

**Family Caregivers Self-Awareness and  
Empowerment Project**

**A Report on Formative Focus Groups**

**FINAL Report**

**September 2001**

Conducted for  
The Family Caregivers Self-Awareness and Empowerment Project  
A joint program of  
The National Family Caregivers Association and the National Alliance for Caregiving

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# **I n t r o d u c t i o n**

In May of 2001, Lake Snell Perry & Associates (LSPA) conducted a series of five focus groups with family caregivers for the Family Caregivers Self-Awareness and Empowerment Project, a joint program of the National Family Caregivers Association (NFCA) and the National Alliance for Caregiving (the Alliance).

The Family Caregivers Self-Awareness and Empowerment Project seeks to counter family caregivers' lack of self-awareness and reluctance to seek assistance through a comprehensive communication campaign aimed at changing the way these caregivers perceive themselves and their role. Ultimately, the project seeks to ensure that family caregivers recognize that their role is distinct and vital, acknowledge the demands of this role, reach out for help, and become their own advocates.

These focus groups are the formative research phase of the Project, the purpose of which is to lay the groundwork for future work and message development. In these groups, LSPA explored barriers to caregiver self-awareness, as well as barriers to self-empowerment – in the sense of recognizing the role and its demands, and working to help themselves deal with these demands. The groups also served as a forum to hear the language and terminology caregivers use themselves, and are comfortable with, in talking about themselves and their caregiving role.

In reviewing these findings, it is important to keep in mind that focus groups are a form of qualitative opinion research. They produce information about the texture of people's attitudes, beliefs, perceptions and opinions, rather than quantifiable, generalizable data. Data collected in focus groups cannot be assumed to represent the views of the population at large.

To gain a comprehensive understanding of these issues, it was important to hear from a variety of family caregivers. Groups were designed to include a mix of:

- New caregivers as well as long-time or “career” caregivers
- Ongoing and past caregivers

- Caregivers who vary as to the extent and intensity of their caregiver duties – that is, whether they are involved in assisting their loved one with just a few Instrumental Activities of Daily Living (IADLs) such as grocery shopping, helping with paperwork, housekeeping and doctor’s appointments, or the full range of Activities of Daily Living (ADLs) such as bathing, dressing, feeding and toileting.
- Relationship to the person for whom they are caring
- Level of acknowledgement in terms of self-identifying with the “Caregiver” designation when undefined<sup>1</sup>

A total of five groups were conducted, broken down as follows:

| Group | Site            | Date    | Group Description                                   |
|-------|-----------------|---------|---|
| 1     | Baltimore, MD   | 5.16.01 | Career, Ongoing, and Former Acknowledged Caregivers |
| 2     |                 |         | New, Non-Acknowledged Caregivers                    |
| 3     | Los Angeles, CA | 5.24.01 | New, Acknowledged Caregivers                        |
| 4     | Kansas City, MO | 5.31.01 | Caregiver Parents of Children with Special Needs    |
| 5     |                 |         | Mixed Acknowledged and Non-Acknowledged Caregivers  |

Focus group participants explored topics by means of two methods. Participants initially discussed topics on their own – that is, without the aid of any materials – so that we could see whether they raised, and how they talked about, the issues in question. Subsequently, participants read and responded to prepared materials which allowed us to explore their reactions to additional language and topics, including some ideas they had not raised on their own. Specifically, participants read and reacted to 1) a detailed definition and description of family caregivers (reprinted on page 10) and, 2) NFCA’s Four Principles Of Caregiver Empowerment (portions reprinted throughout).

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<sup>1</sup> Acknowledgement was measured using the structure from AARP’s *Caregiver Identification Study* (February 2001). In the screening process, potential participants for the non-parent groups were first asked: “Are you currently a caregiver for an adult family member or friend?” Regardless of their response, they were then asked: “Do you have an ill or disabled adult relative or friend whom you care for on a regular basis? This could be someone who just needs a little help, someone in declining health, or someone who is seriously or chronically ill.” *Acknowledged* caregivers are those who answered yes to both questions. *Non-acknowledged* caregivers answered no or don’t know to the first question and yes to the second (this group corresponds with the group the AARP survey calls “actual caregivers.”)

# Executive Summary

The focus group results provide a great deal of insight into how caregivers see themselves and their role, and the barriers to acknowledgement and empowerment. The groups also provide valuable information about language that will be vital in crafting messages targeted to caregivers.

## Caregivers' Disconnect from Caregiver Terminology:

- **Focus group participants are not very familiar or comfortable with the terms "caregiver" and "family caregiver." Despite the fact that they clearly play this role, few self-identify as caregivers in an immediate or enthusiastic way.** While those who identify themselves as caregivers do tend to be more involved in “heavy duty” caregiving, many of those who are “non-acknowledged,” are very involved, intensive caregivers.
- **Most participants, including those who identify more readily with the caregiver label, are ambivalent about the term; some simply do not like it.** Many associate the word “caregiver” with a paid caregiver, which has negative connotations. Moreover, they are hesitant about using the term to describe their role because they feel it does not speak of the love and warmth involved.
- **The term “family caregiver” is a little more well-received than “caregiver.”** Participants feel adding the word “family” softens the term. However, people are less familiar with the term “family caregiver” and so use it awkwardly or not at all in their own speech.
- **Many participants are reluctant to give any name or title to what they do.** Many – especially those caring for spouses or parents – say what they do is “what families do” for each other naturally. Therefore, they are reluctant to think of caregiving as a separate role, distinct from “spouse” or “child.”
- **Other participants object to “labeling” the role for other reasons.** Some say they feel no need to – or actively resist the idea of having – a name, or belonging to a group. Some fear it will become what defines them, blocking out their other selves. Still others feel looking for a title is simply a way to congratulate oneself for doing what they should be doing anyway.

### **Strategic Implications**

Because caregivers are reluctant to embrace the caregiver label, it is important to work to change people's image of that word. It might be advisable to use "family caregiver," as opposed to just "caregiver," and work to raise awareness of this less familiar – but potentially more acceptable – term. It also seems important to stress that this label is not meant to supersede other roles caregivers play, it is just one of many ways to describe what they do for an ill loved one. Lastly, it is also important to reach out to caregivers without relying too heavily on the caregiver label.

### **How Caregivers See Themselves and Their Role:**

- **Understanding how caregivers see themselves, and how they see themselves within their caregiving role, is important in crafting messages.** Most describe themselves as loving and nurturing. Most also say they took on this role because they have the right personality; they are assertive, take-charge types. There are a few caregivers, however, who feel they are caregivers less because of personality than pure circumstance. Simply put they are the "only one" – the spouse, the only child, or the only relative living nearby.
- **Participants differ as to how they view and react to the demands of caregiving. Because it is seen as natural, many are reluctant to complain at all about their caregiving role.** Some feel guilty and are hesitant to say that they feel victimized or taken advantage of. After all, they stress, this is "just life." These individuals must be approached gently. They have to be reminded that just as their role is natural, so is feeling overwhelmed or resentful about it. Those who took on the role more willingly are somewhat less likely to feel openly resentful, but they may be more hesitant to ask for help.

### **Strategic Implications**

How and why people feel they came to be caregivers seems to influence how they feel about the role and how open they are to accepting help. Messages must be targeted or take into account both willing and more reluctant caregivers.

## **Barriers to Empowerment:**

**Beyond this disconnect from current caregiver terminology, there are additional barriers to empowerment and self-help. Even some of those caregivers who are most aware and comfortable in their caregiving role are reluctant to take steps to support themselves in this role.**

- **Caregivers focus on their loved one, not on themselves.** In general, most caregivers see caregiving as a role they play vis-à-vis their loved one, not something they need to support themselves in doing. Many say they are “putting their own lives on hold” to care for their loved one and will “balance it out” later.
- **Many caregivers are hesitant to share duties with other family members.** Participants are reluctant to seek help with their caregiving duties – even from other family members – for many reasons. Some feel that no one can care for their loved one as well as they do, and so feel guilty leaving their loved one with anyone else. Others feel they have no one to ask for help, or are waiting for people to volunteer.
- **Most caregivers are unfamiliar and uncomfortable with outside services.** Participants are especially resistant to the idea of receiving respite services from an outsider. Few were aware that such services are even available, and most assume that they would have to pay someone to provide this service. Many argue that their loved one would not feel comfortable having a stranger care for them. Many say they would not feel comfortable using a respite service to do something “just for themselves,” and would only use such services to get things done like shopping or laundry.
- **Caregivers are reluctant to discuss their caregiving responsibilities at work.** Some of the caregivers have talked with their employers about the affect caregiving has on their work lives, and many have found their employers to be supportive and flexible. However, this is not always the case. Some are reluctant to talk with people at work about their caregiving. A few say they have harmed their careers – or even had to give up jobs – because of their caregiving role.
- **Many caregivers are reluctant to talk about – or even speculate on – whether or how caregiving affects their own health.** They admit to feeling tired and stressed, but few talk of other effects. Only a handful have talked to a doctor about their caregiving. On the other hand, a few say they have been clinically depressed or physically ill as a result of caregiving.

- **There is little or no awareness of caregiving organizations.** Few participants have heard of NFCA, NAC or any other caregiver organization; some are surprised to hear such organizations exists. And, just as participants are reluctant to view themselves as caregivers, so to are they resistant to the idea of joining a group of caregivers – be it a national organization like NFCA or a local support group. Many question what the benefits would be in being part of a group. Some believe you cannot learn to be a caregiver; you “either know how to do it or you don’t.” They also feel such groups would just be an arena for people to complain, or a place people go for recognition, or a “pat on the back” which they do not need. Lastly, they see this as a private role, and simply do not think about their “rights” as caregivers in the public sphere.

**While there are significant barriers to self-awareness, there are some who have crossed the barrier emphatically to become empowered.** There is a strong, vocal minority of caregivers who do appreciate the need for time away, and stress the need for a separate existence and identity from that of caregiver. They have scheduled their lives, to the extent possible, to have time on their own or with other family members. Some view their work as a refuge, others meditate, go to the gym, or have scheduled “nights out.” They value their time away and encourage others in the group to take time for themselves. Taking a break, they argue, makes you a better caregiver.

#### **Strategic Implications**

Most caregivers, if they are looking for help or advice of any sort, are interested in how they can do a better job as a caregiver or improve their loved one’s quality of life. This suggests that the best way to approach caregivers is to start by talking about caregiver resources, ways to help the person for whom they are caring, and improving themselves as caregivers. Then, you can talk about making things better for themselves, focusing on the fact that getting the help and support they need, and taking time for themselves, will make them better caregivers.

### **Parents Who Are Caregivers Are Different:**

- **The participants in our focus group of parents are different from other caregivers in how they view themselves and their role.** While these parents too are somewhat ambivalent about the term “caregiver,” they are more aware of the uniqueness and special demands of their role as the parents (or grandparents) of children with special needs. Those whose children need a great deal of care are especially enlightened in this regard. In general, they see themselves as part of a group with special concerns and needs, and they feel that to do the best possible job as parents they must recognize these special needs.
- **For the most part, these parents talk more easily about feeling overwhelmed and resentful on occasion, and recognize the need for self-care and respite opportunities.** Even while they stress this, they appreciate and value their role.
- **In short, parent caregivers are different. They seek out and have a connection to other caregivers.** Perhaps it is because they believe they are in such an unusual situation – i.e., most other parents have healthy children – that they seek out parents like themselves. A spouse or adult child caring for an aging parent, on the other hand, may not feel so different. Rather, they see their caregiving simply as part of their spousal or child role – and so are much less likely to look to other caregivers for support.

#### **Strategic Implications**

Family caregivers are a diverse group. Parents of special needs children are generally different from spousal caregivers and adult child caregivers of parents. Parent caregivers tend to be more aware of their extraordinary role and its demands. There is a lot to learn from this group – especially those we talked to – about embracing the role while realizing its demands and getting help.

# Detailed Findings

## I. Caregivers' Disconnect from Caregiver Terminology

The terms "caregiver" and "family caregiver" are not familiar to or wholeheartedly embraced by focus group participants, despite the fact that they clearly play this role. Most recognize themselves in the term, especially when it is defined, but few self-identify as caregivers in an immediate or enthusiastic way.

Indeed, some people who are clearly caregivers do not identify with the term at all. Group Two – the non-acknowledged caregivers group in Maryland – was perhaps the best example of this disconnect. Participants in this group, by definition, said "no" or "don't know" to our unprompted caregiver question during recruitment.<sup>2</sup> Yet, as we learned in the group, most help their loved ones with IADLs and even some ADLs on a daily basis.

Focus group results suggest many reasons for this disconnect between participants' duties and their reluctance to identify as caregivers. Some have to do with the term itself. Others have to do with whether participants see this role as distinct from their role as caring family members. Still others rest in a reluctance on the part of caregivers to fully embrace their current role or see themselves as part of a group.

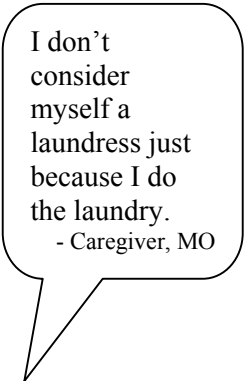
### The Term "Caregiver"

#### Disconnect with the Term

One of the main findings of this research is a lack of identity with the term "caregiver." Though many – in the acknowledged groups, specifically – answered yes to the question in the screener that asked "are you a caregiver," it is

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<sup>2</sup> In the screening process, potential participants were asked: "Are you currently a caregiver for an adult family member or friend?" Regardless of their answer, they were then asked: "Do you have an ill or disabled adult relative or friend whom you care for on a regular basis? This could be someone who just needs a little help, someone in declining health, or someone who is seriously or chronically ill." *Acknowledged* caregivers are those who answered "yes" to both questions. *Non-acknowledged* caregivers answered "no" or "don't know" to the first question and "yes" to the second.



I don't consider myself a laundress just because I do the laundry.  
- Caregiver, MO

clear their attachment to the term is tentative at best. Moreover, as noted above some people who are clearly caregivers said "no" or "don't know" to the unprompted caregiver recruitment question. As one acknowledged Maryland caregiver explains, when she was asked during screening if she were a caregiver, "I know my exact response was, 'I guess I am.'"

When participants are asked to describe in their own words what they do, few volunteer the term. Indeed, many have trouble thinking of a single term – or are even comfortable with the idea that what they do needs a label or description.

### **Even When the Term Is Explained, Few Identify with It**

Even when the term "family caregiver" is explained, some are reluctant to embrace it. Though most react positively to the description of family caregiver presented in the focus group (see box below), they are still reluctant to call themselves caregivers. As a female Missouri participant explains in reaction to the description, "I like this whole premise here and what it says. [But] I have never really cared for the name 'caregiver.'"

#### **FOCUS GROUP HANDOUT: FAMILY CAREGIVERS**

Family Caregivers are people who care for loved ones who are ill, elderly or disabled.

Family Caregivers come from all walks of life – both men and women, people of all ages, races and income levels.

Some Family Caregivers care for their spouses, while others care for parents, children, siblings or other loved ones.

Family Caregivers take care of loved ones with a wide array of medical conditions and diagnoses. Some care for loved ones who need help with the most basic daily activities – such as eating, dressing, bathing. Others care for loved ones who are mostly independent but need help with things like housekeeping, getting to doctor's appointments or paperwork.

There are an estimated 54 million family caregivers in the United States – that's about one in every four adults.

Even among those who do accept the term, many do so reluctantly. As one non-acknowledged Maryland caregiver explains, "That's what the medical world calls

us: Caregivers. So that's what we really are whether we admit it or not. That's what we really are. We are caregivers.”

### Caregiver Has Negative Connotations for Some

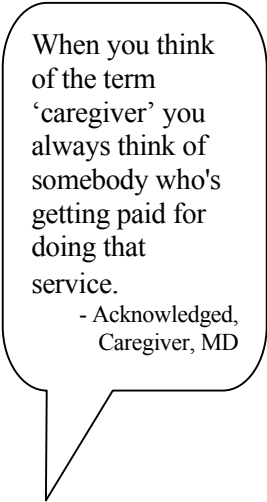
Participants are uncomfortable with the term caregiver because it brings to mind paid caregivers. Many have had bad experiences with paid caregivers – others have only heard tales – but most think of inadequate care provided by a stranger. Even those who have had positive experiences with paid healthcare aides object to the term being applied to themselves and others who care for loved ones. In short, everyone agrees paid caregivers do not love or care for patients the way family members do. As an acknowledged California caregiver explains, “I think another reason that I don't call myself a caregiver or put a label on it is because it's family. Maybe if it were somebody I was being paid to take care of it would be different, but because this is family and I take it personally and I love this person, that's why I don't really call myself a caregiver. It's just family.”

For some, their objections lie less in what the term caregiver does imply, than what it leaves out. They note that it is “cold,” and speaks only to the physical parts of care, not the emotional aspects. A non-acknowledged Maryland caregiver explains, “A caregiver...comes in and feeds you breakfast. You're leaving out the emotional part of it. You're missing the whole connection there.”

The term “family caregiver” evokes similarly ambivalent reactions. On the one hand, participants do feel adding the word family softens the term. However, the term family caregiver is even more unfamiliar and awkward for participants.

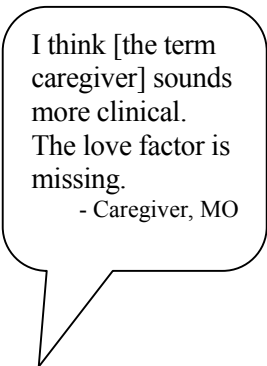
Participants' reactions to the terms caregiver and family caregiver are not completely negative. Some participants appreciate that it has the word “care” in it. In the words of one Missouri caregiver, “I don't mind the word. It always makes me think of ‘tender loving care.’” Participants are also hard-pressed to come up with an alternative. As one Missouri participant explains, “[Caregiver] is as close a word as any.” Participants' own suggestions for a better word reflect a less clinical role, and include more of the love component. They suggest “companion,” “helper,” or just explaining “my father is living with me now.” Participants recognize that these terms too fall short of fully explaining their role.

In short, participants – even though those who are acknowledged – do not instantly or wholly identify with the terms caregiver or family caregiver. Nor are they enthusiastic about the terms.



When you think of the term ‘caregiver’ you always think of somebody who's getting paid for doing that service.

- Acknowledged,  
Caregiver, MD



I think [the term caregiver] sounds more clinical. The love factor is missing.

- Caregiver, MO

## The Role Doesn't Need a Name

### Not a Separate Role, Not “Beyond the Norm”

Most caregivers in the focus groups – with the exception of parents of special needs kids – are reluctant to see their current role as unusual or separate. Simply put this is “what they do.” In their words it is “normal,” “a fact of life,” or “what family means.” As a non-acknowledged Maryland caregiver explains, “I think it’s a normal role . . . That is what family is for.”

Spouses, and to a lesser extent children, have an especially difficult time with the notion that what they are doing is beyond the norm or is different from “being a good daughter” or “being a good husband.” As an acknowledged caregiver in California explains, “To me, taking care of my wife is normal. That’s what a husband should do . . .” In the words of a non-acknowledged Maryland caregiver, “Well, it’s my husband and I love him. We’ve been married for 40 years... That’s the way it is. I married him for better or worse and hopefully things will get better.”

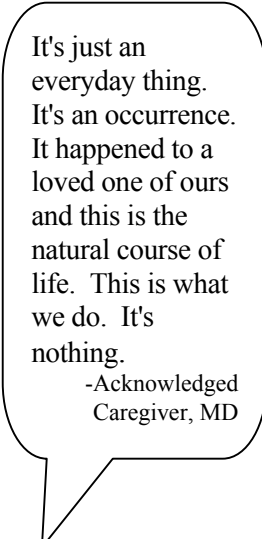
Those with more of a distant relationship to the person they are caring for – those who are caring for an aunt, uncle, friend or grandparent – are more likely to see what they are doing as beyond the norm. As a non-acknowledged Maryland caregiver caring for her aunt explains, “I’ve kind of taken the place of her children I feel like. So mine’s kind of an exceptional circumstance because it’s not really my place to do it. But there’s no one else, so, of course, it falls on me.”

To some extent participants’ reactions to the notion of this being another role are dependent on how the question is asked. In the first groups we asked: “Do you feel like this is just part of what a person normally does for a loved one (like their wife/husband, parent, friend), or do you feel like it goes beyond that?” Participants, especially spouses and children, resist the notion that they are doing anything “beyond the norm.” Indeed, many acted defensive and were offended by the notion that what they were doing was in any way unusual.

### “Lifestyle Change,” “Role Reversal” Are More Well-Received

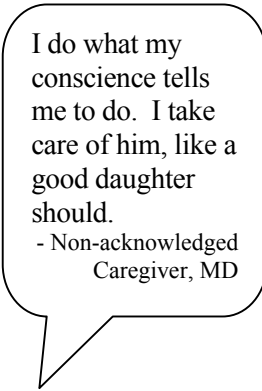
In later groups, we asked this question differently. Specifically, we asked: “Do you think of this as a new or different role for yourself? Do you feel like you’ve entered a different stage of life now that you are helping out a loved one on a daily basis?” Participants’ reactions to this query were less negative.

Participants are more comfortable seeing caregiving as a different “stage of life” or even, in more intensive, ongoing cases, a change in “lifestyle.” In the words of an acknowledged Maryland caregiver, “When my husband was first diagnosed [years ago], I knew that there would be a change as far as our lifestyle and our family’s lifestyle and it



It's just an everyday thing. It's an occurrence. It happened to a loved one of ours and this is the natural course of life. This is what we do. It's nothing.

-Acknowledged Caregiver, MD



I do what my conscience tells me to do. I take care of him, like a good daughter should.

- Non-acknowledged Caregiver, MD

has.” Another explains, “I just think it's a role reversal. When I was growing up my mother and father were always there...Now I'm more like the mother and she's more like the child. To me there's no question that if she needs to be somewhere I'm going to take her.” In short, caregivers are undecided about whether and to what extent caregiving is a separate role and have mixed feelings about how caregiving should fit into their lives.

To stimulate discussion and get reactions to words, phrases and ideas about caregiving, we introduced the “Four Principles of Caregiver Empowerment” developed by NFCA, asking each participant to take a moment to read the principles and underline words that they related to or liked and cross out words they did not relate to or like. Their mixed emotions about how caregiving should fit into their lives may explain their puzzlement over the recommendation to “recognize that caregiving comes on top of being a parent, a child, a spouse” in one of the principles of caregiver empowerment (reprinted below). As a Missouri caregivers asks, “What does that really mean? ... Does that mean that you are first a parent, then a child, then a spouse, and then a caregiver, or does it mean caregiver comes first...?”

Stand up and be counted. Stand up for your rights as a caregiver and a citizen.

*Recognize that caregiving comes on top of being a parent, a child, a spouse. Honor your caregiving role and speak up for your well-deserved recognition and rights. Become your own advocate, both within your own immediate caregiving sphere and beyond.*

### **Recognition Is Okay, Self-Congratulation Is Not**

Most participants balk at the notion that they need a special name for what they do. Some feel looking for a title is simply a way to congratulate oneself for doing what they should be doing anyway. As a non-acknowledged Maryland caregiver explains, “What I do, I do it out of love. I don't do it because it's expected of me. I don't do it because that's the title. I don't really need recognition or anything for it.”

It is because of this discomfort with the idea that they are seeking “a pat on the back” that some react to negatively to the suggestion to “recognize just how extraordinary you are” in another of the empowerment principles (reprinted below). In the words of a California caregiver, “I crossed [that] out.’ I don't think I'm being extraordinary. I'm doing what I want to do.”

Some people only get their strokes by being the martyr. I think there is a lot of that out there.

- Caregiver, MO

Honor, value and love yourself. You're doing a very hard job and you deserve some quality time, just for you. Self care isn't a luxury. It's a necessity.

*Self care is your right as a human being. Step back and recognize just how extraordinary you are, and remember your own good health is the very best present you can give your loved one.*

Despite their reluctance to view their current role as “beyond the norm” or “extraordinary,” there is some recognition that what they are doing is just that. In the words of an acknowledged Maryland caregiver, “I think everyone that's around this table goes above and beyond. I don't think they recognize it or realize that they are.” An acknowledged California caregiver explains, “I'm kind of proud of what I do and I think these people are too. Sometimes we have to remember that what we do is not what most people would do.” In short, most participants agree that the underlying sentiment of empowerment principle number two is important. Indeed, some seem to need to hear this affirmation. In the words of a Missouri caregiver, “[Sometimes] I need some kind of positive up-lift...that will push me, that will give me that extra shove that I need.”

## Participants Are Uneasy about Being Grouped or “Labeled”

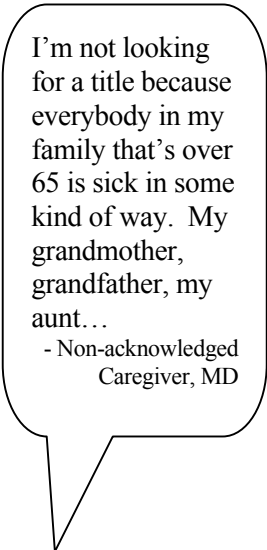
When participants were told that there are 54 million family caregivers in the United States, most are surprised to hear that so many people are in the same situation as they are. Many take comfort in knowing they are not alone. Despite this, many are reluctant to view themselves as part of a larger group of caregivers, for a number of reasons, discussed below.

### Don't Box Me In

Some are resistant because they dislike being grouped or “labeled.” In the words of a Missouri participant, “I do think [being called a caregiver] puts you in a box. I mean, I don't think of myself as a caregiver. I just think of myself as his daughter-in-law. I take comfort from knowing there are a lot of people doing this work, but it certainly wouldn't make me do it more or less to know that others are doing it.” Another Missouri caregiver adds, “I guess my question...is how many labels am I going to die with, because I've got tons of them already. I don't need another one.”

### Don't Limit Me

Another reason caregivers are reluctant to name their role is the fear that this role then becomes all-encompassing; they do not want caregiver to be their defining identity. As a non-acknowledged Maryland caregiver explains, “I think when you say “family caregiver,” it makes it seem like you don't do anything else. Like that's just what you are. And I think everybody here has other lives too that they do in some way. And I think doing this supersedes anything else. I think if you were a teacher. You'd rather be known as a teacher who takes care of a family member than a family caregiver. I think you're saying you have no other life except this.” A



I'm not looking for a title because everybody in my family that's over 65 is sick in some kind of way. My grandmother, grandfather, my aunt...  
- Non-acknowledged Caregiver, MD

Missouri caregiver, clearly overwhelmed by her duties, laments, “I guess I'm a caretaker. I work nights, and that's just my life...I have no life of my own.”

### **Who Me?**

Many participants believe their individual situations are so unique that they could not belong to a group. For example, a non-acknowledged Maryland caregiver, caring for her husband after open-heart surgery explains, “I don't want to be [a caregiver] because I'm hoping it's just temporary. I don't want a title for it. It's my husband and he's sick right now and I'm taking care of him. I don't need a title.”

Other participants feel the level of care they provide sets them apart; they are not caregivers because they do not have to perform ADLs. As an acknowledged California caregiver explains, “My situation is a little bit different than other people's in here. My uncle is not as sick and he's not dying. I don't even know how I would deal with that situation. If I were in the situation that they're in I think that I would be a totally different person.” A non-acknowledged Maryland caregiver also sees herself as different from others in the group; as she explains, “I am sort of fortunate in that way in that my mother can do things for herself. It's just that she doesn't need help sometimes. I'll just leave it and say, ‘I'm not coming today.’”

### **Worrying about the Outcome**

Another reason some caregivers are reluctant to embrace a name for their current situation is that it implies the gravity of their loved one's condition. For example, an acknowledged Maryland caregiver suggests that fear of the future is a big barrier for him; he wonders, “How will I face the outcome? You know the outcome is going to come but being able to face it and come to grips that this is going to happen...”

Other comments seem to suggest that people feel that calling themselves a caregiver is admitting defeat in some ways, just as talking about death and dying is avoided by caregivers. In the words of a Missouri caregiver, “They said my husband would never walk again, and he did. He walked real well. He got everything back...and was doing fine until he had a second stroke. The doctor came in and told my husband that he would never walk again, and my husband is a determined person, and he told me when the doctor left, ‘I will walk again’...So don't give up.”

Still others face different issues in thinking about their future as caregivers. They are reluctant to embrace the caregiver role because their role is temporary for another reason. As a Missouri caregiver explains, “I [am resentful], because when I took on this job, she looked like she was going to live maybe six months. This is going on five years now.” A young man in California who is caring for his mother

admits, “Sometimes I just want her to die so I can go through the grieving and get on with my life....I’m sick of it.”

**Strategic Implications**

Because caregivers are reluctant to embrace the caregiver label, it is important to work to change people’s image of that word. It might be advisable to use “family caregiver,” as opposed to just “caregiver” and work to raise awareness of this less familiar – but potentially more acceptable – term. It also seems important to stress that this label is not meant to supersede other roles caregivers play, it is just one of many ways to describe what they do for an ill loved one. Lastly, it is also important to reach out to caregivers without relying too heavily on the caregiver label.

**Does Acknowledgement Mean Empowerment?**

This research suggests that while those who identify themselves as caregivers more readily are a little more likely to be empowered, the connection between recognition and acceptance of the title and acting on one’s own behalf is not as strong as might be expected. Some of the non-acknowledged caregivers in our groups were very active on their own behalf and some of the acknowledged caregivers had engaged in few or none of these empowering behaviors.

**Strategic Implications**

The bottom line is that this focus group study can neither refute nor fully support the assertion that acknowledged caregivers are necessarily more empowered. We experienced too many exceptions to this rule in the groups. Perhaps more important, because of caregivers’ reluctance to acknowledge their role in terms of current terminology, it is important to encourage empowerment without having to first establish acknowledgement.

## II. How Caregivers See Themselves and Their Role

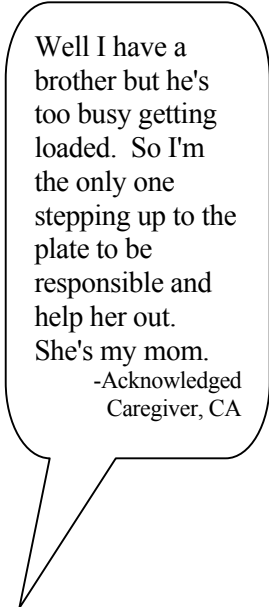
### Who Becomes a Caregiver, and Why

In designing a communication strategy targeting caregivers, it is important to understand how they see themselves. Caregivers describe themselves as “loving,” “nurturing” and “giving.” In the words of a Missouri caregiver, “I think it's definitely a personality thing... Either your life is completely self-centered and focused on yourself, or else you love so deeply, [you] get focused on others. You can be from the same family, [but] you have that difference in personality.” A California caregiver explains, “I've always been a giver from the get go. It's the way I was raised... [We are all givers] that's why we're all here when we've got relatives and friends and family that have just bolted on the whole thing.”

Many also believe the caregiving role fell to them – or they actively took it on – because they are the type of people who “do what’s got to be done.” As a non-acknowledged Maryland caregiver explains, “I’m the youngest [child], but I think I’m probably the most aggressive one. When I saw my mother needed help... I did not wait for somebody else to do it. She looked to me because she knows that’s my personality... I think the rest of my siblings know that it’s going to get done.” Another explains, “I think the one who actually does the caring is the strong personality. They have the need to do it and they want to do it. They're the ones that take over the role whether the others help out or not.” Others admit that they do the caregiving because they feel they are the only ones who will “do it right.”

That having been said, some participants say they became caregivers because of circumstance more than personality. They are the only ones – as opposed to the most well-suited – because they are the spouse, an only child, or the only relative nearby. As a California participant says in describing how he became his grandmother’s caregiver, “I love her [and] I'm the only foolish enough family member still left in the San Fernando Valley.” A non-acknowledged Maryland caregiver caring for her grandmother explains that even though she has siblings in the area, she is the only one not working so “it falls to her.” In short, these caregivers are less likely to see their taking on this role as being personality-driven and more likely to feel forced into the role of caregiver.

Some participants are understanding toward those who are unwilling or unable to act as caregivers. In the words of a Missouri caregiver, “There must be some window that closes in some people.” An acknowledged caregiver recalls, “It was brutal because my mother couldn't take it. She shut down when my dad had his stroke.” Others are more harsh in their judgments; an acknowledged Maryland caregiver describes her sister’s limited involvement in their father’s care as follows, “She’s like a prima-donna type girl who doesn’t work and she wouldn’t go to any trouble for anybody but herself unfortunately.”



Well I have a brother but he's too busy getting loaded. So I'm the only one stepping up to the plate to be responsible and help her out. She's my mom.  
-Acknowledged Caregiver, CA

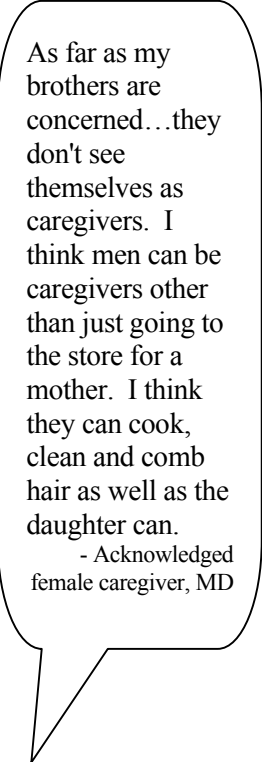
## A Note on Gender

Male caregivers were well-represented in these groups. Most notably, eight of the 10 participants in the California group of new, acknowledged caregivers were men. This included four men caring for a grandparent, two caring for wives, one caring for his mother and one caring for a brother. Participants – especially the men themselves – were surprised to see so many men in the groups. Caregiving is still seen as a female role; one male Californian insisted, “Eighty percent of caregivers are female anyway, across the board.”

Participants believe men are more likely to “fly the coop” when things get tough. As a male career caregiver from California explains, “I had a wife before this that died of cancer. These ladies would call me from some cancer society [and ask], ‘Mr. Lewis do you need any help?’ I finally asked, ‘How come you keep calling me? I don't need help.’ They told me 95 percent of all husbands – and it covered the whole spectrum, it had nothing to do with poor or rich – left their wives. They couldn't deal with the cancer.” Some participants – usually females – say men shirk some of the more intimate caregiving duties. For example, a female caregiver explains, “My brothers feel they cannot be caregivers as far as cleaning the house or bathing her or cooking her food. They basically will take her to the doctor or take her shopping...Most of the caregiving is left to the females.”

Discussions of their caregiving roles suggest men are more likely than women to take on new duties. For example, an acknowledged California man caring for his wife explains, “It's a trick for me because I've never been one to do the cooking and fixing breakfast and all. Now I'm doing that.” Some men are doing things they never imagined. A young man from California talked about having to bathe his grandmother, something with which neither of them is comfortable. Conversely, a female Californian caring for her husband explains, “A lot of the things that I'm doing are things I was doing before. I was cooking and cleaning. But I do have to take care of the things [that weren't] necessary before. So there are some things I was doing before but now it's stepped up a little.”

Participants have mixed opinions about whether women are naturally better caregivers than men. Some do feel women are more well-suited to the role. In the words of an acknowledged female caregiver, “I don't think men are as great as caregivers as women...I don't think they have that nurturing women have.” Others feel it is more an issue of personality than gender. As a non-acknowledged female caregiver puts it, “I don't think it matters if they're a man or a woman. I think it's just personality. My husband was always there for his father who had Alzheimer's and his mother who is legally blind. I think it's just...what you feel inside.”



As far as my brothers are concerned...they don't see themselves as caregivers. I think men can be caregivers other than just going to the store for a mother. I think they can cook, clean and comb hair as well as the daughter can.  
- Acknowledged female caregiver, MD

These findings suggest that gender may affect how people perceive the caregiving role and themselves as caregivers.<sup>3</sup> Men may be more surprised to find themselves playing this role which entails new, different responsibilities than their previous familial role. This may mean they are more aware of their shortcomings and more open to help; it may also mean they are more easily overwhelmed. Women, on the other hand, especially wives, may have more trouble recognizing the extra demands of caregiving because they view them as extension of their wifely role.

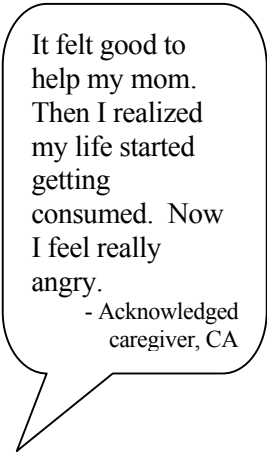
## Feelings about the Caregiving Role

Participants in the focus groups differ widely in terms of how they view and react to the demands of caregiving, and how they feel this role has affected their lives.

A few are angry, resentful and overwhelmed, and openly express these feelings. As a Missouri caregiver caring for her aunt and mother explains, “I’m a single mother of two special needs children on top of it. And my aunt’s children have nothing to do with her and my mother has multiple sclerosis so it’s me – that’s it. I’ve had to leave my job. I’ve had to take a leave of absence. I sleep maybe two hours a night if I’m lucky. I’ve had to alter my entire life. I have no social life. I never go out.” The words of a young man in California who is caring for his mother without much help from his father illustrate the most extreme of these feelings, “There’s a lot of head trip time. It takes up a lot of space in my mind to see my mom deteriorate in front of me. It affects my feelings in life. It makes me angry and I’m pissed at the world right now. The way I encounter other people. If they even rub me the wrong way they could definitely be in trouble the way I feel. So yes, it’s affected my life.”

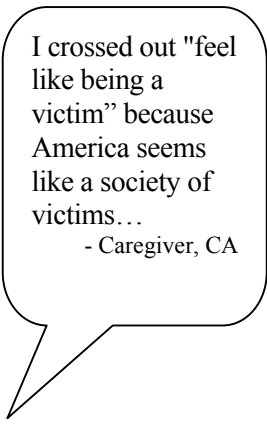
Often people express their resentment toward other family members rather than the loved one who is ill. As one non-acknowledged caregiver from Maryland explains, “I guess for me in terms of the resentment, I am not so much resentful at my grandma as I am my family. Why do I have to go to the brink of insanity before you guys even want to pitch in and help, or do anything...When I ask them to come, ‘Oh, we can’t, we’re busy.’ That’s the biggest piece for me.”

On the other end of the spectrum are those who insist that they are happy with their current role and refuse to acknowledge any negative feelings about it at all. This tendency explains some participants’ defensive reaction to the word “victim” in the first empowerment principle (reprinted below). As one Missouri participant says, “I crossed out: ‘it goes a long way to eliminating the feeling of being a victim.’ Well, I haven’t heard anybody in here who thinks they are a



It felt good to help my mom. Then I realized my life started getting consumed. Now I feel really angry.

- Acknowledged caregiver, CA



I crossed out "feel like being a victim" because America seems like a society of victims...

- Caregiver, CA

<sup>3</sup> Gender issues were not a specific focus of this study. Additional research, including single-sex focus groups, would be needed to fully substantiate these hypotheses.

victim...I think we are all just doing what needs to be done. I think that assumes that you feel like a victim” Another participant adds, “The ones that would think they are a victim just flat don't do it.”

1. Choose to take charge of your life. Don't let your loved one's illness or disability always take center stage.

*We fall into caregiving often because of an unexpected event, but somewhere along the line you need to step back and consciously say, "I choose to take on this caregiving role." It goes a long way toward eliminating the feeling of being a victim.*

Others do feel victimized. As a California caregiver explains, “I think a lot of that has to do with [whether] you are doing it voluntarily You're volunteering yourself to do it. As I'm forced into it and I'm the only one and nobody else wants to do it, well that's a different feeling.”

Most fall somewhere between these two extremes; they admit to feeling stressed on occasion but insist that they are happy playing the role they are playing. The most enlightened have come to terms with their anger and any feelings of victimization. As a Missouri caregiver said during the conversation about the word victim, “Even though none of us in here would say, ‘Oh, I'm a victim,’ I think that layered under many, many deep layers, I think there is a real prevalence [to feel that way]...I think there is a real tendency to mask our own anger terrifically. I mean, there is just a lot of issues here. This [empowerment principal] number one has to stay here.”

Whatever their reaction to the word “victim,” almost all react positively to the idea of making a conscious choice to take on this caregiving role, no matter how it came about. Likewise, most agree it is important to “take charge of your life,” and “not let your loved one's illness or disability always take center stage.” In the words of a California caregiver, “I like the part where it says ‘choose to take charge of your life.’ Basically, take a stand and reach out, have the courage to ask for help. If I learn not to say anything then I'll just feel resentment and then I'll be pissed at myself for allowing this illness to take over my life.”

You do some things because this comes naturally. It's your family and you do it for them. There are some things that you have to do beyond the call of duty because you know that no one else is there to do those things. A lot of times I would make special trips from where I was living. ...I didn't have to do that. I made that special effort to do that...”

- Acknowledged Caregiver, MD

### **Strategic Implications**

How people feel they came to the caregiver role influences how they feel about the role, and how open they are to accepting help and support. Messages must be designed to address both reluctant and more willing caregivers. Acknowledging that men are increasingly taking on this role is also vital. Messages should be more gender sensitive, and may need to specifically address male caregivers' special needs in terms of support and advice.

### **III. Barriers to Empowerment and Self-Help**

Beyond self-recognition, there are additional barriers to empowerment and self-help. Even some of those caregivers who are most aware and acknowledged are reluctant to take steps to support themselves in this role. Most caregivers see caregiving as a role they play vis-à-vis their loved one, not something they need to support themselves in doing. Moreover, many say they are “putting their own lives on hold” to care for their loved one and will “balance it out” later.

#### **The Loved One Comes First**

Some caregivers feel the needs of the person they are caring for come first, no matter what. This tendency to put one’s own life on hold is particularly prevalent among those who are caring for someone who is very ill. For example, a California caregiver explains, “We already know my grandfather is going to pass away within the next four to seven months. The least I can do is to be there for him... I'm not going to abandon him now when he only has four to seven months. I'll wait to balance my life out.” Those caring for a spouse also tend to feel being with and caring for that person takes precedence over any other concerns. For example one Missouri caregiver says she would “rather spend time with [her husband] than do anything else.”

Because of the tendency of caregivers to see their role only as a role vis-à-vis another person, when asked about getting support or help for themselves as caregivers, conversations often come back to getting help for the person in their care, or learning how to be a better caregiver. Only when pushed do they discuss getting support for themselves, and even then many are resistant to the idea. For example, one caregiver was not familiar with respite. When it was explained to her she said, “So it’s not something fun for them to do? It’s just for you to have a break. It’s not something that benefits them...I would be more happy that it would benefit the person that I’m caring for rather than benefit me.”

#### **Not Realizing Help Is Available**

Some caregivers – especially those new to caregiving – simply do not recognize the need to support themselves in their caregiving role. Some are resistant to the very idea that one would need help or advice. As a California caregiver says, “You either know how to care for someone or you don’t. A book can’t help you.”

Many caregivers, especially those who have been in this role for shorter amounts of time, are unaware that there are places to turn for help. Simply put, it has never

occurred to them that there might be resources or ways to help themselves. As one non-acknowledged caregiver from Maryland explained when group discussion turned to resources like respite care and support groups, “I’ve never even heard of that. This is where I’m really ignorant. I’m just so busy taking care of my dad right now and trying to teach that I haven’t had time to research. It’s almost like I don’t have time to go get help. And I don’t know what’s out there that’s what I really need right now.” Even some of the more savvy, experienced caregivers are unaware of the kinds of services available for people in their situations. For example, all but a few are unfamiliar with respite care.

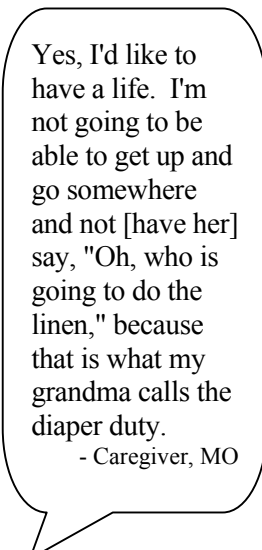
## A Private, Family Matter

Caregivers’ lack of knowledge about available resources, and their feeling that outside support is unnecessary, stems in part from a feeling that caregiving is a private family matter – not a public role. Indeed, many caregivers – especially those who are less acknowledged – are reluctant to even talk to outsiders. As one non-acknowledged Maryland caregiver said when asked how she would describe her role, “I don’t talk to anybody about it. I do it and go home and that’s it. Why do you need to talk about it?” An acknowledged Maryland caregiver explains she probably would not even discuss her situation with friends, saying “I don’t think it’s something that I would really discuss with somebody.” Simply put, some caregivers are isolated mentally and otherwise. They just do not realize there are other people doing this whom they could share with and learn from.

## Self-Care

Some caregivers – especially less acknowledged ones – say they would feel guilty taking time to do things “just for themselves,” and only use breaks to get things done, such as errands or laundry. This, they feel, is part of putting their loved ones first. Some fear offending their loved one by suggesting that they need a break. A comment by a Missouri caregiver illustrates this point: “Grandma knows when I’m upset about something, or if I’m angry...She’ll ask, ‘What’s wrong with you today?’ And I’ll say ‘I really don’t want to talk about it,’ because I’m not going to tell her I need a break and I don’t want to deal. It’s not really an option.”

On the other hand, there is a group of caregivers – generally those who are more acknowledged – who appreciate the need for time away, and stress the need for a separate existence and identity from that of caregiver. They have scheduled their lives, to the extent possible, to have time on their own or with other family members. Some view their work as a refuge, others meditate, go to the gym, or have scheduled “nights out.” In the words of one Missouri caregiver, “I love my job, and I would fight to keep it, to lead a normal life.”



Yes, I’d like to have a life. I’m not going to be able to get up and go somewhere and not [have her] say, “Oh, who is going to do the linen,” because that is what my grandma calls the diaper duty.

- Caregiver, MO

These caregivers value their time away and encouraged others in the group to take time for themselves. For example an acknowledged Maryland caregiver urged others in the group, “Take some time for yourself. Don't feel that you have to be there all the time to take care of this loved one. If you're important and something happens to you then you can't take care of them or yourself.” These caregivers also stress that taking a break makes you a better caregiver. In the words of one Missouri caregiver, “It's a self-defense thing. You just have to, or you will just get so wound up you will find yourself going crazy...or being impatient with the person you are caring for.” A few caregivers also point out that sometimes the person they are caring for might need a break from them.

Some only realized the need for self-care because of a crisis. One Missouri caregiver spent time in a psychiatric hospital. Another had a “breakdown” while driving and thus realized that she needed help. As a California caregiver explains, “Well, accidentally, I got a lot of help that I needed that I didn't even know I needed when [my loved one] went to the hospital in the end of October last year.”

Almost all the participants reacted very positively to the empowerment principal below. Even those who were initially reluctant to embrace the idea of self-care and time away react positively when it is framed in this way. The principal seems to give them permission and justification to act on their own behalf. Perhaps even more important it stresses that remaining healthy and happy makes you a better caregiver. For those who are uncomfortable taking time for themselves, this might be the idea that justifies doing so.

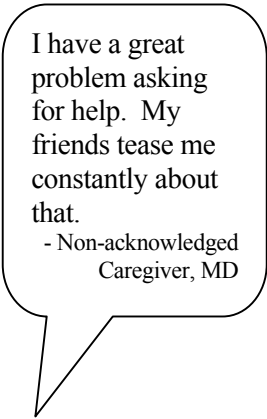
Honor, value and love yourself. You're doing a very hard job and you deserve some quality time, just for you. Self care isn't a luxury. It's a necessity.

*Self care is your right as a human being. Step back and recognize just how extraordinary you are, and remember your own good health is the very best present you can give your loved one.*

## **Reluctance to Ask for Help**

As noted above, to some extent people's willingness to embrace the caregiver label is an issue of personality. Many caregivers are self-selected; they are the take-charge, no-one-can-do-it-like-I-can types. The very characteristics that make these people good caregivers make them reluctant to accept help. In the words of one acknowledged caregiver, “I could have help if we wanted it. I don't think we need it. We don't really need it because I can do whatever we need.”

Participants are reluctant to seek help with their caregiving duties – even from other family members – for many reasons. Some feel that caring for this person is really their responsibility, and feel uncomfortable asking others to help. Often they cite potential helpers’ own responsibilities. For example, a non-acknowledged Maryland caregiver caring for her mother explains why she rarely asks for help from her brother. She explains, “He’s very supportive, but it’s just where we are in our lives. He’s my younger brother and he has three younger children. My daughters are in college. I keep saying to him, ‘You need to be with those children now.’” A Missouri caregiver explains, “I have a daughter who is a RN, and she’s more than willing to help. She lives very close. Although she is in a Master’s program at UMKC, has three kids and a full-time job. She doesn’t have much time to help, but she does.”



I have a great problem asking for help. My friends tease me constantly about that.  
- Non-acknowledged Caregiver, MD

Some have just been turned down too many times. For example, one Missouri participant who admits she wants help did not underline the recommendation to “seek, accept, and at times demand help” in the empowerment principle below. She explains, “The relatives I have here in town just always seem to have an excuse for everything. I asked one day if once a week, they could go over to see David. There are two nephews that say he’s the same as their father. He practically raised them. But they are never there. So I didn’t underline that, because I get tired of listening to excuses.”

Seek, accept, and at times demand help. Don’t be ashamed to ask for help. When people offer assistance, accept it and suggest specific things that they can do.

*Caregiving, especially at its most intense levels, is definitely more than a one person job. Asking for help is a sign of your strength and an acknowledgment of your abilities and your limitations.*

Moreover, many caregivers feel they do a better job caring for their loved ones than anyone else can. In the words of one acknowledged Maryland caregiver, “I’m not a control freak, but when it comes to my parents, unless I do it, it doesn’t get done right and I have a hard time delegating other people to these responsibilities.” Some admit that their inability to ask for help stems from their own issues. As one Missourian caring for her grandmother explains “Well, I feel I should give people a chance [to help]. I shouldn’t be so possessive of the situation. By the same token, [when other family members cared for her] her checkbook hadn’t been balanced in four and half months and she hadn’t had a hair cut...” Another Missouri caregiver insists, “The real deep underlying issue there is that some of us need to be needed a whole lot more than we need to look for help.”

Moreover, these caregivers feel that their loved one's prefer their care to anyone else's, and so feel guilty leaving their loved one with anyone else. As a Maryland caregiver explains, "My father-in-law especially is just very proud and a little bit stubborn in accepting help so I almost feel like it does fall on us. Because he wouldn't feel comfortable with anyone else coming in there and doing what we do. I think once in a while it would be nice if there were a backup."

People are particularly resistant to the notion of having outsiders help care for their loved ones. Hence, the idea of respite services is especially troublesome to the uninitiated. In the words of one Maryland acknowledged caregiver, "My father is the type of person who doesn't take to strangers so he wouldn't want another person to come in."

### **Strategic Implications**

Communications strategies should take advantage of the fact that many caregivers are interested or open to support, advice and information most often if it is about doing a better job caregiving. Giving such advice and support may bring caregivers into contact with organizations or resource centers, and once they are in the fold they can be approached about their own needs as caregivers. Moreover, self-care is best presented as a benefit for not only the caregiver, but also the loved one for whom they are caring.

I feel as though right now nobody knows him better than I do. I know in the morning when he goes in the bathroom, and takes his medicine, and his eye drops. Nobody else would know to do that.

- Caregiver, MO

## **Seeking Help at a Group Level**

Of all the ideas presented in the principals of empowerment, the one reprinted below is the most off-putting to participants. The idea of caregiving as a public role or something requiring rights was completely foreign to almost all the caregivers. In the words of an acknowledged Maryland caregiver, "I didn't like [where it said] 'stand up for your rights as a caregiver and a citizen' and 'speak up for your well-deserved recognition and rights.' It sounds like you're being an advocate for something. I don't think being a caregiver is a political statement where I have rights...It just takes all the softness and the love out of it."

Stand up and be counted. Stand up for your rights as a caregiver and a citizen.

*Recognize that caregiving comes on top of being a parent, a child, a spouse. Honor your caregiving role and speak up for your well-deserved recognition and rights. Become your own advocate, both within your own immediate caregiving sphere and beyond.*

In the non-acknowledged Maryland group, some potential benefits of and reasons for organizing politically – specifically the Family Medical Leave Act and the idea of tax credits – were discussed briefly. For the most part participants reactions were positive. In the words of one participant, “Well, I just feel like it’s something that probably all of us at one time or another may be in that role. So I think on a national level if there’s some type of financial help or aide that that’s really a positive thing.” On the other hand, some participants seem strongly opposed to the idea of politicizing – or even bringing into the public sphere at all – their caregiving. What is most clear from the discussion of the last empowerment principal is that these caregivers – with the exception of the parents of special needs children – are a long way from seeing themselves as a political constituency.

**Strategic Implications**

The idea of caregivers as a political constituency is foreign to most caregivers, and some are very wary of it. Nevertheless, the potential advantages of political mobilization are clear and powerful to some caregivers.

I think there’s an organization for everything from scratching your head to picking your nose... I think that people are so tired of hearing from organizations that are soliciting opinions or money or time.

- Caregiver, MO

## Messengers Matter

Caregivers trust and listen to some sources more than others. Specifically, they want to hear from people who have had similar struggles, and not, in the words of one non-acknowledged Maryland caregiver some “20 year-old whose job it is to write about caregivers.” Likewise, a Missouri parent caregiver explains, “You can get more information from another parent than from a professional in the field.”

Given caregivers strong feelings on this matter, a valuable source of caregiving mentorship might be past caregivers. Indeed some past and career caregivers in our groups seem to have “taken to the role.” Moreover, some feel they would like to and could share a lot of information, advice and support with new caregivers. As a past caregiver from Missouri explains, “I think I’m here mainly to maybe encourage other caregivers because it is really tough. But it really is worth it when you don’t have [your loved one] any more.”

**Strategic Implications**

The best and most effective messengers are those who are perceived to be “real” voices – that is, caregivers who have been through similar experiences.


## IV. Parents Are Different

The participants in our parents' focus group are different from other caregivers in their view of themselves and their role.<sup>4</sup> While they too are uncomfortable with the caregiver moniker, they are more acknowledged and self-aware. Moreover, most are open to help, advice and support. Those whose children are very ill and require an intense level of care are especially likely to be acknowledged, aware and engaged in self-help efforts.

### Caregiver Doesn't Cover It

Parent caregivers are similar to the other caregivers in their reaction to the term "caregiver." They too do not self-identify with the term. In the words of one mother, "[Caregiver is not a term I use.] I'm a parent." Another adds, "I have never thought of myself as a caregiver."

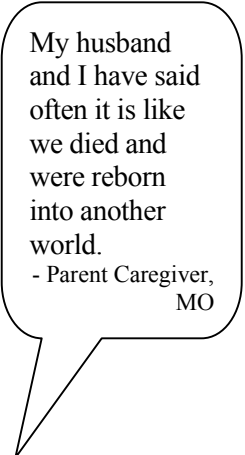
These parents, like other caregivers, are ambivalent about the term "caregiver" and feel it falls short of describing their role. They feel it lacks the element of love that is so central to what they do. As one parent explains, "You need to take care of the medical care, but your very first thing is loving that child." Says another, "There it is, that is the term, learning to give love and receive love."



[I am] always a parent first.  
- Parent Caregiver,  
MO

### Parent Caregivers Are More Self-Aware

Regardless of their lack of familiarity or comfort with the term "caregiver," these parent caregivers are much more aware of the uniqueness of their situation and the special demands of their role. For the most part, they define themselves as the parents – or grandparents – of children with special needs. Those whose children need a great deal of care are especially enlightened in this regard. In the words of one participant, "I think it is a lifestyle. It is a different way of living." Another explains, "Every single aspect of our lives has changed. Everything in our lives revolves around how it will affect Taylor."



My husband and I have said often it is like we died and were reborn into another world.  
- Parent Caregiver,  
MO

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<sup>4</sup> This was an unusual, and possibly atypical, group of parent caregivers. More than half care for children with severe disabilities or illnesses. Moreover, several are involved in a group called Encouraging Families with Exceptional Children Together (EFFECT). EFFECT is a local group whose mission is "to empower families of children with disabilities by providing encouragement, information, support and pathways to services." Parents who are active in EFFECT are generally well-connected and self-aware. That having been said, the results reported above represent what we learned from all the focus group participants. Indeed, the seriousness of their child's condition was a better predictor of acknowledgement and self-help than EFFECT membership.

Most parents embrace the positive aspects of this lifestyle. As one explains, “It’s not like it’s a bad change. It’s just different. I wouldn’t give up anything for what we have now. But everything is new, there is a new way to do everything, and you look at everything differently.” Another says, “Our lives were very fast, our life is now very slow. It takes us a long time to do everything. That’s really nice. We are on a slower pace, you see more of the world this way.”

Parent caregivers also appear more willing to admit that they sometimes feel victimized, overwhelmed and angry. As one explains, “You have feelings sometimes [that you can’t share with] anybody who doesn’t have a child with a disability like, ‘Today I wanted to get in my car, leave my son and my husband and drive and never ever come back.’ If I say that to somebody who doesn’t have a disabled child, they are going to look at me like, ‘What? [You are] the worst mother in the world...’ But someone who has a child with a disability can understand that you feel like that every once in a while.” Another explains, “I still have my one day a month where all I do is cry the entire day.”

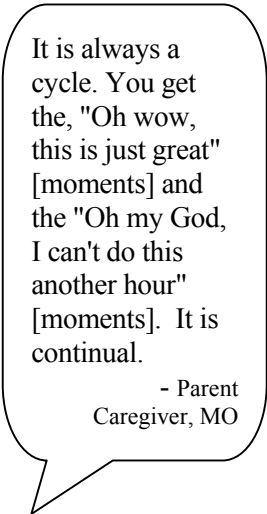
The parents who are most in touch with their positive and negative feelings – that is, those who can express anger without feeling guilt and can recognize the positive aspects of caring for a special needs child – admit that it took them a while to reach their current state. They talk about going through stages to reach this place.

Unlike other caregivers, it seems parent caregivers, and those with very sick children in particular, value being part of a group. As one participant says in explaining her desire to be with other parents of special needs children, “I just didn’t want to feel like I was the only one in this different world that I was living in. I wanted to be around all people like this so that I could think...I am normal in this group. I wanted to feel like that every once in a while.”

## Parents Are More Open to Help, Advice and Support...

Just as they are more likely to define themselves as the parents of special needs children and seek out others in similar situations, so too are parent caregivers more likely to accept and even seek out help, support, advice and encouragement. There appears to be a recognition, especially among those with very sick children, that to do the best possible job as parents they must reach outside themselves and their families. Therefore, they look for support and resources from the community, social services agencies and elsewhere.

There are some, however, who have not availed themselves of any of the help available. Some admit they are aware of very few resources. As one of the participants who is active in EFACT explains, “I probably get ten to 12 calls a week from families whose children have a disability because their doctor has



It is always a cycle. You get the, "Oh wow, this is just great" [moments] and the "Oh my God, I can't do this another hour" [moments]. It is continual.

- Parent Caregiver, MO

referred them to me or something. It saddens me when I get this call when this kid is six years old, and they never got First Steps early intervention. They don't know about the respite funds available through the Kansas City regional center. They have never heard of this, they have never heard of that. It is like, these poor people, why didn't the social worker at the hospital tell them about it?"

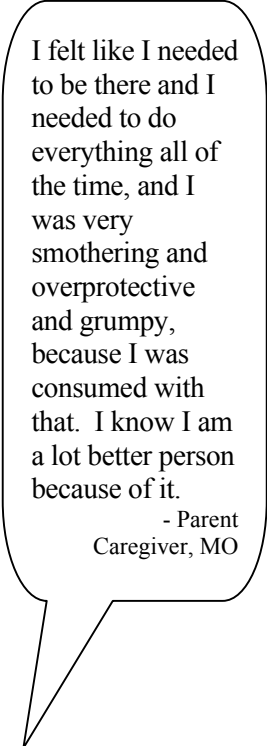
Moreover, parent caregivers seem to have more appreciation than other caregivers for the fact that taking care of their own mental and physical health is vital in their efforts to be a good parent for their special child.

### ...But Self-Care Is Still Not a High Priority for Some

However, as is the case with other caregivers, many parent caregivers do see their caregiver role only as a role they play vis-à-vis their child. Therefore, while they might be open to help, support and advice, they might not be ready to take time solely for themselves. As one parent says, "People who aren't in the disability realm have a difficult time understanding this. What happens with families with children with disabilities, [is that] their lives revolve around those children...At the end of the day they are out of energy, they are out of money, they are out of time. There is no you. There is just the family, no matter what circumstance it is, it is exhausting."

One parent caregiver's description of what she uses her state-provided respite care for illustrates the problem: "I get 20 hours of respite care from the state of Kansas. I thank God. I can go to the grocery store and go to my doctor's appointments. Twenty hours sounds like a lot until you get started. You run like a chicken with it's head cut off." Another explains that she has not been to see the doctor although she knows she should. She explains, "If you are going to the doctor six times a week for your child, even though I might be able to find an hour to go for myself, that's the last thing I want to do, is go to the doctor, but I know that I need to. I don't do it because I don't have time."

There are some parents who have reached a stage where they are ready to put their own needs first sometimes. One explains, "[My husband and I] have decided that once a week we are going out for a couple of hours. It got to where we were angry with each other all of the time, we didn't have any time to communicate...We have forgotten how to do anything fun." Another explains, "I felt guilty if I left the house. I was there all the time, consumed. [Then] in January of '98 I decided that was it, if someone asked me to a movie or to lunch, I was going to go. It was hard for me to make that decision, but I felt that I needed to. I have, and I know that I am a better parent, I am a better wife, I am a much better person because I finally let myself go. It has been better for the kids. I know that they are happy to see me go sometimes."



I felt like I needed to be there and I needed to do everything all of the time, and I was very smothering and overprotective and grumpy, because I was consumed with that. I know I am a lot better person because of it.

- Parent  
Caregiver, MO

## Parents' Ideas about Why Others Are Reluctant

Parent caregivers had some suggestions for why those caring for adults might react differently to their role as caregivers. They point out that caring for your child, especially when they are young, is more natural than caring for a parent or any older loved one or relative. Moreover, there is “a lot more joy in watching someone grow up than waiting for them to die.” They also raise questions of trust and comfort turning to outsiders about such a personal issue.

Lastly, they note that caregivers caring for adults might not have had the time or the support to go through the stages that lead up to the kind of awareness that parent caregivers, especially the most enlightened, have. Parent caregivers admit to feeling suspicious and reluctant to turn to others for help initially. One participant who is now active in EFECT explains that she was not interested at first. As she explains, “They brought in a packet of information, and I was so stunned about the whole thing. I kind of looked through it, but it is just a bunch of gibberish anyway, it doesn't make sense when you don't know what it is, and you have never dealt with this before... I thought, I don't want that. I don't want a bunch of people to feel sorry for me.” Only later did she realize the value of the information and support EFECT provided.

### **Strategic Implications**

Parent caregivers can provide a useful example for how to engage other caregivers, as long as the inherent differences are recognized. They also provide a useful model for establishing a political constituency with a voice.

# Strategic Summary

The focus groups provide valuable insight on how to approach caregivers about self-awareness and empowerment issues. The strategic ramifications of these findings in terms of message creation and dissemination are reviewed below. The first barrier, and perhaps the most difficult, is grabbing the attention of caregivers – especially those who do not self-identify – so we begin there. Then, we discuss the content of messages on awareness and empowerment.

## Reaching Caregivers

Reaching out to the broad caregiver audience is the first step, and this research suggests it is a difficult one. Many caregivers do not self-identify as such; some are completely unfamiliar with the term. Among those who do know the term, many are ambivalent about it, and a few actively dislike it. In short, few embrace the caregiver identity with immediacy or enthusiasm. Moreover, many are uncomfortable labeling their caregiving activities in any way. Based on these findings, we suggest the following as regards making contact with caregivers:

- Because caregivers are reluctant to embrace the caregiver label, it is important to work to change people's image of that word.
- The results suggest using “family caregiver,” instead of “caregiver” and working to raise awareness of this less familiar, but potentially more acceptable, term.
- It is important to reach out to caregivers without relying on the caregiver label. Describing caregiving, as we did in the screener<sup>5</sup>, may attract the attention of caregivers who would otherwise overlook messages.
- Messengers matter when approaching caregivers. Caregivers feel strongly that the most legitimate and compelling messengers are other caregivers.
- Although this was not addressed directly in the focus groups, these results confirm the need for reaching out to caregivers through a variety of media. Only acknowledged, empowered caregivers are likely to turn to caregiving organizations or search caregiver web-sites. Others may only be reachable through more innovative means.

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<sup>5</sup> In the screener, potential participants were asked: “Do you have an ill or disabled adult relative or friend whom you care for on a regular basis? This could be someone who just needs a little help, someone in declining health, or someone who is seriously or chronically ill.”

## Promoting Caregiver Empowerment

Many caregivers are open to the idea of empowerment and self-help, particularly if these ideas are presented in the correct framework and using language that resonates with caregivers. The key is this: Appeals to caregivers must begin from the understanding that they are most comfortable with, and interested in, information about how to better care for their loved ones. Once caregivers have been engaged on this topic, they are more likely to be open to messages about improving their own situation as caregivers.

- **Self-care and personal time are best presented from the premise that taking time for yourself makes you a better caregiver and thus ultimately benefits your loved one.** Presenting self-care in this light gives caregivers permission to take time for themselves, and a justification for doing so. Focusing on the importance of the caregiver's own health, by noting, for example, that "your own good health is the very best present you can give your loved one" is a powerful motivator. Likewise, presenting self-care as a necessity rather than a luxury is convincing.
- **The importance of asking for and accepting help is best presented from the premise that it results in better care for the caregiver's loved one.** Noting that caregiving is often beyond what one-person can handle is persuasive, especially when combined with a reminder that trying to do it all yourself may not be in your loved one's best interest. The notion that asking for help is a sign of strength, not weakness, also resonates with many caregivers.
- **Reminding caregivers that taking on a caregiving role is a choice and that they have the power to take charge of their life goes a long way toward empowering them.** Reminding caregivers that their loved ones benefit if they are proactive caregivers is also compelling. They do not have to embrace the caregiver label, but they do need to acknowledge the role and its demands.
- **Many caregivers do not feel they have much to learn or gain by becoming part of a wider community of caregivers.** The one area in which they might be open to information and guidance is in how to improve the care they give their loved-ones. Once they are approached on this topic other issues can be broached.
- **Approaching caregivers about the value of taking action on caregiving advocacy or education issues is difficult.** Here too, it is important to stress that such activities ultimately benefit the person being cared for. Specific examples are useful. For example, discussion of the Family

Medical Leave Act may resonate with caregivers. Another powerful motivating fact may be the economic value of the services family caregivers provide for "free."

**If the objective of the communication is to engage caregivers and encourage them to consider a new point-of-view or a change in behavior, it is also important to avoid some words, phrases and ideas that may upset or offend some caregivers.**

- Some caregivers, especially less self-aware caregivers, are uncomfortable acknowledging feelings of victimization or resentment. Messages aimed at caregivers need to take this into account. Words like “victim” should be avoided.
- Caregivers are open to a certain amount of recognition of the challenges they face. However, though participants welcome – and some even crave – this recognition, many are uncomfortable with anything they view as self-congratulatory. Therefore, language should acknowledge this.
- Few participants, with the exception of parent caregivers, see their caregiver role as relevant outside their family unit. The idea that this is a public role with rights is unfamiliar to many, and offensive to some. Therefore, messages in this vein should not be overtly political. In most contexts, words like “advocate” and “activist” should be avoided, as should specific calls to fight for the cause.

These findings provide valuable guidance on how to craft messages that will resonate with caregivers, and how to target these communications to caregivers, some of whom do not identify as caregivers.