her medical appointments. Neither she nor I have very much of a social life. She does have friends that visit by phone daily.

She has had home health visits only for a very short period of time, after she had a fall several years ago. They were responsible for helping us get on a patient assistance program for two of her most expensive medications, Proventyl inhalant and Tomoxifen. In the past, these two medications alone cost over $200.00 a month.

I strive to keep a very positive attitude. I am grateful for each day whereby this status quo remains, and not take a turn for the worse. I have just recently started to think of my long term care. I have existed far too long under the Baby Boomer/Scarlet O'Hara mentality of "I'll think about it tomorrow".

In summary, I do the best that I can. Caregiving is a logistical, physical, emotional and financial strain, but I delight in being able to care for my mother. I applaud the National Caregivers Support Program proposed this year. I know that in the future there will be many more opportunities for relief for the nation's caregivers, such as available and affordable respite care and day care tax breaks, reduction in prescription drugs, just to mention a few.

Again, thank you for this opportunity and for your compassion on this issue.

[The prepared statement of Barbara Ann Gaulden follows:]

Barbara Ann Gaulden, Ruston, LA

My name is Barbara Ann Gaulden. I am a high school science teacher at Grambling State University Laboratory Magnet High School located in Lincoln Parish. I also teach in the University's Project Upward Bound Program on weekends and during summer school. Before entering the teaching profession 20 years ago, I worked in the medical field as a certified respiratory therapy technician. I am a caregiver to my lovely and delightful 82 years old mother. I am extremely pleased to be here today and very appreciative that this hearing is dedicated to addressing the crucial issue of family caregiving -- an issue that enormously impacts my daily life and on an hourly basis.

I have a strong paternal and maternal background filled with interesting characters and experiences. I have one sibling, a brother, who is two years my senior and lives in Texas. I have a daughter who for most of her life has helped me in many ways fulfill of my caregiving tasks. I believe this experience is responsible for her deep and abiding interest in elderly affairs. I consider myself to be a part of the newly coined "sandwich generation" caring for a parent and at times assisting my young adult child.

As all encompassing as my present caregiving tasks are, they are minor compared to those of an earlier time in my life. In the early 1980s, my maternal grandmother came to live with my parents in their home. At that time my caregiving duties included my aging parents, grandmother, and my teenage daughter and my son, who has since passed. My grandmother was no longer able to care for herself and maintain her own household. My grandmother died in 1988, at the age of 89 and my father, a well-respected university professor and writer, died in 1996, both at home. She died from a stroke and he from complications with Parkinson's Disease and Congestive Heart Failure. Both were Medicare and Social Security recipients; however, neither were financially well off in life nor left a monetary fortune behind. I imagine that I come from a long line of caregivers. My grandmother and grandfather, the oldest siblings of their families, took primary care financially of many of their respective siblings and parents.

Many would probably find my daily schedule mind-boggling. My mother and I are up at 4:30am, everyday except Sundays, our morning ritual includes her bath, combing her hair, dressing (which includes ironing an outfit), preparing and serving her breakfast as well as preparing her morning snack and noon lunch. Placing the latter two in a small ice chest by her chair. This ritual also includes the dispensing of my mother's medicine. My mother, ambulatory with the aid of a four-pronged walker, has been an asthmatic since infancy. She takes medication for asthma, diabetes, and hypertension daily. Mom had a left breast mastectomy in 1989 and also takes Tomoxifen therapy. Now, if you have noticed in the midst of all of this, I have yet to get myself together and ready to deal with close to a hundred high schoolers.

After years of caregiving, I have our daily ritual and routine "down to a science" (no pun intended, remember I am a science teacher). I leave my mother surrounded by a well-placed fortress of necessities; her cooler, water bottle, med-alert necklace, portable potty, an electrical breathing machine, her basket of magazines, favorite CDs, the telephone, TV remote, and our beautiful little Tibetan Spaniel dog, CoCo, who is the best companion anyone could ever have. At noon, I leave campus to come home and check on her condition. Although leaving campus on breaks is against school policy, I am fortunate enough to have an understanding supervisor and colleague support system. Somedays are better than others. My daughter has left for graduate school which has disrupted our "tag team" approach of caregiving and checking up on mom throughout the day. It also takes an "Act of Congress" (again, no pun intended) to schedule my evening school activities (PTA meetings, required attendance at certain athletic activities, etc.) around my caregiving responsibilities.

Mom is unable to attend church or any social events (she is a member of Delta Sigma Theta Sorority, a national public service organization). I take her to all of her medical appointments often having to take off early from school. Several friends as well as her church's missionary group call throughout the day to check with her. This is a good example of informal support network. How could I ever focus on my job if not for them?

Although I am at times stressed emotionally and financially beyond belief, I am grateful for each day my mother can remain at home and maintain this status quo. However, one of the worst things that could possibly happen happened-- mom fell while at home alone one day. This was before she had medical alert. Luckily, she was near the telephone and conscious to call my daughter at work. After this incident, mom received home health (for a very limited and restricted time)and learned about the medical alert program and a medicine program. I believe that it is unfortunate that such a horrible thing had to occur before I knew about a few of the possibilities available.

I have to admit that I have a talent for positive thinking and count my blessings as they occur. For example, two of her medications, Proventyl and Tomoxifen in the past cost slightly over $200.00 per month (can you imagine this on a teacher's salary). We can now get the Tomoxifen (Nolvadex) for free on a patient assistance program from the manufacturer and the Proventyl at a greatly reduced price. Another blessing is that my job is relatively close to our home. Again, I do consider my work environment to be compassionate and close-knit. I am aware that many caregivers are not as fortunate as I am and could benefit from a some type of family leave benefit similar to the one for pregnant women and expectant fathers. Many companies may want to look into adult day care system for their employees' elderly parents. They [companies] might benefit from tax incentives for offering such programs to employees who are caregivers.

As for taking charge of my own life and future long-term care plans. I am afraid that I have been negligent...carrying the Baby-Boomer/Scarlett O'Hara mentality of "I'll think about it tomorrow" at little too far. I am in recent years attempting to do better.

In summary, I have managed to take on the role of caregiver to the best of my abilities. I try to maintain a sense of humor throughout it all. However, I state that it is a tremendous logistical, physical, emotional, and financial strain more often than not. I constantly worry about what would become of my mother if something happened to me. My daughter is fulfilling her youthful goals and my brother, although just a phone call away, is not familiar with the "ins and outs" of day to day caregiving. I often feel guilty for even mentioning the downside of caregiving.

Specifically, I would like to state my support for the National Caregivers Support Program proposed this year in Congress, especially tax incentives for caregivers and employers who compassionately understand and support them; respite care; and a reduction in prescription drugs. Eventually, there may be incentives such as student loan waivers for new college graduates who committ to work with disadvantaged elders and their caregivers in rural and urban areas for a specified period of time.

Again, I am thankful for this opportunity to make a statement on the behalf of caregivers. We [Caregivers] are indeed looking to Washington for compassionate, understanding, fair, and sensitive legislation.

16

Senator BREAUX. Thank you very much for your testimony. I think that was very eloquently stated and appreciate your being with us. That is a real contribution. Joe, let us hear from you.

STATEMENT OF JOE NASTASI, EXECUTIVE DIRECTOR OF THE OUACHITA COUNCIL ON AGING

Mr. NASTASI. I am Joe Nastasi, who for the past 18 years has served as executive director for the Ouachita Council on Aging. We are also the area agency on aging for the Ouachita Parish Planning and Service area. We are a private, non-profit agency located in Monroe, Ouachita Parish.

First, I'd like to provide some demographics on our area. There are now some 25,000 senior citizens living in Ouachita Parish, of which one-third are minorities and one in every four are at or below the poverty level. They make up 17 percent of the total parish population. The typical elderly person is a white woman between the age of 65 to 70, she is widowed, and living alone on a fixed income and who is very dependent on her social security. Those who are 85 and older make up 7 percent of the elderly population. Of significance, and according to the 1990 census, there has been a 14 percent increase in those 60 and older, while the general population of the parish increased only a little over 2 percent. In the surrounding parishes, which are all rural, there are some 40,000 plus elderly persons and the demographics are similar to those in Ouachita, with some having higher percentages of elderly as they are remaining in place, while the young are leaving to seek better employment. So, there are more older people out there in those parishes.

We in Louisiana are fortunate in that our state legislature in the 1960's established a Council on Aging in every parish. The State also provides funding in addition to that funding that matches the Federal dollars, under the Older Americans Act. However, that funding is inadequate.

The Ouachita Council on Aging concentrates its efforts on those services that help our elderly remain in their homes as long as possible to prevent premature institutionalization. Seniors are much happier in their own abode.

We provide a wide variety of services. We operate one Senior Center and 12 satellite sites located in neighborhoods where seniors live, and we support two independent senior centers in the parish.

Some of our services—and, I'll not go into detail with them, because we have provided a brochure, but I'd like to outline them—one or two I might talk on.

First is information and assistance and referrals; Adult Day Health Care, which is fantastic program, which we now do in partnership with St. Francis Medical Center; Assessment and screening. We operate a Medicaid Enrollment Center, which does Medicaid applications, QMBs, SLMBs, and work with getting people SSI enrolled.

We have an in-home respite program. We're doing personal care. We send somebody in the home to spend 3 hours, so that caregiver can get out of that home or do what she needs, to buy groceries, just to go to bed, or do something.

We have housekeeping services, sending someone in the home to clean that elderly's home. Transportation, which is vital to getting people to dialysis, heart and cancer centers, as well as to their medical appointment, and other non-emergency trips.

We have a Medical Alarm Closet, in conjunction with the Medical Auxiliary, we have all kinds of durable medical equipment—hospital beds, wheelchairs, potty-chairs, all of those things that the seniors in many instances can't afford to buy.

Congregate meals and nutrition education. We have home delivered meals. In this parish we deliver over 500 meals a day. On the weekends we made arrangements through churches and several of our businesses whose employees prepare and deliver over 125 meals on the weekends.

Telephone companions—that's an emergency response system that's vital where they pin it around their neck, if they fall, they can get help within a matter of minutes.

Material aid—food, clothing, fans, heaters, we help them pay their utilities and the rent.

Wellness—many types of programs at our senior centers and satellite sites that they can come and get such things as blood pressure checks, cholesterol and blood sugar screenings, annual flu and pneumonia shots.

Legal Assistance—we have a lawyer available if they have a legal problem.

And, elderly housing.

While these services are vital, we do not have the funding to serve all persons that need these services. There's a long waiting list for some of these vital services.

We, as do all Councils on Aging, act as an entry point for seniors to receive services or obtain information and assistance. We tell them where they can go to get it.

Time does not permit me to go into details. I have, for the Committee, copies of our brochures, which define the services, and gives locations. I have provided them or will provide them with our annual report, which goes into much detail as to cost and funding as well as the services.

Every day, we are confronted with our inability to provide the necessary assistance that the caregivers need and deserve. I just wish you would spend, Senator, one day in our office, to see and hear these individuals who are so dedicated to their loved ones, who are so frustrated. We had one young man come in Thursday just furious that he couldn't get any services. I have a wonderful staff that calmed him down and got him where he could go—and we think he's going to be all right to get the services he needs for his 4 year old mental child.

But, you need to hear all of this, how dedicated they are and unless help comes soon—unless help comes soon, they're going to need care themselves. We have heard that, and I think it is very, very important.

I do appreciate the opportunity to appear before this Committee, and I do strongly recommend that the Congress do something about this family caregiving and let's get the Older Americans Act passed. Thank you.

[The prepared statement of Joseph Nastasi follows:]

Comments of Joseph Nastasi, Executive Director
Ouachita Council on Aging, Inc./AAA

I am Joseph Nastasi, who for the past 18 years has served as Executive Director of the Ouachita Council on Aging, Inc./AAA, non-profit agency in Monroe, Ouachita Parish, La..

First, I'd like to provide this Sub-Committee some demographics on our area. There are now some 25,000 senior citizens living in Ouachita Parish, of which 1/3 are minorities, and one in every four are at or below the poverty level. They make up 17% of the total parish population. The typical elderly person is a white woman between the ages of 65 to 70, widowed, and living alone on a fixed income and who is dependent on social security. Those 85 and older are 7% of the elderly population. of significance, there has been a 14% increase in those 60 plus, while the general population of the parish increased only 2.12%. In the surrounding parishes, which are all rural, there are some 40,000 plus elderly persons and the demographics are similar as to Ouachita, with some having higher percentages of elderly as they are all remaining in place, while the young are leaving to seek better employment.

We in Louisiana are fortunate in that our State Legislature in the 1960s established a Council on Aging in every parish. it provides funding in addition to that match money the federal government provides under the Older Americans Act.

The Ouachita Council on Aging concentrates its efforts on those services that help our elderly remain in their homes as long as possible to prevent premature institutionalization. Seniors are much happier in their own abode.

We provide a wide variety of services. We operate one Senior Center and 12 satellite sites located in neighborhoods where seniors live, and we support two other independent senior centers.

Some of our services are:

- Information and Assistance/Referrals
- Adult Day Health Care Center
- Assessment and Screening
- Medicaid Enrollment Center for:

- Medicaid applications
- Qualified Medicare Beneficiary (QMB) applications
- Specified Low-Income Medicare Beneficiary (SLMB) applications
- SSI application information

In-Home Respite/Personal Care
Housekeeping Services
Transportation, including wheelchair-lift equipped vans for dialysis, heart, and cancer centers, and other non-emergency transportation.
Medical Equipment Loans - hospital beds, walkers, wheelchairs, potty-chairs, etc.
Nutrition and Nutrition Education & Counseling

- Congregate Settings
- Home-Delivered Meals (Meals-On-Wheels)

Telephone Companions - an emergency response system
Material Aid - Food, clothing, fans, heaters, payments on utilities and rent

Wellness - many types, such as: foot care, blood pressure checks, cholesterol and blood sugar screenings, annual flu and pneumonia shots
Legal Assistance Services
Elderly Housing

While these are vital services, we do not have funding for all persons and there is a long waiting list for some of these vital services.

We, as do all Councils on Aging, act as entry points for seniors to receive services or obtain information and assistance.

Time does not permit me to go into details. I have, for the Committee's use, copies of our brochure, which defines services, and gives location of all other providers of services for the elderly in our community.

Finally, I strongly urge the Congress to pass a bill this session providing assistance to family caregivers. Every day we are confronted with our inability to provide the necessary assistance these caregivers need and deserve. I just wish you could spend one day at our office to see and hear these individuals who are so dedicated to their loved ones, yet unless help comes soon, will themselves need care.

I do appreciate the opportunity to appear before this Committee.

Senator BREAUX. Thank you very much, Joe. Next we will hear from Charlotte Moore. Ms. Moore.

STATEMENT OF CHARLOTTE MOORE, TEAM LEADER FOR SENIOR SERVICES, ST. FRANCIS SENIOR PLAZA

Mrs. MOORE. Thank you, Senator Breaux, it's my pleasure to be here today. I'm going to talk to you about St. Francis Senior Plaza. But, before I talk about the Senior Plaza, I need to give you a little background of how the Plaza came about.

St. Francis Medical Center is a non-profit organization of the Franciscan Missionaries of our Lady located in Monroe, Louisiana. Opening in 1913, the hospital is a part of the long-standing community history and tradition. As a part of the St. Francis Medical Center's strategic planning, the hospital was committed to develop a Center of Excellence for Elderly Affairs. St. Francis Medical Center historically has cared for the aging community and acknowledges that that population is a significant portion of their market. Seniors represent approximately 60 percent of the hospital's in-patient population and 30 percent of outpatients. St. Francis Medical Center was responsive to several issues that prompted senior services commitment. These issues included rapidly increasing senior demographics, significant shifts in reimbursement, and different needs and expectations of a "young/old" senior population and a need to continue to build a fully integrated delivery health care system. It was apparent to St. Francis leadership that the traditional models of care were not appropriate or acceptable and that a new model must be designed to accommodate seniors with greater needs and expectations that included prevention, wellness, and holistic components.

Realizing that a community centered model was important outside the parameters of downtown acute care campus, a feasibility study was initiated that included a search for an appropriate location. That ideal location was found in the 39,000 remaining square feet of a vacated Wal-Mart store that was centrally located between lower and higher economic communities. The Plaza was designed as a community centered facility exclusively serving seniors in Northeast Louisiana.

In the beginning, several things influenced our thinking. We knew the senior segment of our population was growing at a rapid rate and that it had in fact intensified the need for tailored primary care for older adults. We looked at the demographics in Louisiana and Ouachita Parish and correlated them to the national growth trends. We found that the 65 plus population of Louisiana represented 500,000 people with 11 percent of all ages. The population increase between 1990 and 1996 was 6.5 percent. I think this is something that is very unique to this area and that we all need to listen to very closely. Northeast Louisiana has the highest percentage of elderly in the state and is considered a future growth area for senior adults who are aging in place. In the St. Francis Medical Center service area alone, there are 80,000 Medicare beneficiaries with another 45,000 who are age 55 to 64.

Some other considerations for our unique and innovative approach were the young/old population group, having very different expectations of health care. We knew that the Federal and state resources (Medicaid and Medicare) were rapidly decreasing and ailing, and that traditional models of healthcare designed along the "sick model" would no longer meet the needs and challenges of either consumers or healthcare funding sources.

Finally, we realized that the community centered services with viable partnerships would be a necessary link for this system to be successful. St. Francis set out to design a new healthcare delivery system, one that was designed especially for 55 and over seniors, and that spanned the quality of life continuum beyond healthcare to include social, educational, and wellness components. Viable partnerships were nurtured between St. Francis, the University of Louisiana at Monroe and the Gerontology Department, and the Ouachita Council on Aging.

The vision for a new model of service delivery for seniors was followed up with creative planning and community collaboration. Throughout the planning and development phase, the architect and key service personnel were guided by a consulting gerontologist who kept the process focused intensely on senior appropriate issues, such as colors, lighting, outdoor patio space, accessibility, furnishings, and suite locations. Now that it is complete, the Senior Plaza is a hub of services for the elderly that makes up the existing St. Francis programs, and some new ones that we added to it—community collaboration between NLU Institute of Gerontology and the Ouachita Council on Aging.

Several other groups have joined us since we opened a year ago. The Alzheimers Association is there and also the Monroe City Schools has a GED class for seniors. And, it is real cute in that class—the oldest one is 84 and the youngest one is 63.

Some other services in the Senior Plaza are St. Francis Senior Health Clinic, where the area's only Gerontologist is located; St. Patrick's Partial Health Hospitalization Program and the ULM Institute of Gerontology Research Center; within that, we have a computer lab, where we are teaching seniors how to use the computer. We teach basic, intermediate and Internet. We have graduated 500 over the last twelve months and we have 200 on our waiting list.

We also have St. Francis Agency, located within the Senior Plaza, which is a Medicaid supplement insurance. We also have Geriatric Rehabilitation Services and Our Community Case Management and Geriatric Assessment Department is also there. We have home health, hospice and home infusion.

But, one of the things that we are most proud of is our Ouachita Adult Day Care, which is in partnership, once again, with the Ouachita Council on Aging. I have to stop here and say, Senator Breaux, that I feel like that Day Care is probably the best kept secret in healthcare. It's a wonderful program for seniors or adults that are living at home with people who work. It's just like child day care, only it provides, many, many more services. We feed them lunch, there's activities for them, and they're supervised until they go home at 2 o'clock, or 3 o'clock, or 5 o'clock, which ever.

When we first started this program, we realized that we wanted to expand it. Right now, Medicaid pays for a portion of the Day Care clients. We wanted to expand the fore pay part of it, because we felt like this was a need that we could give the community that they had not had the opportunity to have before. So, we set about thinking that if we could establish a scholarship for those people who, like your mom and dad and my mom and dad and everyone out here in the audience who has worked all their lives, and need that, you have a funding source for the very poor and the very rich probably don't need it—but, those people who have worked every day of their lives, paid their income tax, have been a viable part of society, really cannot afford to pay for day care. So, we thought if we had a scholarship fund that we could offer to people with dementia and other problems, that we would really be filling in a gap. We realize that government cannot do it all, so we went to this concept in the scholarship fund. I went to several people in the community and CenturyTel has donated some money to us. But, I'm proud to say that today we established the Kitty Degree Scholarship Fund at the Ouachita Adult Day Care. And, Ms. Kitty has generously given us a $110,000.00 over the next 4 years for Adult Day Health Care. So, we're very proud to be able to say that today.

I can honestly say that the Senior Plaza took a tremendous commitment on the part of everyone in the community. It has been a very viable part of the community for the last year. We realize that there are some things we have to do different, but it's been a wonderful place for seniors to be able to come to under one roof and receive so many benefits.

I'm very proud to say that it's enjoyable to go to work every day and see that I am helping so many seniors, and they are getting so much out—and I know so many of you in this room have that same feeling. But, I would certainly love for Senator Breaux and his staff to come see us one day at the Senior Plaza and just see what a great unique concept it is in Northeast Louisiana. Thank you.

[The prepared statement of Charlotte Moore follows:]

Statement of Charlotte Moore
St. Francis Senior Plaza
Monroe, LA

St. Francis Medical Center (SFMC) is a non-for-profit organization of the Franciscan Missionaries of our Lady located in Monroe, Louisiana. Opening in 1913, the hospital is a part of the long-standing community history and tradition. As a part of the recent SFMC strategic planning, the hospital committed to the development of a Center of Excellence for Elderly Affairs. St. Francis Medical Center has historically cared for the aging community and acknowledges that population as a significant portion of their market served. Seniors represent approximately 60% of the SFMC's in-patient populations and approximately 30% of outpatients. SFMC was responsive to several issues that prompted senior services commitment. These issues include: rapidly increasing senior demographics, significant shifts in reimbursement, different needs and expectations of a "young/old" senior population and a need to continue to build a fully integrated delivery health care system. It was apparent to the SFMC leadership that the traditional models of care were not appropriate or acceptable and that a new model must be designed to accommodate seniors with greater needs and expectations and include prevention/wellness/holistic components. THE SFMC intended to collaborate and desired relationships with partners, who like themselves had creditable history and commitment to the senior community.

Realizing that a community centered model was important outside the parameters of the downtown acute care campus, a feasibility study was initiated that included a search for an appropriate location. The ideal location was found in the 39,000 remaining sq. feet of a vacated Wal-Mart building that was centrally located between lower and higher socioeconomic communities. The location was on public transit lines with a large parking lot for easy access capability. The remaining portion of the Wal-Mart space was occupied by Books-a-Million and Sports & Co. The Plaza was designed as a community centered facility exclusively serving seniors in Northeast Louisiana.

In the beginning, several things influenced our thinking. We knew the senior segment of our population was growing at a rapid rate and that had in fact intensified the need for tailored primary care for older adults. We looked at the demographics in Louisiana and Ouachita Parish and correlated them to the national growth trends. We found the 65+ population of Louisiana represented 500,000 people which was 11.9 percent of all ages. The population increase between 1990-96 was 6.5 percent. Northeast Louisiana has the highest percentage of elderly in the state and is considered a future growth area for senior adults who are aging in place. In the St Francis Medical Center service area alone, there were 80,000 Medicare beneficiaries, with another 45,000 who were ages 55 to 64.

Some other considerations for our unique and innovative approach were that the young/old population group have very different expectations of healthcare. We knew that the federal and state resources (Medicare and Medicaid) were at capacity and ailing, and that traditional models of healthcare designed along the "sick model" would no longer meet the needs and challenges of either consumers or healthcare funding sources.

Finally, we realized that a community centered services with viable partnerships would be a necessary link for this system to be successful. SFMC set out to design a new healthcare delivery system, one that was designed especially for 55-and-over seniors, and that spanned the quality of life continuum beyond healthcare to include social, educational, and wellness components. Viable partnerships were nurtured between SFMC departmental team leaders, Northeast Louisiana University Institute of Gerontology, and the Ouachita Council on Aging.

The NLU Institute of Gerontology is located on the campus of Northeast Louisiana University in Monroe, Louisiana. It is a flagship University for aging, education and research for the state of Louisiana. Their

19

mission is three fold, education, research and service. The philosophy of the NLU Institute of Gerontology is to provide academic courses and training in gerontology for college students; present workshops and seminars in the field of aging; and administer and conduct research in the area of gerontology. Community service programs are provided through the Institute of Gerontology. These services include the Retired and Senior Volunteer Program (RSVP), Senior Community Service Employment Program (SCSEP), JTPA for Older Workers and Elderhostel.

The Institute of Gerontology plays a significant role in the community. Currently, the Institute of Gerontology has several hundred students enrolled in the undergraduate program and the graduate certificate program. The Master of Arts in Gerontology has over fifty students enrolled in the three-year-old program. In addition the NLU Institute of Gerontology opened a Resource/Research Center located in the Library of the St. Francis Senior Plaza. A full time Librarian is available to assist Seniors with checkout items such as books, audio and video tapes as well as information, journals, magazines and newspapers. The Resource/Research Center offers Computer Classes to Seniors free of charge. This computer skills lab offers Basic, Intermediate, and Internet Classes five days a week. The Library at the Senior Plaza offers comfortable reading/study areas throughout and is available for book reviews and signings as well as informational meetings.

Ouachita Council on Aging (OCA) is the designated Area Agency on Aging, with 12 Activity Centers that have congregate meal sites. During the past year, they served 1,116 people meals at the congregate meal sites and approximately 600 persons with Home Delivered Meals/Meals on Wheels throughout Ouachita Parish. Ouachita Council on Aging is an advocate for older citizens, administering programs and coordinating services for elderly persons. OCA is involved in the delivery of some twenty-five different programs, as well as operating a Senior Center and an Adult Health Care Center that is located in the Senior Plaza.

The vision for a new model of service delivery for seniors was followed up with creative planning and community collaboration. There was no downside, and this is what brought the three distinguishable services together. Throughout the planning and development phases, the architect and key service personnel were guided by a consulting gerontologist who kept the process focused intensely on senior appropriate issues such as colors, lighting, outdoor patio space, accessibility, furnishings, flooring, suite location, etc. Now that it is complete, the Senior Plaza is a hub of services for the elderly that's made up of existing SFMC programs, new SFMC services, and community collaborative services. The new services include NLU Institute of Gerontology Resource/Research Center and the MedWise Primary Care Clinic under the medical direction of Dr. Sunil Prem, M.D., the regions only Geriatrician. Dr. Prem is a Fellowship trained physician who has been well received in the community. The goals for all patients who come to the MedWise Clinic include: aging with grace; living with dignity; staying active, ambulatory and physically fit, living near loved ones as long as possible; making timely decisions about the end of life care; and educating caregivers on medically complex issues.

The services/programs of the Senior Plaza include:

- MedWise Primary Care Clinic
- Ouachita Adult Day Health Care
- St. Patrick's Partial Hospitalization Program
- St. Frances Home Services:
- * Home Health
- * Hospice
- * Home Infusion
- NLU Institute of Gerontology Resource/Research Center with Library & Computer Lab
- Geriatric Rehabilitation Services

- Community Case Management/Geriatric Assessment
- Secure Partners/Serria Health and Life Insurance
- Ouachita Council on Aging Activity Center
- St. Francis Prime Time Club
- 2 Conference Rooms
- Calendar of events/activities

To our knowledge, this unique collaborative model has not been replicated to date in the United States. However, this model could be replicated in any city with a population of approximately 50,000 or more where senior service organizations were willing to pool resources for an actual center. It is not the physical plant in itself that offers the replicability potential, but it is the collaborative opportunities of any community, regardless of size or resources that is replicable. Senior Plaza is "one" communities approach to expanding and strengthening senior services through community collaboration.

The Senior Plaza took tremendous commitment, communication and determination to come to fruition. The first few meetings to discuss this collaborative effort to craft a multi-purpose complex for senior adults was tense with all of the different organization's agendas. These seasoned organizations as expected were bewildered by the complex issues they were confronted with in geriatric care, education and services. However, they were all determined to provide adult seniors with the services and activities suited to their particular needs.

One of the outcomes of a collaborative model of this nature is that it does provoke thought on how segregated agency agendas can be, how diverse organization goals can be and how individually limited resources can be. There is potential however, for balance in a community collaborative model because providing more comprehensive and better services are typically underlying goals for most organizations.

The Senior Plaza brought together several competing groups to form a partnership whose philosophy recognizes that people 55 and older need specialized service. The construction of the Senior Plaza in the community was a way to demonstrate to the public that these different groups can come together for a common cause. Aging brings both challenges and opportunities and by having a place "just for seniors" brings about some positive awareness that our society needs.

To date, the Senior Plaza is on target with established outcome measurements of increased market share, reduced hospital average length of stay, financial targets, monthly utilization targets, customer satisfaction, and community receptiveness to the model. On the average, approximately 200 seniors per day access one or more of the services/programs within the Senior Plaza. In fact the Senior Plaza has been awarded "Best in Category Award for Remodeling and/or Renovation Project by *The Society for the Advancement of Gerontological Environment* (SAGE) and will be published in the Nursing Homes Magazine's Design '99 innovative awards issue for long term care.

The impact Senior Plaza has been extremely positive as anticipated. The community has benefitted from the new services expanded services, and most importantly, it's accessible. The Senior Plaza has through a broad array of services/programs enhanced a continuum of care for seniors that encompasses social, health, psychological, and educational components. Earlier this fall over 1800 flue vaccines were given at the Senior Plaza to seniors 65 and older. In addition, the Monroe City School Board holds a bi-weekly GED and literacy class for seniors. The youngest student is 64 and the oldest is 86 years old.

These three organizations had goals that led to the large prize of providing what is called "seamless care" to patients. They knew if it was done right, it was going to save money, and people were going to have the opportunity to be in control of their health care. There were more reasons to collaborate than not. For SFMC the reasons to collaborate are: shrinking funding; acknowledgment of significant increasing market;

continuum of care expansion, desire to increase community values as a community asset; and desire to collaborate for increased capabilities. For NLU: limited funding; restricted research environment; increased collaborative grant opportunities; advance gerontology placement for assistantship, certified and graduate students; enhance community presence; and contribute to quality of life for seniors. For OCA: limited funding, space capacity; service capacity; grant opportunities; expand quality of life services for seniors; and the desire to reach the private sector.

The pooling of resources from these three organizations certainly increased ability that did not exist in the independent environments. While SFMC predominantly funded the capital for the physical structure, those costs are offset by sq. footage leases from the Council on Aging. Through two different grants, $30,000 was secured to defray costs of stocking the Library within the Resource/Research Center. Various levels of labor through staffing is supported by all three organizations, which increases the cost effectiveness of the model. In addition, the Senior plaza provides an excellent internship and assistantship site for Gerontology students. SFMC realizes benefits of cost effectiveness in its ability to care for seniors in alternative environments outside the realm of expensive acute care services.

Continuation is integrated securely within the scope of work for all three organizations. In reality, expansion is underway for several of the programs that were underestimated from a utilization standpoint in the development stage. The computer classes currently have a waiting list of over 300 people! The adult Day Health Care has applied for and was awarded additional Medicaid slots for funding, the activity and education facilities are at capacity, and the G.E.D. classes have a waiting list. There is approximately 2,500 sq. feet of the original floor plan that was left undeveloped for future growth. At the present time, an expanded conference room/dance floor for ballroom dancing is under construction. The three organizations remain committed to the relationship that contributed to the reality of the Plaza and they continue to explore other collaborative opportunities with one another as well as considering other partners.

Senator BREAUX. Thank you very much, Mrs. Moore. Next we will hear from Joy Huff—Mrs. Huff.

STATEMENT OF JOY HUFF, ADMINISTRATOR AND CEO, CHRISTUS ST. JOSEPH'S HOME

Mrs. HUFF. Thank you. Senator Breaux, I am honored today to speak at a field hearing and to speak about an innovative concept of two healthcare providers, each very unique, and how we are uniting together to address the caregiving needs of seniors in an historically underserved area of Monroe.

Christus St. Joseph's Home has been providing care to Monroe's elderly for over 55 years. We provide skilled nursing, intermediate nursing, and assisted living services all on one campus. Christus St. Joseph's Home is part of the Christus Health System, which is one of the ten largest Catholic health care systems in the United States. This Faith-based system includes more than 30 hospitals and long-term care centers spanning five states.

Last year, Christus St. Joseph's Home became involved with a local outreach program, the Booker T Outreach Center through our sponsoring congregation, the Sisters of Charity of the Incarnate Word, from Houston, TX, through their affiliation with the McAuley Institute. The McAuley Institute receives funding from the Sisters of Charity and is the Technical Assistant for the Booker T Outreach Center.

The Outreach Center is dedicated not only to providing referral services to the citizens of its community but to see that adequate housing is also available. The center is committed to revitalizing this neighborhood.

The connection was imminent—an elderly community with many needs and a health care system dedicated to the poor and the underserved. As background, the Booker T Community is the largest neighborhood in Monroe. It has a population of 6500, with 60 percent of that population being over the age of 65. The average age in Booker T is 75. Most of these elderly are homeowners with an average income of $376.00. Most are on SSI since employers of that generation did not pay Social Security taxes for their employees.

There has been no new construction in Booker T for over 15 years. And, as a result, most family members have chosen to leave the neighborhood for better opportunities. The conditions of the housing are deplorable. Many do not have adequate or even working plumbing; many have holes in the ceilings and the floors; many have rodents; some even receive electricity from neighbors, with extension cords and bare light bulbs. The housing needs are great, but these elderly are proud. They do not want to be moved from this community where they have homes and have raised their children.

As a result, the Booker T Outreach Center and Christus St. Joseph's are teaming together with the help of the McAuley Institute to develop a unique model of care as an option for caregivers. This model will allow seniors to stay and "age in place" in their community. It is our vision that we will build affordable continuum of care that will include 28 independent living apartments, a 40 unit assisted living complex, and a 40 bed nursing facility and Alzheimers unit.

Currently, the only type of long term care provided in Booker T is intermediate care. There currently is not available independent or assisted living. the seniors have no options for remaining independent except to stay in unfavorable, unhealthy, unsafe homes or to move to a nursing home. As you are aware, it is important for seniors to remain independent as long as possible.

The challenge for this concept is the ability to find subsidized assisted living funding. Without subsidies, this level of care cannot be met for these seniors. Assisted living, as we all know, is defined as a combination of housing, health care and supportive services with minimal assistance with activities of daily living, such as bathing, medication assistance, and dressing. Louisiana does not currently provide any assistance for this level of care.

There are monies available for subsidized independent living apartments. There is also Medicaid funding available for nursing facility care; however the funding level is the lowest in the country at $63.21 per day, which is $22.00 a day below the southern regional average for nursing home care.

We feel that this project will allow this community to stay intact. It is our vision that family care givers will see this as an opportunity for help and relief from the burden and stress of caregiving. As I stated earlier, most of these children of these seniors do not live in this neighborhood any longer and would require long distance caregiving or that the senior would have to move out of the community.

As a provider of care to the elderly for almost 20 years, I have seen the needs change. It is collectively our responsibility to see that seniors, regardless of their economic status are afforded a safe, secure and healthy community in which to live. This concept will provide for that for this underserved community.

Thank you.

[The prepared statement of Joy Huff follows:]

Good afternoon. My name is Joy Huff. I am CEO of CHRISTUS Health Monroe which operates CHRISTUS St. Joseph's Home, a 132 bed nursing facility and CHRISTUS St. Joseph's Assisted Living Center, a 60 unit assisted living center.

Senator Breaux, I am honored to be included in this field hearing today and to speak an innovative concept of how two providers, each very unique, are uniting to address caregiving needs of seniors in an historically underserved area of Monroe.

CHRISTUS St. Joseph's Home has been providing care to Monroe's elderly community for over 55 years. We provide skilled nursing, intermediate nursing, and assisted living services all on one campus. CHRISTUS Health Monroe is a part of the CHRISTUS Health System which is one of the 10 largest Catholic health care systems in the United States. This faith-based system includes more than 30 hospitals and long-term care facilities in five states.

Last year, CHRISTUS St. Joseph's Home became involved with a local outreach program, the Booker T Outreach Center through our sponsoring congregation's, the Sisters of Charity of the Incarnate Word, Houston, TX, affiliation with the McAuley Institute. The McAuley Institute receives funding from the Sisters of Charity and is the Technical Assistant for the Booker T Outreach Center.

The Booker T Outreach Center is dedicated to not only providing referral services to the citizens of its community but to see that the adequate housing is also available. The center is committed to revitalizing this neighborhood.

This connection was immanent - an elderly community with many needs and a health care system dedicated to the poor and underserved. The Booker T Community is the largest neighborhood in Monroe. It has a population of 6500 with 60% of the population being over the age of 65. The average age in Booker T is 75 years. Most of the elderly are homeowners with an average monthly income of only $376. Most are on SSI since employers did not pay social security taxes for these residents.

There has been no new construction in this community for almost 15 years. Most family members have chosen to leave the neighborhood for better opportunities. As a result, the conditions of the housing is deplorable. Many do not have adequate or even working plumbing; many have holes in the ceilings and the floors; many have rodents; some even receive electricity from neighboring houses with extension cords and bare light bulbs. The housing needs are great - but the elderly people in this community are proud. They do not want to be moved from this community, where they have homes and have raised their children.

As a result, the Booker T Outreach Center and CHRISTUS Health Monroe are teaming together with the help of the McAuley Institute to develop a unique model of care as an option for care givers. This model of care will allow seniors to "age in place" in their own community. It is our vision that we will build an affordable continuum of care that will include 28 independent living apartments, a 40 unit assisted living complex, and a 40 bed nursing facility and Alzheimer unit.

Currently, the only type of long term care provided in the Booker T community is intermediate care. There currently is not available any independent or assisted living. The seniors have no options for remaining independent except to stay in unfavorable, unhealthy, and unsafe homes or to move to a nursing home. As you are well aware, it is very important for seniors to remain independent for as long as possible.

The challenge for this concept is the ability to find funding for subsidized assisted living. Without subsidies, this level of care is not affordable for these seniors. Assisted living is defined as a combination of housing, health care and supportive services that responds to individual needs with minimal assistance with activities of daily living, such as bathing, medication assistance, and dressing. Louisiana does not

23

currently provide any assistance for this level of care.

There are monies available for subsidized independent living apartments. There is also Medicaid funding available for nursing facility care; however the funding level is the lowest in the country at $63.21 per day, which is $22 a day below the southern regional average for nursing home care.

We feel that this project will allow this community to stay intact. It is our vision that family care givers will see this as an opportunity for help and relief from the burden and stress of care giving. As I stated earlier, most of the children of these seniors do not live in this neighborhood any longer and more than likely would have to move their parent from this neighborhood to get the proper care.

As a provider of care to the elderly for almost 20 years, I have seen the needs change. It is collectively our responsibility to see that seniors, regardless of economic status, are afforded a safe, secure, and healthy community in which to live. This concept will provide that for this underserved neighborhood.

Senator Breaux, thank you for allowing me to address this committee and I will be happy to answer any of your questions.

24

Senator BREAUX. Thank you and thank all of the panelists. I think you all have provided some insights into what is happening in the community and what is happening with some of the institutions that are involved.

Joy, let me ask you, how is the project you talked about being financed—is that strictly private or are you talking about the apartments and some of the things you all talked about.

Mrs. HUFF. There's some Federal dollars available.

Senator BREAUX. Is HUD money involved in that.

Mrs. HUFF. Well, the independent living.

Senator BREAUX. And, Joe, on the services that you provide through the Council on Aging, do you find that it's more and more people trying to take care of parents, or elderly, in their homes than there were?

Mr. NASTASI. We see it every day, Senator, Every day we get calls—what am I going to do; how am I—what can I handle, how am I going to do this, where can I get this service—you know—why aren't you providing more money—why aren't we providing more money.

Senator BREAUX. Do you ever get asked if Medicare covers any kind of long term care—I bet you get that question asked all the time?

Mr. NASTASI. It doesn't.

Senator BREAUX. That is, most people think it does——

Mr. NASTASI. They think it should—and it should.

Senator BREAUX. I bet you more people that call think it probably does until they find out, you have to tell them no, it does not.

Let me ask Ms. Gaulden, are you the only one that's providing the care for your mother, the other children in the family live nearby or not?

Ms. GAULDEN. I have a brother. He lives in Texas. And, I'm the only one—it's just the two of us.

Senator BREAUX. So, the burden is really on you?

Ms. GAULDEN. Definitely.

Senator BREAUX. I don't want to get too personal about it, but I would imagine that you are talking about respite care for you—I mean there's got to be an awful lot of people out there that are just like you are, that work every day at full time jobs and then do other—even more than full time job, taking care of an 83 year old mother. How do you get a break?

Ms. GAULDEN. I hardly ever get a break, honestly. I enjoy my work and I consider that my break, and going shopping—grocery shopping. Honestly, very seldom do I get a break.

Senator BREAUX. Is there any type of services, Joe, through the Council that—try and encourage, I guess, volunteers to sort of come in and maybe help relieve someone like Ms. Gaulden—are there probably hundred in the Ouachita Parish area?

Mr. NASTASI. She lives in Union Parish—Lincoln Parish.

Senator BREAUX. How about for Ouachita—for every Barbara Golden in Lincoln Parish, there's probably maybe two or three in Ouachita Parish.

Mr. NASTASI. At least. We try to work with our volunteers, with our church groups. There's a lot being done with the church groups. They do—unfortunately, I have found—and I'm not knocking the church groups, but their neighbor is the person sitting next to them in the pew, it's not that person—that poor person that lives across town. So, I'm constantly chiding them about that.

Senator BREAUX. This is not Jessie Ventura chiding them.

Mr. NASTASI. But, we do get a lot of support in Ouachita from some volunteers. They're very interested—but, it does not meet the total need. You need somebody there almost every day.

Senator BREAUX. Mrs. Moore, I'm intrigued and interested in the concept of the Adult Day Care Center. One of the programs that we've started in the government, which has been unusually successful is the Headstart programs and the day care for children. But, when we sort of reach the stage in our life when we are approaching that status, again, as an elderly citizen, the concept of adult day care is extremely important. What stage are you in in providing, I didn't quite understand—is it an ongoing program?

Mrs. MOORE. Actually, it's been around for about 20 years. Joe has had this program—one of the first in the state as a matter of fact. But, they had the Medicaid part of it. They moved it to the Senior Plaza when we moved in there a year ago and we were wanting to expand it for those people who did not qualify for Medicaid, that's what the scholarship will be able to provide, to help those people who——

Senator BREAUX. People would be brought or bused in, perhaps, or by van?

Mr. NASTASI. We provide the transportation.

Senator BREAUX. And, what do you have them doing while they are there?

Mrs. MOORE. Oh, my goodness, they are so busy, the time goes by so fast. They do chair aerobics, they do crafts—arts and crafts. We have health talks for them. We do health monitoring, watch their medicines for them. It's just complete day care, just like you would do——

Senator BREAUX. And, what would—could you guess or estimate what their age range would be for those that come there?

Mrs. MOORE. Well, in our particular program right now, it's 66 to 92.

Mr. NASTASI. There's a full care plan that's done for these individuals.

Senator BREAUX. Sounds like 92 is an old age, but one of my colleagues in the U.S. Senate—Senator Strom Thurman is 96 and he cares for the rest of us. I guess the situation that we're talking about now—the huge problem is when they can't do the day care, which is what Ms. Gaulden's mother is in. I mean, she is home bound and someone has to sort of be with her at her place, as opposed to being able to go out to a center. Did your mother—was she ever able to do something like that before she became older?

Ms. GAULDEN. Actually, I checked last year when I saw in the newspaper, the only comparison, a new day care center was being open. I didn't have any information about what was involved and I went there and found out immediately that the cost would be too much for me. I felt like she could go a day or two somewhere, if it was affordable—you know—and I would be willing to pay something, but I couldn't even afford a day——

Senator BREAUX. I think that what we're trying to do here is to gather information outside of Washington, which is important, I've always felt—to listen to people back home about the problems that are real problems that we have every day. And, I think that what we've heard today, both from our first witness and also the professors at ULM about what they're doing and what the research is indicating and also from these panel members right here, is real—I think—insight into what so many people in this country are experiencing in regard to aging and what we need to do about it.

From my perspective, I think two of the most important things that needs to be done are: Number 1 is information—information for the Baby Boom Generation as to what is available, what is needed, what they can expect, where they can go to find the services, how much the services are going to cost, how much planning should be done when you're in that middle age period, for yourself when you get older or also for your parents who happen to be aging at the current time. Information, information, information—this pamphlet that is out there in the back is very, very helpful, very well done by the National Alliance for Care Giving and funded by the Equitable Foundation. It is very, very good information. Also now, with the use of the Internet—so many people find out everything they need to know through the Internet and we need to do a great deal more of providing information through the Internet services which are available to more and more Americans. I've always said, I said it earlier, seems like we can find out more information about a microwave or the toaster oven and when it's going to break and how much it's going to cost to fix it and what's the best buy, than we can in finding out the health care services, and which ones are the best, which ones are having problems, which ones are doing a poor job, which ones are doing a terrific job. We need more information.

And, our legislation that Senator Grassley and I have introduced, I think will go a long ways to providing under the Older Americans Act, greater information for the caregiver support program. And, that information is extremely important. That's No. 1.

But, No. 2 is the second big hurdle that we as a nation have to somehow find a way to address, and that is the cost of care giving. How do we pay for these programs, how do we pay for long term care that's short of nursing home care or a hospital stay. How do we help not only the poorest among us, who are helped through Medicaid, but also those in the middle income area who are having a rough time and work every day, but can't seem to make ends meet sufficiently to provide the type of caregiving that they want to provide to their parents and that their parents have come to expect. Those are the two challenges that we as a nation face in this particular area, among other many challenges that we are facing. So, this information is helpful.

I appreciate the attendance of our guests in the audience. I am very pleased with the coverage that we've gotten from the local media. I think that's very, very important. And, I want to thank once again ULM and Lawson Swearingen for hosting our hearing today, for Richard Hood who helped organize the hearings and also the reception and also for the panelists who have come and I know in many cases have taken time from a very busy personal schedule to be with us to share their thoughts, which I think are very, very important. I would mention Daphine Golden who is a grad student here in the gerontology program. She's been very helpful to us and also our staff—Senator Grassley's staff and my staff who have helped put this together. So, I want to thank you all once again.

Before I say adjourned, if anyone has any suggestions or questions that they would like to ask, I think it would be very helpful to just drop me a note, just pick up a pen, give me a call. It's easy to write to me, it's just, Senator John Breaux, I'm in the Hart Building in Washington, so it's easy to remember. If you just put Senator John Breaux, Hart Building—that is H-A-R-T—Washington, D.C., I'll get your note, or I'll get your phone call and then send it to me, because I'm trying to gather as much information and suggestions as we possibly can get.

I have to go back to Washington this evening, but we will be back, and thank you for a wonderful opportunity in the hearing this afternoon.

Thank you.

[Whereupon, at 3:25 p.m. the committee was adjourned.]

APPENDIX

LONG-TERM CARE SERVICE NEEDS OF AMERICAN INDIAN ELDERS

THE INDIAN HEALTH SERVICE SANTA FE SERVICE UNIT

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES
Public Health Service
Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion

LONG-TERM CARE SERVICE NEEDS OF AMERICAN INDIAN ELDERS:

THE INDIAN HEALTH SERVICE
SANTA FE SERVICE UNIT

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Note: The opinions expressed in this document are those of the authors and do not necessarily represent those of the participating institutions.

26

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This report is dedicated to Indian elders and their family caregivers in the IHS Santa Fe Service Unit.

TABLE OF CONTENTS

LONG-TERM CARE SERVICE NEEDS OF AMERICAN INDIAN ELDERS

INDIAN HEALTH SERVICE
SANTA FE SERVICE UNIT

EXECUTIVE SUMMARY

Background and Introduction

The Santa Fe Service Unit (SFSU) of the Indian Health Service (IHS), located in northern New Mexico, provides all types of health care to 11 Pueblo tribes and inpatient services to the Jicarilla Apache tribe. Although over 1,300 Pueblo elders aged 55 years and older reside in the service unit, as elsewhere in reservation and other rural settings, formal long-term care services for American Indian elders are currently lacking or inadequate to meet their complex and interrelated medical and social care needs.

The primary goal of this project was to document the health and related care needs of SFSU elders in order to provide information for long-term care service development or assistance. Additionally, because much of the long-term supportive care required by these elders is provided by family members, the situation of informal caregivers was examined to determine which formal services would assist them in taking care of functionally impaired elders.

Assessment Methodology: The methods used in this study included a number of quantitative and qualitative data collection techniques. Information on existing services for elders in the SFSU was gathered through in-person and telephone interviews with state and tribal aging service providers and IHS staff, and through a review of available resource inventories. This information was used to evaluate the extent to which currently available services approximate the recommended continuum of long-term care required by functionally impaired older adults.

A modified version of the Older Americans Resources and Services (OARS) instrument was employed to obtain a multidimensional functional assessment of elders' resources, capabilities, and service needs and use. In addition to collecting basic demographic information, the OARS questionnaire is designed to assess an individual's resources and capabilities in five general areas: social and economic resources, mental and physical health, and the ability to perform routine activities of daily living. The instrument also evaluates each individual's use of and need for health and social services.

In order to assess the situation, perceived needs, and service preferences of family caregivers, a survey of the primary or main family member caring for functionally dependent elders was conducted. In addition, focus group discussions were held with primary family caregivers to obtain an in-depth understanding of their activities and perceived burdens related to providing elder care.

The Status of Long-Term Care in the SFSU

The health and related services required by the older adult population encompass preventive services, ambulatory care, acute and extended inpatient care, as well as in-home and other community-based medical and social support services that reduce the risk for functional impairment and promote the independence of elders. Within this so-called "continuum of long-term care," services currently provided by the IHS in the SFSU are primarily focused on ambulatory and acute inpatient care. Some in-home services including patient education and patient monitoring following hospitalization are also delivered by IHS through public health nurses and by the tribes through Community Health Representatives. A number of important aging services are provided in the service unit through Title VI programs including in-home and congregate meals, transportation, recreation, and information and referral. In-home medical and social supportive care for nursing-home eligible elders is available through the state-wide Disabled and Elderly Medicaid Waiver Program (DEMWP). The two American Indian DEMWP providers within the SFSU offer case management, homemaker/companion, and respite care. One of these programs also provides skilled nursing care within the home. Eligibility restrictions and waiting lists, however, limit the availability of DEMWP services for elders who need in-home supportive care. The Senior Companion Program offers home visiting and limited amounts of housekeeping assistance to elders. Finally, other service modalities including extended inpatient care, adult day care, and assisted living facilities are available within the region, but SFSU elders' access to these services is often limited by geographic distance, eligibility criteria, waiting lists, cultural differences, bureaucratic barriers, and costs.

Elder Health Status, Social Resources, and Service Needs

Sociodemographic Characteristics: To determine the status and characteristics of elders in the SFSU a sample of 429 persons aged 55 years and over was surveyed. The respondents' median age was 69 years and close to one-third of the sample was in the age group 75 years and older, who are at greatest risk for health problems, related functional impairment, and the need for long-term care. Fifty-nine percent of the sample were women. Fifty-eight percent of sample elders were currently married, 30% widowed, approximately 4% divorced or separated, and 8% never married. The vast majority of elders (69%) had less than a high school degree. Most elders live with others. The household composition of the sample was: alone (12%), married couple (21%), others-no spouse (31%), and married living with others (36%). Fifty-five percent of elders reported that they had one or more children living in the home, and 39% lived in a household with at least one grandchild.

Social Resources: A majority of SFSU elders appear to have adequate social resources. The most important social resource is the availability of a person to provide care during sickness or disability, and how long such assistance would be available to the elder. Ninety-six percent of the respondents claimed to have someone who would give them help if they became sick or disabled, and 79% of those with assistance said that it would be available as long as needed. The order of the most likely caregivers to SFSU elders was an adult child (58%), spouse (22%), sibling (8%), and grandchild (4%). According to an assessment of the elder's social resources made by the interviewer, the majority (78%) of elders had stable and adequate social resources. However, 14% had more tenuous social resources, and 8% lacked available help from family or others if they were to become disabled for an extended period of time.

Economic Resources: The most common annual income range among the elders sampled was $4,000-4,999. Three-quarters of sample elders lived below the poverty level, and 88% lived below 125% of the poverty level. Overall, elders' view of their financial situation was negative. Sixty-six percent reported that they had no financial reserves in case of an emergency, and 66% said they did not have enough financial resources to meet current expenses or only have enough to barely meet their expenses. The interviewer's assessment of the elder's economic resources showed that while 38% of the respondents were judged to have ample income and/or financial reserves, one-third of SFSU elders had marginal economic resources, and the remaining 29% were economically deprived to some extent. The economic status of sample elders is reflected in their low rates of participation in health insurance plans that are privately-paid or paid through employer contributions.

Mental Health: Fifty-six percent of elders said that their current mental health was good or excellent. In a separate interviewer rating of the elder's mental health functioning, the majority (85%) of elders were judged to have good or better mental health. An additional 14% evidenced some impairment in mental health functioning ranging from mild (11%) to moderate (2%) or severe (1%). Findings from cognitive status measures indicate that 3% of the SFSU respondents have some level of cognitive impairment. However, because these measures have not been validated for an American Indian population, the data on cognitive status were not used for further analyses in this report.

Physical Health: Fifty-six percent of sample elders rated their health as good or excellent, however, 55% felt that their health troubles interfered with their routine activities. The most prevalent illnesses were arthritis/rheumatism (26%), high blood pressure (22%), diabetes (16%), and circulation trouble (12%). Arthritis/rheumatism was the most debilitating of these conditions. The most common medications taken by elders were high blood pressure medicine (20%), arthritis medication (13%), prescription painkillers (9%), pills for diabetes (9%), and insulin injections (5%). Over one-quarter (26%) of elders reported comorbid health problems (10% reported three or more disease conditions).

Activities of Daily Living: The OARS instrument collects information on 13 activities of daily living with respondents indicating their level of functioning for each activity. Among the instrumental activities of daily living (IADLs) the highest levels of impairment (i.e., needs some help or unable) were in getting places (36%), going shopping (32%), and doing housework (32%). Among the physical activities of daily living (PADLs) levels of impairment were highest for walking (9%), bathing (8%), and transferring and bathing (5% each). Not unexpectedly, for each of the PADLs and IADLs, the proportion of those elders requiring some assistance or who are unable to do the task increased significantly with age, with the highest levels reported among those aged 75 years and older. The most likely helpers with activities of daily living were an adult child (62%), spouse (19%), or grandchild (8%).

Need for and Use of Services: Overall, elders indicated substantial levels of health and health-related service needs. The foremost expressed service need was for an overall review of their condition (54%). The next most prevalent service needs were for information and referral (51%), regular monitoring (33%), transportation (26%), administrative assistance (i.e., managing one's personal or business affairs) (26%), and housekeeping assistance (25%).

Three main "clusters" of needed services were identified (i.e., the needs for the specific services in each cluster were interrelated). The need for one or more of the *assessment/case management services* (overall review, information and referral, administrative assistance, transportation) was identified by 64% of elders. Forty-three percent of elders reported a need for one or more of the *in-home services* (meal preparation, housekeeping assistance, regular monitoring, and continuous care). Twenty-five percent of respondents cited a need for additional *health care services*, including medical care and physical therapy. Elders who need *assessment/case management services* were more likely to report multiple physical symptoms (e.g., heart pounding, loss of balance, feeling weak), were frequently anxious, felt that their vision was poor, and lacked their own transportation. The need for *in-home services* tended to be reported by elders with IADL impairments, those who were older, felt that they had poor overall health, and women. Additional *health care services* were cited as a need primarily by those who reported that health problems limited their participation in activities, and those with multiple physical symptoms.

Family Caregivers' Situation, Perceived Needs, and Service Preferences

Sources of Caregiver Burden: The family caregivers who participated in the focus group discussions expressed a strong cultural sense of obligation to care for their elderly family members, no matter how functionally dependent they might become. Consistent with this, nursing home placement was considered an unacceptable option for these caregivers. Despite the satisfaction these caregivers experienced at being able to provide assistance to a relative in need, they reported several major types of burden associated with their caregiving responsibilities. These included (1) anxiety about managing severe disease conditions in the home, (2) problems with difficult psychosocial aspects of care such as an elder's noncompliance or depression, (3) strains on family relations, and (4) negative effects on their own health and well-being.

The caregivers' worries about in-home care management included dealing with and preventing complications of chronic disease and having to operate medical equipment. They felt that current levels of patient education and monitoring were insufficient to support their caretaking efforts. In addition, caregivers felt that the social and behavioral aspects of caring for a frail elder were not adequately addressed by health care providers. The impact of caretaking responsibilities on family life was also emphasized by the caregivers who described frequent competing demands between elder care and other family or work responsibilities. In addition, caregiving had negative effects on their own physical and psychological well-being, particularly among caregivers providing physically demanding assistance or having to constantly supervise the elder. Despite these difficulties, the caregivers emphasized their preference for in-home and community-based long-term care services that would supplement rather than replace their own efforts.

Family Caregiver Characteristics: The majority (88%) of the 73 primary family caregivers who participated in the survey were women. Caregivers were most often a daughter (51%), wife (14%), husband or son (6% each), or daughter-in-law (4%). The median age of the primary family caregivers was 50 years, and most (46%) were married. Sixty-three percent of caregivers reported that they also cared for at least one child under age 18 in their household.

The majority (75%) of caregivers resided in the same household as the care recipient. Close to 20% of caregivers were currently employed, however, virtually all the caregivers also reported that they had altered their work status in some way in order to accommodate their caregiving responsibilities. The most common monthly household income range among the caregivers was $851-$1,250. Over half of the caregivers felt that they enjoyed good or excellent health, and most (56%) reported that their health did not interfere with caregiving duties. About 15% of caregivers, however, indicated that their health impeded caregiving either to a moderate or great extent.

Elder Care Recipient Characteristics: Sixty-three percent of the elders receiving assistance from these family caregivers were women, and the median age of the care recipients was 83 years. Slightly more than half (52%) of these elders were described by caregivers as requiring assistance because of physical health problems; 3% were judged to need help because of impairments in memory or judgment, and one-third had both physical and cognitive limitations. The care recipients were highly impaired, requiring assistance with an average of three out of five PADLs (bathing, toileting, dressing, transferring, and eating), and an average of 7.5 out of eight IADLs (shopping, using the telephone, using transportation, fixing/cooking meals, taking medicine, doing housework, managing money, and dealing with governmental and other agencies).

Various cognitive and behavioral problems that have been found to be stressful to caregivers were present among elders receiving care. Between 10% and 20% of the care recipients were reported as always having a problem with recalling recent events, orientation to season, understanding simple instructions, finding his or her way around the house, or recognizing familiar people. Approximately one-third of elders were frequently nervous or worried, and 22% were constantly restless or agitated. Close to half of the care recipients experienced incontinence either occasionally (38%) or always (10%). Given the level of impairment of many of these elders, almost half (48%) of the caregivers reported that the care recipient could only be left alone for one hour or less.

Caregiving Assistance Provided by Family Members: The median length of time that these caregivers had been the primary source of assistance to their elderly family member was five years. Meal planning and preparation were the most frequent types of assistance, provided daily by approximately 80% of caregivers. Help with personal care (dressing, bathing, hair care, or teeth care), household chores, shopping, banking or paying bills, taking medications, and checking on the elder at night, were also tasks performed on a daily basis by about 40% or more of caregivers. More than three-quarters (78%) of caregivers in the sample reported that other family members provide some level of assistance with the elder's care. The mean number of secondary caregivers was two, and they were most often the elder's daughter (53%), son (39%), grandchild (38%), or sister (25%). These additional family helpers most often assisted with instrumental activities, rather than the physical ADLs.

Caregiver Burden: When asked to identify their most important current problem as a caregiver, respondents described a wide range of concerns. The most frequently mentioned problems included isolation and lack of companionship for the elder (14%); lack of opportunities for respite (12%); the caregiver's own advanced age and ill health (10%); and lack of assistance with elder care from other family members (10%). Over 60% of caregivers perceived their elder care responsibilities to be physically and emotionally demanding. Forty-five percent reported sleep interruption because of the elder's care needs (63% of whom reported interrupted sleep three or more times per week).

Caregiver burden was also measured among these caregivers with a culturally validated version of a standard 22-item instrument. Factor analysis of the responses identified five major types of burden experienced by these caregivers: (1) lack of caregiver efficacy (e.g., uncertain what to do about elder); (2) role conflict (e.g., feeling pulled between elder and other responsibilities); (3) negative emotions (e.g., feeling angry around elder); (4) role strain (e.g., feeling that there is not enough time for oneself); and (5) guilt (e.g., feeling like one should do more for elder). Caregiver characteristics associated with each of these types of burden were also identified as a basis for targeting interventions for family members assisting frail elders.

Possible reasons for discontinuing caregiving that were identified by the respondents included further deterioration of the elder's health (23%); a deterioration of the caregiver's physical or mental state (22%); if the elder became bed bound (16%); if the elder required constant supervision (10%); problems with bowel or bladder control (7%); if the elder's mental state worsened (6%); and other family commitments (4%). The largest percentage of caregivers (52%) reported that they would somehow manage to continue caregiving. However, 36% of caregivers indicated that they did not know what circumstances might lead to the discontinuation of care, and 1% of caregivers felt that they were currently no longer able to provide care.

Service Preferences: Respondents endorsed a range of in-home and community-based services as potentially helpful to them as caregivers. The following services were rated by the respective proportions of caregivers as being either "very helpful" or "extremely helpful": regular monitoring of the care recipient (89%), information about the elder's health problems and what to expect about the elder's condition (85%), caregiver training (82%), case management (81%), respite care (80%), information about health services (77%), assistance with the elder's physical care (73%), day care (70%), information about social services (58%), and caregiver support groups (49%). In contrast, only 37% of caregivers indicated that nursing home care would be similarly helpful to them.

Recommendations for Long-Term Care Service Development in the SFSU

Recommendation #1: Develop Comprehensive Geriatric Assessment: Formal assessment of the elder's overall condition—including medical, psychosocial, and functional capabilities and problems—is recommended as a basis for health prevention, maintenance, and rehabilitative care of older adults in the SFSU. The rationale for recommending comprehensive geriatric assessment included the lack of a geriatric focus in current IHS services; the ranking of a review of one's overall condition as the most needed service by over half (54%) of SFSU elders; and the demonstrated proportion of elders with multiple disease conditions and functional limitations who are at-risk of needing routine assistance.

Comprehensive geriatric assessment in the SFSU should be conducted by a multidisciplinary team of medical and social service providers, should identify those elders at-risk for functional decline through appropriate clinical criteria, and should be carried out at an established interval. A standardized assessment instrument that promotes information sharing relevant to IHS and non-IHS service planning and provision should be employed. The assessment process should also include an in-home evaluation in addition to the assessment within a clinical setting. Existing comprehensive geriatric assessment programs at the Zuni-Ramah Service Unit and the Southern Colorado Ute Service Unit offer models for implementing this service in the SFSU.

Recommendation #2: Expand and Integrate Case Management: Case management—including assessment of an individual's need for services, arranging for service delivery, and monitoring outcomes—is critical to facilitating access to timely and appropriate care for older adults. Although various case management functions are carried out in the SFSU by CHRs, public health nurses, by Title VI, and the Disabled and Elderly Medicaid Waiver Program, these services often lack formal interagency coordination and are insufficient to meet existing needs among SFSU elders. The rationale for expanding and integrating case management services is based on the identified need by 64% of SFSU elders for one or more services in the *assessment/case management services* cluster. In addition, family caregivers strongly endorsed the potential helpfulness of care coordination and information about care for elders.

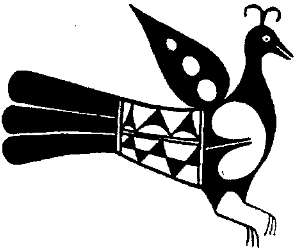
The development of coordinated long-term care programs by IHS and non-IHS aging services providers is a necessary step toward implementing an adequate system of geriatric case management in the SFSU. The interagency committee on long-term care legislated by the state of New Mexico in 1998 (House Bill 372) and charged with creating a coordinated long-term care service delivery system, provides a mechanism for joint planning by all agencies relevant to elder care in the service unit.

Recommendation #3: Secure and Expand Support Services: In order to fully develop the continuum of long-term care services that promotes elders' independence and delays functional decline, the range of in-home and other community-based services available in the SFSU must be expanded. This recommendation is based on the identified cluster of *in-home* *services* for which 43% of elders in the SFSU sample reported some level of need, as well as on family caregivers' and SFSU service providers' views of the need for in-home and community-based services. Substantial proportions of primary family caregivers strongly endorsed the potential helpfulness of such support services as regular monitoring of the elder (89%), respite care (80%), assistance with the elder's physical care (73%), and adult day care (70%). Service providers in the SFSU also emphasized the need for home health care, homemaker services, companionship services for elders, and respite care for family caregivers.

Various in-home and community-based services are provided to elders in the SFSU. However, their availability is limited. Recommended options for increasing available in-home services include expanding the scope of services provided through the Senior Companion Program (now limited to visitation and light housekeeping), and providing funding for services such as respite care to be provided through the Senior Community Service Employment Program (a U.S. Department of Labor job training and employment program). Moreover, Medicare and Medicaid reimbursement should be pursued by IHS and the tribes as a means to fund additional in-home and community-based support services.

Recommendation #4: Develop Family Caregiver Training: Developing and implementing programs of family caregiver training—educational interventions to increase these caregivers' level of knowledge and skills in assisting a functionally dependent elder—is recommended as a primary means of supporting the efforts of family caregivers in the SFSU. This recommendation was informed by several findings including the need expressed by the focus group participants for more information on elder care, and the perceived helpfulness of information about the elder's health problems and training on how to manage the elder's situation (endorsed by 85% and 82%, respectively, of caregiver survey respondents). The particular training needs identified by caregivers were: learning about the care recipient's disease condition, including its expected course and care requirements; techniques for in-home medical care management and preventive health maintenance; psychosocial aspects of care including dealing with an elder's difficult behaviors or depression; and how to facilitate and improve information sharing, communication, and help among family members. A variety of training resources exist in the area (e.g., IHS clinical staff and health educators, voluntary organizations such as the Alzheimer's Disease Association, and university-based resources) that could be coordinated to develop a program of family caregiver education for the SFSU.

CHAPTER 1



BACKGROUND AND INTRODUCTION

This report describes the research methods, findings, and service recommendations resulting from an assessment of long-term care needs of older adults in the Indian Health Service Santa Fe Service Unit (SFSU), New Mexico. The project, which was initiated at the request of the Indian Health Service (IHS), was conducted as a collaborative effort between the Health Care and Aging Studies Branch, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention (CDC), the IHS, and the Minority Aging Research Institute, Department of Applied Gerontology, University of North Texas.

The SFSU, located in northern New Mexico serves the health care needs of 11 Pueblo communities—San Juan, Santa Clara, Taos, San Felipe, San Ildefonso, Nambe', Picuris, Pojoaque, Cochiti, Santo Domingo, and Tesuque—and provides inpatient care only to the Jicarilla Apache tribe. According to the 1990 U.S. Census, there are 1,352 Pueblo elders aged 55 and over in the area. The major impetus for this planning project was an insistent request from the tribes in the SFSU to the IHS for the development of services to meet the medical and related chronic care needs of the growing number of American Indian elders.

The current lack of long-term care in the service unit is by no means unique in Indian Country. Recommendations from the 1,400 American Indian elders and senior services providers who participated in the 1992 National Indian Conference on Aging, ranked the need for long-term care as first among health concerns for elders nationwide (National Indian Council on Aging, 1993). A roundtable of experts on long-term care convened in 1990 by the IHS Office of Planning, Evaluation, and Legislation also acknowledged the lack of a focus on geriatric health within the IHS and highlighted the necessity for developing a "continuum of care," i.e., a complete range of home, community-based, and institutional care services to meet elders' health and supportive care needs (Indian Health Service, 1993).

The IHS roundtable consensus statement further emphasized the need for systematic data on American Indian elders' long-term care status from which service development can proceed:

> Long-term care in reservation settings...has yet to be defined or quantified, and requires more analysis than has been done so far. Required data is either outdated or nonexistent. Needs assessments, particularly functional assessments, have not been extensively done on a community level. The data from these assessments must form the basis for measurements of demand as well as the planning and design of services (Indian Health Service, 1993, p. 5).

This long-term care assessment within the SFSU represents one of a growing number of efforts to document the health and functional status of American Indian elders, the services currently available to them, and the situation of family members providing in-home care to frail elders. The emphasis of this research project has been on producing policy-relevant data and recommendations that can guide the development of comprehensive and culturally appropriate services for American Indian elders.

Overview of the Continuum of Care in the SFSU

The Continuum of Care Concept. The current long-term care situation in the SFSU can be evaluated in terms of the continuum of care (see Evashwick, 1987) presented in Figure 1.1 below. Bold type denotes those services currently provided by IHS; italics indicate non-IHS service providers.

FIGURE 1.1

CONTINUUM OF LONG-TERM CARE SERVICES IN THE SFSU BY CATEGORY

Extended Inpatient
Skilled nursing care
Intermediate care
Psychiatric intermediate care
Swing beds
Nursing home follow-up
Respite care

Acute Inpatient
Medical/surgical
Psychiatric
Rehabilitation
Comprehensive geriatric assessment
Geriatric consultation service

Ambulatory
Physician care
Outpatient clinics
Geriatric assessment clinics
Day hospital
Adult day care
Mental health clinic
Satellite clinics
Psychosocial counseling
Alcohol and substance abuse

Outreach/Linkage
Screening/outreach
Information and referral
Telephone contact
Transportation
Emergency response system
Support groups

Wellness/Health Promotion
Educational programs
Wellness clinics
Recreational/social groups
Senior volunteers
Congregate meals

Housing
Continuing care communities
Senior housing
Congregate care facilities
Adult family homes

Home Care
Home health
Hospice
High technology home therapy
Durable medical equipment
Home visitors
Home delivered meals
Homemaker and personal care

This comprehensive array of long-term care is broadly defined as including prevention services, ambulatory care, acute and extended inpatient care, in-home medical and social support services, as well as outreach and linkage services that enhance access to care, and supportive housing (Estes & Harrington, 1985; Evashwick, 1987). Creating a continuum of care and enhancing access to these services has been a major objective of national long-term care policy since the mid-1970s. The rationale underlying the continuum of care concept is that by providing a spectrum of services appropriate to the elderly person's level of need, functional independence can be maximized and unnecessary utilization of costly services—inpatient care in particular—can be reduced. The continuum of long-term care is thus focused on community-based services, i.e., care provided in non-institutional settings such as the home, day hospitals, or adult day care centers. These services are intended to accommodate the multiple and interrelated needs of the elderly with progressive dependency who are defined as being "at risk" for institutional care.

Case management, which includes assessing the individual's need for services, arranging for these services to be delivered, and monitoring client outcomes, is also considered to be a key component of the continuum of care (Steinberg, 1985; Weiss, 1987). This service coordination mechanism is designed to rationalize service delivery by ensuring that services are appropriately matched to the elderly person's particular set of needs. Ideally, geriatric assessment is conducted by multidisciplinary case management staff in order to provide a holistic view of the individual's health, functional status, and social support (Kane, 1985).

The extent to which the long-term care services currently available in the SFSU approximate this continuum of care is described in the following sections. This overview of the status of the continuum of care in the SFSU is intended to provide a framework from which to consider problems and issues in the existing long-term care environment.

IHS Services. As indicated in Figure 1.1, services provided by IHS to older adults in the SFSU are primarily in the areas of ambulatory care and acute inpatient care. Inpatient and outpatient care are delivered at the Santa Fe Indian Hospital, a 55-bed facility, and primary medical and health maintenance services are also provided by two health care centers (Taos and Santa Clara), and three satellite health care stations (San Felipe, Santo Domingo, and Cochiti). Other health maintenance and monitoring services such as post-hospital follow-up and health education, are delivered in patients' homes by IHS public health nurses and by Community Health Representatives (CHRs), health care paraprofessionals provided through IHS-funded tribal programs.

In addition, the 36 CHRs in the SFSU who serve Pueblo elders provide several outreach and linkage services such as transportation to medical appointments, case finding, i.e., the identification of individuals in need of services, and information and referral. A current breakdown of the approximate percentage of SFSU CHRs' time spent by service type with those aged 55 years and over is as follows: transportation/delivery (26.8%), non-emergency care (17.4%), monitoring (14.0%), case management (5.1%), interpretation (1.9%), homemaker (1.0%), health education/personal care (0.9%), emergency care (0.9%), case finding (0.7%), and environmental and home safety assessment (0.3%).

Title VI Programs. Other important services in the continuum of long-term care are provided to elders in the SFSU by tribally-operated programs created under Title VI of the Older Americans Act and coordinated through the New Mexico Indian Area Agency on Aging. These Title VI services, shown in Figure 1.1, consist primarily of home-delivered and congregate meals, transportation, recreation activities at community senior centers, and information and referral services. Transportation services are primarily to enable elders to do shopping or run errands, to attend social and recreational activities, and in some communities, to go to health care appointments.

Disabled and Elderly Medicaid Waiver Program. The state-funded and operated Disabled and Elderly Medicaid Waiver Program (formerly Coordinated Community In-Home Care), that was established in 1983 as an alternative to institutionalization, offers in-home supportive assistance to elders throughout New Mexico who are state-certified as eligible for nursing home care. This project provides a range of services through local contracting provider agencies (between 70 and 90 agencies statewide) including case management, nursing care, homemaker/companion, adult day health care, respite care, assisted living, personal care services, emergency response, rehabilitation therapies (physical, occupational, and speech therapies), and environmental modification. The specific long-term care service package offered to clients in a particular location varies depending on the provider agency.

The Disabled and Elderly Medicaid Waiver Program contracts with two provider sites within the SFSU. A program serving the Eight Northern Pueblos and another serving San Felipe and Santo Domingo (as well as the pueblos of Cochiti, Santa Ana, Sandia, Jemez, and Zia) offer case management, homemaker/companion, and respite care. The latter program, operated through a licensed home health agency, also provides skilled nursing care to clients. The Eight Northern Pueblos program has applied for a home health license in order to be able to expand their service package to include skilled nursing care.

Other Non-IHS Services for Older Adults. A number of the remaining categories of care in Figure 1.1—including extended inpatient care, adult day care, and assisted living facilities—are available within the region. However, all of these facilities are non-Indian and are located outside the immediate vicinity of the reservations. Home visitation and minimal amounts of housekeeping assistance are also provided to elders through county-operated Senior Companion programs.

Gaps in the Continuum of Care. Considered from the perspective of the continuum of care, the current American Indian long-term care service system in the SFSU contains a number of critical gaps and shortages. Areas of particular need include home-based support services (i.e., assistance with activities of daily living including personal care and housekeeping); comprehensive case management, including multidisciplinary patient assessment and monitoring; family support services such as caregiver education, adult day health care and respite care; and adult residential or other assisted living facilities (John, 1991). Existing IHS services are targeted to maternal and child health or, at best, the general adult population, lack a formally defined geriatric orientation, and are focused on acute care needs. Budget reductions during the 1980s, followed by stable funding in recent years for Title VI programs, have limited the types of support services provided by these programs (John, 1995). Limitations of the Disabled and

Elderly Medicaid Waiver Program include waiting lists and other problems of service access, as well as the lack of sufficient numbers of nursing home eligible clients in particular geographic areas to create a sufficient funding base for local programs. Finally, although various important long-term care services are available off-reservation in the SFSU, access to these services is often made virtually impossible by geographic distance, eligibility criteria, waiting lists, cultural differences, bureaucratic barriers, and costs.

The Role of Family Caregiving. Within this service context, the family is the primary and often sole provider of in-home care for reservation-dwelling elders (John, 1988; 1998) and family members frequently undertake extreme demands in preventing the institutional placement of an elderly relative (Manson, 1993). It is believed that patterns of IHS service use by older adults in the SFSU reflect the burden of service need on families, and mirror trends described by Manson (1989) for other service units. Specifically, some people have observed that older patients are repeatedly hospitalized for acute episodes of chronic disease, and are discharged to home situations that often have inadequate resources for managing the patient's condition. IHS staff anecdotally report that in response to the burden of caring for a frail elder at home, relatives often bring elders with vague complaints to the Santa Fe Indian Hospital on a Friday in order to have them admitted for weekend respite.

These observations emphasize the significant role of *informal caregiving*, i.e., the assistance of family and other tribal members, in the present long-term care system within the SFSU. Because these informal caregivers constitute a key component of the long-term care environment in the service unit, this assessment focuses on the joint capacity of formal and informal care to meet the current level of need for services among older adults in the service unit.

Objectives of the Assessment

The objectives of this long-term care assessment are to: (1) describe the population of functionally dependent adults aged 55 years and over within the SFSU, and to distinguish clinically relevant subgroups among this population;[1] (2) document the extent of informal care provided by family members to elders with chronic care needs; and (3) further analyze the strengths and weaknesses of the current formal long-term care service system within the SFSU to accommodate the needs of the target population.

Examples of key research questions addressed under Objective 1 include estimating the proportion of "low-risk" elders in the 55 and older age group (those who primarily require assistance with household tasks and checking/monitoring), and the proportion of "high-risk" elders in the 55 and older age group (those who require continuous medical/nursing supervision or are highly dependent in two or more activities of daily living). Analyses related to Objective 2

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[1] The target population for this project was defined as aged 55 years and older to correspond to the service population criteria for all Title VI programs in the SFSU except Taos Pueblo, which uses age 60 as its age criterion.

focused on estimating the proportion of elders with and without family caregivers who can provide help on an extended basis, identifying the impact of caretaking on family caregivers, and describing these informal caregivers' perceptions of needed and culturally appropriate long-term care services. Finally, Objective 3 involved documenting the status of the continuum of care in the SFSU and current patterns of service use among the target population, and estimating the extent of need for those categories of long-term care services relevant to the scope of IHS service provision. The goal of this report is to synthesize these research findings into specific recommendations for long-term care service development by the IHS in the SFSU.

Assessment Methodology

A multi-faceted approach was employed to assess the long-term care service needs of older adults in the SFSU. This approach included (1) the use of multifunctional assessment data from existing long-term care studies, (2) a review of existing long-term care services in the area, (3) conducting interviews with health and aging services providers, (4) conducting a survey of primary family caregivers of frail elders, and (5) holding focus group interviews with primary family caregivers.

These data sources and methodologies were chosen to include measures of *normative need* (e.g., the number of service visits per 100 frail elderly population), *expressed need* (consumer views of needed and appropriate services), and *relative need* (the gap between existing service levels in a target community and other reference communities) (Kettner et al., 1990). Normative or objective indicators are useful in generating service goals based on established standards of need. Measures of expressed or subjective need, on the other hand, provide information that assists planners in designing a service delivery system that is responsive to particular, and perhaps, diverse target groups. Due to the overall lack of information on the long-term care experiences of American Indians and their family caregivers (Manson, 1989), indicators of expressed need were given particular attention in this planning effort. Finally, relative need measures address issues of service equity by examining resource availability and unmet need for services. Each of the project data sources and methodologies is described below.

1. Long-Term Care Multifunctional Assessment Data

The major source of information on elders' health and functional status for this project was a data set compiled from multi-dimensional assessment studies conducted by the Title VI programs through funding provided by the Administration on Aging (AoA) in 1987. The data were analyzed and tribal-specific reports were written by Robert John, Ph.D. supported by funding from the AoA and the Andrus Foundation. This project included eight communities within the SFSU: Picuris, Pojoaque, Nambe', Tesuque, Taos, Santa Clara, San Felipe, and San Juan Pueblos (John, 1991). The data include observations from a sample of 429 persons in the Title VI service eligible population in these communities. In Taos Pueblo, this population included those aged 60 and over; for the remaining communities, the respondents were drawn from those aged 55 years and over. Title VI staff served as the survey interviewers, and in each community the interviewers attempted to administer the survey to as many tribe members fitting the age selection criterion as possible. In seven out of the eight pueblos surveyed, the percentage of the elders who participated in the survey represented from 67% to 79% of these communities' older residents; in Santa Clara, the sample included 32% of tribal members aged 55 years and older. Although three of the 11 communities within the service unit are not represented in this study population, due to concerns about potential respondent burden in conducting further surveys of elders, a decision was made by the SFSU Health Board to base the estimation of elders' long-term care needs on the existing data.[2]

Description of the Older Americans Resources and Services (OARS) Instrument. A slightly modified version of the Older Americans Resources and Services (OARS) instrument, a standardized multifunctional assessment tool developed at Duke University (Fillenbaum, 1988), was employed to collect these data. The instrument was revised for use with an American Indian population by The Institute for Gerontological and Research Education (TIGRE) at New Mexico State University. The OARS instrument is designed to obtain a multidimensional functional assessment of an older individual's resources and capabilities, and service needs and use.

The OARS instrument is organized into five sections; only those sections used in the current needs assessment project are described here. In addition to basic demographic information, the instrument assesses an individual's resources and capabilities in five general areas of well-being known as SEMPA: (S) social and (E) economic resources, (M) mental and (P) physical health, and (A) ability to perform routine activities of daily living. Examples of key variables in this section include the measures of social integration and informal support, the presence of functional limitations resulting from physical health problems, a checklist of mental health symptoms, and level of functional capacity to perform 13 routine activities of daily living.

Another section of the instrument collects information about an individual's health and social service needs and use of 23 generic service categories. The services included constitute a continuum of long-term care modalities, ranging from primary medical care to the types of support services necessary to maintain functionally dependent older adults in community settings. Data on the 16 services relevant to the scope of IHS care and aging services delivery in the SFSU are examined in this report. These include transportation, mental health services, nerve medication, personal care, nursing and medical care, assistive devices, physical therapy, continuous care, regular monitoring, housekeeping assistance, meal preparation, overall review of condition, information and referral, management of personal affairs, and personal skills training (i.e., rehabilitation therapies and training such as speech therapy, reality orientation, or training for the blind or handicapped).

Data Analysis. Descriptive and multivariate statistical analyses of these multidimensional assessment data focused on the health and functional status profile of the target group, the adequacy of informal support available to these elders, their use of and unmet

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[2] It is believed that those elders who were not surveyed are similar to the elders who participated in the study. Thus, the available data constitute a sample representative of the target population in the SFSU.

need for long-term care services, and the identification of risk factors associated with these service needs.

2. Survey of Primary Family Caregivers

Background and Purpose. One important area that was not addressed in the community surveys of elders is the situation of informal caregivers of functionally dependent elders in the SFSU. The purpose of the caregiver survey was to determine caregivers' perceptions of the caretaking situation and problems, including caregiver burden and needed support services. Caregiver burden—the stresses experienced in providing care to a functionally dependent elder—has been shown to be highly predictive of families' decisions to discontinue the caregiving role and to seek institutional care for the care recipient (McFall & Miller, 1992). In particular, the intent of the survey was to understand caregivers' perceptions of their situation, problems, and needs in order to better assist them in maintaining their impaired family members in community-based care settings.

Description of the Primary Family Caregiver Survey Instrument. The survey instrument was designed to collect information on variables found to be significant determinants of caregiver outcomes in previous caregiving studies. These variables include the care recipient's physical impairments, cognitive deficits, and behavioral problems, the types and frequency of assistance provided by caregivers, the length of time since assuming the caregiving role, caregiver health status, and other sociodemographic characteristics such as age and family relationship, the availability of caregiver substitutes, and caregivers' perceptions of stresses associated with caregiving (Noelker & Townsend, 1987).

In addition, caregivers' preferences for a range of community-based support services including such modalities of care as adult day health care and respite care were determined. The questionnaire items that identified needed support services were based on previous research findings concerning the most common needs of caregivers. Among the most salient of these needs are knowledge of the disease and its expected clinical course, knowledge of health and social services for the patient, strategies to manage difficult patient behaviors, social support, assistance with the physical care of the patient, physical relief through respite care, and support from a health professional such as a nurse or social worker (Pringle, 1989). Caregivers' perceptions of the acceptability of institutional placement for the elder were also examined.

Where possible, existing survey items and scales were used in the instrument. Strawbridge and Wallhagen's (1991) Caregiving Tasks scale was used to measure the frequency of help provided to the care recipient for sixteen types of activities. The 22-item scale used to measure caregiver burden is an adaptation of Zarit et al.'s (1980) Burden Interview, which was validated for use with Pueblo Indian caregivers (Hennessy & John, 1995).

Sample Selection and Data Collection. The respondent selection criteria targeted the primary or main family caregiver of functionally dependent elders. Sample member recruitment was carried out by the SFSU Title VI program directors who were familiar with families in their respective communities providing care to one or more elderly relatives. These Title VI program staff were asked to identify the family member (e.g., spouse, child, grandchild, sibling, in-law, or any other relative) who provides the most care to an elder, aged 55 years or older, who needs help with at least one personal activity of daily living (such as bathing, grooming, dressing, toileting, mobility, and eating), or with two instrumental activities of daily living (such as meal preparation, household maintenance, and shopping). A total of 73 caregivers in the SFSU participated in the survey that was also administered by the Title VI staff. A one-day interviewer training session was conducted by the project researchers in survey research methods and the administration of the instrument.

Data Analysis. Two types of analysis of the survey data were conducted. First, a descriptive analysis of caregivers' status, characteristics, and preferences for long-term care services was performed. Second, multivariate analyses were conducted to examine the effect of caregiver status and characteristics on perceived burden.

3. Focus Group Interviews with Primary Family Caregivers

Background and Purpose. Focus group interviews are a qualitative methodology involving unstructured small group discussions of 6 to 12 persons designed to elicit opinion-type responses on a defined topic of interest (Stewart & Shamdasani, 1990). Focus groups are typically used to capture the type of in-depth information that closed-ended survey questions do not provide, and are among the qualitative research methods recommended for effective public health program planning (Stillman, 1992). This methodology has been successfully used with American Indians in past research on geriatric health (Barduhn et al., 1992).

Focus groups were employed for two primary purposes in this project: (1) to supplement survey results with an in-depth understanding of caregivers' views of their situation and perceived service needs; and (2) to determine the content validity of the caregiver burden scale to be used in the survey instrument.[3]

Focus Group Participants. Unlike survey samples that are selected to meet the requirements of inferential statistics, focus group participants are chosen to represent a "theoretical" or "purposive" sample of individuals who are homogenous along various characteristics of interest. In the present study, primary caregivers who provide substantial amounts of assistance with activities of daily living to an impaired elderly family member were recruited to participate in focus group discussions.

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[3] A culturally distinctive experience of caregiving among American Indians was suggested by a previous small-scale study based on interviews with 10 American Indian caregivers (Strong, 1984). The present study, however, represents the first instance in which a scale for measuring caregiver burden has been validated for this population.

In order to avoid sensitization of the survey research participants, the focus group participants were identified and recruited from several pueblos outside the SFSU by Title VI program directors who co-moderated the discussions with the project researchers. Three focus groups were conducted with caregivers from these pueblos. The 33 focus group participants ranged in age from 24 to 79 and had been providing care to one or more functionally dependent elders for periods of less than a year to over twenty years. These participants included both men and women and a variety of family relationships (spouses, siblings, in-laws, adult children and grandchildren).

Data Collection and Analysis. The focus group discussion was organized so that participants first responded to a general question about the experience of caregiving and the kinds of problems they have encountered as caregivers of elders with chronic health care needs. The second part of the discussion involved an item by item review of the caregiver burden scale in which the focus group participants were asked to indicate the relevance and appropriateness of each question to caregivers such as themselves.

The focus group discussions lasted from one and a half to three hours, and were tape recorded with the consent of the participants. The tape recordings were transcribed verbatim, and the narrative text was subsequently analyzed using the constant comparative method, a qualitative data analytic technique (Strauss & Corbin, 1990). This method involves a content analysis of the text to identify and describe themes and associations in the participants' responses. In the analysis of these data, particular attention was given to documenting and exploring issues of caregiver burden, perceptions of the current long-term care service system, and expressed needs for services.

4. Service Environment Inventory

Current information on aging services for the entire SFSU—including the three communities that did not participate in the earlier project—was collected through telephone and face-to-face interviews with IHS staff, the Title VI program directors, the New Mexico Indian Area Agency on Aging director, and other key aging services program personnel, as well as from existing resource inventories. The resulting service information is described for the SFSU as a whole, with individual communities referred to as necessary.

Summary

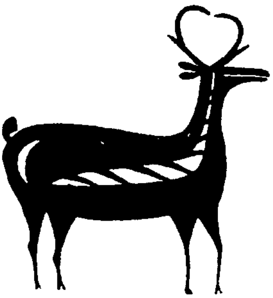
The components of this long-term care assessment are summarized in Table 1.1.

Table 1.1
SFSU Long-Term Care Assessment Summary

Research Questions	[illegible]	Sample	[illegible]
Elders' health and functional status, service utilization, unmet needs, and informal care received	[illegible]	Sample of 429 persons aged 55+ (60 + in Taos) in 8 SFSU communities	Descriptive and multivariate analyses
Types and extent of care provided by family caregivers; caregiver characteristics; impact of caregiving; preferences for support services	[illegible]	Purposive sample of 73 family caregivers of frail elders	Descriptive and [illegible]
Family caregivers' views of problems and issues involved in in-home care of frail elders; perceived needs for supportive care	[illegible]	33 family caregivers of frail elders	[illegible]
Status of the continuum of long-term care services in the SFSU	[illegible]	All communities served by the SFSU	Documentation of existing IHS and non-IHS health and social services for elders

Findings from each of these components are described in the following chapters of the report. Because this report was written to be accessible to a wide range of audiences, details of the statistical procedures used in data analysis are not included but are available upon request. The report concludes with recommendations for developing and expanding long-term care services within the IHS Santa Fe Service Unit.

CHAPTER 2



ELDER HEALTH STATUS, SOCIAL RESOURCES, AND SERVICE NEEDS

This section of the report documents the health and functional status, the social resources, and service utilization and needs of American Indian elders in the SFSU. As discussed in Chapter 1, the data presented in this chapter were taken from those items in the OARS instrument that can be used to characterize groups "at-risk" for a range of long-term care services. Emphasis is given to the factors that have been demonstrated in previous studies to be significantly associated with nursing home placement. According to Kane and Kane (1987), these risk factors include advanced age, living alone, lack of social supports, certain diagnostic conditions (including incontinence and dementia), physical disabilities (e.g., problems with activities of daily living, problems with instrumental activities of daily living, use of ambulatory aids, or being bed bound), and increased health care visits or inpatient stays.

The first part of this chapter presents descriptive information on these and other respondent characteristics and service needs. The second part of the chapter presents findings from multivariate analyses used to distinguish clusters or "packages" of services needed by SFSU elders, and the respondent characteristics that predict the need for each identified cluster of services.

Sociodemographic Characteristics

Age and Sex. The age distribution of the SFSU sample of 429 elders 55 years of age and over who participated in the study is shown in Table 2.1. The mean age of the respondents was 70 years (median=69); the oldest individual in the sample was 106. Although more than two-thirds (68%) of the respondents were in the age groups referred to by gerontologists as the "young old" (60-74 years) or younger, close to one-third of the sample were aged 75 years and over. These individuals comprise the so-called "old-old" age group, who are at the highest risk for health problems and associated functional deficits, and typically have the greatest need for long-term care services.

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[1] Race (i.e., being white) was also among the significant predictors of nursing home placement. However, this factor is not relevant to the present study sample.

Table 2.1
Age Distribution

55-59	60 (14.0%)
60-64	84 (19.6%)
65-69	76 (17.7%)
70-74	70 (16.3%)
75 years and over	139 (32.4%)

Women were somewhat more likely than men to participate in the study. Fifty-nine percent of the SFSU sample were women compared to 52% of the population over age 55 in the communities included in the study (U.S. Department of Commerce, 1986).

Household Composition. Because of the way in which the information on people living in the household is collected in the OARS instrument, it is not possible to determine the precise household composition of these elders. Categorization into four basic types is possible and does represent meaningful differences in living arrangements. As shown in Table 2.2, the vast majority (87.9%) of respondents were living with others.

Table 2.2
Household Composition (in percentages)

Married with Others	35.7
Others-No Spouse	30.8
Married Couple	21.4
Alone	12.1

The frequency of each type of household member is indicated in Table 2.3. Approximately 55% of SFSU elders report that they have one or more children living in the home. Unlike the household information collected by the Census Bureau, no individual is designated as household head in the OARS instrument. Therefore, it is not possible to determine whether an elder is living with one of their adult children or whether one or more adult child is living with them. On the other hand, the OARS instrument does provide a better indication of the extent to which elders live in the same household with one or more grandchildren. Indeed, 39% of SFSU elders live in a household with at least one grandchild.

Table 2.3
Household Members by Type (in percentages)

Spouse	56.5
Child(ren)	54.8
Grandchild(ren)	39.0
Sibling(s)	3.8
Other Relative(s)	3.1
Other (non-relative)	1.7
Parent(s)	1.4
Friends	0.7
Grandparent(s)	0.5
Paid Helper	0.2

There were exceptionally few households that contained a parent, friend, or paid helper. Although it is true that the presence of relatives other than children and grandchildren drops off sharply, the unmistakable conclusion is that SFSU elders live with a variety of kin. Overall, this provides support for the idea that household boundaries among rural/reservation Indians are permeable (Red Horse et al., 1978) and that extended family arrangements are common.

Marital Status. Marital status is another indicator of the social support of the older person. As shown in Table 2.4, although the majority of respondents were married, 42% were either widowed, divorced or separated, or had never married.

Table 2.4
Marital Status (in percentages)

Married	58.2
Widowed	29.7
Never Married	7.6
Divorced-Separated	4.4

A cross-classification of marital status and household composition revealed that 73% of the elders who lived alone were widowed, 9% were divorced or separated, and 16% had never married.

Educational Attainment: The level of formal education attained by the majority of SFSU elders was less than a high school degree. Forty-one percent of respondents had attended grade school only, and another 28% had some high school education. Twenty percent were high school graduates, and another 11% had additional education past high school.

Economic Resources and Health Care Coverage

This section describes the amount of income, income adequacy compared to each elder's needs, and poverty status among the respondents in the SFSU. In addition, information is presented on the extent of self-reported health and medical care coverage among this group.

These indicators of economic resources and health care coverage are important in this assessment of long-term care needs in that they suggest the financial limitations facing older adults in the SFSU and their reliance on publicly-funded sources of health care. As described in Chapter 1, publicly-funded long-term care services available within the SFSU are extremely limited, and the ability of the target population to access needed services—either through entitlement or private payment—is consequently restricted.

Table 2.5 shows that among these SFSU adults aged 55 years and over, the peak annual income bracket was $4,000-4,999. Substantial numbers of SFSU elders are in the lowest and middle income ranges, with far fewer in the upper income ranges.

Table 2.5
Annual Income (in percentages)

0-$499	3.0
$500-999	1.6
$1,000-1,999	4.6
$2,000-2,999	7.9
$3,000-3,999	13.6
$4,000-4,999	22.2
$5,000-6,999	16.8
$7,000-9,999	14.6
$10-000-14,999	11.1
$15,000-19,999	2.2
$20,000-29,999	1.4
$30,000-39,999	0.5
$40,000 and over	0.5

The relationship between annual income and the number of persons supported by that income was used to calculate each household's status in relation to the official poverty level. As seen in Table 2.6, an overwhelming majority of SFSU elders live below the poverty level (100% of poverty).

Table 2.6
Poverty Status (in percentages)

Below Poverty Level	75.1
100% to 125% Above Poverty Level	13.0
125% to 200% Above Poverty Level	9.4
Above 200% of Poverty Level	2.5

There is general consensus that official poverty status denotes extreme deprivation. Many gerontologists consider 125% of poverty to be a more accurate standard by which to judge whether income can provide the basic necessities of life. By this higher standard, approximately 88% of the study respondents have income below 125% of the poverty level.

Another view of these elders' financial status is provided by a subjective evaluation of how well their financial resources take care of their needs. Sixty-six percent of elders reported that they do not have financial reserves to cover emergency expenses. Consistent with this, a majority (61%) said that they have difficulty meeting routine expenses, and an additional 5% reported that they are unable to meet their routine expenses.

The interviewers' ratings of the economic status of each respondent are contained in Table 2.7.

Table 2.7
Interviewer's Rating of Overall Economic Resources (in percentages)

Excellent	6.8
Good	31.2
Mildly Impaired	33.3
Moderately Impaired	23.3
Severely Impaired	4.2
Totally Impaired	1.2

Each interviewer's assessment is based on whether or not the interviewer believes that all the subject's needs are being met. A small percentage of elders were rated as having excellent economic resources, i.e., having both ample income and financial reserves. Close to a third of elders were judged as having good economic resources, that is, ample income but no reserves or adequate income with reserves. An additional third of respondents, however, were rated more at the margin of economic well-being, or mildly impaired. Elders in this category are considered to have either adequate income but no reserves or somewhat inadequate income with reserves. Although this group may not currently experience economic problems, any unanticipated expenses would be a serious threat to their economic well-being. Individuals evaluated as experiencing the remaining impairment levels (29% of elders) already experience some level of economic deprivation. Moderately impaired individuals have somewhat inadequate income and no reserves. Severe impairment signifies a person with totally inadequate income whether or not they have reserves and total impairment denotes someone who is destitute (completely without income or reserves).

Health Care Coverage. As shown in Table 2.8, although somewhat fewer than a quarter of respondents identified themselves as participants in the Medicaid program, the only means-tested health care for which information was collected, the high rate of coverage under "other insurance (hospitalization and doctor)" reflects Indian Health Service (IHS) benefits available at no cost to all tribal members in the SFSU. The reliance on publicly-funded sources of health care is further indicated by the low rate of coverage of respondents under "other insurance (hospitalization only)," which would include plans that were privately-paid or involved employer contributions.

Table 2.8
Health and Medical Care Coverage by Source
(in percentages)

Medicaid	23.0
Medicare Plan A (hospitalization only)	26.7
Medicare Plan A and B (hospitalization & doctor)	22.5
Other insurance (hospitalization only)	8.2
Other insurance (hospitalization & doctor)	69.7

Social Resources

The items selected from this section of the OARS instrument attempt to assess the extent of the individual elder's contact with others, whether this amount of contact is satisfactory, if someone is available to help should the person become sick or disabled, and how long the respondent believes such help would be available. These questions provide information on the elderly individual's social network. The question in the social resources section of the instrument that is most relevant to the present study concerns the availability of a person to provide care during sickness or disability and how long such assistance would be available. The information provided by this question indicates each elder's perception of the availability and capacity of informal caregiving should a need arise for such assistance.

SFSU elders experience some degree of social isolation. Among SFSU elders, 19.1% said that they have not spent time with anyone who does not live with them in the past week, and an additional 35.8% had spent time with someone only once. However, nearly three-quarters of respondents stated that they see their relatives and friends as often as they want, with the remaining 25.7% saying that they were somewhat unhappy with the frequency of contacts with friends and relatives.

A high percentage of SFSU elders reported the availability of caregiving assistance if they were to become sick or disabled. More than nine out of ten (95.5%) of the elders claimed to have someone who would give them help in the case of illness or incapacity. Of these elders who believe that help is available, 79% said that such assistance would be available as long as needed. Another 10.3% of SFSU elders said that they could count on help for only a few weeks to six months and another 10.8% said that help would only be available now and then.

When asked to identify the source of assistance in the event of sickness or disability, the rank ordering of the most likely caregivers to SFSU elders was an adult child (57.6%), spouse (22.1%), sibling (7.6%), grandchild (4.1%), niece or nephew (3.8%), or other person (4.6%). These results do not differ greatly from other studies.

The last measure of the adequacy of elders' social resources comes from an evaluation made by the person who interviewed them. Table 2.9 presents the distribution of these summary ratings.

Table 2.9
Interviewer's Rating of Overall Social Resources (in percentages)

Excellent	17.9
Good	60.1
Mildly Impaired	14.0
Moderately Impaired	4.0
Severely Impaired	3.3
Totally Impaired	0.7

Mild impairment was defined in the instrument as: social relationships are unsatisfactory, of poor quality, few; but at least one person would take care of him (her) indefinitely, or social relationships are fairly satisfactory, adequate; and only short-term help is available.

These assessments indicate that the social assistance available to the majority (78%) of respondents was assessed to be good or better. Fourteen percent of elders had somewhat tenuous social resources, lacking in either quality or quantity of available help. Individuals rated in the three categories of greatest impairment did not meet the condition of having assistance for an "indefinite" period of time. Thus, a total of 8% of elders would not be able to draw upon sufficient help from family or significant others in the event of long-term incapacity.

Physical Health

This part of the instrument is designed to assess the extent of illness experienced by the respondent during the past six months, prescription medications taken within the past month, the presence of 27 medical conditions and the extent to which these conditions interfere with activities, the use of and need for medical devices and prostheses, and subjective aspects of physical health.

One gauge of physical health is the number of days during the past six months that an individual was too sick to carry on usual activities. Approximately two-thirds (66.3%) of SFSU elders said that illness had not limited their usual activities at all during that time period. The second largest group claimed to have been limited for a week or less (21.3%). At higher levels of disability due to recent illness, 7.7% of the sample reported having had an illness that imposed activity limitations for more than a week but less than a month; 3.4% were limited for one to three months, and 1.2% experienced protracted illnesses of four to six months.

The majority of SFSU elders (61.9%) reported having used a physician's services during the past six months. However, the median number of visits per elder during that time period was only one visit. According to their self-report, hospitalization within the last six months was relatively common among the sample members. Twenty-two percent of respondents said that they had been hospitalized during that period. The average number of days in the hospital was 28.6. However, this figure is largely attributable to a small number of individuals who had stays of two months or more. In contrast, only two respondents reported a stay in a nursing home or rehabilitation center during the last six months.

The OARS instrument collects information on 18 prescription medications. Table 2.10 details the percentage of SFSU elders taking these types of prescription medications. As can be seen, medication for arthritis, hypertension, diabetes, and pain were the most frequently used medications among this group.

Table 2.10
Prescription Medication Use During Last Month (in percentages)

High Blood Pressure Medicine	19.5
Arthritis Medication	12.8
Prescription Painkiller	9.0
Pills for Diabetes	9.0
Insulin Injection	5.2
Water or Salt Pills	5.0
Drugs for Circulation	3.1
Nitroglycerin Pills for Chest	2.6
Digitalis Pills for Heart	2.4
Antibiotics	2.4
Ulcer Medicine	1.9
Sleeping Pills	1.9
Blood Thinner Medicine	1.2
Tranquilizers	1.2
Thyroid Pills	1.2
Seizure Medicine	0.7
Cortisone	0.7
Hormones	0.5

The information on prescription drugs gives one indication of medical conditions experienced by the target population. The OARS instrument also collects information on the presence of 27 specific illnesses and the extent to which these illnesses interfere with a person's activities. This information is presented in Table 2.11. For each of the conditions it is possible to establish the proportion with that condition and the extent to which the illness interferes with their activities—not at all, a little, a great deal, or an unspecified amount.

The most prevalent illnesses among persons aged 55 years and over in the SFSU are arthritis/rheumatism (26%), high blood pressure (22.1%), diabetes (16%), and circulation trouble (11.5%). Arthritis/rheumatism was the most debilitating among these conditions with 7.6% of elders reporting that arthritis/rheumatism interfered a great deal with their activities. None of the elders in this sample said that they experience epilepsy, cerebral palsy, multiple sclerosis, or muscular dystrophy.

Table 2.11 Medical Condition and the Extent to It Interferes with Daily Activities

Medical Condition and Level of Interference	Percentage	Medical Condition and Level of Interference	Percentage
Arthritis or Rheumatism		High Blood Pressure	
Does Not Have	74.0	Does Not Have	77.9
Not at All	5.5	Not at All	10.5
A Little	10.7	A Little	6.2
A Great Deal	7.6	A Great Deal	1.9
Unspecified Amount	2.1	Unspecified Amount	3.6
Glaucoma		Heart Trouble	
Does Not Have	96.9	Does Not Have	93.1
Not at All	0.7	Not at All	2.6
A Little	1.2	A Little	2.1
A Great Deal	1.0	A Great Deal	1.2
Unspecified Amount	0.2	Unspecified Amount	1.0
Asthma		Circulation Trouble	
Does Not Have	99.3	Does Not Have	88.5
Not at All	0.5	Not at All	1.9
A Little	0.2	A Little	5.7
A Great Deal	-	A Great Deal	2.9
Unspecified Amount	-	Unspecified Amount	1.0
Emphysema or Bronchitis		Diabetes	
Does Not Have	98.3	Does Not Have	84.0
Not at All	0.5	Not at All	6.7
A Little	1.0	A Little	4.5
A Great deal	0.2	A Great Deal	1.4
Unspecified Amount	-	Unspecified Amount	3.3
Other Stomach		Anemia	
Does Not Have	96.4	Does Not Have	99.3
Not at All	1.2	Not at All	-
A Little	1.7	A Little	0.5
A Great Deal	0.2	A Great Deal	0.2
Unspecified Amount	0.5	Unspecified Amount	-
Tuberculosis		Ulcers	
Does Not Have	98.8	Does Not Have	98.8
Not at All	0.5	Not at All	0.2
A Little	0.2	A Little	1.0
A Great Deal	-	A Great Deal	-
Unspecified Amount	0.5	Unspecified Amount	-

Medical Condition and Level of Interference	Percentage	Medical Condition and Level of Interference	Percentage
Liver Disease		**Physical Effects of Stroke**	
Does Not Have	99.8	Does Not Have	96.7
Not at All	0.2	Not at All	0.5
A Little	-	A Little	1.4
A Great Deal	-	A Great Deal	1.2
Unspecified Amount	-	Unspecified Amount	0.2
Kidney Disease		**Parkinson's Disease**	
Does Not Have	99.3	Does Not Have	99.8
Not at All	0.2	Not at All	-
A Little	0.2	A Little	-
A Great Deal	-	A Great Deal	-
Unspecified Amount	0.2	Unspecified Amount	0.2
Other Urinary		**Alcoholism or Cirrhosis**	
Does Not Have	99.0	Does Not Have	97.7
Not at All	0.2	Not at All	0.8
A Little	0.5	A Little	0.8
A Great Deal	-	A Great Deal	0.4
Unspecified Amount	0.2	Unspecified Amount	0.4
Cancer or Leukemia		**Speech Problems**	
Does Not Have	99.0	Does Not Have	98.6
Not at All	-	Not at All	-
A Little	0.2	A Little	0.5
A Great Deal	0.2	A Great Deal	0.7
Unspecified Amount	0.5	Unspecified Amount	0.2
Skin Disorders		**Thyroid/Gland Problems**	
Does Not Have	98.6	Does Not Have	98.8
Not at All	0.2	Not at All	0.7
A Little	1.0	A Little	0.5
A Great Deal	-	A Great Deal	-
Unspecified Amount	0.2	Unspecified Amount	-
Polio			
No	99.8		
Not at All	0.2		
A Little	-		
A Great Deal	-		
Unspecified Amount	-		

Although the mean number of self-reported disease conditions in this group was relatively low (mean=1.1; SD=1.2), a sizeable proportion of respondents did experience significant comorbidity, i.e., the presence of multiple conditions. Sixteen percent of elders reported having two disease conditions, and an additional 10% reported suffering from three or more conditions.

Another question inquired about the extent and type of each respondent's physical disabilities. Approximately 12% of respondents reported one of these problems: partial paralysis (5.5%), total paralysis (0.7%), missing or non-functional limbs (2.4%), or broken bones (3.3%). Questions asking elders to rate their eyesight (with compensation of glasses or contacts) and hearing provided information on deficits in these areas.

Table 2.12
Self-Assessed Eyesight and Hearing (in percentages)

Eyesight	
Excellent	4.3
Good	45.0
Fair	32.9
Poor	17.5
Totally Blind	0.2
Hearing	
Excellent	9.9
Good	49.1
Fair	27.0
Poor	12.9
Totally Deaf	1.0

Table 2.13 lists the frequency of use of 11 supportive devices and prostheses. Thirty percent of respondents reported that they used at least one type of supportive equipment; 12.3% also reported that they needed an aid or prosthetic device that they did not currently have. One weakness of this version of the OARS instrument is that it fails to integrate the need for eyeglasses into this list of aids. Therefore, the extent of use and need for this common prosthesis cannot be determined.

Table 2.13
Use of Supportive Devices and Prostheses (in percentages)

Dentures	32.2
Cane	13.8
Hearing Aid	6.0
Walker	3.6
Wheelchair	2.1
Leg Brace	1.9
Back Brace	1.0
Artificial Limb	0.7
Colostomy Equipment	0.2
Catheter	0.2
Kidney Dialysis Machine	•

The following three tables contain information on each respondent's own evaluation of their health status. Self-perceived health, a commonly used subjective indicator of health status, is strongly associated with a person's objective physical and mental health status (Deforge et al., 1989; Kivela & Pahkala, 1989; Permanyer-Miralda et al., 1991) and is also an independent predictor of mortality (Wannamethee & Shaper, 1991; Idler & Angel, 1990). In addition, self-perceived health is a good proxy indicator for chronic disease conditions that have a heavy burden of symptoms and result in a poor prognosis (Idler & Angel, 1990), and it has been shown to be sensitive to comorbidity (Stewart et al., 1989).

Table 2.14 demonstrates that although the modal health status category is good, 45% of respondents rated their overall health as either fair or poor.

Table 2.14
Self Rating of Overall Health (in percentages)

Excellent	5.4
Good	50.9
Fair	36.3
Poor	7.3

It is notable that over half (54.8%) of the respondents felt that health troubles impeded their ability to carry out their usual activities to some degree. Indeed, close to one-fifth of these respondents felt that they were impeded "a great deal" by their health problems (see Table 2.15).

Table 2.15
Self-Assessment of How Much Health Troubles Impede Activities(in percentages)

Not at All	45.3
A Little	36.6
A Great Deal	18.2

Table 2.16 shows the interviewer's independent rating of the respondent's overall physical health. Forty-six percent of respondents were rated as experiencing some degree of physical impairment. Over 16% were assessed as having at least moderately impaired health.

Table 2.16
Interviewer's Rating of Overall Physical Health (in percentages)

Excellent	4.9
Good	49.2
Mildly Impaired	29.4
Moderately Impaired	12.8
Severely Impaired	2.8
Totally Impaired	0.9

Mental Health

Among the questions selected from the OARS instrument that assess mental health status were self-rated mental health status, a 15-item test of psychiatric functioning derived from the Minnesota Multiphasic Personality Inventory (MMPI), and the interviewer's assignment of an overall mental health rating.

Table 2.17 presents the distribution of responses to the self-rated mental health question. These results indicate that, while most respondents felt that their psychological well-being was good or better, 44% rated themselves as fair or poor in this regard.

Table 2.17
Subjective Rating of Overall Mental Health (in percentages)

Excellent	7.3
Good	49.1
Fair	39.8
Poor	3.8

Construction of an additive index of mental health functioning based upon each elder's response to the 15 items of the MMPI (shown in Table 2.18) is another means to evaluate mental health status. A score of five or more indicates impaired mental health functioning (Fillenbaum, 1988). According to this standard, 22.4% of SFSU elders evidenced impaired mental health functioning. These results should be interpreted with caution; however, since the MMPI has been shown to produce higher scores for American Indians than for whites (Pollack & Shore, 1980).

Table 2.18
Affirmative Responses to Aspects of Mental Health (in percentages)

Difficulty keeping balance	30.5
Couldn't get going	29.7
Sleeps fitful and disturbed	27.4
Feels useless at times	27.0
Not been well most of time	17.3
Feels weak all over	15.8
No one understands me	15.7
Troubled by headaches	14.9
Wants to leave home	13.5
Does not wake fresh and rested	12.8
Heart pounds or shortness of breath	12.7
Feels lonely most of time	9.4
Does not find life interesting	8.5
Someone planning evil against me	5.4
Not happy most of time	5.2

In addition to the mental health measures described above, a rating of each elder's overall mental health was done by the interviewer based upon the information provided and their interaction with the subject. The distribution of the interviewers' ratings is presented in Table 2.19.

Table 2.19
Interviewer's Rating of Overall Mental Health (in percentages)

Excellent	14.5
Good	70.9
Mildly Impaired	11.4
Moderately Impaired	1.6
Severely Impaired	1.2
Completely Impaired	[illegible]

This assessment of the prevalence of mental health impairment among SFSU elders indicates a considerably smaller proportion of impairment than evidenced by the MMPI findings. In addition to the cultural validity issues that have been raised about the MMPI, another possible explanation for this finding is that the very serious and formal evaluation required by the OARS instrument contradicts a common Native American ethic not to judge others in such an integral aspect of individuality. Moreover, in a small American Indian community the interviewers might have found it difficult to assign a poor mental health rating because of negative reflections on the individual as well as on the community.

Cognitive Functioning

The OARS instrument contains a 10-item preliminary questionnaire (also known as the Short Portable Mental Status Questionnaire or SPMSQ) that is intended to assess the reliability of each respondent's cognitive functioning. Based on standards established by the developers of the OARS instrument (Fillenbaum, 1988) of 5-6 errors among non-white community residents, approximately 3% of the SFSU respondents would be considered to have moderate cognitive impairment despite the fact that many of the questions have limited relevance to American Indian elders' cognitive and social experience. For example, the two most frequently missed questions among SFSU elders were the identity of the former President (61% incorrect) and the math problem (58% incorrect). Among some American Indian elders even the age and birth date questions are difficult.

Although information on the prevalence of cognitive impairment among the older population in the SFSU is important for long-term care planning, because of these cultural factors, the validity of the available OARS survey data on cognitive status is questionable. For this reason, the cognitive impairment data were not used in the multivariate analyses that are presented later in this chapter.

Ability to Perform Activities of Daily Living

The OARS instrument collects information on 13 routine activities of daily living and each respondent indicated their level of functioning from being unable to perform the activity to being able to perform it without assistance. Two additional questions in this section of the instrument provide information on incontinence and the identity of people who help the respondent with the activities of daily living.

The activities of daily living can be divided into two types; physical activities and instrumental activities. The physical activities of daily living (ADLs) include basic self-care tasks—eating, dressing, taking care of one's appearance, walking, getting in and out of bed, and bathing. The instrumental activities of daily living (IADLs) are activities necessary to live independently in the community, and are more complex than the physical domain of functioning represented by the ADLs (Guralnik & Lacroix, 1992). These activities include using the telephone, getting places, going shopping, preparing meals, doing housework, taking medicine, and handling money. The ability to perform the physical activities of daily living provides an indication of the degree to which elders are at-risk of the need for long-term care services whether from family or in an institutional setting.

Table 2.20 presents the distribution of responses to the IADL items for three age groups: less than 65 years, 65 to 74 years, and 75 years and over. Not unexpectedly, these data reveal a clear and statistically significant association of IADL impairment with age. That is, for each IADL item, the proportion of those able to perform the activity independently decreases with age, while the proportion of those requiring some assistance or who are unable to do the task increases.

Table 2.20
Ability to Perform Instrumental Activities of Daily Living By Age Group (in percentages)

Instrumental Activity	Without Help	With Some Help	Unable
Use Phone			
55-64 years	90.9	4.2	4.9
65-74	[illegible]	10.3	[illegible]
75+	[illegible]	27.3	19.5
Total	[illegible]	**13.5**	[illegible]
Get Places			
55-64 years	[illegible]	16.0	2.1
65-74	[illegible]	30.8	[illegible]
75+	[illegible]	54.3	[illegible]
Total	[illegible]	**32.9**	[illegible]
Go Shopping			
55-64 years	[illegible]	9.8	2.8
65-74	[illegible]	21.9	[illegible]
75+	[illegible]	45.0	15.3
Total	[illegible]	**24.9**	**6.9**
Prepare Meals			
55-64 years	[illegible]	6.9	2.8
65-74	[illegible]	11.0	4.8
75+	[illegible]	20.9	11.6
Total	[illegible]	**12.7**	[illegible]
Do Housework			
55-64 years	[illegible]	12.7	4.2
65-74	[illegible]	22.9	7.6
75+	[illegible]	32.6	16.3
Total	[illegible]	**22.4**	**9.3**
Take Medicine			
55-64 years	96.5	2.8	0.7
65-74	91.8	8.2	[illegible]
75+	73.6	23.3	3.1
Total	**87.8**	**11.0**	**1.2**
Handle Money			
55-64 years	95.1	3.5	1.4
65-74	87.7	11.6	0.7
75+	71.3	24.0	4.7
Total	[illegible]	**12.6**	**2.1**

An examination of the percentage impaired (i.e., requiring some help or unable to do the activity) among the total sample for each IADL category shows the greatest extent of limitation in the areas of getting places, doing housework, and going shopping. Close to a third or more of the elders in the SFSU sample evidenced at least some impairment in these activities. Twenty-three percent were unable to use the telephone independently, 18.9% had some dependence in preparing meals, and 14.7% and 12.2%, respectively, were limited in their ability to handle money or take medications.

Table 2.21 presents the distribution of the ability to perform physical activities of daily living for the three age groups. As with the IADLs, the general pattern of association of impairment with age is likewise found for the ADLs, with those in older age groups experiencing greater activity limitation. Overall percentages of impairment for each of the activities shows the highest degree of limitation in the ability to walk, with 8.8% of the respondents requiring assistance, and in the ability to bathe, which 7.9% of elders could not do without some assistance. Lesser percentages needed help with taking care of their appearance and transferring in and out of bed (4.8% each). Close to four percent of elders experienced limitation in the ability to dress themselves, and 1.4% had some dependency in the ability to eat.

Table 2.21
Ability to Perform Physical Activities of Daily Living By Age Group (in percentages)

Physical Activity	Without Help	With Some Help	Unable
Eat			
55-64 years	98.6	1.4	
65-74	99.3	0.7	-
75+	97.7	1.6	0.8
Total	98.6	1.2	0.2
Dress			
55-64 years	98.6	0.7	0.7
65-74	97.9	1.4	0.7
75+	92.2	6.2	1.6
Total	96.4	2.6	1.0
Take Care of Appearance			
55-64 years	97.2	2.1	0.7
65-74	96.6	2.1	1.4
75+	91.5	7.8	0.8
Total	95.2	3.8	1.0
Walk			
55-64 years	95.8	3.5	0.7
65-74	92.4	6.9	0.7
75+	84.5	14.7	0.8
Total	91.1	8.1	0.7
Get In and Out of Bed			
55-64 years	97.9	2.1	-
65-74	94.5	4.8	0.7
75+	93.0	6.2	0.8
Total	95.2	4.3	0.5
Bathe			
55-64 years	96.5	2.8	0.7
65-74	90.4	8.9	0.7
75+	89.1	9.3	1.6
Total	92.1	6.9	1.0

Among non-Hispanic whites, one of the most important indicators of the ability to remain independent in a community setting is incontinence, and the OARS instrument contains two questions about this condition. Incontinence problems were reported by 5% of respondents. Among SFSU elders, approximately 2.3% soiled or wet themselves 1-3 times a week.

A follow-up question requested information on the identity of the person(s) who helped each elder with one or more of the activities of daily living. SFSU elders identified four types of kin who provide them with assistance. Among the respondents, 62% identified an adult child as the helper, 19.2% a spouse, 7.7% a grandchild, 5.5% a niece or nephew, and 1.6% a friend. This pattern provides supporting evidence for conclusions offered above in the discussion of household composition and social resources that these elders typically have a large familial support network and anticipate assistance from a wide variety of kin relations. Indeed, the kin relations that these respondents believe would provide assistance in case of sickness or disability tend to be the same relatives these elders identify as the people who provide actual assistance with activities of daily living.

The interviewers' ratings of each person's ability to perform routine activities of daily living are contained in Table 2.22.

Table 2.22
Interviewer's Rating of Ability to Perform Activities of Daily Living (in percentages)

Excellent	15.9
Good	43.4
Mild Impairment	25.9
Moderate Impairment	9.6
Severe Impairment	4.0
Total Impairment	1.4

The majority (59.3%) of respondents fall into the top two categories of persons who can perform the activities of daily living without assistance. Slightly more than a quarter of SFSU elders were classified as mildly impaired, that is, able to prepare his or her own meals and able to get through any single day without help but needing occasional assistance with one to three of the other twelve activities. The remaining elders, 15% of the entire sample, need some level of regular care. Close to 10% of elders were rated as being moderately impaired. This category is comprised of people who require regular assistance with at least four activities of daily living as well as those individuals who are unable to prepare their own meals. These individuals are at elevated risk for losing their independence. The 4% of SFSU elders judged to be severely impaired were those who need assistance on a daily basis, but not necessarily throughout the day or night. Finally, at the highest level of impairment, approximately 1% of the SFSU sample were considered to be totally impaired, the category of highly impaired individuals who need regular assistance with the activities of daily living throughout the day and/or night. This last group is at high risk of need for institutional care unless adequate family assistance is provided.

Need for and Use of Services

Information was collected on 16 services relevant to long-term care. Receipt of a particular service within the last six months, the identity of the service provider (whether an agency or family/friends), and the perceived need for additional assistance was collected about each of these services. Table 2.23 contains information on the percentage of SFSU elders who received a particular service within the last six months.

Table 2.23
Service Use During Last Six Months (in percentages)

Transportation	77.4
Medical Care	59.2
Prosthetic Devices	38.7
Regular Monitoring	36.1
Information and Referral	22.7
Housekeeping Assistance	22.4
Administrative Assistance	21.5
Continuous Care	20.1
Meal Preparation	18.2
Overall Review	16.7
Physical Therapy	9.9
Nursing Care	9.2
Personal Care	8.9
Nerve Medication	3.6
Mental Health Services	3.4
Personal Skills Training	1.7

Table 2.24 documents the percentage of SFSU elders who expressed a need for each of the 16 long-term care services. The foremost needed service, cited by over half of the respondents, was the need for a review of one's overall condition, i.e., an evaluation of individual health and functioning and resources to meet self-care needs. A similarly high percentage of elders expressed the need for information about and referral to services appropriate to his or her needs. The need for regular monitoring or checking to make sure the elder has not become ill or is unable to get help, was indicated by a third of SFSU elders.

Table 2.24
Perceived Need for Specific Services (in percentages)

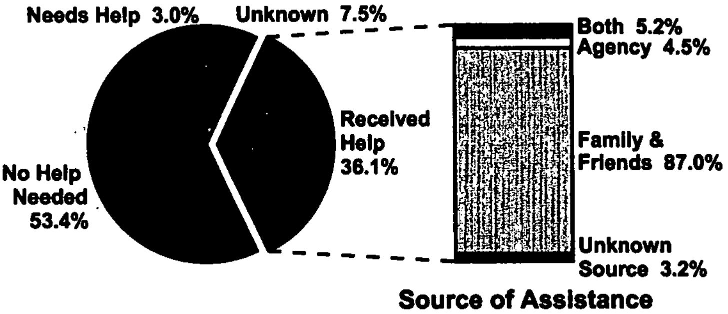
Overall Review	53.8
Information and Referral	51.3
Regular Monitoring	32.6
Transportation	26.3
Administrative Assistance	26.2
Housekeeping Assistance	24.5
Continuous Care	18.7
Medical Care	18.4
Meal Preparation	16.7
Physical Therapy	13.8
Prosthetic Devices	12.3
Nursing Care	11.1
Mental Health Services	9.9
Personal Care	7.3
Nerve Medication	6.8
Personal Skills Training	4.7

Approximately one-quarter of the SFSU sample stated that they needed assistance with managing their personal or business affairs (administrative assistance), housekeeping or transportation. The next most prevalent needs—ranging from 10% to 18% of respondents—are all related to health care, including medical care, physical therapy, prosthetic devices, nursing care, and mental health services. Fewer than 10% expressed the need for personal care, nerve medication or for personal skills training.

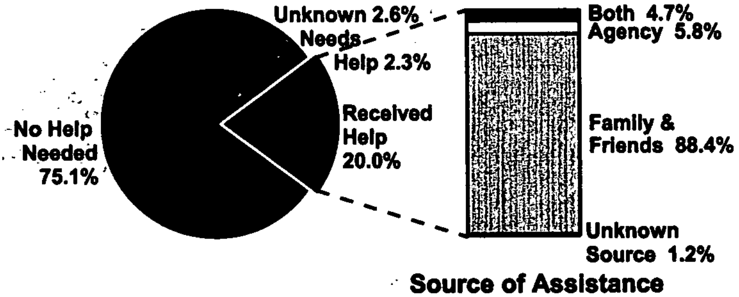
The series of charts on the following pages and Table 2.25 document the actual pattern of service assistance for 10 service needs. The majority of elders receive assistance from family or friends for regular monitoring, continuous care, administrative assistance, transportation, meal preparation, housekeeping assistance, and personal care. An agency is the primary service provider for only three services: information and referral, physical therapy, and nursing care. These charts also reveal that the greatest unaddressed need for services is for information and referral. Thirty-five percent of the sample expressed a need for information and referral but had not received this type of assistance in the last six months. The next highest unaddressed needs were for physical therapy (8%), administrative assistance (6%), and housekeeping assistance (6%).

Source of Support for Specific Type of Assistance

Regular Monitoring

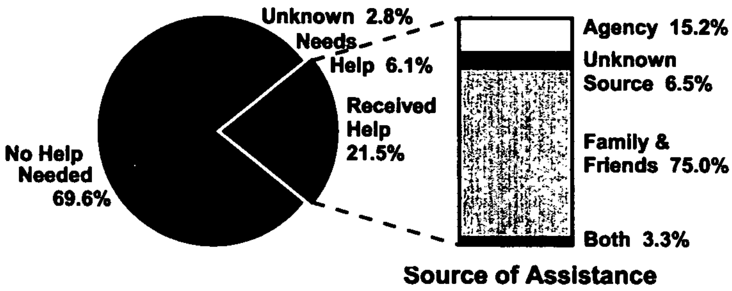


Continuous Care

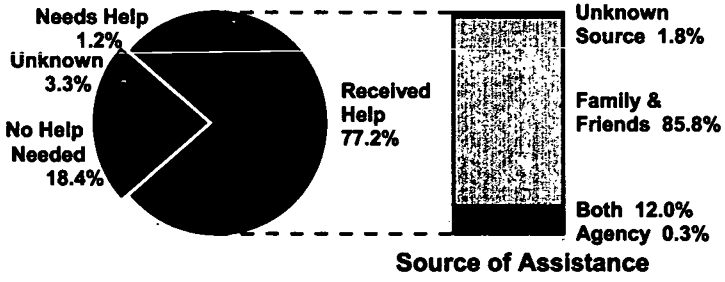


Source of Support for Specific Type of Assistance

Administrative Assistance

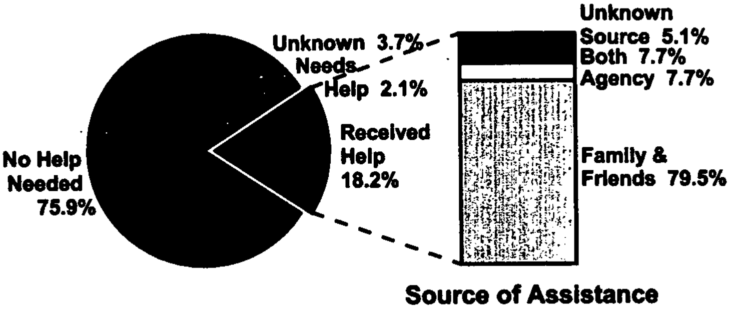


Transportation

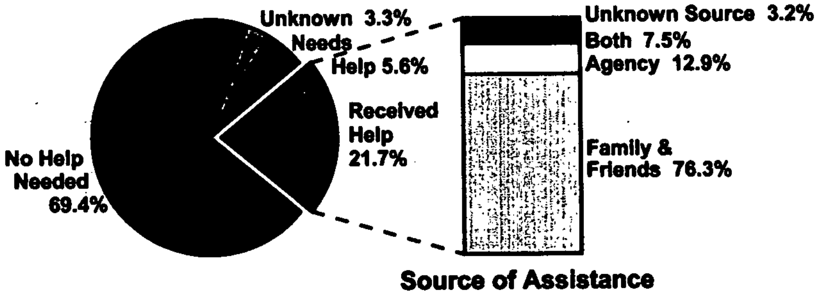


Source of Support for Specific Type of Assistance

Meal Preparation

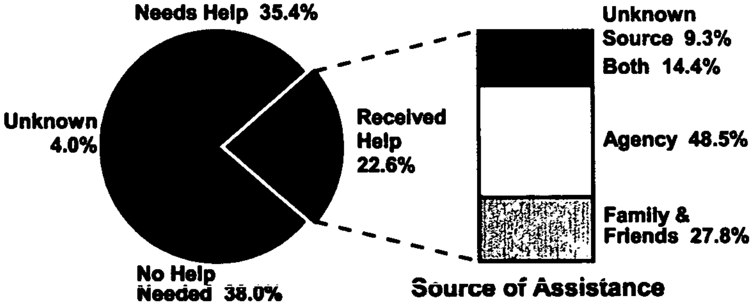


Housekeeping Assistance

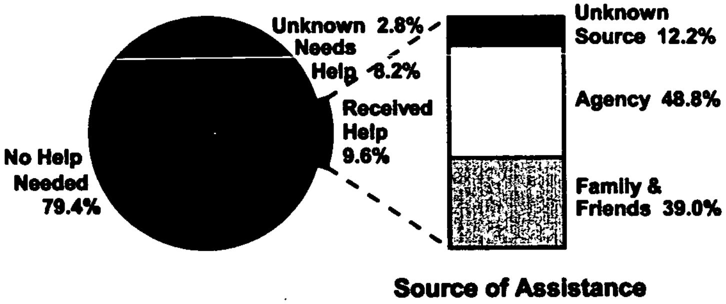


Source of Support for Specific Type of Assistance

Information and Referral

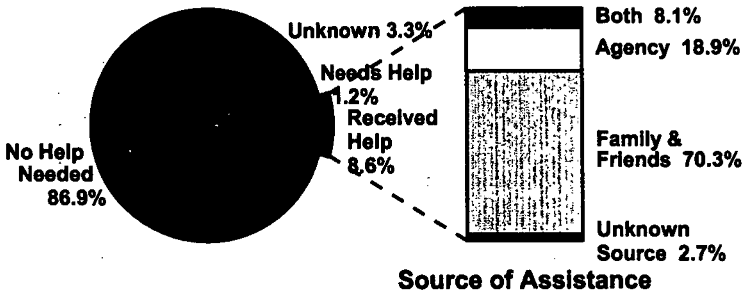


Physical Therapy



Source of Support for Specific Type of Assistance

Personal Care



Nursing Care

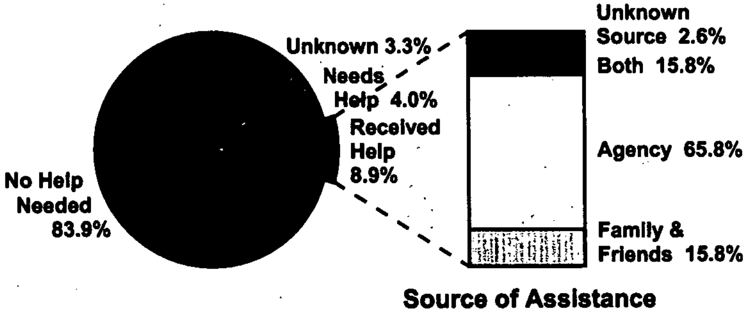


Table 2.25
Source of Support for Specific Type of Assistance (in percentages)

Service	Received	Family or Friends	Hired Help or Agency	Both	Unknown Source
Transportation	77.2	85.8	0.3	12.0	1.8
Regular Monitoring	36.1	87.0	4.5	5.2	3.2
Information & Referral	22.6	27.8	48.5	14.4	9.3
Housekeeping Assistance	21.7	76.3	12.9	7.5	3.2
Administrative Assistance	21.5	75.0	15.2	3.3	6.5
Continuous Care	20.0	88.4	5.8	4.7	1.2
Meal Preparation	18.2	79.5	7.7	7.7	5.1
Physical Therapy	9.6	39.0	48.8	-	12.2
Nursing Care	8.9	15.8	65.8	15.8	2.6
Personal Care	8.6	70.3	18.9	8.1	2.7

Service Need Clusters

Beyond documenting the amount that each service was needed by the SFSU elderly population as a whole, further consideration was given to how service needs tend to group together in clusters. This information not only provides information necessary to the planning process, but also provides useful knowledge for service providers. From either perspective, it is beneficial to know what service needs would best be viewed as a package as opposed to those that are limited, isolated, or specialized needs (see National Indian Council on Aging, 1981, p. 27).

To obtain the cluster information, a statistical procedure was used to assess the degree to which the need for each of these services was associated with the need for each of the other services. The following chart indicates the social service clusters and the associated markers/risk factors (respondent profiles). The clusters represent the services with the greatest affinities, as well as a list of the individual (unclustered) services that did not relate to any of the other service needs. In analyzing the results, it appears that there are several types of services that are perceived as needed by SFSU elders. These services can be grouped under in-home care, assessment/case management, and health care services.

Figure 2.1
Service Need Clusters

Service Cluster (Percent in Need)	**Risk Factors**
In-Home Services (42.7%) Meal Preparation Housekeeping Assistance Regular Monitoring Continuous Care	**Impaired IADLS** **Health conditions which limit activities** **Advanced age** **Poor subjective ratings of overall health** **Female gender**
Assessment/Case Management (64.1%) Overall Review Information and Referral Transportation Administrative Assistance	**Multiple somatic symptoms** **Lack of own transportation** **Worrying often or very often about things in general** **Poor subjective rating of vision**
Health Care Services (25.2%) Medical Care Physical Therapy	**Feeling that health problems limit participation in desired activities** **Multiple somatic symptoms**
Individual Services (unclustered) Mental Health Services Prosthetic Devices Personal Skills Training Nerve Medication Personal Care Nursing Care	

From the standpoint of service administration, the cluster analysis provides insight into how to design and/or deliver services to address needs that tend to occur in conjunction with each other. It is also useful to know which of the services require primary agency attention and which service needs are less of a priority. In order to make recommendations, it is helpful to evaluate the characteristics of people who need assistance with each cluster of services. In addition, useful recommendations depend on knowledge about the social service environment and the strengths and weaknesses of current agency activities. Each of these issues is important in placing the specific service recommendations in a proper context.

Risk Factors Associated with Service Needs

To determine the profile of individuals who need each cluster of services, information provided by each elder about their situation was used to identify the characteristics that placed elders at risk of the need for each service cluster. Regression analysis was used to analyze the predictor variables. Regression analysis enabled the researchers to isolate the variables that have the best predictive capability, while controlling for the effects of other variables in the model. Variables that were not significant were eliminated from the model until only significant variables remained.

Cluster 1: In-Home Services. Cluster analysis indicated an association among the needs for meal preparation, help with housework, regular monitoring, and continuous care. This set of service needs was interpreted as the need for in-home care, and 42.7% reported a need for one or more of these services. The inability to perform instrumental activities of daily living is the strongest predictor of perceived need for in-home services. Clearly, those elders who experienced difficulties with IADLs (impaired ability to perform housekeeping, meal preparation, go shopping, go places out of walking distance, take their own medicine, and handle money) were the most likely to feel that they needed more in-home care. Difficulty performing the instrumental activities of daily living is a significant and strong predictor of the perceived need for in-home services. The other four significant variables also influence the perceived need for in-home services. However, they have substantially less influence than instrumental activities of daily living. Of the subjective indicators, the feeling that health problems inhibit participation in desired activities is significant (the more health problems inhibited participation in desired activities, the more likely respondents were to express a need for in-home services), as was the respondent's subjective health rating (the worse the elder rated their health, the more likely they were to express a need for these services). Age and gender are significant demographic predictors, although weakly influential: older respondents and females were more likely to express a need for these services. Objective measures of ADL functioning are the best predictors of elders' desire for in-home care (IADL scale measures).

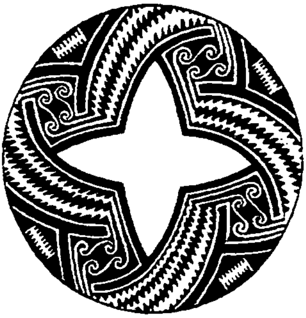
Cluster 2: Assessment/Case Management. Cluster analysis identified a second cluster composed of the need for an overall review of their condition (including health, mental health, and social and financial situation), the need for someone to organize or coordinate assistance, the need for more transportation than is currently available, and the need for someone to manage personal business or legal affairs. These services should be viewed as a basic services package that most elders in the SFSU need. Elders want to have their situation assessed, want assistance in obtaining the services they need (over half want information and referral services: 51.3%), access to these services (transportation), and assistance with the management of personal business affairs. Almost two-thirds of this sample expressed a need for one or more of the services in this cluster (64%).

Somatic symptoms are the most significant predictors of need for the assessment/case management service cluster. Elders who experience multiple somatic symptoms (heart pounding, loss of balance, feeling weak and in ill health most of the time) are significantly more likely to express a need for an overall assessment of their condition and case management services. The analysis also indicates that elders who lack their own transportation are more likely to express a need for this service cluster. Additionally, elders who worried more about things in general and/or had poorer eyesight (with glasses or contacts) were significantly more likely to express a need for assessment, case management, and service access.

Cluster 3: Health Care Services. Additional medical care and physical therapy are the services that make up this cluster. One-quarter (25.2%) of the elders surveyed need one or both of these services. The subjective feeling that health problems inhibit participation in desired activities was the best predictor of an individual's perceived need for additional health care services. This indicates that SFSU elders' perception that health problems limit participation in desired activities has a significant and moderately strong influence on their perception of the need for health care services. Elders who perceive that health problems inhibit participation in desired activities are more likely to feel they need additional health care than they are currently receiving. Elders who experience somatic symptoms are also much more likely to perceive a need for additional health care services. This indicates that somatic symptoms, such as heart pounding, loss of balance, feeling weak, and feeling in ill health most of the time, influences an elder's perception about health care needs. Elders who report higher levels of somatic symptoms feel they need more health care services than they are currently receiving.

CHAPTER 3

FAMILY CAREGIVER FOCUS GROUP INTERVIEWS



This chapter presents findings from the focus group interviews with family caregivers of functionally impaired elders, who currently provide the majority of in-home long-term care in the service unit. As described in the section on methodology in Chapter 1, these focus group interviews were intended to provide an in-depth understanding of the situation of primary family caregivers and of their perceived needs.

The Cultural Context of Caregiving in the SFSU

Planning appropriate service programs for ethnic families requires an understanding of the cultural context of elder care—including values about dependency—(Dicharry, 1986; Hernandez, 1991). Knowledge of this cultural context is also important because existing studies on family caregiving have focused almost exclusively on non-Hispanic white caregivers for whom the impact of caretaking has been evaluated in terms of constraints placed on individual freedoms and opportunities, and effects on nuclear family relationships (Choi, 1993). The assumptions about family structure and Western values that inform previous research on caregiving are not necessarily relevant to the experience of the American Indian caregivers in the SFSU. These caregivers are typically part of extended multigenerational families (see Chapter 2), and share a value orientation that is focused on the needs of the group, rather than those of the individual. Others (Baines, 1992; Wasinger, 1993) have described this same cultural framework as an important consideration for health care delivery to American Indians.

From an American Indian cultural framework, the focus group participants viewed their assistance to functionally dependent family members as an expression of their identity as American Indians:

> *As you grow up you learn to respect your elders [because] they took care of you when you used to be younger, so you sort of have the obligation inside of you to where you should take care of them. And I think that follows for all Indians.*

Caregiving was thus regarded as a reflection of the cultural ethos of interdependency (Red Horse, 1980) and reciprocity among the generations (Shomaker, 1990; Cf. Shomaker, 1989):

> *We talk to our kids and tell them that Grandpa needs our help. There's things he can't do by himself and we need to be there with him. And it kind of helps them to see the future. Where we make them see that we won't all be healthy all the time. You just have to talk to them and teach them that there's that responsibility that you have for the elderly...any elderly person.*

The unacceptability of institutional care for elders was repeatedly emphasized by these caregivers who considered nursing home placement to be a non-Indian practice, and who typically expected to provide home care regardless of the elder's level of frailty. As one caregiver remarked:

> *Whites, I think they can just put their relatives away in a home as long as they have money. Indians have more compassion for them. They would rather take care of them at home. None of us would really want [to put someone in a nursing home]...just 'cause they're unable to take care of themselves.*

Female relatives were described as most often assuming the role of primary or main caregiver. Many of the caregivers who were adult children or grandchildren of the care recipient also had to divide their time between elder care and taking care of their own children or grandchildren. This situation parallels findings reported for caregivers in the general population referred to as the "sandwich generation" (Miller, 1981) or "women in the middle" (Brody, 1981). These terms refer to adults who have both the responsibilities of caring for dependent children and for dependent parents. Several women also discussed the experience or the expectation of serial caregiving, that is, providing assistance to several elders in succession, for example, to a mother, and subsequently, to a mother-in-law. A few caregivers were also taking care of more than one elder concurrently, for example, both grandparents, or a husband and a brother.

In contrast to caregivers in other studies (primarily whites), the focus group participants defined the stresses associated with caregiving as constituting a "burden" in a manner that was consistent with their orientation to the needs of the group, rather than of the individual. That is, burden was attributed to having outside responsibilities that limited one's ability to be a good caretaker, rather than viewing caregiving as interfering with outside activities and personal interests. One respondent expressed this interpretation of caregiver burden as follows:

> *Sometimes I say 'Mom, I just wish I could stay home with you all day long.' But I have a job and [have to] keep up my standard of living. And sometimes I just wish I could stay home with her, and I think it becomes a burden when you have a job and have to tend to her, too. I work with the public school, so I have the whole summer. So, we're just on a countdown now. Three months, then I'll be home all day long during the summer with her. But having to hold a job and taking care of a homebound person is a big burden.*

Although these caregivers expressed satisfaction in being able to fulfill the cultural prescription to provide care for a frail family member, in the absence of a full range of formal support services they could, and in many cases did, experience substantial burdens associated with caregiving, as described in the following section.

Sources of Caregiver Burden

The focus group participants identified four major sources of burden related to their caregiving responsibilities: (1) anxiety about managing severe disease conditions in the home, (2) problems with difficult psychosocial aspects of care, such as care recipients' noncompliance and depression, (3) strains on family relations, and (4) negative effects on health and personal well-being.

In-Home Medical Care Management. Family members caring for elders with severe and/or multiple disease conditions described the worry and uncertainty they experienced especially in the early phases of caregiving or after a change in the elder's health condition. Caregivers were particularly uncertain about having to learn how to provide care to amputees or deal with other complications of diabetes or with high-tech medical equipment in the home. The following comments by the focus group participants illustrate these concerns:

> *She was a new amputee and I was sort of scared because of the stump she had...her amputation was below the knee and I've never taken care of anybody like that so I was kind of scared to handle it...She had a sore on the big toe and we had to fight with that because I was afraid if that gets infected Grandma would lose both legs.*

> *They're both on medication, and that's the hardest part, because being diabetic there's so much complications and there's so much that goes on, and each time they go to the clinic they're always coming back with different kinds of medicines and that's hard.*

> *[My mother] was on oxygen and was feeding through the nose. And for the first time when she got the machine, I was afraid, 'cause I had no medical experience, no First Aid...Eventually I got used to it, but at first I was scared...So I think if you do have somebody that you can call on, [like a] CHR, you feel a little comfortable.*

Although CHRs or public health nurses provide patient education and monitoring, many caregivers believed that current levels of these services were inadequate, and they often felt stranded without sufficient professional backup for care on the reservations. For example, a woman who was caring for her extremely frail grandparents, both of whom had diabetes with multiple complications, explained that on several occasions when the pueblo's one CHR was not available during a medical crisis, she had resorted to calling the tribal police for assistance.

In addition to gaps in care, another related concern of caregivers was the perceived lack of continuity of care among service providers. Some caregivers, in fact, felt that the rehabilitation or maintenance of the elder's condition was compromised by the lack of timely and coordinated attention to medical needs:

> *We've got problems with a lot of health care providers that they won't come. [They say] 'We'll come in three months, we'll come in three weeks, and we'll help you to start giving her walks'...the leg [to be fitted with a prosthesis] is still dangling there, and nobody has showed up. PHS, welfare, and everybody, tell us that they're going to help us, CHRs, we haven't gotten nobody to come.*

A nonresponsive medical service system with a short institutional memory is a source of caregiver frustration. As one respondent put it:

> *Sometimes I have to go back down to the clinic and tell the whole story back over and over again. It's hard for me to.*

Provision of Psychosocial Care. One significant caregiving task that is often overlooked in descriptions of family assistance to frail elders is the provision of emotional support or "cheering up" the care recipient (Horowitz, 1985). The focus group participants identified such efforts to motivate the patient or to deal with the behavioral or psychological problems associated with an elder's disabilities, as an important and particularly stressful aspect of caregiving. Several caregivers described the frustration and helplessness which they experienced in trying to assist a depressed or noncompliant elder:

> *I think some of the problem is her attitude toward her problems. I feel like sometime she has given up and she doesn't want to do anything that the doctors or the therapists tell her to do because she kind of went home and that's it. She didn't want to do anything. She sleeps all day long.*
>
> *And it's hard to get her to do things. So one thing that we can't get her to do is her exercises on her legs. And she won't do that. She's supposed to be doing her own arm exercises. She won't do that either.*
>
> *We were told that if we didn't get her out of that depression that my mother-in-law was in that she would just go downhill and it would be all downhill until death...if we couldn't get her out of that feeling she had like she gave up and she didn't want to try anymore.*

These caregivers reported that they typically received little or no information from health care providers on psychosocial aspects of care, and often through trial and error, had to devise strategies on their own for dealing with these distressing behaviors.

Strains on Family Relations. The impact of caregiving responsibilities on family interactions and relationships was another major source of burden for family caregivers. Many caregivers received some degree of support and assistance from other family members, with whom they could share some or all caregiving tasks. Those who did not have this help or whose family members did not understand the requirements of care, however, often experienced stress from the competing demands of elder care and other family or work responsibilities, as illustrated by the following comments:

> *I feel that I need to do whatever I can for her [mother-in-law], so I spend as much time as I need to at her house and then I go and do whatever I need to do. And sometimes, it's an all day thing and I get a little bit of feedback from my husband when he comes home he'll say, 'Well, what did you do today? You didn't clean the house, and you didn't do this and that.' And that's the burden. I feel like I'm being pulled two ways.*

> *We are always having to be there [at care recipient's home] overnight....I feel I don't have enough time. We used to get up, myself to go to work, my daughter, I drop her. I go to work, they go to school....They stay there [at care recipient's] until nine, ten o'clock...Then you have to get up the next morning again...It got to where...sometimes I didn't want to get up in the morning and come early or go back late. And finally, it was just to the point where finally one day I just stayed overnight and I didn't go back home for a few months.*

The strain that accompanied the lack of family assistance and concern could also increase the burden felt by the primary caregiver as well as affect the psychological well-being of the elder:

> *I'll take care of my mother as long as she's alive. That's the way I look at it. And right now she's doing real good. I take her out, and we have a good time, just going out together. But it does hurt. You feel like you have to do it all. She's got family down in [another community], and do they ever come to see her? They never do. And that's what hurts her. Because nobody comes to see her. And I'm not even her daughter, I'm her stepdaughter.*

Negative Effects on Personal Health and Well-Being. A number of researchers (Gallagher et al., 1989; Haley et al., 1987; Pruchno & Potashnik, 1989) have documented negative physical and mental health consequences as an important caregiving outcome. Several caregivers in the focus groups who were faced with physically demanding caregiving tasks such as lifting or transferring a nonambulatory elder, or responding to the care recipient's needs on a 24-hour basis, reported being chronically fatigued or experiencing other health problems:

> *I couldn't sleep nights. I got to go in to the doctor. She gave me pills and I didn't want to take too much, I might fall asleep and not hear my mother. Because at night she calls me if she has to get up.*
>
> *I have to get up and deal with her bedpan, and so it's like I'm dragging out of bed with puffy eyes the next morning. I'm tired during the middle of the day...[at mealtime] at home I go through it again.*

For a number of these caregivers, the physical and psychological demands of caregiving were compounded by a situation that is extremely rare among white caregivers— the lack of modern conveniences such as central heating, a washing machine, or indoor plumbing:

> *It is hard with those two [care recipients]. My back has been hurting, I pick her up the wrong way sometimes. I pulled a muscle in my spine [while chopping wood for the stove], and my back was hurting for almost two weeks. I kept pulling myself to try to keep them [care recipients] warm, and I had to struggle for six days to come back down, [do] the same things, go back up, do the same things, get water.*

These concerns for personal health also influenced many of the caregivers' perception of their ability to sustain the level of support needed by the elder. As one respondent in her 60s noted:

> *I cook for her, I feed her, I give her her pill, I take her to the doctors. I do everything. And I also had a slight stroke...you know, it is a stress, and you feel like you're there by yourself, you can't get out and do for yourself. But with me, I think I've gotten old within the three years that I've been there [providing care].*

Sources of Caregiver Satisfaction

In addition to the sources of caregiver burden described above, the focus group participants also described the circumstances that contributed to their sense of efficacy as caregivers and their ability to persevere in their efforts. These sources of caregiver satisfaction included (1) achieving control over caregiving by developing fixed routines for managing the medical and non-medical aspects of care, (2) creating family consensus about the caregiving situation and its demands, and (3) obtaining periodic respite from caretaking.

Routinization of Care. The ability to organize caregiving tasks into a predictable routine with a known magnitude of demands has been recognized in previous studies as an important factor in managing the caregiving situation (Albert, 1990; Matthews & Rosner, 1988). The focus group participants likewise emphasized the necessity of developing caregiving regimens that minimize disruption of other household activities and avoid crises in the care recipient's medical condition. For example, several caregivers described their daily schedule of activities for managing the care of functionally dependent elders with diabetes, including such tasks as blood glucose testing, the administration of insulin, skin care, monitoring care recipients' compliance with dietary restrictions, and for amputees, assistance with prostheses. In combination with other medical conditions and functional impairments, such care requirements could easily overwhelm novice caregivers or even experienced caregivers faced with the new and increasing care requirements of a progressively dependent elder.

The focus group participants stressed that having adequate information on patient care was one of the keys to developing efficient and effective routines for in-home care of frail elders:

> *I really wasn't afraid or scared to take care of her, because I had already gone through some of the training and some of the experiences. So I was very comfortable giving her insulin, or giving her bath, or giving her exercises. And I wasn't hesitant about it [or] being afraid that I might hurt her or do more harm for her.*

It is worth noting that even seemingly simple care techniques or low-tech devices that promote control over care management and greater independence on the part of the elder, bolstered caregivers' confidence and enhanced their sense of caregiving efficacy:

> *And we had a hard time before, but now the nurse gave us a medication box that has Monday through Sunday and then morning to bedtime, and we've got that all figured out.*
>
> *As far as dressing she [the care recipient] uses a hook. She does that all by herself, I don't help her. I told her, 'You're going to have to learn how to do that.' She'll get her stocking and put it on and pull it with that. She does a real good job.*

Caregivers were particularly reassured by seeing improvement in the care recipient's condition, and they responded to incremental gains in the elder's functional abilities or medical status as evidence that they were doing a good job. As has been observed in other studies (Kinney & Stephens, 1989), the "uplifts" or satisfactions of caregiving were directly related to the well-being of the patient:

> *I started treating her every day, it was an everyday thing. To this day, it's every other day, and we've got it licked, so her skin is beginning to grow back. And she's not hurting as much as she did.*

> *She's doing real good now. She's not walking, but she walks with a walker, not by herself. But she helps herself quite a bit.*

Achieving Family Consensus on Caregiving. Because of the central importance of the extended family context to caregiving for the focus group participants, the necessity of reaching an understanding among family members regarding expectations of the caregiver and the strains involved in caregiving were emphasized. Some caregivers described how they had successfully divided responsibilities for caregiving tasks among family members. Mobilizing assistance from family members, even if limited, was important to establishing a sense of stability and success in the caregiving situation.

Others, however, were frustrated in attempting to convey to family members the extent of the burden they experienced in caring for their elderly relative, or in their efforts to communicate the care recipient's requirements for care. Several caregivers who had been faced with such difficulties explained that they had resolved or significantly improved these situations by "calling a family meeting" or holding a family meeting with relevant health care providers who initiated—in some cases—and facilitated communication and the family decision-making process:

> *I guess we needed somebody else that was not a family member to kind of speak out...and we had the CHRs there, we had the community PHS nurse that comes out twice a week, and the doctor was there, and then the family members were there. And then we just kind of got together and we put in [our views] and it came out real good and we do have our meetings about every three to four months to kind of get support from the doctor's point of view on the medical situation. And then we iron out some of the problems that we have among the family.*

Obtaining Respite from Caregiving. The focus group participants, especially those caring for elders with heavy care demands or who required constant supervision, also acknowledged the value and necessity of getting a break or occasional respite from their caregiving duties:

> *You have to get out once in a while. If you don't get out you go crazy or something. That's what I do. I have to find somebody to leave her with at least a day to go out and do what you've got to do. Because it really gets to you, too.*

> *And it does help...if you get up and communicate with people. It refreshes your mind. You're willing to do it all over again. But you have to take [time for yourself]. I've learned that. Just getting out...I do have her 24 hours...And sometimes I wish somebody would come out and say 'Hey, I'll take care of her today.'*

As these comments indicate, these caregivers felt that their well-being and outlook on caregiving depended on the availability of caregiver substitutes who were willing to periodically relieve them of caretaking responsibilities. Those caregivers who did not have such opportunities for respite expressed the highest levels of burden among the focus group participants.

The focus group participants' descriptions of their caregiving situations and the stresses and obstacles they experienced in providing care to frail elderly family members point to several modalities of needed long-term care services in the SFSU that are discussed in further detail in Chapter 5. What is important to emphasize here is that rather than wanting to substitute formal services for their own assistance, these caregivers expressed their strong preference for the development of long-term care services that could supplement—not supplant—family efforts to maintain frail elders in the home environment. In the next chapter, quantitative findings are presented on family caregivers' needs and service preferences obtained from the survey of primary family caregivers in the service unit.

CHAPTER 4

PRIMARY FAMILY CAREGIVER SURVEY

This chapter presents the findings from the survey of family caregivers of frail elders in the SFSU. As described in Chapter 1, this survey was designed to answer the following questions: who are the primary caregivers to frail elders; what are the characteristics of these caregivers (e.g., age, health status, are they working outside the home, are they also caring for dependent children); what types of assistance and how much assistance do these caregivers provide to elderly care recipients; what is the extent of assistance provided by other extended family members to frail elders; to what extent do the care recipients utilize existing long-term care services; how burdensome do family caregivers perceive the caregiving situation to be; which aspects of caregiving are most burdensome to these caregivers; and, what kinds of additional long-term care services do family caregivers feel would be useful to support their caregiving activities? These questions are addressed in each of the following sections of this chapter.

Caregiver Characteristics

The 73 sample members included 64 women and 9 men. Daughters were the most frequently represented type of caregiver (50.7%), followed by wives (13.7%), husbands and sons (5.5% each), and daughters-in-law (4.1%). The remainder (14.8%) were comprised of other family members (nieces, a nephew, and a granddaughter) or other non-kin (live-in partners).

The caregivers ranged in age from 16 to 85 years with a median age of 50 years (SD=15.5). The sample included nearly equivalent proportions of caregivers who were married (45.7%) and those who never married (41.4%), 11.4% were widowed, and 1.4% were divorced or separated.

Table 4.1, which presents information on the composition of the caregivers' households, indicates that many of the respondents were living in extended family situations.

Table 4.1
Caregiver Household Members by Type (in percentages)

Child(ren)	70.8
Spouse	41.7
Parent(s)	43.1
Grandchild(ren)	30.6
Other(s)	29.2
Grandparent(s)	5.6

The majority of caregiver households (70.8%) included one or more children and 41.7% included a husband or wife. A sizeable proportion of households, however, also included one or more parents (36.1%), one or more grandchildren (30.6%), or other types of relatives (29.2%), most often siblings and their siblings' children. One or more grandparents were living in a small percentage of households (5.6%). The median household size of the caregivers was five individuals (mean=5.3; range=18; SD=3.3). In addition to their caretaking duties, the majority of caregivers (63.4%) reported that they also had responsibilities for the care of one or more children under age 18 within their household.

Over three-quarters (75.3%) of the caregivers were living with the care recipient. Among those who were not co-residing with the elder, the mean length of the trip from the caregiver's residence to the elder's home was 22 minutes, or just under half an hour (range=2.45 hours; SD=37.3 minutes).

Approximately one-fifth of the caregivers were employed either full-time (16.7%) or part-time (2.8%). Although 41% were unemployed, many reported that their employment had been affected by their caregiving responsibilities, i.e., they had either quit a job (28.8%), had to reduce their work hours (35.6%), or had to take unpaid leave to provide care (32.9%). The typical monthly household income among the caregivers was $851-$1,250.

The majority of the sample reported that they were in good or excellent health (33.3% and 22.2% respectively); however, an additional 41.7% rated their health as "fair," and the remaining 2.8% said that they were in poor health. Consistent with their self-assessed health status, the majority of these caregivers indicated that their health did not interfere at all with their caregiving responsibilities (55.6%), or interfered with caregiving only to a small extent (29.2%). A total of 15.3%, however, felt that their health was an impediment to caregiving either to a moderate extent (12.5%) or to a great extent (2.8%).

Care Recipient Characteristics

The caregivers in this study were providing care for elders who ranged in age from 58 to 103 years with a median age of 83 years (SD=10.5). Sixty-three percent of the care recipients were female. In 52% of the cases, caregivers identified a physical health problem as the reason the elder needed help; 2.7% of elders were described as requiring assistance because of a problem with memory and/or judgment, and an additional one-third (32.9%) of the cases involved both physical and cognitive impairments. The remainder (12.3%) involved other functional causes or dependencies such as chronic alcoholism or blindness. Caregivers viewed the care recipients as relatively dependent: close to 60% of respondents judged their relative to be "very dependent," and 31% felt that the care recipient was "somewhat dependent."

Table 4.2 presents information on the care recipients' limitations in ability to carry out activities of daily living. These include physical self-care tasks (bathing, toileting, dressing, transferring, and eating) as well as instrumental activities (shopping, using the telephone, using transportation, cooking/fixing meals, taking medicine, doing housework, managing money, and dealing with governmental and other agencies) that are necessary to personal and household maintenance.

On average, these elders required assistance with three (SD=1.7) out of the five physical activities of daily living. The care recipients were even more dependent in the performance of instrumental activities of daily living. The mean number of dependencies with these eight tasks was 7.5 (SD=.81).

Table 4.2
Care Recipient Limitations in Physical and Instrumental Activities of Daily Living (in percentages)

Activity	Some Help Needed	Cannot Perform the Activity
Bathing	54.8	23.3
Using the toilet	50.7	9.6
Dressing	60.3	11.0
Moving in and out of bed and chairs	49.3	17.8
Eating	18.1	2.8
Shopping	20.5	76.7
Using the telephone	24.7	65.8
Using transportation	19.2	80.8
Cooking/fixing meals	15.1	75.3
Dealing with agencies	4.1	95.9
Taking medicine	42.5	46.6
Doing housework	16.7	80.6
Managing money	25.0	70.8

Dealing with an elder's cognitive impairments and behavioral problems due to deficits in memory and judgment or other functional losses have been shown to be particularly stressful to caregivers (Noelker & Poulshock, 1982). The frequency of specific cognitive problems among the care recipients is shown in Table 4.3.

Although significant proportions of these elders occasionally experienced common types of memory problems such as remembering recent events (56.2%) or remembering words (30.6%), more serious types of cognitive impairment were also present among this group. Between 10% and 20% were reported as always having a problem with recalling recent events, orientation to season, understanding simple instructions, finding his or her way around the house, and recognizing familiar people.

Table 4.3
Frequency of Cognitive Problems in Care Recipients (in percentages)

Task	Occasionally a Problem	Always a Problem
Remember recent events	56.2	15.1
Remember what season it is	38.4	12.3
Remember words	30.6	8.3
Understand simple instructions	40.3	12.5
Find his/her way around the house	16.4	15.1
Speak sentences	15.1	2.7
Recognize people he/she knows	34.2	19.2

Five types of behavioral difficulties among the care recipients were also surveyed. As shown in Table 4.4, approximately one-third of these elders frequently exhibited nervous and worried behavior, and over 20% were constantly restless or agitated. Comparatively few elders experienced routine problems with getting lost (6.8%) or exhibiting potentially dangerous behaviors (4.1%).

Table 4.4
Frequency of Behavioral Problems in Care Recipients (in percentages)

Behavior	Occasionally a Problem	Always a Problem
Wandering or getting lost	16.4	6.8
Constantly restless or agitated	47.2	22.2
Nervous or worried	57.5	30.1
Potentially dangerous behaviors	19.2	4.1
Making it to the bathroom on time	38.4	9.6

Incontinence has been shown to be a special behavioral problem that is strongly associated with caregiver stress and is a significant predictor in the decision for nursing home placement among the general population (Noelker & Townsend, 1987; Zarit et al., 1986). Incontinence was a problem to some degree for close to half (48%) of the care recipients in this study. Although the survey question did not ask if this was urinary or fecal incontinence, 38% of elders were reported to occasionally have "problems making it to the bathroom on time," and another 10% experienced this problem frequently.

Many behavioral problems require caregivers' close attention and surveillance in order to prevent accidents or other adverse consequences due to poor judgment or functional losses. Close to one half (47.9%) of the caregivers reported that the care recipient required constant supervision, i.e., could be left alone for only one hour or less.

Types and Extent of Assistance Provided by the Caregivers

The sample included both novice and seasoned caregivers. The length of time reported as being the primary caregiver to a frail elder ranged from 3 months to 32 years with a median of 5 years (mean=6.8; SD=6.1). The number of hours that caregivers said they spent helping the care recipient on a typical day ranged from 1 to 24, with a mean of 8 hours (SD=4.4). The responses to this question were obviously a matter of the caregiver's interpretation—although no caregiver is literally providing care to an elder for 24 hours, these responses reflect the fact that some caregivers have to be available to respond to the elder's needs on a 24-hour basis.

Table 4.5
Types and Extent of Assistance Provided By Primary Caregivers (in percentages)

Caregiving Activity	Several Times a Week	Every Day
Assistance with eating	4.1	2.7
Personal care	9.7	55.6
Toileting	5.5	30.1
Walking	11.3	21.1
Transferring in and out of bed, chair, or couch	9.6	34.2
Meal planning	2.8	79.2
Meal preparation	2.8	81.9
Banking, paying bills, or other financial matters	5.5	45.2
Shopping, appointments, or running errands	23.6	38.9
Personal communications (letters, phone calls, etc.)	18.1	20.8
Laundry or other household chores	24.7	43.8
Transportation	16.4	37.0
Taking medications	20.5	42.5
Carrying out prescribed treatments	6.8	24.7
Contact M.D. or other health care workers	2.7	8.2
Nighttime check	4.2	47.2

Table 4.5 presents information on the frequency of assistance with 16 activities that the caregivers provided to elders. The response categories for these items included never, rarely, several times a month, several times a week, and every day. Table 4.5 presents responses to the last two categories that indicate a significant level of assistance.

The most frequently provided types of assistance involved the planning and preparation of meals, with approximately 80% of caregivers performing these tasks every day. Help with personal care (i.e., dressing, bathing, hair care, or teeth care), household chores, shopping, banking or paying bills, transportation, taking medications, and checking on the elder at night, are also exceptionally common everyday tasks reported by these caregivers. Despite the obvious burden of time involved in providing assistance at these levels, previous research has suggested that it is the type of task rather than the intensity of assistance, that caregivers find burdensome (Montgomery et al., 1985; Noelker & Poulshock, 1982; Reece et al., 1983). For example, providing help with toileting or with other intimate tasks, especially if the care recipient is a parent of the opposite sex, can be a difficult or distressing task for a caregiver. Likewise, tasks that demand physical strength such as transferring an elder from one place to another, are also often perceived as burdensome. Both of these types of assistance were provided several times a week or more by significant proportions of these caregivers.

Types and Extent of Assistance Provided by Other Family Members

Almost 22% of caregivers have no assistance from other family members. However, more than three-quarters (78.1%) of caregivers in the SFSU sample reported that other family members provide some level of assistance with the caregiving tasks listed above. Table 4.6 identifies these other relatives involved in caregiving.

Table 4.6
Family Members Who Provide Assistance to Primary Caregiver by Relationship to Elder

Relationship	Percentage
Daughter(s)	53.5
Son(s)	39.3
Grandchild(ren)	37.5
Sister(s)	25.1
Other Relatives	17.9
Brother(s)	14.3
Spouse	3.6

A care recipient's daughter was the most frequent type of secondary caregiver, and 18% of primary caregivers reported that two or more of the elder's daughters assisted them. As can be seen in Table 4.6, these additional family helpers were by no means predominantly female relatives. Close to 40% of the respondents had one or more of the elder's sons helping them, and in 11% of these cases, two or more sons provided assistance. The elder's grandchildren were another important type of ancillary caregiver identified by 37% of respondents. The care recipients' brothers and sisters as well as other types of family members such as nieces and nephews, were likewise frequently involved in caretaking.

The mean number of these secondary caregivers was 1.9 (range=14, SD=2.1). Among the caregivers who reported receiving help with caregiving tasks, 55% of respondents reported one additional caregiver, 30.4% reported two, and 14.3% reported three or more. Table 4.7 shows the frequency of assistance provided by secondary caregivers for each of three types of caregiving tasks—help with physical activities of daily living (ADLs), help with instrumental activities of daily living (IADLs), and supervision/checking on the care recipient. "Routine" assistance with these tasks indicates that it was provided weekly or more frequently, and "occasionally" denotes that help was rendered less than weekly.

Table 4.7
Types and Frequency of Assistance Provided by Other Family Members (in percentages)

Type of Assistance	Frequency of Assistance		
	Total with Help	Routine	Occasional
Help with ADLs	31.5	91.3	8.7
Help with IADLs	61.6	86.4	13.6
Supervision/Checking	20.5	53.3	46.7

The most frequently reported type of assistance from other informal caregivers was help with IADLs. Among caregivers with ancillary help (61.6%), the majority (86.4%) reported that it was provided on a regular or routine basis. Help with more demanding tasks was far less common. Only 31.5% of primary caregivers were assisted by other family members with the elder's physical activities of daily living. However, where help from a secondary caregiver existed, the vast majority of caregivers with this type of supplementary assistance (91.3%) received routine rather than occasional help. In addition, 20.5% of caregivers received help from secondary caregivers in supervising or checking on the elder. In more than half (53.3%) of the instances where this type of assistance was provided, routine assistance was provided at least once a week.

These types of assistance from other family members are, of course, not mutually exclusive. That is, secondary caregivers could assist the primary caregiver with more than one of these types of activities. Indeed, 42% of caregivers received additional family help with both ADLs and IADLs.

Formal Service Use by Care Recipients

Table 4.8 summarizes the care recipients' use of formal long-term care services. These include health and social services that were received "on a regular basis," i.e., at least twice a month.

Table 4.8
Care Recipients' Use of Formal Long-Term Care Services

Health Services	Percentage
Medical Care	57.5
Community Health Representative	30.1
Nursing Care	28.8
Counseling	17.8
Physical Therapy	11.0
Disabled & Elderly Medicaid Waiver Program	2.7
Social Services	**Percentage**
Meals (home-delivered or congregate)	76.7
Transportation	45.2
Senior Companion	28.8
Personal Care	11.0
Social/Recreational	8.2
Regular Monitoring	6.8
Information and Referral	5.5
Senior Escort	4.1
Housekeeping Assistance	2.7
Laundry/Diaper	2.7
Outreach	1.4

Among the health-related services, over half (57.5%) received medical care, about one-third received regular nursing care and Community Health Representative visits (28.8% and 30.1% respectively), and 17.8% received counseling services. Only a small percentage received physical therapy (11%), and Disabled and Elderly Medicaid Waiver Program services (in-home services provided to elders evaluated as eligible for and in need of nursing home placement) were used by 2.7%. Overall, and in relation to the level of impairment, these elders receive few medical services on a regular basis.

The receipt of social services by elders is also relatively low. The only social service received by a majority of elders was congregate or home-delivered meals (76.7%). Senior transportation services (45.2%) were also relatively common. Senior companion services were received regularly by fewer than one-third of these elders (28.8%). Exceptionally few elders received regular assistance with personal care, social recreational services, regular monitoring, information and referral, senior escort services, housekeeping assistance, laundry/diaper services, or outreach.

Sources and Extent of Caregiver Burden

The survey included a large number of questions intended to characterize the stresses or burden experienced by respondents due to their elder care responsibilities. These questions included an open-ended query to identify problems from the respondent's own perspective, questions concerning caregivers' perceptions of the physical and emotional demands of caretaking, and a multi-item scale to measure different aspects of caregiver burden.

Self-Identified Problems. In order to elicit the survey respondents' views of their most salient problems as caregivers, they were asked to reply to the open-ended question, "What would you say is your most important problem right now as a caregiver?" The responses to this item were recorded verbatim by the interviewers and subsequently categorized. The categories of responses are shown in Table 4.9 by frequency of occurrence.

It is worth noting that 12.3% of the responses to the question about the caregiver's most important current problem indicated that the caregiver did not have any particular problem with elder care at present. The most frequent type of problem, identified by 13.5% of the caregivers, concerned isolation and lack of companionship or supervision for the elder. Several caregivers were concerned about the toll that loneliness or boredom was having on the care recipient, while others indicated the potential risks involved in having to leave a functionally dependent elder alone during the day while they were at work. The lack of opportunities for respite was mentioned by 12.3% of caregivers. Responses in this category ranged from the general wish to "get some time off once in a while" to more specific frustrations about being unable to go to work or to take a vacation due to caregiving responsibilities.

The next most frequently cited problems concerned the caregivers' own advanced age and personal ill health, and lack of assistance with caretaking from other family members. Both categories of problems were mentioned by about 10% of respondents. Comments from caregivers who mentioned the latter included, for example, the desire for increased support and involvement in elder care, and the need for others to be more understanding of the demands of caretaking on the primary caregiver. The lack of routine health assessment or monitoring of the care recipient's status (e.g., "the need to have a nurse around for health screening and constant monitoring") was also identified as a significant problem by 7.4% of the respondents. Aspects of the environment, including deficiencies in housing, were another theme that appeared in 7.4% of the caregivers' responses. For example, one caregiver mentioned the difficulties that the lack of an indoor toilet caused for the care recipient, while others described the problems involved in managing incontinence without access to laundry facilities in the home. Another problem identified by 7.4% of the respondents that is closely related to the issue of access to facilities and services was the lack of transportation. Respondents who cited not having transportation explained, for example, that this situation interfered with getting the elder to a clinic for check-ups or doing other necessary errands on behalf of the care recipient.

Table 4.9
Caregivers' Self-Identified Most Important Current Problem

Problem	Percentage
Elder isolated/lacks companionship/supervision	13.5
None	12.3
Lack of respite	12.3
Personal health/old age	9.9
Lack of help from family members	9.9
Lack of health assessment/monitoring	7.4
Environmental/housing problems	7.4
Lack of transportation	7.4
Need for homemaker	6.2
Elder's behavior problems	6.2
Other	4.9
Need for caregiver training	2.5

As in the caregiver focus group discussions described in the previous chapter, several caregivers (6.2%) cited having to deal with behavioral aspects of elder care as a major problem. These caregivers' concerns ranged from compliance and service refusal issues—e.g., "problems having her take her medicine the right way," "has eye problems but won't go to the doctor"—to dealing with depression in the care recipient. The same proportion of responses (6.2%) identified the need for homemaker assistance. The need for caregiver training on elder health issues was also mentioned by a number of the respondents (2.5%) as their most important current problem. Examples of responses in this category included "some knowledge in caring for sick people," and "need to have nutrition education because of change in diet when elderly began dialysis treatment." About 5% of the responses related to other concerns, for example, the desire to return to the way life was before taking on the care of a frail elder.

Physical and Emotional Demands of Caregiving. The respondents' perceptions of the physical and emotional demands of their elder care responsibilities were also examined. Respondents were asked, in view of the assistance provided to the elder, to rate how physically and how emotionally demanding they considered providing this help to be. The distribution of responses to the two questions about the extent of these perceived demands are presented in Table 4.10.

Table 4.10
Perceptions of the Physical and Emotional Demands of Caregiving (in percentages)

Level of Demand	How physically demanding	How emotionally demanding
Not demanding	6.8	9.7
A little demanding	32.9	22.2
Somewhat demanding	23.3	31.9
Very demanding	37.0	36.1

Over 60% of respondents indicated that they considered their elder care responsibilities to involve substantial physical and emotional demands, i.e., to be "somewhat demanding" or "very demanding." Indeed, close to 40% of these respondents rated their provision of help as very demanding physically or emotionally.

Sleep deprivation is another important issue that effects the health and coping abilities of caregivers. Tending to the needs of infirm elders who require nighttime assistance with activities such as toileting or taking medications often results in sleep interruption of the caregiver. Forty-five percent of the caregivers in this study reported that their sleep is interrupted because of the elder's care needs. Of these respondents, close to a quarter (23.3%) reported two episodes of interrupted sleep in an average week, and 63.3% reported three or more instances of sleep interruption.

Subjective Caregiver Burden. In order to further quantify the sources and extent of subjective burden experienced by these caregivers, a 22-item caregiver burden scale was administered. The response categories for this scale were: never, rarely, sometimes, quite frequently, and nearly always. Table 4.11 presents the percentages for the three response categories that indicate a significant level of perceived burden.

Table 4.11 indicates that the vast majority of respondents quite frequently or nearly always felt that the elder is dependent upon them and that the elder seems to expect them to take care of him/her as if they were the only one on whom the elder could depend (83.5% and 79.2% respectively). Sixty-four percent of the respondents quite frequently or nearly always felt that they could be doing a better job of caregiving. Additionally, about one-half felt afraid of what the future holds for the elder (49.3%), or strained when around the elder (48.7%). Over one-third reported that quite frequently or nearly always they felt unable to care for the elder much longer (35.2%), or pulled between elder care duties and other responsibilities for family or work (34.2%). About one-third felt that they did not have enough time for themselves (30.1%), or did not have enough money to care for the elder (30.1%).

Table 4.11
Endorsement of Caregiver Burden Measures (in percentages)

Burden Item	Sometimes	Quite Frequently	Nearly Always
Dependent upon caregiver	15.1	49.3	34.2
Elder exclusively dependent on caregiver	15.3	54.2	25.0
Could be doing a better job	12.3	52.1	12.3
Fear of future	26.0	26.0	23.3
Strained around elder	29.2	30.6	18.1
Unable to care for elder much longer	14.1	18.3	16.9
Pulled between elder and other responsibilities	42.5	27.4	6.8
Not enough time for self	46.6	23.3	6.8
Not enough money	37.0	17.8	12.3
Elder asks for more help than needed	49.3	21.9	5.5
Uncertain what to do about elder	25.0	22.2	2.8
Lost control of life because of caregiving	19.4	19.4	5.6
Elder negatively affects other relationships	28.8	19.2	4.1
Embarrassed by elder's behavior	16.4	11.0	8.2
Overall, feel burdened by elder	34.2	16.4	2.7
Not as much privacy as desired	30.1	9.6	6.8
Social life has suffered	45.8	11.1	4.2
Should be doing more for elder	54.8	11.0	4.1
Feel angry around elder	26.0	11.0	2.7
Wish could leave care to someone else	23.9	8.5	1.4
Caregiver's health has suffered	21.9	9.6	-
Uncomfortable having friends over	8.2	4.1	1.4

Of the remaining measures of perceived caregiver burden, about one-fourth of the respondents quite frequently or nearly always felt that the elder asks for more help than he or she needs (27.4%), were uncertain about what to do about the elder (25%), that they had lost control of their lives because of caregiving (25%), and that the elder care recipient has a negative effect on their relationships with other family members or friends (23.3%). A smaller proportion of caregivers quite frequently or nearly always felt embarrassed by the elder's behavior (19.2%), burdened overall by elder care (19.1%), that they did not have as much privacy as they desired (16.4%), that their social lives had suffered because of caregiving (15.3%), that they should be doing more for the care recipient (15.1%), or felt angry when around the care recipient (13.7%). Finally, a very small percentage of caregivers reported quite frequently or nearly always feeling that they wished that they could relinquish caregiving responsibilities—"just leave care to someone else"—(9.9%), that their health had suffered because of caregiving (9.6%), or felt uncomfortable having friends visit their home because of the elder (5.5%).

Types of Caregiver Burden

Responses to each of the separate burden items are informative about these commonly experienced aspects of caregiver burden. However, various aspects of burden may tend to be related—that is, those caregivers who experience a particular type of burden may tend to also experience another particular type. Therefore, identifying specific dimensions of burden is crucial to planning services to address these separate types of caregiver stress (McKinlay et al., 1995). In order to identify significant types of perceived burden among the respondents, the burden scale data were analyzed using a statistical procedure known as factor analysis.

Table 4.12 presents the five types of caregiver burden, and the burden scale items that are related to each other. These factors can be interpreted as meaning that respondents who tended to endorse one of these items strongly (i.e., to indicate that they experienced this type of burden more frequently), also tended to endorse the other items more strongly

The first type of burden is composed of five interrelated items: (1) how often do you feel that you will be unable to take care of the elder much longer, (2) how often do you feel you have lost control of your life since you've become a caregiver, (3) how often do you wish you could just leave the care of the elder to someone else, (4) how often do you feel uncertain about what to do about the elder, and (5) overall, how often do you feel burdened in caring for the elder? This group of interrelated items indicates the degree to which the caregiver is experiencing serious questions about how long they will be able to continue caregiving to the elder. This type of burden may be viewed as reflecting the caregiver's feelings of efficacy in providing care to the elder. Caregivers who experience high levels of this type of burden may portend the breakdown of care, and that the elder is at some risk of neglect or institutionalization.

The second type of burden included the following five items: (1) how often do you feel pulled between caring for the elder and trying to meet other responsibilities for your family or work, (2) how often do you feel that the elder currently effects your relationship with other family members or friends in a negative way, (3) how often do you feel that you don't have as much privacy as you would like because of the elder, (4) how often do you feel that your social life has suffered because you are caring for the elder, and (5) how often do you feel that the elder seems to expect you to take care of him/her as if you were the only one he/she could depend on? These items measure the degree to which caregiving interferes with other interpersonal relationships and role expectations, and is, therefore, identified as role conflict.

Table 4.12
Types of Caregiver Burden

Caregiver Efficacy
- Unable to care for elder much longer
- Lost control of life because of caregiving
- Wish could leave care to someone else
- Uncertain what to do about elder
- Overall, feel burdened by elder

Role Conflict
- Pulled between elder and other responsibilities
- Elder negatively affects other relationships
- Not as much privacy as desired
- Social life has suffered
- Elder feels respondent is only one to care for

Negative Emotions
- Embarrassed by elder's behavior
- Angry around elder
- Uncomfortable having friends over

Role Strain
- Elder asks for more help than needed
- Not enough time for self
- Strained when around elder
- Health has suffered

Guilt
- Should do more for elder
- Could do more for elder

A third type of caregiver burden was identified from the following three items: (1) how often do you feel embarrassed over the elder's behavior, (2) how often do you feel angry when you are around the elder, and (3) how often do you feel uncomfortable about having friends over because of the elder? This group of questions indicates the extent of a caregiver's negative emotions toward the elder, the caregiving situation, and perceived social limitations brought about by caregiving responsibilities.

The fourth type of burden suggest problems within the caregiving role and the degree to which the caregiver is experiencing pressure from the demands of the caregiving situation. The interrelated items include: (1) how often do you feel that the elder asks for more help than he/she needs, (2) how often do you feel that because of the time you spend with the elder that you don't have enough time for yourself, (3) how often do you feel strained when you are around the elder, and (4) how often do you feel your health has suffered because of your involvement with the elder? This type of burden measures the degree to which caregiving produces role strain.

Finally, the last type of burden is composed of two items: (1) how often do you feel you should be doing more for the elder, and (2) how often do you feel you could do a better job in caring for the elder? These items measure the perceived degree of guilt indicated by the caregivers over the caregiving situation. Higher levels of this type of burden indicate feelings of inadequacy by the caregivers concerning the extent and quality of their caregiving activities.

Predictors of Caregiver Burden

The next step in examining caregiver burden was to determine which caregivers are most likely to experience the five different types of burden—lack of caregiver efficacy, role conflict, negative emotions, role strain, and guilt. In order to do this, regression analysis was used to identify the characteristics of caregivers, the characteristics of the elder, and of the caregiving situation itself that predict the different types of burden. The statistically significant predictors of each type of burden are presented in Table 4.13.

Table 4.13
Predictors of Types of Caregiver Burden

Caregiver Efficacy	Current relationship with elder Physically demanding Self-rated health status
Role Conflict	Health maintenance activities Work loss
Negative Emotions	Relationship with elder Health maintenance activities Household income
Role Strain	Preparing/planning meals Physically demanding Memory loss
Guilt	Health maintenance activities IADL assistance Preparing/planning meals Others help with caregiving

Perceived Caregiver Efficacy. The most important predictor of perceived efficacy is the current relationship between the elder and the caregiver. Those caregivers who currently experience a very close relationship with the elder were less likely to have generalized feelings of inefficacy. The extent to which caregivers feel that the caregiving situation is physically demanding also influences feelings of efficacy. The more caregivers felt that caring for the elder is physically demanding, the more she or he has doubts about the efficacy of the caregiving situation. Additionally, the caregiver's self-rated health status is a significant predictor of feelings of efficacy: the better the caregiver's self-rated health status, the greater the feelings of efficacy or competence in taking care of the elder.

Role Conflict. Two variables were significantly associated with this type of caregiver burden. Activities necessary to maintain an elder's physiological health (i.e., providing help with eating, helping the elder take medications, helping the elder with prescribed treatments, contacting physicians about medications and/or treatment needs, and checking on the elder during the night) had the greatest influence on role conflict among respondents in this sample. The more the caregiver was required to provide support to the elder for facilitating health maintenance, the greater the feelings of role conflict.

Secondly, the amount of work loss due to caregiving was also a predictor of a sense of role conflict among respondents: the greater the work loss because of caregiving, the greater the degree of role conflict expressed by the respondents. Obviously, this is a result of the competing expectations associated with the role of health maintenance provider to the elder. In other words, the greater the involvement of the caregiver in basic health maintenance activities, the more likely they were to perceive that caregiving conflicted with other roles of spouse, worker, or parent.

Negative Emotions. The current relationship between the elder and caregiver was the strongest predictor of negative emotional feelings on the part of the caregiver: the closer the relationship with the elder reported by caregivers, the less likely caregivers were to express negative emotions toward the elder. Providing physiological health maintenance was also a significant predictor of negative emotions: the more physiological health maintenance required of the caregiver, the greater the degree of negative emotions that were expressed toward the elder. Finally, household income influenced the experience of negative emotions toward the elder—higher levels of income were associated with decreased negative feelings toward the elder. Admittedly, it is probably not the income itself that reduces negative feelings toward the elder, but rather the increased standard of living, material comforts, and free time which income provides that mitigate the negative emotions expressed toward the elder.

Role Strain. Planning and preparing the elder's meals was the strongest predictor of this type of burden. The more caregivers were responsible for planning and preparing meals for the elder the greater the feelings of role strain. Secondly, the degree to which the respondents felt the caregiving situation was physically demanding also influenced feelings of role strain. The more physically demanding the respondent felt caring for the elder was, the more likely they were to express feeling role strain. Thirdly, the amount of memory loss exhibited by the elder increased the level of role strain expressed by caregivers. Although the weakest indicator of personal strain, those respondents who reported caring for elders with higher levels of difficulty remembering recent events, remembering what season it is, remembering how to find his/her way around the house, and recognizing people he/she knows also expressed higher levels of role strain.

Guilt. The last type of burden was composed of two items that measure the perceived degree of guilt felt by caregivers over the caregiving situation. This type of burden indicates the caregiver has feelings of inadequacy about the extent and effectiveness of their caregiving activities. Among the significant predictors of guilt, providing physiological health maintenance has the strongest influence on this type of burden. The more a caregiver does to support basic health maintenance activities, the more likely they are to feel guilty. This is undoubtedly a result of the increased sensitivity to the elder's physiological frailty brought about by providing repeated help with basic tasks such as eating, taking medications, helping the elder with prescribed treatments, contacting physicians about medications and/or treatment needs, and checking on the elder during the night.

In contrast, providing help with instrumental activities of daily living is inversely related to feelings of guilt. The more respondents provided help with the elder's banking, bill paying, or other financial matters, shopping or other errands, laundry, providing transportation for the elder, and helping the elder with writing letters or phone calls, the less likely they were to express feelings of guilt. Planning and preparing meals for the elder also reduced the level of guilt among caregivers. Finally, whether or not the respondent received help from other family members or friends with caregiving activities is a significant predictor of the level of guilt expressed by caregivers. Those caregivers who received help from others expressed increased levels of guilt over the caregiving situation. Thus, although help from others may be beneficial, the use of others as caregivers tends to increase guilt feelings. It is not clear whether this guilt stems from a feeling that by getting help with caregiving that this means that they have not succeeded in fulfilling their caregiving responsibilities (i.e., represents a personal failure) or whether this represents an indirect indicator of an impending failure of the caregiving situation.

Service Preferences

An additional section of the survey asked respondents about their views of a range of community-based and extended care services that they would consider helpful to them as caregivers. For each of the following services, respondents were asked to indicate if they would find the service, not at all helpful, a little helpful, moderately helpful, very helpful, or extremely helpful. Table 4.14 presents the proportion of respondents who rated the services to be potentially of considerable benefit (i.e., either very helpful or extremely helpful).

Consistent with the focus group findings that caregivers are apprehensive about managing serious health problems in the home setting, as shown in Table 4.14, the greatest percentage of survey respondents (89%) rated "regular monitoring of the care recipient by a professional—either a nurse, social worker, CHR, or senior citizens program staff" as being very helpful or extremely helpful. Likewise, 84.9% gave this rating to the provision of information about the elder's health problems and what to expect about the elder's condition, and 82.2% saw similar utility in caregiver training (i.e., "training about how to manage the elder's situation, for example, learning about how to deal with difficult behaviors"). Thus, caregivers expressed extremely favorable views of services that would enhance their knowledge about the status and likely course of the care recipient's health condition, services that would impart techniques for care management, and most importantly, the availability of professional support for reviewing the elder's status on a routine basis.

Table 4.14
Services Rated as "Very Helpful" or "Extremely Helpful"

Service Modality	[illegible]
Regular monitoring of care recipient	[illegible]
Information about elder's health problems and what to expect about elder's condition	[illegible]
Caregiver training	[illegible]
Case management	[illegible]
Respite care	[illegible]
Information about health services	[illegible]
Assistance with elder's physical care	[illegible]
Day care	[illegible]
Information about social services	[illegible]
Caregiver support group	[illegible]
Nursing home care	[illegible]

Sizeable proportions of the respondents also endorsed the helpfulness of services that would improve access to and coordination of care, i.e., information about health services (76.7%) and case management (80.6%); services that would provide physical relief to the caregiver—respite care (79.5%) and assistance with elder's physical care (72.6%)—were also rated as being extremely helpful. In addition, a majority of respondents felt that day care (69.9%) and information about social services (58.3%) would be of great assistance to them. About half of respondents (49.3%) also judged caregiver support groups to be a very helpful or an extremely helpful service option. Finally, nursing home care (37%) was seen as the least helpful service alternative by caregivers.

Reasons to Discontinue Caregiving

The caregivers were also asked to identify possible circumstances under which they might discontinue providing care. This question was asked as an open-ended item, and research staff subsequently coded the responses into one or more of the categories. As shown in Table 4.15, the majority of caregivers (52.1%) expressed that they would not consider relinquishing their responsibilities as primary caregiver, but would somehow manage to continue caregiving in spite of any changes in their own condition or the condition of the care recipient. This sentiment is consistent with that expressed in the caregiver focus groups, i.e., that they would endeavor to provide care no matter how frail the elder were to become. The next most frequent response was "don't know," given by 35.6% of the respondents, indicating perhaps that they had not considered this option or viewed the risk as unpredictable. However, sizeable proportions of these caregivers cited worsening physical or mental health status, whether their own or that of the care recipient, as a threat to the continued care of the elder. About one-fifth each indicated that they would consider discontinuing care if their own physical or mental health (21.9%) or the physical health of the care recipient worsened (23.3%). Only a small percentage identified a non-health related problem as a potential reason that they would discontinue care. Although only a small percentage, it should be noted that 1.4% of caregivers stated that they already believe that they no longer are able to provide care.

Table 4.15
Circumstances Under Which Caregivers Might Discontinue Assistance to Elder (in percentages)

None: I would manage somehow	52.1
Don't know	35.6
If elder's physical health problems worsened	23.3
If own health or mental state worsened	21.9
If elder became bed bound	16.4
If elder required constant supervision	9.6
Problems with bladder or bowel accidents	6.8
If elder's mental state worsened	5.5
Other family commitments	4.1
No longer able now	1.4

As a further indicator of caregiver stress, the survey included the question, "Have you ever considered nursing home placement?" Eighteen percent of the caregivers indicated that they had considered this option. An affirmative answer to this question was significantly correlated with the caregiver's self-rated health (r=-.42, p<.0001), with the caregiver's perception of caregiving as emotionally demanding (r=.25, p<.04), and with the following characteristics of the care recipient: number of physical activities of daily living impairments (r=.32, p<.01), number of cognitive problems (r=.27, p<.02), and the presence of incontinence (r=.25, p<.04). Thus, although caregivers in the focus groups strongly expressed the view that nursing home placement of a frail elder was a culturally unacceptable care option and the vast majority of the survey respondents reported that they had never considered institutionalization, an identifiable subgroup of the survey respondents had considered this alternative.

CHAPTER 5

LONG-TERM CARE SERVICE RECOMMENDATIONS

This concluding chapter of the long-term care report outlines specific recommendations for the development of geriatric services by the IHS in the SFSU. The recommendations presented address health and health-related services that are within the purview of IHS service provision, as well as areas where IHS services might effectively be linked to non-IHS aging services as a means of improving or expanding the continuum of long-term care available to Indian elders.

Four priority recommendations for health care services to elders emerged from the findings of this study: (1) develop formalized comprehensive geriatric assessment; (2) expand and integrate existing case management functions; (3) secure/expand the capacity to provide support services; and (4) develop family caregiver training. The rationale for each of these recommendations is discussed below, followed by examples of existing American Indian long-term care programs, where available, in these areas. Finally, potential models and mechanisms for the delivery of long-term care service innovations in the SFSU are described. Several of these recommendations are consistent with the stated goals of the IHS Elder Health Care Initiative (EHCI), that was implemented in 1995 out of the IHS Office of the Director and charged with developing an Elder Health Care Program (Stenger et al., 1996). These corresponding EHCI goals are cited below.

Recommendation #1:
Develop Comprehensive Geriatric Assessment

Rationale. Comprehensive geriatric assessment is "a multidimensional, often interdisciplinary diagnostic process designed to define an elderly individual's medical, psychosocial, and functional capabilities and problems to arrive at an overall plan for therapy and long-term follow-up" (Rubenstein & Wieland, 1989, p. 145). Because the health problems of elders are frequently complex, interrelated, and qualitatively different in their presentation than in younger adults, a periodic comprehensive assessment of the older adult's health and functional status is considered the cornerstone of quality geriatric care. Comprehensive geriatric assessment is often referred to as comprehensive functional assessment because one of its principal goals is to restore function rather than to eliminate disease in patients who typically have several coexisting (comorbid) chronic disease conditions. Documented benefits of comprehensive geriatric evaluation include enhanced diagnostic accuracy (indicated by the increased number of new diagnoses per patient), improvements in various functional status domains including cognitive and affective functioning, reduction in problems with polypharmacy, decreased use of acute hospital services, and reduction in mortality (Rubenstein & Wieland, 1989; Manton, 1992).

The recommendation to develop this service in the SFSU parallels one of the IHS Elder Health Care Initiative's goals (#4): to "develop the capacity to provide [preventive services and] functional assessments annually for each elder and comprehensive geriatric assessment for the frail elderly" (Stenger, 1997, p. 70). This recommendation is based on the current lack of a systematic geriatric focus in IHS service provision in the SFSU; on SFSU elders' ranking of a review of their overall condition (including an assessment of their health status and self-care abilities) as their most needed service (54% of survey respondents); and on the health and functional status profile of elders in the service unit (described in Chapter 2 of this report). Specifically, more than one-quarter of elders aged 55 years and over in the SFSU (26%) reported comorbid health problems (10% reported 3 or more disease conditions). Forty percent of elders experienced some limitations in functional capacity, with the highest proportion of functional dependency occurring among elders over 75 years of age. Thus, comprehensive geriatric assessment has significant potential for primary, secondary, and tertiary prevention with elders in the service unit who are at-risk for functional decline. Comprehensive geriatric assessment could clinically evaluate the need for services identified by 25.2% of elders in the health care services cluster (additional medical care and physical therapy).

Recommendation #2:
Expand and Integrate Case Management

Rationale. The recommendation to expand and integrate case management for elders in the SFSU reflects another of the IHS Elder Health Care Initiative's goals (#3) to "facilitate access of American Indian/Alaska Native elders to timely and appropriate care" (Stenger, 1997, p. 70). Studies of case-managed long-term care for the elderly have demonstrated benefits including a reduction in unmet needs for services, as well as increased client and caregiver confidence that they are receiving needed care (Benjamin, 1992). Various case management functions—including case finding, assessment, care planning, service brokering and follow-up—are carried out in the SFSU by CHRs, public health nurses, and by staff of the Title VI and the Disabled and Elderly Medicaid Waiver programs. Case management provided to older adults in conjunction with these programs is currently limited, however, by fragmentation and lack of service coordination, by gaps in service due to the competing needs of other segments of the patient population, or by narrow eligibility criteria that restrict services to elders requiring skilled nursing care.

The unmet need in the SFSU for formalized geriatric assessment—the foundation of the case management process—has been described in the preceding recommendation. The findings from this study also document the need for the improved integration and expansion of other key case management services. As described in Chapter 2, the need for assessment/case management services—including overall review of one's condition, information and referral, management of personal affairs, and transportation—represented the most common "cluster" or group of interrelated needs among elders in the SFSU.[1] Sixty-four percent of survey respondents reported needing one or more of these services. The characteristics of elders in need of these services included those with multiple physical symptoms, those who lacked their own transportation, reported being frequently worried, and had poor vision. Based on these characteristics, these elders may represent individuals who perceive a growing vulnerability in themselves and their situation rather than the group of elders who are already highly impaired. Under these circumstances, case management can serve as an effective means of prevention.

The perceived need for improved care coordination discussed in the focus groups and documented in the survey of family caregivers also suggests the potential benefits of enhanced case management in the SFSU. Over 80% of family caregivers surveyed indicated that case management (i.e., someone to organize or coordinate the kinds of help that the elder needs and make arrangements to get that help) would be very helpful or extremely helpful to them. The vast majority of these caregivers (85% and 58%, respectively) also indicated that information about health services and information about social services would be very helpful or extremely helpful to them as caregivers. These caregivers' concerns about the adequacy of patient monitoring, delays in service delivery, the need for more information and assistance in accessing available services, and perceived gaps in communication among health care and social service providers concerning care recipients' needs, all emphasize the benefit of an expanded case management function, including periodic geriatric assessment and systematic patient monitoring, follow-up, and brokering/advocacy in helping these elders and their families obtain needed services.

Recommendation #3:
Secure/Expand the Capacity to Provide Support Services

Rationale. The recommendation to secure/expand the capacity to provide support services to elders and their caregivers in the SFSU parallels Goal #2 of the IHS Elder Health Care Initiative, i.e., to "promote the development of a continuum of comprehensive home and community-based programs that keep elders within their families and communities" (Stenger, 1997, p. 70). This recommendation is based on several study findings including the identified cluster of in-home services that elders reported needing, as well as family caregivers' and SFSU service providers' perceptions of the potential helpfulness of various in-home and community-based services.

The need for one or more in-home support services—including assistance with meal preparation and housekeeping tasks, regular monitoring, and continuous care—was the "cluster" of interrelated care needs reported by 42.7% of elders in the SFSU. Elders identified as most in need of this cluster of services were those with health conditions that limited their activities, particularly their ability to carry out daily household tasks, those who were older, those who perceived their overall health status as being poor, and women.

In addition to elders' perceived needs for support services, findings from the family caregiver survey and focus groups described in Chapters 3 and 4 indicate these caregivers' perceptions of the need for supportive care in the SFSU. Family caregivers (89% of survey

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[1] Although transportation is not typically defined as part of case management, it is a service that, like case management, enhances access to care.

respondents) strongly endorsed the potential helpfulness of "regular monitoring of the care recipient by a professional—either a nurse, social worker, CHR, or senior citizens program staff." Likewise, 70% of caregivers surveyed reported that adult day care would be very helpful or extremely helpful to them; 73% of caregivers felt that assistance with the elders' physical care would be similarly helpful, and 80% also endorsed the helpfulness of some form of respite care. The focus group participants' expressed needs for an occasional break from caregiving and daytime programs that would allow caregivers to work or attend to other responsibilities also point to the utility of respite services and adult day health care where elders can receive health and social services in a group care setting. The need for these types of services was particularly emphasized by caregivers whose elderly relatives required constant supervision or had other intense care demands. Indeed, studies of respite care (Knight et al., 1993) and adult day care have suggested that these services are effective in alleviating caregiver burden.

Service providers in the SFSU also reported instances of frail elders being locked in at home for safety by family caregivers who had no one to look after the elder during the day while they were at work. These service providers concurred that home health care, homemaker services, companionship services for elders, and respite care for their family caregivers, were priority areas for the development of long-term care for their service population.

Recommendation #4: Develop Family Caregiver Training

Rationale. The IHS Elder Health Care Initiative includes objectives for geriatric education of both providers and consumers (Stenger et al., 1996). The Geriatric Education Center at the University of New Mexico, Albuquerque, has been funded by the U.S. Public Health Service to conduct geriatric training with health care providers including IHS and non-IHS program staff since 1994. To date, however, the needs of family caregivers for training in various aspects of elder care have not been systematically addressed within the SFSU.

The findings from the family caregiver survey and focus group discussions highlight some of the principal problems and coping strategies of these informal care providers who have been referred to as the "hidden" or "invisible patient" (Baldwin, 1988; Fengler & Goodrich, 1979). Among these American Indian family caregivers, strongly endorsed cultural values that mandate caregiving to elderly relatives reinforced efforts to provide needed assistance, no matter how frail the care recipient. Many of the caregivers who participated in this study provided help to elders despite often feeling technically incompetent to carry out needed treatments, ill-equipped to deal with care recipients' psychological and behavioral problems, and lacking necessary personal resources—including time, energy, and the understanding and cooperation of others.

The need for caregiver training, i.e., educational interventions designed to enhance caregivers' level of knowledge about caring for a functionally dependent elder, was a major concern of the focus group participants. This finding was reinforced by the survey respondents: 82.2% felt that "training about how to manage the elder's situation" would be very helpful or extremely helpful to them, and 85% also felt that "information about the elder's health problems and what to expect about the elder's condition" would benefit them. An indication of the extent of interest and demand for this service was the fact that several of the focus group attendees came to these discussions precisely because they were under the impression that these sessions involved caregiver training.

The topics on which these caregivers said they wanted more information are consistent with those identified in other surveys of family caregivers of disabled adults (Matthis, 1992). The topics most frequently mentioned by the focus group participants included: learning about the care recipient's disease condition, including its expected course and care requirements; techniques for in-home medical care management and preventive health maintenance; psychosocial aspects of care including coping with the upsetting behavior of the care recipient; and facilitating communication and exchanging information among family members.

The desirability of services that would facilitate family decision-making about the caregiving situation were also mentioned by a number of the focus group participants. As described above, several caregivers discussed the usefulness of periodic family meetings with health care professionals to clarify the elder's condition and needs, and to promote the development of a consensus among family members concerning caretaking demands as well as how some difficult caretaking responsibilities could be shared.

The benefits of caregiver training that would address these caregivers' expressed needs for information and support have been demonstrated across a variety of research studies. Caregiver training has been shown to enhance family coping as well as care recipient outcomes (Davidizar, 1992). A controlled study of the effects of professionally-guided caregiver support and education groups on institutionalization rates among care recipients, for example, demonstrated a reduction in the rate of nursing home placement from 17.2% to 5.2% (Greene & Monahan, 1987). Another controlled study of the impact of a spouse caregiver support group on care recipient health care costs showed significant outpatient, inpatient, and total cost savings (Peak et al., 1995). Other caregiver education programs have demonstrated benefits in assisting caregivers to develop a greater sense of competence about the care recipient's disease process and to function with greater independence (Chiverton & Caine, 1989).

Examples of American Indian Long-Term Care Programs

This section describes existing examples of American Indian long-term care programs relevant to the preceding recommendations in order to illustrate the process and potential for such services within the SFSU.

Examples of Comprehensive Geriatric Assessment Within the IHS. Two examples of the use of comprehensive geriatric assessment within the Indian Health Service are described here to illustrate the process and potential for such a service within the SFSU. The programs currently in operation are in the Southern Colorado Ute Service Unit (SCUSU) and in the Zuni-Ramah Service Unit.

In the SCUSU, information on the elder is collected with a standardized assessment tool that includes items on personal background, current support services, social network and social support in case of sickness and disability, measures of psychosocial and cognitive status, functional status, physical examination and nursing assessment data, and an environmental and home safety assessment. The caregiver burden scale that was used in the present study is also administered to the accompanying family caregiver of the elderly patient as part of the assessment process.

Comprehensive geriatric assessment in the SCUSU is targeted to the frail elderly who are defined as those with substantial functional impairments, having experienced a recent decline in functional status, or other markers for frailty such as repeated falls. The various portions of the assessment are conducted by the respective members of a multidisciplinary team including a public health nurse who serves as the team leader, a physician, psychologist, social worker, and a sanitarian who administers the environmental and home safety assessment. The assessment process is closely coordinated with service provision by the various disciplines who conduct a follow-up at three months after assessment. Although thus far no formal program evaluation of the outcomes of geriatric assessment in the SCUSU has been conducted, the clinical staff there report that it has been effective for problem identification and in case management of older patients (Dr. George Maxted, personal communication).

The second example of an assessment service for older adults within the IHS is the Zuni Elders' Clinic which has provided geriatric assessment targeted to frail elders in the Zuni-Ramah Service Unit since 1995 (Miller & Finke, 1996; Finke & White, 1997). Criteria for referral to this service include recent functional decline, confusion, falls, polypharmacy, or social crises. Referral sources include primary care physicians, senior center staff, home health, and public health personnel.

The assessment process begins in the elder's home where, prior to an initial clinic visit, a home safety assessment is conducted by either a public health nurse or home health nurse. If the elder needs transportation assistance for the subsequent clinic visit, it is also arranged by the nurse during the home visit. The Elders' Clinic is held monthly at the PHS Indian Hospital at Zuni where a two-hour assessment of the elder is performed by a multidisciplinary team consisting of a gerontological clinical nurse specialist, a physician, a pharmacist, a psychologist, an audiologist, a dietician, a physical therapist, and a dentist. The elder's primary family caregiver is also included in the assessment.

The assessment consists of evaluations of the elder's ability to carry out activities of daily living, bowel and bladder function, sleep, vision, hearing, dentition, nutrition, risk for falls, cognitive and emotional status, family stress, financial and social resources, health behaviors, existing medical problems, and medications. Assessment results are provided to the elder's primary health care provider and referrals are also made for needed services. The Zuni Elder's Clinic program has yet to be fully evaluated. However, results indicate that 36% of clients have had a reduction in the number of their prescribed medications, and that the program has been well-received by both elders and their caregivers. In addition, the program's developers report that another benefit of this effort has been improved integration of services and tribal programs for elders in the community (such as Title VI programs and CHRs).

In-Home Support Services for American Indian Elders. One example of a program of support services for American Indian elders and their family caregivers has been operating through the Montana Office on Aging since 1993. The Crow Eldercare Program, which is targeted to elders with dementia, employs a case management team consisting of a registered nurse and a social worker who assess the elder's needs, develop a care plan, and provide ongoing care management. Six trained respite care providers assist the care recipients with transportation, socialization, companionship, household chores, personal care, and other activities intended to benefit the elder and provide relief to the primary caregiver (Povilonis, 1995). In 1995, the program also added adult day care one afternoon per week. The Crow Eldercare Program is funded as a demonstration project by the Health Resource Service Administration with matching tribal funds and currently serves 28 elders.

Delivery of Long-Term Care Innovations in the SFSU

The concluding section of this chapter on long-term care service recommendations for the SFSU offers specific suggestions on mechanisms and models for delivering these service innovations. These programmatic suggestions are made in acknowledgment that the IHS Elder Health Care Initiative's priorities for long-term care development are based on the maximum utilization of existing resources.

- **Develop Interagency Long-Term Care Policy.** Because several of the recommendations described above have implications for interagency coordination of efforts, a necessary step in achieving the objectives of these recommendations is to develop a shared long-term care policy that will implement and sustain geriatric case management. This would include the IHS as well as tribal programs (e.g., Title VI and CHRs) and state programs such as the Disabled and Elderly Medicaid Waiver Program. Legislation passed in the New Mexico State Legislature in 1998 (House Bill 372) created an interagency committee on long-term care charged with creating a coordinated long-term care service delivery system. Although IHS and the tribes should proceed to implement community-based and in-home long-term care services, the participation of IHS in this committee would facilitate joint planning of long-term care system innovations in the SFSU.

- **Implement In-Home and Clinic-Based Geriatric Assessment Targeted to Frail Elders.** Comprehensive geriatric assessment is a critical and potentially cost-effective long-term care service that can be implemented in the SFSU with existing IHS clinical and non-IHS aging service resources including those health and social service providers that typically compose a multidisciplinary assessment team (at a minimum this would include a physician, nurse, social worker or other social service provider). This service, to be conducted at an established interval, should target individuals at-risk for functional decline through criteria based on level of ADL impairment, advanced age, changes in social support system, or other relevant clinical markers. The two models of comprehensive geriatric assessment within the IHS described above offer examples of how this process might usefully be structured within the SFSU's rural geographic setting. Because of the importance for providers to understand and evaluate the living environment of the elder, an in-home assessment should be conducted. The IHS health centers and satellite clinics in the SFSU offer convenient locations that are equipped for the multidisciplinary team to conduct a full assessment. Due to the key part played by family members in elder care, the primary family caregiver should also be included in the assessment process. A standardized multidimensional geriatric assessment instrument that facilitates maximum sharing of information by IHS and non-IHS service providers should be adopted for use. Formalized mechanisms to ensure referrals to other long-term care providers based on assessment findings also need to be implemented.

- **Pursue Options for Medicare/Medicaid Reimbursement of Support Services.** As discussed in Chapter 1, among the limitations of the Disabled and Elderly Medicaid Waiver Program in providing care to elders in need of in-home health and social support is its focus on those elders meeting eligibility criteria for nursing home level of care, lengthy waiting lists, and lack of sufficient numbers of eligible clients to support local program providers. Currently the Disabled and Elderly Medicaid Waiver Program services being provided within the SFSU include only some of the services (i.e., case management, homemaker/companion services, respite care, and skilled nursing in San Felipe and Santo Domingo) that are reimbursable through this program. The Eight Northern Pueblos program is seeking a home health license to expand their current service package to include skilled nursing, and Medicare certification is presently being sought by the home health agency serving San Felipe and Santo Domingo in order to be able to provide additional medical services. Expansion of this service package to add other needed support services should also be pursued through interagency coordination and planning including the IHS, the tribes, and other aging services providers. Clearly, the need also exists for support services for elders in the SFSU who do not meet the Disabled and Elderly Medicaid Waiver Program criteria for frailty level or income. The PACE (Program of All-Inclusive Care for the Elderly) model of long-term care that provides a comprehensive package of services to frail elders under risk-based capitated payments from Medicare and Medicaid is an option that has received some consideration from IHS and non-IHS service providers in the SFSU. However, although a PACE program has recently begun operation in New Mexico (at St. Joseph's Hospital in Albuquerque), this long-term care model has never been successfully implemented in a rural setting,[2] and it is also estimated that a client base of between 300 and 500 nursing home eligible elders is required for a PACE program to be financially viable. The alternative of securing Medicare and Medicaid reimbursement for health and health-related support services to elders through some form of demonstration project should be vigorously pursued. The Crow Eldercare Program described above, although small in scope, represents one example of a successful demonstration program of case-managed support services funded through federal and tribal funding.

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[2] The PACE project implemented in 1993 by the Cherokee Nation in Talequah, Oklahoma has since closed its operation.

- **Expand the Scope of Services Provided through the Senior Companion Program.** Under the current regulations of the Senior Companion Program, the assistance that can be provided to elders is limited to visitation and minimal amounts of housekeeping. The fact that Senior Companions cannot provide other needed types of assistance to elders is often a source of frustration to family members, to elders, and to Senior Companions themselves. Our survey of primary family caregivers indicated that 28.8% of the elders in caregiving situations already receive the services of a Senior Companion. Expanding the scope of in-home help delivered by Senior Companions to include services that could reasonably be performed by these volunteers (especially respite care) would strengthen a valuable long-term care resource that is currently in place in the SFSU. This expansion of long-term care services performed by Senior Companions could be accomplished at minimal additional cost and without the development of a new aging services program.

- **Explore the Feasibility of SCSEP Funding for In-Home Services.** One possibility for funding a demonstration project for the provision of in-home support services is available through the Senior Community Service Employment Program (SCSEP), a U.S. Department of Labor program. The National Indian Council on Aging is the national contractor for administering this program to tribes. The SCSEP program provides funding for job training and employment of tribal members aged 55 years and over and allows elders to work up to 20 hours a week under the supervision of a host agency. These funds could be used to prepare and hire senior workers to provide various in-home services, particularly needed assistance with activities of daily living and other care activities including respite. Because the SCSEP program does not provide transportation for workers, the Title VI programs are one feasible option for the administrative placement of these workers, whose transportation to elders' homes could be provided by Title VI van drivers as part of their home-delivered meals route.

- **Coordinate Training Resources for Family Caregiver Education.** A variety of training resources are available within the IHS Albuquerque Area that can be coordinated to develop a program of family caregiver education within the SFSU. These include, for example, IHS clinical staff and health educators, voluntary organizations such as the Alzheimer's Disease Association, and university-based resources. These resources should be organized to plan a didactic and experiential program of culturally appropriate caregiver education. Although no examples of formalized family caregiver training programs in elder care specific to the American Indian family context were found to guide programmatic features of such an intervention, a wide variety of caregiver education programs exist that might be suitably adapted to this population of caregivers. One example of a family caregiver education program with features that might be considered for use in the SFSU is Training the Elderly and Their Caregivers In the Home (TEACH)[3]

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[3] The TEACH program was developed in Florida for use with minority family caregivers.

that provides in-home instruction on elder care including demonstration of care techniques. The findings on the situation and experiences of family caregivers in this report also provide a framework for considering what the content of such a program might include and the context of its delivery. Funding for the implementation of this intervention could be pursued through the Administration on Aging or the Robert Wood Johnson Foundation.

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