Jennifer Heston-Mullins, PhD, LISW
March 6, 2020

A Communication and Care Coordination Resource for Caregiving Families
Valuing the Invaluable: 2019 Update
Charting a Path Forward

Susan C. Reinhard, Lynn Friss Feinberg, Ari Houser, Rita Choula, and Molly Evans
AARP Public Policy Institute

In 2017, about 41 million family caregivers in the United States provided an estimated 34 billion hours of care to an adult with limitations in daily activities. The estimated economic value of their unpaid contributions was approximately $470 billion.
National Family Caregiver Support Program (NFCSP)

- Established in 2000
- First federally-funded initiative designed to provide support to informal caregivers
- Provides grants to states and territories using a formula based on the number of individuals ages 70 and older
- NFCSP grantees provide:
  - information to caregivers about available services
  - assistance to caregivers in gaining access to the services
  - individual counseling, organization of support groups, and caregiver training
  - respite care
  - supplemental services, on a limited basis

ACL, n.d.
Inequitable Care and Support

- Significant reliance on a primary caregiver
  - 61% of caregivers of individuals 50+ identified as primary
  - 44% were “sole” caregivers
  - 16% indicated the involvement of a secondary caregiver or caregivers

NAC/AARP, 2015
Called upon federal departments to create a National Family Caregiver Strategy

Expand caregiver support programs (CARE Act, paid family leave)

Establish a public-private, multi-stakeholder innovation fund

Address diversity of family caregivers

(National Academies of Science, Engineering, and Medicine, 2016)
Recognize, Assist, Include, Support, Engage (RAISE) Family Caregivers Act of 2017

- Authorizes the Department of Health and Human Services (DHHS) to establish and maintain a family caregiving strategy
- Creates no new programs or initiatives
- Deliverables include report, national strategy, and advisory council
- Priorities (of national family caregiving strategy)
  - Adoption of person- and family-centered care
  - Care planning that involves caregivers and care recipients
  - Financial security and workplace issues
  - Improved respite care options
  - Support for education and training programs

(Administration for Community Living, 2019)
Recent Scripps Caregiving Research


- Caregiver Assessment in Ohio’s Adult Assessment for Nursing Facility Level of Care Programs: Testing a Caregiver Assessment Tool with the OHCW (2014 – 2015)
### THE ZARIT BURDEN INTERVIEW

Please circle the response that best describes how you feel.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite Frequently</th>
<th>Nearly Always</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you feel that your relative asks for more help than he/she needs?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2. Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. Do you feel embarrassed over your relative’s behaviour?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Do you feel angry when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Are you afraid what the future holds for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Do you feel your relative is dependent on you?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Do you feel strained when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>10. Do you feel your health has suffered because of your involvement with your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>11. Do you feel that you don’t have as much privacy as you would like because of your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

**© 1983 Steven Zarit**

**Interpretation of Score:**
- 0 – 21: little or no burden
- 21 – 40: mild to moderate burden
- 41 – 60: moderate to severe burden
- 61 – 88: severe burden

(Zarit, Reever & Bach-Peterson, 1980)
Caregiving Stresses and Strengths

- The caregiving situation creates a particular level of stress for the caregiver. (Caregiving Stresses)

- Caregivers also bring a particular set of strengths to the caregiving situation. (Caregiving Strengths)

- To achieve successful care at home, caregiving stress cannot exceed caregiving strength. (Keeping a healthy stresses to strengths ratio)
Balancing Caregiving Stresses and Strengths

It's important to be aware of how much caregiving stress you are experiencing. It's just as important to be aware of the strengths that you bring to your caregiving situation. Ideally, you want your strengths to be greater than your stresses.

Use the graph below to help you visualize your stresses and strengths at this point in time. Shade the boxes that correspond with how much stress and strength you feel right now. These numbers may change as your caregiving situation changes, so it's important to think about them regularly. Paying attention to your specific stresses and strengths can help you and those who support you in your caregiving. As you think about these numbers, think about what can be done to change the numbers so that your stresses are as low and your strengths as high as possible.

### Examples of different stresses/strengths:

<table>
<thead>
<tr>
<th>Stresses</th>
<th>Strengths</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

![](image1.png)
My eight may be your three.

Each caregiver and family is different, and sources of stresses and strengths are personal and individual.
SUPPORTING THE CAREGIVER
A Planning Tool for Family and Friends

Caregiver’s List: What would really help and when

1. 
2. 
3. 

Family and Friends’ List: What you can do and when

1. 
2. 
3. 

Note: If you are unable to provide help yourself but are able to pay another person or service to help in some way, you can offer that here:
Family Communication Problems

- Not seeing eye-to-eye about what’s needed, wanted, and possible
- Failing to acknowledge that each family member’s decisions affect other family members
- Doing without talking or without actually deciding
- Excluding some family members from the process
Our Family
Our Way
Goals of *Our Family, Our Way*

- Improve communication between family members about care and support

- Ensure that the person with care needs is included in conversations and decisions about care and support

- Increase the involvement of family members and others so that one caregiver is not responsible for all care and support
Our Family, Our Way Components

- Individual Tools
- Family Meeting
- Shared Assessment
- Family Care and Support Plan
- Follow-up Plan
## Individual Tools

### Health Consideration

<table>
<thead>
<tr>
<th>Health Consideration</th>
<th>I’m not sure</th>
<th>No limitation</th>
<th>Some limitation</th>
<th>Major limitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vision</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taste/Smell</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### The home...

<table>
<thead>
<tr>
<th>The home...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has rooms and hallways clear of clutter.</td>
</tr>
<tr>
<td>Has non-skid rugs.</td>
</tr>
<tr>
<td>Has safe stairways (clutter free, handrails, clearly marked, well lit).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care or support activity</th>
<th>What PERSONAL help is required?</th>
<th>Who is helping now?</th>
<th>What DEVICES are used and needed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much personal help do you require with the following activities:</td>
<td>N/A</td>
<td>I’m not sure</td>
<td>I require no help</td>
</tr>
<tr>
<td>Bathing or showering</td>
<td>N/A</td>
<td>I’m not sure</td>
<td>I require no help</td>
</tr>
<tr>
<td>Dressing</td>
<td>N/A</td>
<td>I’m not sure</td>
<td>I require no help</td>
</tr>
</tbody>
</table>
## Shared Assessment

<table>
<thead>
<tr>
<th>Health Consideration</th>
<th>No limitation</th>
<th>Some limitation</th>
<th>Major limitation</th>
<th>Can’t agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Vision</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Taste/Smell</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### The home...

<table>
<thead>
<tr>
<th>Requirement</th>
<th>N/A</th>
<th>Yes</th>
<th>No</th>
<th>Can’t agree</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has rooms and hallways clear of clutter.</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td>Mom does not feel “her papers” are a problem</td>
</tr>
<tr>
<td>Has adequate outdoor lighting.</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td>front porch light is burned out</td>
</tr>
<tr>
<td>Has an emergency response system. (e.g., Lifeline)</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Care or support activity

<table>
<thead>
<tr>
<th>Activity</th>
<th>What PERSONAL help is required?</th>
<th>Who is helping now?</th>
<th>What DEVICES are used and needed?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Requires no help</td>
<td>Requires some help</td>
<td>Requires much help</td>
</tr>
<tr>
<td>How much personal help does your PWCN require with the following activities:</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bathing or showering</td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Dressing</td>
<td>X</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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**MIA MIAMI UNIVERSITY**

Scripps Gerontology Center
An Ohio Center of Excellence
# Family Care and Support Plan

<table>
<thead>
<tr>
<th>Who will do what and when to address...</th>
<th>N/A</th>
<th>Steps we might take</th>
<th>Who will take the lead</th>
<th>Who else will be involved</th>
<th>When we will take these steps</th>
<th>Can't agree or Undecided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing</td>
<td></td>
<td>hearing test for dad</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Bladder or bowel control</td>
<td></td>
<td>Dad wants a urinal next to his bed at night.</td>
<td>Mom will order a urinal from the pharmacy and make sure it's by dad's bed at night.</td>
<td>Tonya will pick up the urinal from the pharmacy.</td>
<td>Mom will order the urinal this week and let Tonya know when it's ready for pick-up.</td>
<td></td>
</tr>
<tr>
<td>Physical mobility</td>
<td></td>
<td>Physical therapy</td>
<td>Dad will talk to Dr. Mullins about therapy at his next appointment</td>
<td>Tonya will drive Dad to the therapy appointments</td>
<td>Dad's next appt. with Dr. Brown is August 2nd.</td>
<td></td>
</tr>
</tbody>
</table>

## Who else is available to provide care and support?

<table>
<thead>
<tr>
<th>Extended family or friends</th>
<th>What might they do?</th>
<th>Community Services</th>
<th>What might they do?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neighbor Dean (Tim’s dad)</td>
<td>mow lawn or shovel snow when Tim’s not available</td>
<td>Meals on Wheels</td>
<td>provide lunch so mom doesn’t have to cook during the day</td>
</tr>
<tr>
<td>Cousin Kathy</td>
<td>drive Dad to appointments when Becky isn’t available</td>
<td>Home Care Agency</td>
<td>help with bathing Dad</td>
</tr>
<tr>
<td>Mom’s friend Margie</td>
<td>take Mom out to lunch so she can get a break</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Follow-Up Plan

At the end of the family meeting, the family decides:

- How do we want to communicate with each other going forward?
- How are we going to update what’s needed, wanted, and possible?
- When will we meet again?
- What are the areas where we are undecided or we can’t agree right now?
OFOW Pilot Study and Refinements

Pilot Research Questions

• Will a structured, self-guided process for communication and care coordination work for caregiving families?

• How does the use of a structured, self-guided process impact family members’
  – Communication
  – Stresses
  – Sharing of care
  – Satisfaction
  – Health and well-being
## Pilot Eligibility Requirements

### Is your family eligible? Your family is eligible if:

1. The parent (age 60+) needs help with **at least one personal care task** (such as bathing, dressing, grooming, etc.) **AND/OR** **at least three instrumental tasks** (such as housekeeping, meals, shopping, transportation).

2. The parent who needs help does **not** have a diagnosed dementia.

3. The parent who needs help is living in the community (this is, not in a nursing home).

4. The parent has at least two family members: either a spouse/partner and at least one adult child **OR** at least two adult children. (Adult children include step children and children-in-law. The children may live at a distance from the parent.)
Pilot Sample

- 9 families and 36 participants
  - 9 persons with care needs (ages 67 – 94 years)
  - 8 “primary” caregivers
  - 15 “secondary” caregivers
  - 4 “co-caregivers”

- Little racial diversity

- Socioeconomically diverse
  - Annual household incomes ranged from less than 25,000 to over 100,000
Pilot Findings

 ➢ A self (family)-guided process will work and families found it feasible and helpful

 ➢ There were changes in family communication and decision-making

 ➢ Families either affirmed or made changes to their care and support arrangements
  ➢ Changes made were more equitable
Feasibility

- All participants completed the individual tools prior to their family meeting

- All 9 families completed the shared assessment portion of the process

- Varying levels of adherence to the process
  - Some families made adaptations
Helpfulness

“[I]t helped identify the load that I have on my plate...and bring awareness to everything I do. Putting it down on paper allowed everyone to see that.”

“Being able to see how the caregivers look at the same situation I'm looking at.”
Helpfulness

“For me, I think it took things that were kind of here, there, and everywhere, and I guess the picture I have is taking a funnel and putting it all in there and having it synthesized and put in proper order so that you can look at it, think about it, and come to conclusions—one, or more than one person.”
Helpfulness

“It’s a structured process. It forces you to think about these things. Not at random because you may forget things that we aren’t aware of.”
Changes in Family Communication

- Individual tools exchange and shared assessment had the greatest impact
  - Most families recognized and reconciled perceptual incongruence

- Communication was inclusive and explicit
  - Inclusion of the person with care needs

- Families made plans to continue having discussions
Changes in Family Communication

Time 1 (before completing individual tools):

Son (Primary CG): “We never really did sit down and plan how we were going to deal with mom's aging in who was going to take care of her. And I was kind of available and willing to do it so pretty much that's the way it played out. It was never just a conscious decision and we never really discussed it. It kind of evolved and happened.”

Mother (PWCN): “It's hard to explain because when [son] first came, he came from [another state] to be closer to the family, it was like he inherited the job. Nobody asked him, everyone assumed because he was here he would do it. But it wasn't like a one-on-one, like [son], can you do this? Nobody consulted with [son] or myself.”
Changes in Family Communication

Time 2 (after family meeting):

Son (Primary CG): “We really weren't communicating, everyone was just assuming. The feeling was pretty much it's getting done so what's the problem? You know, out of sight, out of mind. I think with these kinds of things, I think the big thing is getting people to realize there is something going on here and maybe we need to address it and take a look at it.”

Mother (PWCN): “[The family meeting] was an open session, they talked about their answers openly. To me it was very much revealing and proves to me that the family could work together...I felt that each one wanted to wholeheartedly do something, but had no guides or leadership before.”
Inclusion of the Person with Care Needs

Person with Care Needs

“It brought to light what I was thinking and what they were thinking, because usually I don't converse that much about myself with them.”

Caregiver

“We need to talk more often amongst ourselves about that—including mom. How she's doing? Is she getting what she needs?”
Affirmation of Care and Support Arrangement

- **Satisfied affirmation**
  “It works for us right now.”
  “It’s kind of under control.”
  “We are all getting along really good.”

- **Temporary affirmation**
  “It doesn't need to change, but I know that if and when it does, it will happen with no problem.”

- **Resigned affirmation**
  “I don't like it, but I can't do anything about it.”
  “I learned we were in agreement about me carrying the brunt of the work.”
  “I'm okay with it, if I have to, but...I don't like depending on them for anything.”
Changes to Care and Support Arrangement

In one family:

- Secondary caregivers agreed to increase their time with the parent and provide the primary caregiver a “day off” each week.

- Agreed that the primary caregiver would receive “the lion’s share” of assets upon parent’s death.

- Agreed that family members least involved in the care would be informed about, but not included in, day-to-day decisions about care.
Participant Feedback for Revisions

- Bulk
- Redundancy
- Opportunity to “opt out” of sections
- Potential for an electronic version of the materials
Additional OFOW Resources

- Instructions for downloading and printing materials

- Videos
  - What can a family meeting do for us?
  - How do we hold a family meeting?

- Tip sheets
  - Who should be included in our family meeting?
  - Preparing for your family meeting
  - General communication tips for your family meeting
  - What should we do about major differences in our family meeting?

- Helpful Resources booklet

- Sample agenda for follow-up meetings
What’s next?

- Building Evidence for the Our Family, Our Way Communication and Care Coordination Process for Caregiving Families (2020-2021)
New OFOW Study

- Recruiting families with at least three (18+) family members (including the person with care needs). The family members may live at a distance from the person with care needs.

- The person with care needs must:
  - Be age 60 or older
  - Live in the community (does not reside in a nursing home)
  - Not have a diagnosis of dementia
  - Require assistance with at least one ADL (e.g., bathing, dressing, grooming, toileting) AND/OR two IADLs (e.g., housekeeping, meals, transportation)
Thank you!

Jennifer Heston-Mullins
hestonjl@MiamiOH.edu
(513) 529-1858
References


