

Our Family, Our Way:

A Family Communication and Care
Coordination Guide for Aging Parents and
their Adult Children

KATHRYN B. MCGREW, JENNIFER L. HESTON
ERIN M. KELLY, NYTASIA HICKS



SCRIPPS GERONTOLOGY CENTER
An Ohio Center of Excellence



MIAMI UNIVERSITY

**Our Family, Our Way:
A Family Communication and Care
Coordination Guide for Aging Parents
and their Adult Children**

**Kathryn B. McGrew, PhD
Jennifer L. Heston, PhD, LISW
Erin M. Kelly, MSW
Nytasia Hicks, MSW**

November 2017

This project was funded by a grant from the Retirement Research Foundation.

Table of Contents

List of Tables	i
List of Figures	ii
Executive Summary	iii
Background	iii
Methods.....	iv
Major Findings and Outcomes	v
Background.....	1
Review of the Literature.....	4
Research Questions	15
Methods.....	15
Tools and Guide Development.....	16
Individual developmental interviews.....	18
Sampling and recruitment	18
Data gathering	19
Analysis.....	20
Individual cognitive interviews	20
Sample and recruitment	20
Data gathering	20
Analysis.....	21
Guide development and construction	21
Tools and guide development and construction expert review panel	21
Testing version of tools and Guide for intervention	22
Managing the risk of a family-directed process.....	22
Implementation: The Our Family, Our Way Intervention	23
Sampling and recruitment.....	23
Data gathering.....	25
Time 1 and 2 evaluation tools and interviews	29
Time 3 interviews	30
Family interviews.....	30
Intervention evaluation and analysis	30
The family as unit of analysis: Data gathering, analysis, and reporting	30

The constraint of network confidentiality.....	32
Findings.....	33
Two Findings as Context.....	34
Outcomes.....	36
Effects on communication and decision-making processes	37
Perceptual incongruence in family communication about care	38
Perceptual incongruence about what is needed	38
Perceptions about underlying health conditions	38
Perceptions about environmental considerations.....	39
Perceptions about what help is required	39
Perceptions about what is happening (who is helping) now.....	40
Congruence about what is wanted	40
Congruence about what is possible.....	41
Recognizing and reconciling perceptual incongruence: The role of the individual tools and the tools exchange.....	42
Do family members recognize perceptual incongruence? Recognition of perceptual incongruence from Time 1 to Time 2	43
Do family members reconcile perceptual incongruence? The Shared Assessment.....	44
Do family members acknowledge decision interdependence?	45
Do family members engage in explicit decision making?	46
Do family members engage in inclusive decision making?.....	48
Effects of the family meeting on inclusiveness of decision making.....	49
Inclusion in the Our Family, Our Way experience: What participants' hindsight tells us about inclusive communication and decision making	50
Reported overall impact on family communication from Time 1 to Time 2.....	52
Changes in the care and support arrangement	54
Managing expectations	55
Affirmation of the status quo	55
What is effect of the intervention on changes in PWCN self-care ?	56
What is effect of the intervention on changes in caregiver involvement ?.....	57
What is effect of the intervention on changes in use of formal services or other informal supports ?	57
What is effect of the intervention on changes on indirect supports or resource transfers ?	58

Changes in actual and perceived equality research question 3: What is the impact of changes in the care and support arrangement, including indirect support and resource transfers, on actual and perceived equity?.....	59
The impact of the tools exchange and the family meeting on actual equity.....	59
Perceived equity: Changes from Time 1 to Time 2.....	60
Changes in distress	63
Changes in family efficacy	63
Outcome conclusions.....	64
Risks.....	67
Feasibility	67
Assessing fidelity.....	68
Acceptability.....	71
Ease of individual tools.....	71
Ease of the Shared Assessment.....	72
Ease of family goal statement.....	73
Ease of completing the Family Care and Support Plan.....	74
How likely to are participants to use the Guide again?.....	74
Likeliness of recommending the Guide to others.....	75
Recruitment response.....	76
Perceived benefit (helpfulness).....	76
Perceived burden.....	77
Perceived effectiveness.....	77
Ethical issues.....	78
Overall fit for a self-guided process.....	79
Sustainability of communication and changes in the care and support arrangement.....	80
T3 interview updates: Implications for sustainability.....	80
Limitations	80
Network confidentiality.....	81
Intervention adherence issues.....	81
Effects of study participation on OFOW experience and outcomes.....	81
Effect of payment?.....	82
Discussion and Implications for Further Development and Study.....	82
Self-Guided vs. Professionally Facilitated Process.....	83

Revisions to the Tools	83
Revisions to the Process	84
Inclusiveness	84
References	86
Appendix A Family Summaries.....	96
Appendix B Evaluation Tools.....	114

LIST OF TABLES

Table 1. Intervention Participant Demographic Data	24
Table 2. Research Questions, Data Sources, and Measures	27

LIST OF FIGURES

Figure 1. Theoretical and Research Framework.....	6
Figure 2. Guide Process and Tools	16
Figure 3. Implementation Timeline: Our Family, Our Way: A Family Communication and Care Coordination Guide for Aging Parents and their Adult Children	28
Figure 4. The Effect of Heightened Consciousness at Time 2: Hypothetical Individual Reactions	35

EXECUTIVE SUMMARY

BACKGROUND

In 2009, there were 42.1 million family caregivers in the U.S., and 8 in 10 caregivers provide care to adults age 50 and over (Feinberg, 2012). The ability of many older adults to remain at home with a chronic illness or disability is especially dependent on a “primary” family caregiver; too often, other family members are underutilized or even marginalized. Inequitable care and support arrangements are the outcome in part of ineffective family communication and decision-making processes. Signs of ineffective family communication about care include information deficits; perceptual incongruence about care needs, values, goals, and preferences; implicit or de facto “decisions;” and explicit but exclusionary decision making that leaves some parties out of the process altogether. An inequitable care and support arrangement is one consequence of these communication challenges.

To address these challenges, we designed and pilot-tested a family-directed communication and care coordination guide (Our Family, Our Way) for community dwelling older adults with chronic illness and/or disability (persons, parents, or partners with care needs, or “PWCN”s) and their adult children. The objectives of the intervention were to facilitate improved family communication processes and changes in the family’s care arrangement. The intervention was designed to *indirectly* facilitate the intermediate outcome of a more equitable actual and perceived care and support arrangement and the distal outcomes of reduced individual distress and improved perceived family efficacy.

The intervention includes the following steps, using the tools and guidelines in the Our Family, Our Way Guide: 1) Each family member, including the PWCN, independently completes a set of individual tools: assessment of the PWCN’s underlying health conditions, environmental considerations, and care needs; statements of personal goals for self and others; and individual care and support capacities, limits, and preferences; and 2) A family meeting of all participating members is held and conducted according to structured guidelines in the Guide. To begin the meeting, family members exchange their completed individual tools. Using family tools in the Guide, the family conducts a shared assessment of what is needed, wanted, and possible in the care and support arrangement. A family care and support plan is completed. Although affirmation of the status quo is a possible outcome of the family meeting, the purpose of the meeting is to create a space and structure to negotiate changes in the care and support arrangement, as needed and wanted, using the tools exchanged among members.

METHODS

Our major research questions were: 1) What are the effects of the intervention on family **communication and decision-making** processes related to care and support? 2) What is effect of the intervention on **changes** in the family care and support arrangements? 3) What is the impact of changes in the care and support arrangement on actual and perceived **equity**? 4) What is the impact of changes in equity on individual appraisals of **distress**? 5) What is the impact of the intervention process and related changes on perceived **family efficacy** about care and support decision making and planning? And 6) What is the feasibility of the intervention (Guide content and process) for all family members?

The research design had four parts: 1) “Guide” development including individual tools about what is needed, wanted, happening, and possible in the care arrangement; family tools (a Shared Assessment parallel to individual tools, and a Family Care and Support Plan); and guidelines for a family-directed family meeting; 2) implementation; 3) evaluation of outcomes; and 4) assessment of intervention feasibility.

Participants: In the tools and Guide development phase, we conducted face-to-face individual interviews ($n = 16$ followed by cognitive interviews ($n = 6$) with PWCNs, spouses, and adult children or children-in-law. We also employed a review panel of experts ($n = 6$). In the implementation phase, nine families (ranging from three to six members; $n = 36$ enrolled in the intervention. Our sample was limited to families of PWCNs age 60+, with *no diagnosed cognitive impairment*. PWCNs ranged in age 67 to 94; seven of the nine were female and two were male. 17 of the 27 caregivers were female; 10 were male. Primary caregivers ranged in age 47 to 84 four were male, including three spouses, and four were female, including one spouse. (One family had four participating co-caregivers. That, is none was designated as primary.) All members of eight families were white; all members of one family were African-American. Household income of PWCNs ranged from under \$25,000 to over \$100,000. PWCN impairments ranged from three IADLs only to three PADLs¹ with multiple IADLs². The majority of participants were from Ohio. One family was from another Midwestern state.

Data gathering and analysis: The family was the unit of analysis. Only two sources of data were “family” data: optional family interviews with three families; and data from the family tools in the completed Guides. All other data sources were individual. We used “multi-family member interview studies” (MFMS) (Eiskovits & Koren, 2010; Reczek, 2014), constructing a coherent understanding of each family’s background, experience, and outcomes by integrating data gathered from the family’s individual members. We conducted face-to-face or telephone interviews at Time 1, pre-intervention; Time 2, post-intervention (after the family meeting); and Time 3, up to two

¹ Personal Activities of Daily Living

² Instrumental Activities of Daily Living

months later. We used mixed methods. Our quantitative measures included existing scales or their modifications and newly constructed scales or instruments designed for our specific research questions. We also analyzed data from the individual and family tools in the participants' completed Guides. Qualitative methods included open-ended questions and semi-structured probes related to the scales administered in the interviews.

To determine whether particular family characteristics correlated with other characteristics and/or appeared to have an effect on the level and nature of intervention outcomes, we rated each family as high, middle, or low on the following characteristics: level of care (PADL/IADL impairment and/or self-imposed care demands, from the Guide individual tools); level of strain (self-rated physical strain, emotional stress, social loss, and financial burden, from the Guide individual tools); perceptual congruence (level of agreement in the Guide individual tools), “going-in” family efficacy (collective rating of family efficacy by family, in Time 1 interviews), and intervention fidelity (using a set of indicators about adherence to the guidelines). We also considered family size and the composition of caregiver roles, for example, spousal vs. filial primary caregivers. The high/middle/low ratings for each family were negotiated as a research team, establishing demarcations and comparing each family to the others, by characteristic.

MAJOR FINDINGS AND OUTCOMES

All members of all nine families completed the intervention and the evaluation through Time 2. The intervention very clearly achieved the first objective, improved family communication, for all but one of the families (and that family's assessment was mixed). At Time 2, 24 of 34³ participants reported that their family's communication had improved. Only 2 of the 34 reported that communication had worsened. As families, eight families reported improved communication and one family reported both worsened and improved communication. One of the most striking findings was the effect that the tools exchange during the family meeting had on reconciling areas of perceptual incongruence about what is needed, wanted, and possible in the care and support arrangement.

The intervention also achieved the second objective, changes in (or consensus affirmation of) the care and support arrangement for six families. Changes in the care and support arrangement were not dramatic but were essentially more equitable, that is, secondary caregivers and/or the PWCN planned to do more, and the primary caregiver would do less. We were not able to reliably interpret the effects of changes in the care arrangement on intermediate and distal outcomes of perceived equity, reported distress, and family efficacy. In terms of family characteristics (size, composition, level of care, level of strain, perceptual congruence, family efficacy, and intervention fidelity), none appeared to be linked to the level or type of changes in the care arrangement. We conclude that the combination of the family's *perceived need or motivation to change* and the

³ Two missing responses

family's readiness and capacity to negotiate change using the Our Family, Our Way tools and basic guidelines had the greatest impact on outcomes.

The Guide and process are feasible as a family-directed intervention, although we identified some risks. We argue that the option of a family-directed process is important; it is not only simpler, less intrusive and less costly than a professionally facilitated process, but it is also empowering to families who experience success on their own. There was a wide range of adherence to the guidelines (intervention fidelity); this had implications not only for modifications to the Guide and the family-directed process, but also for interpreting our other findings. There was a high level of Guide and process acceptability among participants. The vast majority of participants reported that they were very or somewhat likely to use the Guide again and that they were very or somewhat likely to recommend the Guide to others. (This included the family with a more negative outcome.) No participants reported that they were unlikely to use the Guide again or that they were unlikely to recommend the Guide to others.

We learned that essential core features of the intervention go a long way in facilitating positive outcomes in the Our Family, Our Way process. The first of these is the individual owning of perspectives about what's needed, what's happening now, what's wanted, and what's possible, using the individual tools. Second is the family's simple coming together, *including the PWCN*, in a structured way to pay attention to the shared situation at hand. Third is the process of engaging in a negotiated assessment by confronting and reconciling areas of incongruence. All of these features are the foundation of the Shared Assessment. A final core feature is the built-in expectation that something positive and helpful will happen as a result of the meeting. In summary, by facilitating inclusiveness, explicitness, and a recognition and reconciliation of individual perceptions, wants, and capacities, successful outcomes can be achieved. Our task going forward is to maintain these core features in subsequent modifications to the Guide and process.

BACKGROUND

In 2009, there were 42.1 million family caregivers in the U.S., and 8 in 10 caregivers provide care to adults age 50 and over. (Feinberg, 2012) U.S. society has long depended on family caregivers for long-term services and support. The value of that care for all adults in 2013 was estimated at \$470 billion (Reinhardt, Feinberg, Choula, & Houser, 2015), and the financial, physical, social, and emotional costs to families are significant.

While keeping care at home has always been the goal of most older adults, the national “balancing” movement toward even more home- and community-based care necessitates a corresponding increase in reliance on families. One of the most significant current trends in long-term services and supports is emphasis on not only delaying or avoiding institutional care, but also deinstitutionalizing nursing home residents. Caregivers are more vital than ever.

Most informal care happens in immediate families. A 2015 study of caregiving to older adults in the U.S. by the National Alliance for Caregiving and AARP found that 47% of caregivers to adults age 50 and over were caring for a parent or parent-in-law and 1 in 10 cares for a spouse. Families are now smaller and more geographically dispersed; care has become more medical in nature, and the period of care has lengthened. Policy shifts and demographic and geographic trends suggest an urgency to bolster support for family caregivers, that is, to broaden and strengthen family care and support.

We use the terms *care* and *support* in our proposed project to include two qualitatively different kinds of assistance provided in families. We conceive of *care* as ADL (PADL⁴ and IADL⁵) assistance; we conceive of *support* as all other assistance, such as financial help, material resources, home modifications, and the like. Boaz et al., (1999) distinguish between the provision of time, sharing household space, and money or material resources. Importantly, Boaz et al., finds that sharing household space and financial assistance not only “complement” but actually reduce time spent in direct care. They argue that such support is not sufficiently attended to in the study of caregiving families. Family networks generally share care but, there is significant variation in the “intensity” of the contribution (Tolkacheva, van Groenou, & van Tilburg, 2014). The more children there are in a family, the greater the likelihood that the parent will receive filial care; the more care provided by one’s siblings, the more care the adult child gives (Tolkacheva, van Groenou, & van Tilburg, 2010).

Inequitable care and support arrangements

The ability of many older adults to remain at home with a chronic illness or disability is especially dependent on a “primary” family caregiver; too often, other family members are underutilized or even marginalized. Primary caregivers assume a very large proportion of care load. In a study by the National Alliance for Caregiving and AARP (2004), 37% of caregivers to

⁴ Personal Activities of Daily Living

⁵ Instrumental Activities of Daily Living

an older adult (age 50+) identified as the “sole caregiver.” Of the remaining 63%, 68% reported an adult child as a secondary caregiver. In a recent, updated report (NAC/AARP, 2015), 61% of caregivers of individuals 50+ identified as primary; 44% were “sole” caregivers and 16% indicated the involvement of a secondary caregiver or caregivers. Importantly, being a “sole” caregiver does not mean that there are no potential secondary caregivers in the family. It may mean that potential secondary caregivers are simply not involved or are perhaps “crowded out” by the activities of the primary caregiver.

The experiences of spousal and filial caregivers are different in many ways. Spousal caregivers provide care for individuals with greater disability for longer periods and with more negative outcomes than other caregivers (Seltzer & Li, 2000). Filial caregivers are more likely to have competing obligations such as work and their families of procreation. Filial caregivers may live at a distance from their aging parents. In a 2006 national report on caregiving, Wolff and Kasper (2006) identify declines in secondary caregiver involvement and more primary caregivers “going it alone.” Spousal caregivers were the most likely to go it alone and adult children were more likely to have competing demands. The authors argue that primary caregivers “may serve as the critical link in maintaining community residence, they are an important target for government, health plan, or employer policies that provide financial support or other assistance to caregivers.”

That caregiving can be stressful has been clearly argued and demonstrated in decades of social science literature. Only recently have we come to pay attention to the potential rewards and satisfactions possible in the caregiving experience and relationship. In the 2015 Special Issue from the White House Conference on Aging published in *The Gerontologist*, Roth, Fredman, and Haley (2015) call for a “more balanced portrayal.” They make four recommendations to achieve this goal, one of which calls for greater support for primary caregivers with additional resources “including secondary caregivers,” suggesting a networking approach to caregiving. Tolkacheva, van Groenou, and van Tilburg (2011) write that a primary caregiving adult child experiences lower burden when tasks are shared across the caregiving network for longer periods and shared without disagreements among the other members of the network.

We argue that there is an inequity in family distribution of care and support that needs to be “redressed” (Ingersoll-Dayton, Neal, Ha, & Hammer, 2003). Equity issues are most obvious among adult-child siblings, but can also surface in families with a primary spousal and secondary filial caregiver or caregivers. In our project, we address both spousal and filial primary caregivers. Spousal caregivers are included in the intervention, in which case filial caregivers are likely to be secondary. Ultimately, however, our intervention targeted adult children, as either secondary supports to primary spousal caregivers or to primary filial caregivers (their siblings). We believe that the structure of the intervention crosses the different family dynamics inherent in both models.

Why does equity in family care and support arrangements matter? Cicirelli (1992) found that parents whose children were more equally involved in their care exercised greater autonomy than did parents with a dominant primary caregiver. Smerglia and Deimling (1997) argue that

family adaptability and decision-making satisfaction, after caregiver type, are the best predictors of caregiver depression. Lack of social support and inequitable support may be two different things, yet many studies about the impact of weak social support on negative caregiver outcomes do not discern the underlying equity issue. For example, lack of support was identified by family caregivers as a cause of institutionalization (Buhr, Kuchibhatla, & Clipp, 2006), but the type of support is not clear. As Sutor, Gilligan, Pillemer, and Pruchno (2013) report in a study of tension among siblings related in part to maternal favoritism, siblings are important sources of support for primary adult child caregivers, but sibling tension can be a major source of their interpersonal stress. Kwak, Ingersoll-Dayton, and Kim (2012) reported the effect of primary caregivers' perceived lack of family member support on family conflict. In a study of the impact of family conflict on adult child caregivers, Strawbridge and Wallhagen (1991) found that the greatest cause of conflict was "insufficient help" from a family member. Siblings or siblings-in-law were the greatest source of conflict (70%). Schulz, Beach, Cook, Martire, Tomlinson, and Monin (2012) found in a national telephone survey of caregivers that 44% reported a lack of choice in the arrangement. Lack of choice was associated with a number of negative outcomes, including greater emotional stress, physical strain and poorer health.

Unequal caregiving as indicated by the presence of a primary caregiver and a secondary caregiver in a family does not indicate, *ipso facto*, inequity in the arrangement. It does, however, invite a critical take on the arrangement. Matthews and Rosner (1988) propose five styles of caregiving participation to parents among adult siblings: routine, backup, circumscribed, sporadic, and dissociative (or what Davey & Szinovacz, 2008, call "reliably uninvolved"). In our conceptualization, routine caregivers would be considered primary, and others, in the presence of a primary, would be considered secondary. Importantly however, a distribution of such types in one family is not inequitable *per se*. Instead, it is the critical take or subjective appraisal of those contributions as "fair share" (Brody, 1990; Lerner, Somers, Reid, Chiriboga, & Tierney, 1991; National Alliance for Family Caregiving in the U.S., 1997) or not that determines the equity of the arrangement. That said, as we discuss later, we are also interested in deepening the family caregiving bench by boosting the *actual* support of secondary caregivers, potentially increasing actual equity. Moreover, we also consider possibilities for enhancing the person with care needs (PWCN⁶) self-care or use of resources in efforts toward actual equity. Ultimately, we are interested in redressing both perceived and actual inequity in the family care and support arrangement so as to reduce individual distress and to improve perceived family efficacy about decision making and planning.

⁶ PWCN also stands for parent/partner with care needs.

In this report, we present the design, implementation and evaluation of “Our Family, Our Way: A Family Communication and Care Coordination Guide for Aging Parents and their Adult Children,” a family-directed, structured process for achieving an improved care and support arrangement through negotiating a shared assessment and corresponding plan. Following a review of the literature, we describe the development of the Guide, its implementation with nine families, and an analysis of outcomes and feasibility.

REVIEW OF THE LITERATURE

What can we do to help families achieve more equitable care and support arrangements? We need to start by taking a family systems approach to caregiving. Davey, Janke, and Savla (2005) sound an explicit call for this approach. Caregiving to older adults is what Silverstein, Conroy, and Gans (2008) and Lerner, Somers, Reid, Chiriboga, and Tierney (1991) call “a family affair.” Matthews (1987) conceptualized the family as the “primary caregiver.” She argues that rather than focusing on a primary caregiver and a parent we should focus on the “parent-caring system” to include the primary caregiver and the “sibling subsystem” (p. 185). We take this one step further and argue that the “system” includes the parent with the care need, who, unless completely helpless, is engaging in some degree of self-care that is part of the distribution of care in the family. Additionally, we argue that PADL and IADL performance is not fixed and does not always decline. Self-care can increase (for example, a parent learning to use a microwave leading to greater meal prep independence), and the parent with care needs has an important role in the distribution of care in the family. As well, the research and practice focus on caregiving dyads, i.e., the primary caregiver and the care receiver, has itself marginalized secondary caregivers. Other relatively recent conceptualizations of a family approach to caregiving include caregiving “networks” (Davey, Janke, & Savla, 2005) and “convoys of care” (Kemp, Ball, & Perkins, 2013), with an emphasis on “care collaborations” (p. 4) that include not only the family but also formal systems of care, including institutional settings.

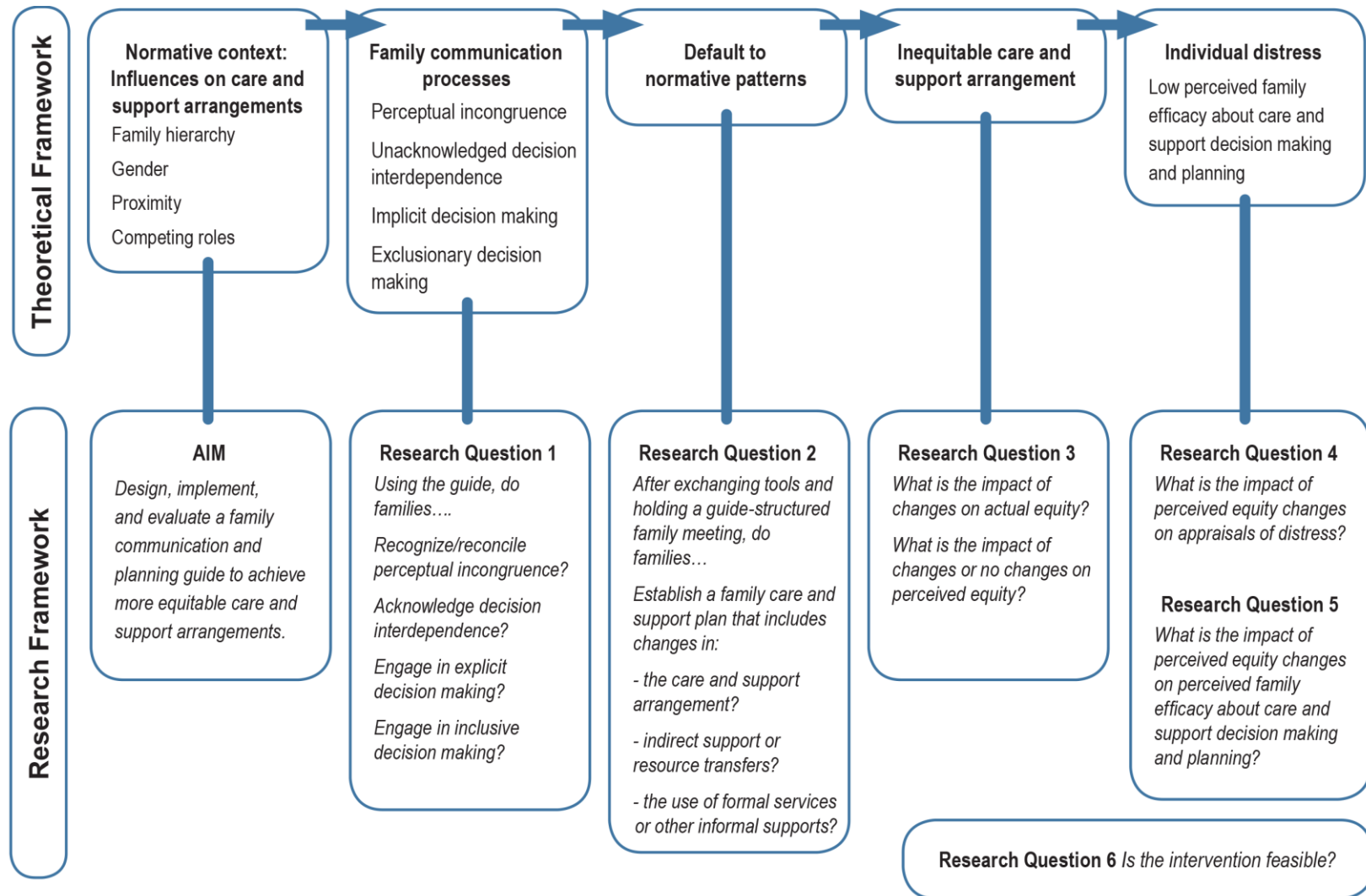
Indeed, family systems theory provides the theoretical underpinning of this project, while equity theory, with its roots in social exchange theory, and collective efficacy as it is developed from self-efficacy theory inform our theoretical framework for the study (See Figure 1). Individual care and support decisions are inherently family decisions. At the family level, we explored the following family phenomena: communication processes, care arrangements and the equity of distribution, and collective appraisal of efficacy. At the individual level we looked at effects of distribution equity on distress.

It is important to recognize that although, there is “considerable two-year stability in primary adult-child caregivers” (Szinovacz & Davey, 2013, p. 227), care and support arrangements in families change over time. In one of several studies of family caregiving using Health and Retirement Study (HRS) data, Szinovacz and Davey (2007) found that, over a two-year period, more than one fourth of primary caregivers in adult-child caregiving networks had changed; nearly three-quarters had remained stable. They argue that such data “underlines the need to shift

caregiving research toward a dynamic life course and family systems perspective” (2007, p. 280). Primary caregivers most likely to remain in their roles are daughters and those who live in close proximity to parents. Changes in caregivers are more likely the more children a parent has (Szinovacz & Davey, 2013). At the family system level, the same authors found that change in caregivers occurred in nearly half (45.8%) of the families. Seventeen percent of families added a caregiver and in 21% of families an adult child ended caregiving without replacement by a sibling (Szinovacz & Davey, 2013).

Although families as systems seek equilibrium, chronic illness and disability inject a significant level of uncertainty and disequilibrium. We would argue that there are opportunities for achieving greater equity at these change points. In fact, some of the changes identified in the literature may in fact be attempts at equity and include “turn-taking” (Richlin-Klonsky & Bengston, 1996, p. 274), supplementary vs. complementary help (Tennstedt, McKinlay, & Sullivan, 1989) negotiated care (Connidis & Kemp, 2008; Finch & Mason, 1993), bargaining (Engers & Stern, 2002; Pezzin, Pollak, & Schone, 2007) or a trading off (Wolf, Freedman, & Soldo, 1997), and a “sibling group process” (Tolkacheva, van Groenou, & van Tilburg, 2010, p. 752).

Figure 1. Theoretical and Research Framework



We argue that inequitable care and support arrangements and specifically inequitable reliance on a primary caregiver are the outcome in part of ineffective family communication and decision-making processes. Individual decisions about care in families are by their nature interdependent (Wolf et al., 1997): what one family member decides to do or not to do affects what another family member decides and so on. Poor communication leads to default arrangements that are biased toward normative care and support roles. In fact, we argue that primary caregiving itself has become normative. Opportunities are missed to think outside the normative box about who does what, when, where, and how.

As a way to understand inequity in care and support arrangements it is helpful first to consider who is likely to become a primary caregiver and why. Research⁷ has identified a number of relationship factors that contribute to the likelihood of caregiving. These include attachment (Cicirelli, 1993; Karantzas, Evans, & Foddy, 2010); obligation (Gans & Silverstein, 2006; Pyke, 1999); reciprocity (Dwyer, Lee, & Jankowski, 1994; Henretta, Soldo, & Van Voorhis, 2011; Neufeld & Harrison, 1995; Silverstein, Conroy, Wang, Giarrusso, & Bengtson, 2002) and parental expectations (Leopold, Raab, & Engelhardt, 2014). However, there are a number of variables that have become pathways to care and they contribute to the inequity of the care arrangement. In addition to patterns of attachment and affection, personality, and personal values, societal norms play a strong role in predicting who is more and less likely to provide care. As unspoken “rules” about behavior, social norms render family members especially vulnerable to assuming roles and tasks uncritically and possibly unfairly.

Normative context

Engers and Stern (2002) describe the “typical primary caregiver, other than a spouse” as “an oldest daughter, single, out of the labor force, and living with parent or nearby” (p. 73). This description accounts for each of the following normative factors that contribute to primary caregiving. We regard these norms as *negotiables* in decision making about care and support.

Family hierarchy/Lineage. Although gender (below) is overwhelmingly named as the strongest factor in predicting who will provide care in a family, in fact family hierarchy is the first rule of caregiver “assignment.” It is so fundamentally normative we rarely think about it. When an older adult requires care, if a spouse is present and able he or she becomes primary, then adult children, then children-in-law, then other family members or friends (Shuey & Hardy, 2003). Step-children (rarely distinguished from other adult children in caregiving studies) represent a complicated issue. Step-children of significantly later marriages are less likely to feel obligated as part of the hierarchy of care (Ganong & Coleman, 2006; Ganong, Coleman, Killian, & McDaniel, 1998).

Gender. After the rule of family hierarchy, gender is overwhelmingly the most powerful of caregiving norms; it is well established that women are more likely than men to provide care in

⁷ Research into factors that “predict” caregiving generally focus on the primary caregiver, a bias in much of the literature.

families and is what Szinovacz and Davey (2008) call “the gender mandate of care” (p. 143). Wives are more likely to care for their husbands than vice-versa; and daughters are more likely than sons to provide parent care and to be primary filial caregivers. The gendered nature of care is at the heart of much of the care and support inequity in families. There is a vast array of literature exploring the nuances of gender and care. Tolkacheva, van Groenou and van Tilburg (2010) conclude that the presence of daughters in the family has a powerful effect on the distribution of care. Simply put, although “siblings jointly provide caregiving to their parent...a child provides less care when he or she has available sisters” (pp. 752-53). Importantly, recent studies suggest that with all of the scholarly attention on women as carers, men are getting short shrift. In fact, it is important to note that Leopold, Raab, and Engelhardt (2014) found in an HRS study that daughters are “overrepresented only in transitions to mother care” (p. 300).

Proximity. As a predictor of spousal care, proximity is of virtually no significance because proximity (co-residency) is generally assumed, but the power of proximity is considerable when it comes to parent care by adult children. It can be a challenge to determine which comes first, the proximity or the caregiving. Did the adult child provide care because s/he was close by? Or did s/he or the parent move to be close by because of the need for care? In a longitudinal study of older mothers, Pillemer and Suito (2013) found that adult child primary caregivers were more likely to live in proximity and concluded that proximity predicts parent caregiving rather than the reverse. The special power of co-residency (the ultimate in proximity) is especially salient. Co-residing caregivers are far more likely to be primary than secondary caregivers (Pezzin, Pollak, & Schone, 2015). U.S. families have become increasingly geographically dispersed, and at farther distances. Long-distance caregivers are more likely to be secondary caregivers (Neuharth & Stern, 2002) and are receiving increasing research and program attention for their unique caregiving challenges.

Competing roles. Norms may function to preclude decision making (the *norm* has decided) and implicit “decisions” reinforce the norms. Factors such as competing roles are revealed to be normative when they are framed within families and from family to family as “legitimately excused” (Connidis & Kemp, 2008). Legitimacy is a normative construct. Such notions interfere with our imaginations about how the “excused” might become more engaged or otherwise provide support. Roles that compete with caregiving include employment, raising children, and caring for another family member. In a Netherlands study, Tolkacheva, van Groenou, & van Tilburg (2014) found that equal employment status between children predicted a higher likelihood of equal care sharing. Having more children reduces an adult child’s likelihood of parent care (Grundy & Henretta, 2006). Fingerman, Pitzer, Chan, Birditt, Franks, and Zarit (2011) found that “Boomers are typically more involved with their children than with their aging parents” and that divorce and remarriage “dampen intergenerational obligation in some families.” Finally, Szinovacz, and Davey (2013) find that proximity is a more powerful predictor of care than competing obligations.

Family communication processes

Why do families default to normative expectations of care and support, and why does the distribution of care and support roles and activities remain “stubbornly unequal” (Wiesmann,

Boeije, van Doorne-Huiskes, & Den Dulk, 2008, p. 341)? The caregiving arrangement is ultimately a product of interdependent decisions among family members in the family context. Cicirelli (1992) conceptualized a “family decision-making system” with subsystems (such as mother-daughter dyads). Scholars have theorized a number of influences on care arrangements in families, for example, family *types*: consensus-sensitive, environment-sensitive, distance-sensitive, and achievement-sensitive (Fitzpatrick, 2013); collectivist vs. individualist (Pyke, 1999); and family *processes* “volunteered vs. solicited assistance” (Pyke, 1999) and *patterns* of communication, e.g., self-protective vs. pro-social (Finch & Mason, 1993).

The family communication and decision-making process has been examined through rational choice models such as social exchange theory (Emerson, 1976; Blau, 1973) and economic theories, including game theoretic frameworks (Byrne Goeree, Hiedemann, & Stern, 2009; Pezzin et al., 2015) including discrete game models (Fontaine, Gramain, & Wittwer, 2009), efficiency models (Pezzin, Pollak, & Schone, 2007), supply-and-demand models (Wolf, 2014), strategic play (Hiedemann & Stern, 1999), and bargaining models (Engers & Stern, 2002; Pezzin, Pollak, & Schone, 2015; Pezzin & Schone, 1999; Silverstein, Conroy, & Gans, 2008). Most of these theories presuppose a rational orientation to decision making which many critics have decried as problematic in families with long histories of complex socioemotional relationships (in which hardly anything is completely rational). Others cite altruism (Becker, 1974; Becker, 1976); a shared concern for parent well-being as a “family-specific public good” (Pezzin, Pollak, & Schone, 2015, p. 9); and sibling solidarity or mutual caring (Volkom, 2006) as limiting or side-stepping rationality; yet family members are at least to some degree self-interested and are likely to weigh the costs and benefits of their decisions about care and support.

In their “substantive theory of caregiving,” Caron and Bowers (2003) describe two phases of family care and support decision making: the interrelational phase in which perceived consequences of care are evaluated, and the pragmatic phase in which the focus is on the tasks at hand. Though expressed as phases, Caron and Bowers note that they are not necessarily linear, that is, that a focus on the tasks at hand may precede a consideration of the consequences about who provides which care, where, and how.

Whether interrelational or pragmatic decisions are being made, the caregiving literature suggests four communication problems that may lead to a default to normative care expectations and inequity in the care and support arrangement: perceptual incongruence about care needs, values, goals, and preferences; unacknowledged decision interdependence; implicit or de facto “decisions;” and explicit, but exclusionary decision making that leaves some parties out of the process altogether. These four problems were the key points of correction in our intervention, designed to achieve more equitable care and support arrangements.

Perceptual incongruence

Family decision making and planning about the who does what, where, when, how, and even why in the care and support arrangement can be significantly impeded by perceptual

incongruence about *what is needed, what is wanted, and what is possible*. Incongruence has been noted in perceived level of dependence in the person with care needs (Bravell, Zarit, & Johansson, 2011; Horowitz, Goodman, & Reinhardt, 2004; Magaziner, Simonsick, & Hebel, 1988); in values and preferences (Whitlatch, Piiparinen, & Feinberg, 2009); in the need for communication (Fried, Bradley, O’Leary, & Byers, 2005; McGraw & Walker, 2004); and in expectations about care (Hauser & Beckman, 1984). A number of scholars have explored the problem of perceptual incongruence, focusing on caregiving dyads (caregiver and care receiver), (Cicirelli, 1992; Whitlatch et al., 2009; Zweibel & Lydens, 1990) and its association to negative outcomes. These outcomes include diminished emotional well-being and caregiver strain (Cicirelli, 1983) and negative effects on the bond in the caregiving relationship (Noelker & Poulshock, 1983). Pruchno, Burant, and Peters (1997) identified family typologies about levels of agreement about elder behaviors in families, from high agreement to low agreement families. They found significant differences in high agreement and low agreement families, with implications for perceived burden, caregiving satisfaction and relationships.

A study of caregiving dyads by Zweibel and Lydens (1990) found significant perceptual incongruence in a test of 18 items covering objective characteristics of both caregiver and care receiver, characteristics of the dyad, and feelings about the caregiving relationship. With the exception of 4 of the 18 items, at least one quarter or more of the dyads gave incongruent responses. Disagreement was greatest in areas of “what is needed” and “what is possible”: “unmet support need” (p. 64), level of care receiver dependence, the availability of secondary caregivers, and appraisal of the patience level of the caregiver.

More recently, Whitlatch and colleagues, (Reamy, Kim, Zarit, & Whitlatch, 2012; Whitlatch, Piiparinen, & Feinberg, 2009) have explored incongruence in “what is wanted,” or the values and preferences of caregiver and care receiver, with a focus on caregiving dyads with a person with early-stage cognitive impairment. In the Reamy et al., study caregivers “consistently underestimated” the care receiver’s values for autonomy, burden, control, family and safety. In the Whitlatch et al., study, the same values and preferences were measured. Although there was general agreement about the importance of preferences, the ordering of those preferences saw less congruence. Finally, there is evidence of incongruence in perceptions among siblings about the relative contributions of family members to the care arrangement (Matthews, 1987; Pillemer & Sutor, 2006; Sutor & Pillemer, 2007).

Zweibel and Lydens (1990) conclude that the problem of perceptual incongruence calls for inclusion of both the caregiver and the care receiver in the assessment of the care receiver’s needs and both care receiver and caregiver capacities in the planning process. We extend this argument beyond the dyad, to include secondary caregivers in the evaluation of what is needed, wanted, and possible. Until family members are on the same page, or at least until they have an understanding about where their differences lie, the opportunity for effective caregiving decisions and planning is compromised and the likelihood of defaulting to normative and inequitable patterns of care and support is increased.

Unacknowledged interdependence

As a form of communication, negotiation requires an acknowledgement of tradeoffs and exchanges inherent in individual choices. Costs, benefits, and tradeoffs are difficult to calculate and facilitate in a bargaining situation where the interdependence of decisions is left unstated and unacknowledged. (Hatfield, Traupmann, Sprecher, Utne, & Hay, 1985; Pezzin, Pollack, & Schone, 2015) This phenomenon is linked to its consequence, implicit or de facto decision making, below.

Implicit or de facto decision making

Implicit or de facto decision making occurs when either the family is at an impasse or when no clear-cut decision has been made. Implicit decisions may be made by dominant family members, reflecting power imbalances in the family. The interdependence of decisions becomes evident when a decision has been made implicitly and thus narrows the choices for other family members. Implicit or de facto decisions are open to complaints by individuals who have either been passive about the decision or were excluded from it (Galvin & Brommel, 1991). Although much of the literature about implicit decision making, and equity in general, focuses on dyads, particularly married or dating couples, there is some literature about group (family) decision processes. Wiesmann, Boeije, van Doorne-Huiskes, and Den Dulk (2008) note that individuals operating under implicit agreements may have regarded some role distribution issues as “not worth mentioning” (p. 341) but that are in fact consequential. Pecchioni (2001) identified two mechanisms that undermine explicit communication about care: the caregiver’s idea that s/he already knows what the person with care needs wants or needs; and denial, or a resistance or unwillingness to talk about what is wanted or needed. In a study of Mexican American caregiving adult children, Radina, Gibbons, and Lim (2009) suggest that implicit decision making is a mechanism for avoiding family conflict. Not all implicit decision making results in bad or inequitable decisions. Some implicit decisions reflect shared preferences and the decision “goes without saying.” In situations of perceptual incongruence, however, the risk of unwanted or unhelpful de facto decisions is arguably high.

Exclusionary decisions

Explicit decision making that acknowledges perceptual differences and the interdependence of decisions goes only part way toward effective family communication about care and support. Communication and decisions that exclude family members (very frequently the person with care needs) represent another risk for inequitable care and support arrangements. A number of recent initiatives have been undertaken to achieve person-centered care, especially in health care settings as an approach to improving health and quality of life outcomes. This increasingly embraced concept and practice has now expanded to person- and family-centered care (PFCC) (Feinberg, 2014). Many decisions about the care and support of the person with care needs are made on behalf of but without the very individual of concern (Whitlatch & Menne, 2009). There is very little literature about the effects of the exclusion of active or potential secondary

family caregivers from the family communication process, but in fact, research emphasis on caregiving dyads and the scant attention to family processes is exclusionary itself.

We have argued that when family members are not on the same page (or do not acknowledge where each other stands), do not acknowledge the interdependence of their decisions, engage in implicit and/or exclusionary decision making, the propensity of families to default to normative expectations leaves families vulnerable to inequitable care and support arrangements. We now turn to a closer examination of the concept of equity and the implications of inequitable care and support arrangements for individual family members and the family as a whole.

Equity theory and inequitable care and support arrangements

Equity in relationships is a comparative measure of the cost-benefit ratios of individuals in the relationship (Walster, Walster, & Berscheid 1978). When one individual's cost-benefit outcome in a given situation is better or worse than another's, there is inequity in the relationship and the situation. Individuals in an inequitable situation may either over-benefit or under-benefit from the relative contributions of themselves and others. According to the theory, the consequence of inequity for both over-benefiters and under-benefiters is distress (Walster, Berscheid, & Walster, 1973). Also according to the theory, individuals respond to inequity-related distress by doing any of three things: they may attempt to restore or strive toward "actual" equity by acting to change contributions and hence the cost-benefit ratios; they may change their perceptions of the relative contributions to make them seem fairer (called psychological equity); or they may actually end the relationship (Walster, Walster, & Berscheid, 1978).

Several studies have looked at equity issues in long-term care decisions. Using 2002 HRS data, Johnson (2008) found that aging parents and their adult children make cost-benefit calculations in making long-term care decisions and that they consider the opportunity costs of the adult child. In a study of stroke survivors and their caregivers, McPherson, Wilson, Chyurlia, and Leclerc (2010) found that those care receivers who evaluated themselves as over-benefiting in their care relationship had much higher scores on the Self-Perceived Burden Scale than those stroke survivors who reported that they were in an equitable care relationship, or were actually under-benefiting. Other literature suggests that the cost-benefit equation is not so simple and that perceived obligation intrudes upon decision making in a way to disrupt the cost-benefit equation. Silverstein, Conroy, and Gans (2008) propose filial obligation is "a strategic factor" (p. 75) in the allocation of support. The idea that the operative equation is really a cost-*obligation*-benefit equation has implications for perceived equity.

Equity as fairness of the care and support arrangement is inevitably subjective and for our study purposes the perception of equity matters as much, if not more, than actual equity, to the extent that actual equity can be measured. That said, we are interested in both actual and psychological equity as mechanisms for influencing appraisals of distress and family efficacy and as a means of deepening the family caregiving bench for all its practical benefits. We looked at actual changes in the care and support arrangement as a way to examine changes in actual equity.

Silverstein, Conroy, and Gans (2008), attempt to measure actual equity among family caregivers (or prospective caregivers) in their study of the family member contributions relative to their proximity to the person with care needs. The authors identify over-providers, under-providers, and equitable providers accordingly. We are not suggesting that more care is always better. In fact, Matthews and Rosner (1988) propose that a “principle of least involvement” (p. 187) is normative and that it functions to preserve autonomy (the ability to choose level of contact and engagement) of all family members.

Perceived equity requires a collective assessment of individual care and support limits and capacities that are mediated by individual and collective values, goals, and preferences and by ideas about reciprocity and other family-specific dynamics (Ingersoll-Dayton et. al, 2003). Lawrence, Goodnow, Woods, and Karantzas (2002) assert that a “shift in attitude” (p. 493) about the care and support division of labor can occur without an actual change in that arrangement. It is important to note that families do not necessarily expect care arrangements to be equal. In their qualitative study of sibling negotiation of parental support, Connidis and Kemp (2008) found that the distribution of the care was “rarely described or anticipated as being equal” (p. 232).

It is important to remind here about the role of the person with care needs in the equity of the care and support arrangement. The family-centered approach to our framework includes the self-care decisions and capacities of the person with care needs. The parent who has refused to learn to use the microwave might, in the interest of equity, decide to do so to relieve his daughter from daily trips to his home. Or, he might decide to accept a home-delivered meals service to the same end. He or she might also choose a new living arrangement or agree to the use of his/her financial resources to restore some balance to inequities.

Individual distress

Distress as examined in our project is not to be confused with stress, a much broader term and the subject of much caregiving research and intervention, for example, the widely utilized Stress Process Model of Pearlin, Mullan, Semple, and Skaff (1990). We focus on the distress that is experienced by family members specifically as relates to inequity, in particular, the inequity of the care and support arrangement. Again, there are two sources of distress related to inequity: perceived under-benefitting in a relationship and situation and perceived over-benefitting (Hatfield et al., 1985; Sprecher, 2001; Sprecher 2016). Equity-related distress can be experienced as frustration, anger, resentment (particularly when care defaults to gender lines) (Hequembourg & Brailer, 2005), disappointment, self-recrimination and guilt among the over-benefitting, a lack of confidence in the relationship, dislike of the other, and maladaptive responses, such as discontinuing communication or ending the relationship (as is perhaps observed in the “reliably uninvolved,” above) (Strawbridge & Wallhagen, 1991). The perception of equity may be influenced by rather small gestures of exchange or support; it is notable that simple expressions of gratitude from siblings can go a long way in compensating for perceived inequity (Amaro & Miller, 2016). Socioemotional support and the exchange of financial resources are forms of redressing inequities that we sought to address and examine in our intervention. We are concerned about

unresolved distress and our intervention was designed to ease it at some level by correcting communication problems and restoring or building toward actual equity and/or perceived equity.

Low perceived family efficacy

Self-efficacy is the belief in one's capacity to achieve one's goals, solve problems, or perform specific tasks. It is derived primarily from social cognitive theory, but also from social learning theory and attribution theory (Bandura, 1977). Perceived efficacy, according to the theory, derives from sources of information available to the individual: mastery experiences (successfully accomplished tasks); vicarious experience (task-performance observed in others); persuasion from others; and physiological states (e.g., health, strength, energy). Collective efficacy, according to Bandura, Caprara, Barbaranelli, Regalia, and Scabini (2011) functions in much the same way as personal or self-efficacy, but collective efficacy is more than a sum of individual members' beliefs; instead it is "an emergent group-level attribute" (p. 65). According to Bandura (2000), collective efficacy, or family efficacy, affects among other things a family's sense of its problem-solving ability and the effective use of its resources. Our intervention was designed to provide a decision making and planning mastery experience for participating families. We expect that when families achieve more equitable care and support arrangements through collaborative decision making, they will raise their perceived family efficacy about those processes. We examined the impact of perceived equity changes (or not) on perceived family efficacy about care and support decision making and planning.

Collective family efficacy is not measured by a "group mind" (Bandura, Caprara, Barbaranelli, Regalia, & Scabini, 2011, p. 429) but is an assessment by individual members about the family as a whole. It relies on individual judgments evaluated together as a "holistic efficacy appraisal" (p. 429). Scales to measure perceived family efficacy focus on the family's capacity to work together to manage family routines, reach decision consensus, "promote reciprocal commitments, agree to decisions that require some sacrifice of personal interests, provide emotional support for each other in difficult times and in stressful situations," (Bandura, Caprara, Barbaranelli, Regalia, & Scabini, 2011, p. 429) and so on. These indicators of family efficacy are the very targets of our intervention.

Conclusion

In our intervention, we regard improved family communication processes that lead to changes in the care arrangement as proximal outcomes; more equitable actual and perceived care and support arrangement as intermediate outcomes; and reduced individual distress and improved perceived family efficacy as distal outcomes.

There are several care coordination tools for families and other support systems available on paper and online, but many presume a foundation of communication without which the tools are unlikely to be used; and, importantly, most existing care coordination tools leave out the care receiver, an egregious omission. Many interventions focus on dyads only, and some of the more

successful interventions require intensive professional involvement at considerable cost. We address these issues with this project.

RESEARCH QUESTIONS

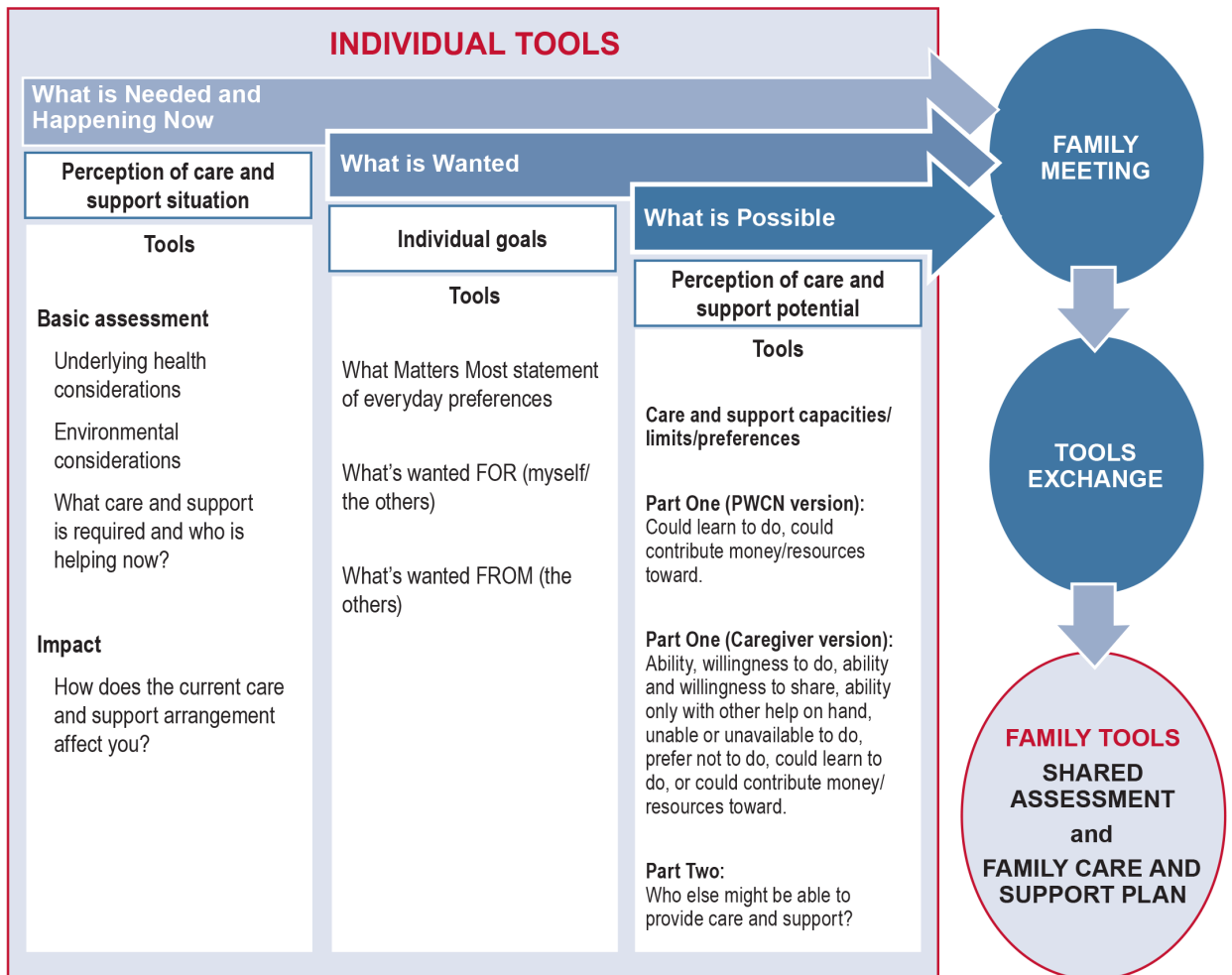
- 1) What are the effects of the intervention on family **communication and decision-making** processes related to care and support? Do family members recognize/reconcile perceptual incongruence? Acknowledge decision interdependence? Engage in explicit decision making? Engage in inclusive decision making?
- 2) What is effect of the intervention on **changes** in PWCN self-care; caregiver involvement; indirect support and resource transfers; and use of formal services or other informal supports?
- 3) What is the impact of changes in the care and support arrangement, including indirect support and resource transfers, on actual and perceived **equity**?
- 4) What is the impact of changes in equity on appraisals of **distress**?
- 5) What is the impact of the intervention process and related changes on perceived **family efficacy** about care and support decision making and planning?
- 6) What is the feasibility of the intervention (Guide content and process) for all family members?

METHODS

This was a mixed methods study. Our quantitative measures included existing scales; modifications of or extrapolations from existing scales; and newly constructed scales or instruments designed for the Guide and for our specific evaluation questions. Some of the instruments served as both communication tools in the family Guide and as data for our analysis. Qualitative methods included structured, semi-structured, and open-ended questions in individual and family interviews.

We present our methods (sampling/recruitment, data gathering, and analysis) for distinct phases and sub-phases of the project: tools and Guide development (individual exploratory interviews, cognitive interviews, expert review panel); Guide implementation with nine families (the intervention); and evaluation.

Figure 2. Guide Process and Tools



TOOLS AND GUIDE DEVELOPMENT

The basic framework for the tools and Guide was established before the study began [Figure 2]. The Guide and process were designed to correct family tendencies toward implicit and exclusionary decision making by requiring explicit and inclusive communication among members. It provides a structure for that communication. The format includes the following steps: 1) Each family member independently completes a set of tools (assessment of the PWCN's care and environmental needs; independent declaration of personal values, goals, and preferences; and communication of individual care and support capacities and limits); and 2) A self-directed family meeting of all participating members is held and conducted according to structured guidelines in the Guide. To begin the meeting, family members exchange their completed tools. The family

conducts a shared assessment of what is needed. A family care plan is constructed. Although affirmation of the status quo is a possible outcome of the family meeting, the purpose of the meeting is to create a space and structure to negotiate changes in the care and support arrangement (PWCN self-care; caregiver care and support; and/or indirect support and resource transfers) using the tools exchanged among members.

We constructed individual and family tools to help family members think and communicate about what is needed, what is wanted, and what is possible in the family's care and support arrangement (who is doing what, where, when, and how). In the tools development phase, in an iterative process, three Scripps researchers (the Principal Investigator, a research associate, and a doctoral student) gathered and reviewed existing related tools for comparison or adaptation; and constructed tools informed by ongoing analysis of individual interviews conducted.

The following tools were constructed:

Individual Tools

Before you begin: What matters most?

What's Needed?

Underlying health considerations

Environmental considerations

What care and support is required and who is helping now?

When are you providing (caregivers)/receiving (PWCNs) care and support?

How does the current care and support arrangement affect you?

What's Wanted?

What's wanted FOR (myself/the others?)

What's wanted FROM (the others?)

What's Possible? Parts One and Two

Part One (PWCN version): Could learn to do, could contribute money/resources toward

Part One (Caregiver version): Ability and willingness to do, ability and willingness to share, ability only with other help on hand , unable or unavailable to do, prefer not to do, could learn to do, or could contribute money/resources toward

Family Tools

Step One: Achieving a Shared Assessment of What's Needed

Shared Assessment: Underlying Health Considerations

Shared Assessment: Environmental Considerations

Shared Assessment: What Help is Required and Who's Helping Now?

Shared Assessment: When is Help Being Provided?

Step Two: Working Toward a Statement of Shared Goals

What's Wanted FOR Each Other?

Shared Goal(s) Statement

What's Wanted FROM Each Other?

Step Three: Arriving at the Best Possible Care and Support Arrangement for Your Family

Our Family Care and Support Plan

Plan for Addressing Underlying Health Considerations

Plan for Addressing Environmental Considerations

Plan for Care or Support Activities

The Follow-up Plan (What's next?)

Plan for Ongoing Communication and Care Coordination

Plan for Ongoing Revision to What's Needed, Wanted, and Possible

Plan for Meeting Again

Plan for Revisiting Unresolved Areas

To develop the actual tools and Guide, we used several methods, in the following order:

Individual developmental interviews

The objective of the individual interviews was to inform the content, language and structure of the tools and Guide. We conducted exploratory interviews with parents/partners with care needs (PWCNs), spousal caregivers, primary filial caregivers, and secondary filial caregivers.

Sampling and recruitment

Recruitment of individual participants for the tools development interviews and of families for the intervention and evaluation was a challenge. Our partnering agencies were not as effective as we had hoped in helping to identify and recruit participants. We had intended to conduct focus groups which proved to be a logistical challenge. We sought referrals from caregiver support professionals at Area Agencies on Aging (AAAs); emails to directors of AAAs; email blasts and flyers to a Parkinson's wellness community in southwest Ohio; word of mouth; and social media (Scripps Gerontology Center Facebook page). These efforts were ultimately effective for both individual interview and family intervention recruitment. Even so, we experienced a two-month delay in the actual start of the intervention phase. This in turn placed some time pressure on that phase.

Our project targets families with the following composition: a parent age 60 or over who has at least two caregivers: a spouse/partner and adult child, or at least two adult children (children include step-children and children-in-law). In terms of care need, the initial criterion for participation was impairment in "at least one PADL," such as bathing, dressing, and/or grooming. Early interview participants told us that the tools and processes we explored with them could have

been useful earlier in their care and support experience, that is, when the person with care needs required less help and the patterns of care and support (who will do what, where, when, and how) were being established. Our decision to loosen the PADL/IADL criteria was based on that input alone, but had the benefit of deepening the prospective pool of participants, both for individual interviews and for the intervention with families. Final eligibility criteria included:

- 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, and transportation).
- 2) The parent who needs help does **not** have a diagnosed dementia
- 3) The parent who needs help is living in the community (that is, not in a nursing home).
- 4) The parent has at least two family members: either a spouse/partner plus 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.)

We conducted 16 individual face-to-face interviews in the tools and Guide development phase of the project (three PWCNs, five spouses, four adult child primary caregivers, one adult child-in-law primary caregiver, and three adult child secondary caregivers). Fourteen of these participants were female (three PWCNs, four spouses, five primary caregivers and two secondary caregivers); two were male (one spouse, and one secondary caregiver). Each individual was compensated \$25.00 for the interview.

Data gathering

Our exploratory developmental face-to-face interviews were semi-structured and allowed room for the researcher's spontaneous questions according to the care-related experiences of the interview participants. Our questions were framed to gain an understanding of the care arrangement, how the arrangement came to be, who was involved in family conversations if any occurred, the level of congruence about wants and needs for self and others involved in the care arrangement, the possibilities for the care and support arrangement, and the ability of the family to have a conversation about the care arrangement. The individual interviews allowed us to probe individual circumstances in depth and we were also able to gather detailed reactions to our ideas and drafts of tools as they developed. Importantly, as a research team, we were engaged in the process of tools and Guide design simultaneously with the developmental interviews. Sometimes we were able to obtain feedback about an existing tool under consideration for adaptation; at other times, we explored rough ideas about original tools under development. We made spontaneous decisions in each interview about the types of tools and ideas most relevant to the particular interview participant and adapted our interview accordingly. Using this process of emergent design, the last several of our developmental interviews were framed by increasingly developed ideas and tools. The feedback was increasingly more specific and prepared us well for the cognitive interview phase of tools and Guide development.

Analysis

Our interviews were audio-recorded and transcribed verbatim. We sought to identify issues and record suggestions to make decisions about tool choices and modifications; to identify gaps, redundancies, appropriate language, and presentation. We analyzed the interviews to identify areas of concern not addressed by our tools or the Guide; to identify language used to describe experiences and characteristics of care; and to identify themes of concern about the process of family communication about care. Additionally, we organized observation notes made on tool drafts by the researcher during the interview. Finally, in those interviews in which we incorporated an opportunity to complete the draft of one or more tools under development, we identified issues of clarity, content, and structure.

Individual cognitive interviews

Following initial tools development, we conducted face-to-face cognitive interviews to revise and refine the components of late-stage drafts of the tools by walking through them with interview participants. The objectives were to revise and refine language; identify gaps, redundancies or contradictions; and adjust the organization of the tools.

Sample and recruitment

We used convenience sampling and recruitment for the cognitive interviews, relying on referrals from the social or professional networks of our colleagues. Our goal was to conduct individual cognitive interviews with two PWCNs, two spousal caregivers; two primary filial caregivers, and two secondary filial caregivers. In the end, we conducted cognitive interviews with one PWCN, one spouse, one primary adult child caregiver, one co-caregiver, and two adult child secondary caregivers ($n = 6$). The PWCN was male (age 98); all others were female. Each individual was compensated \$25.00 for the interview.

Data gathering

We provided tools drafts and asked the participant to complete the tools while we observed. We timed the tools completion while observing and making notes about the process. In the interview, we used a combination of think-out-loud and probing techniques (Beatty & Willis, 2007), but did so after the fact. That is, we allowed participants to complete a tool for timing purposes before walking through their thinking about the tool items and structure. Where time allowed in these interviews, we also sought reactions to the tools that would inform the structure and content of the Guide.

Analysis

Interviews were audio-recorded and researcher-identified relevant sections were transcribed verbatim. Verbatim records were important in identifying issues related to vocabulary and clarity of questions. Text and observation notes from the cognitive interviews were reviewed as a research team as we revised the content, language and structure of tools.

While not an initial part of the design, following our first round of cognitive interviews and tool modifications, we re-interviewed three individuals (the PWCN and the two secondary caregivers) to get feedback on some of the more troublesome or complicated tools. These interviews were unstructured; we shared tool drafts and sought input about optimal language and structure to assure intended responses.

Guide development and construction

A fourth researcher, a Scripps post-doctoral fellow, was brought onto the project to assist with Guide development and with data gathering and analysis of the intervention. The four researchers met regularly to design, write, and revise the Guide. This process was informed by our analysis of individual interviews and by input from our expert review panel, below.

Tools and guide development and construction expert review panel

The tools development phase and the guide development and construction phase overlapped. Toward the end of this period of overlap, the following five experts reviewed and provided comments on drafts of the tools and the Guide from their particular areas of expertise.

- 1) Dennis Cheatham, MFA, BFA Assistant Professor, Communication Design, Department of Art, Miami University, Oxford, Ohio
- 2) Laurie Petrie Roche, MSJ, Vice President Communications, Council on Aging of Southwestern Ohio, Inc., Cincinnati, Ohio
- 3) Heather Nelson, MGS, LSW, Case Manager, Elderly Services Program, Lifespan, Inc. Butler County, Ohio
- 4) Patty Callahan, MSW, LISW, Information and Referral Specialist and Caregiver Advocate, Central Ohio Area Agency on Aging, Columbus, Ohio
- 5) Christine Foley, RN, Director, Home Health, Benjamin Rose Institute on Aging, Cleveland, Ohio

A sixth expert, Carol Whitlatch, PhD, Research Scientist and Assistant Director of Research and Education, Benjamin Rose Institute on Aging, Cleveland, Ohio, who served as a

consultant at multiple points in our project, also provided comments on tools and guide drafts in this phase.

Testing version of tools and Guide for intervention

The final version of the Guide developed for implementation and evaluation is the structure of the Our Family, Our Way experience, with detailed instructions. It includes the individual tools (What's Needed and Happening Now? What's Wanted? What's Possible?) and family tools (a Shared Assessment and a Family Care and Support Plan) generally parallel to the individual tools (See Figure 2). There are two versions of the Guide, one for caregivers and one for PWCNs.

Guidelines explain each of the individual and family tools: their purpose, how to complete them, how to think about them, and how each section or tool is related to the other. In a very structured Family Meeting Guide, guidelines direct the tools exchange process among family members and the process for completing the Shared Assessment and the Family Care and Support Plan, including a follow-up plan. The Guide also includes troubleshooting guidelines, from how to respond to major differences, to where specifically the family can find mediation or counseling in the geographic area⁸. Finally, readiness checkpoints built into the Guide provide the family an opportunity to assess its own risk during the process.

[For access to Guide contents, Individual Tools, Family Tools and Family Resources Booklet, please refer to the contact information at the end of this report.]

Managing the risk of a family-directed process

The family-directed (self-guided) feature of the intervention has important implications for Guide content and process and was a significant target of our feasibility evaluation. A family-directed process is appealing because it can be conducted and adapted according to a family's situation, schedule, and geographical distance; and it does not require professional resources. However, it is not without its risks; as we have established, family care is a sensitive family issue and the explicit and inclusive nature of this intervention presents some challenges. In fact, Ingersoll-Dayton (2003) report that when siblings seek to achieve equity and fail, their levels of distress actually elevate. We acknowledge this “can-of-worms” risk and it was part of our rationale for treating the project as a pilot with limited scope. The guidelines embedded in the Guide are

⁸ We constructed and provided a 35-page Family Resources Booklet as a supplement to the Guide. The booklet contains local, state, and national resources that offer long-term care information, services, and support for families targeted in our study. Categories of resources are: (Ohio) Area Agencies on Aging, Family Care Navigator, Other Service Locators, Care Coordination, Caring for the Caregiver, Communication and Family Dynamics, Counseling, Mental Health and Addiction Services, Driving Assessment Resources, Elder Abuse, Neglect, Fraud, and Exploitation, Family and Elder Mediation Services, Federal Agencies and Programs, Financial Tools, General Information and Helpful Tips, Helpful Technologies, Housing/Relocation, National Organizations, Planning Guides, and Webinars.

critical to addressing these issues. That said, much of their effectiveness depends on family adherence to the instructions.

As a first step in managing risk, the guidelines begin by helping families decide if the Guide is right for them. In making that determination, we believe that there are three kinds of families: 1) those who do not need the Guide (although we believe most families could benefit from improved communication about care and support); 2) those with enough family tension or conflict that they could not (or should not) complete the process without a mediator; and 3) all others. As indicated above, the Guide began with a “Is this Guide right for your family?”

IMPLEMENTATION: THE OUR FAMILY, OUR WAY INTERVENTION

To evaluate the impact and feasibility of the intervention, we recruited qualified families to participate in all its stages.

Sampling and recruitment

The sampling eligibility criteria for families were the same as those used in the developmental interviews. Our goal was to test the Guide with 10 families with at least one PWCN, one primary caregiver, and one secondary caregiver. We over-recruited and ultimately nine families participated in the intervention. A total of 29 families responded to our recruitment efforts. We were unable to reach seven of those families following their attempt to contact us. We screened the remaining 22 families; six did not qualify and two did not follow up after their screening. The remainder (14) were enrolled in the project. Five of those fourteen withdrew before they began, mostly due to death or illness. None of the participating nine families withdrew from the intervention or the study after they had begun. Each family was compensated \$300.00 for their participation following the completion of the Time 2 interviews with all of the family’s participants.

One family was recruited through an individual’s participation in the first round of developmental interviews; the family member expressed strong interest in participating with her family. Our most effective strategy was reaching out to the Parkinson’s Wellness Community in the Cincinnati area, with email blasts and flyers distributed at a symposium. Three of the nine families were recruited through this community. Other families were recruited through the same approaches identified for our individual participant recruitment.

Table 1 provides a summary of demographic data for all intervention participants.

Table 1. Intervention Participant Demographic Data

Participating Family Members	Relationship to PWCN	Living Arrangement & Distance	Gender	Age Range	Marital Status	Education	Employment	Household Income (\$)	Self-Rated Health
PWCNs N = 9		7 House 1 Independent Living 1 Assisted Living	7 Female 2 Male	67-94	5 Married 3 Widowed 1 Divorced	2 High School 3 Some College 2 College Grad 2 Post Grad	0 Full-time 2 Part-time 7 Not Employed	3 <25,000 2 25-50,000 3 50-100,000 1 100,000+	0 Excel 6 Good 1 Fair 1 Poor 1 No Answer
1 Caregivers N = 8	4 Spouse 3 Daughter 1 Son	7 Co-reside 1 3 min	4 Female 4 Male	47-84	5 Married 1 Widowed 0 Divorced 2 Never Married	1 High School 4 Some College 2 College Grad 1 Post Grad	1 Full-time 0 Part-time 7 Not Employed	3 <25,000 1 25-50,000 4 50-100,000 0 100,000+	1 Excel 6 Good 1 Fair 0 Poor 0 No Answer
Co-Caregivers N = 4 (all one family)	0 Spouse 3 Daughter 1 Son	1 <10 min 2 10-12 min 1 4.5 hr	3 Female 1 Male	52-62	2 Married 0 Widowed 2 Divorced 0 Never Married	1 High School 0 Some College 2 College Grad 1 Post Grad	4 Full-time 0 Part-time 0 Not Employed	0 <25,000 0 25-50,000 1 50-100,000 3 100,000+	2 Excel 1 Good 1 Fair 0 Poor 0 No Answer
2 Caregivers N = 15	0 Spouse 8 Daughter 4 Son 2 Daughter-in-Law 1 Son-in-Law	1 Co-reside 6 1-10 min 5 11-20 min 2 21-30 min 1 30+ min	10 Female 5 Male	34-74	11 Married 0 Widowed 2 Divorced 1 Single/Never Married 1 Partnered	3 High School 4 Some College 2 College Grad 6 Post Grad	9 Full-time 3 Part-time 1 Full & Part 2 Not Employed	1 <25,000 1 25-50,000 7 50-100,000 6 100,000+	7 Excel 4 Good 4 Fair 0 Poor 0 No Answer

It is worth noting the normative roles and patterns of care arrangements reflected in our sample, i.e., family hierarchy, proximity, gender, and competing roles. As we established earlier, primary caregivers are more likely to be spouses, female, more likely to reside with the person with care needs, and less likely to be employed. Three of the four spousal (primary) caregivers in our sample are male, and one is female. The three of the remaining four primary caregivers are female, and one is male. Seven of the eight primary caregivers reside with the person with care needs. Seven of the eight primary caregivers are not employed, while one is employed full-time. Only two of the secondary caregivers are not employed. One family has four co-caregivers (three female and one male). All work full-time and none reside with the person with care needs.

Who was included **within** each family?

One of the most complicated decisions we made about participation was how much to require of families in their decisions about which family members participated in the project and how much to allow to emerge naturally. There were implicit tradeoffs either way. If we required family members to include all eligible members (PWCN, spouse of PWCN, all children, step-children and children-in-law of PWCN), we would learn how a fully inclusive implementation worked (or did not work). On the other hand, if we allowed families to make their own decisions about who would be involved in the project, we would learn how families naturally regard the purpose of the process and how they approach engaging (or not) family members in such an experience. Consistent with the name of the project (Our Family, Our Way) we opted for the latter approach and allowed families to determine participation. (It bears noting that, had we required fully inclusive participation, we believe that the inherent recruitment challenge would have been nearly insurmountable.) We speak more to this tension between the study protocol and the Guide protocol in our limitations section. In the end, no families included all eligible members in the process. Family members most likely to be excluded were children living at a distance, children-in-law, and step-children.

Data gathering

After the completion of all participating family members' Time 1 interviews (below), the Our Family, Our Way Guides were provided to individual family members in three-ring binders. The binders included removable wire-bound individual tools at the appropriate point in the Guide. (Also provided were a pen, a few blank sheets of ruled three-ring paper and a pad of post-it notes.) An additional, "recorder version" of the Shared Assessment and Family Care and Support Plan was provided for each family.

Each of the four project researchers was assigned a participating family or families. The lead researcher for each family did all of the logistics (communications, Guide deliveries and pick-up, where applicable) and all data gathering (Time 1, 2, and 3 interviews; and family interviews

where applicable) with that family. This strategy allowed the researcher to construct a coherent story about the family's experience; it also provided step-by-step continuity for the families.

Multiple sources of data were included in the evaluation of the intervention:

- 1) Individual telephone or in-person interviews, including structured (a set of scales), semi-structured, and open-ended questions and probes. We conducted individual telephone or in-person interviews with each of the participating family members at Time 1 (T1), before the individuals received their individual tools and the Guide; and at Time 2 (T2), after their family meeting. We conducted a Time 3 (T3) short follow-up interview up to eight weeks after the Time 2 interview with 24 of the 36 participants.
- 2) The completed individual and family tools from the Guides.
- 3) Optional in-person family interviews after the family meetings. Three families participated in a family interview, with some combination of family members present.
- 4) Extraneous notes made by participants on their tools or Guide, Post-it notes, margin notes.
- 5) Other communications (between researchers and participants) related to the logistics of participation also served as data that, though not systematically analyzed, served to inform our findings about process.

These data sources and measures are organized by research question in Table 2 below.

Table 2. Research Questions, Data Sources, and Measures

Research Question	Data Sources and Measures
1. What are the effects of the intervention on family communication and decision-making processes related to care and support? Do family members recognize/reconcile perceptual incongruence? Acknowledge decision interdependence? Engage in explicit decision making? Engage in inclusive decision making?	Completed individual Guide tools (side-by-side congruence analysis) Completed Shared Assessment (family tool) Eye-to-eye scale @ T1/T2 Explicitness scale @T1/T2 Inclusiveness scale @T1/T2 Communication improvement scale @ T2 Semi-structured individual interview @ T1/T2/T3 Family interview
2. What is effect of the intervention on changes in PWCN self-care; caregiver involvement; indirect support and resource transfers; and use of formal services or other informal supports?	Completed Family Care and Support Plan (family tool) Semi-structured individual interview @ T1/T2/T3 Family interview
3. What is the impact of changes in the care and support arrangement, including indirect support and resource transfers, on actual and perceived equity ?	Completed Family Care and Support Plan (family tool) Perceived fairness scale @ T1/T2 Semi-structured individual interview @ T1/T2/T3 Family interview
4. What is the impact of changes in equity on appraisals of distress ?	Distress scale @ T1/T2 Semi-structured individual interview @ T1/T2
5. What is the impact of the intervention process and related changes on perceived family efficacy about care and support decision making and planning?	Family efficacy scale @ T1/T2 Semi-structured individual interview @ T1/T2
6. What is the feasibility of the intervention (Guide content and process) for all family members?	Acceptability scales @ T2 Semi-structured individual interview @ T2/T3 Family interview

The implementation timeline is provided in Figure 3 in the form of the timeline document provided to family participants in the intervention and evaluation.

Figure 3. Implementation Timeline: Our Family, Our Way: A Family Communication and Care Coordination Guide for Aging Parents and their Adult Children

Step	Timeline	Task	Description
Step 1	Before starting	30-minute phone interview	The researcher will ask each participating family member (in separate phone calls) a series of structured questions about your family's care arrangement.
		Guides delivered to family members	The researcher will mail a Guide to each participating family member.
Step 2	Within two weeks of Guide delivery	Complete written tools	Each participating family member will complete the set of short written tools that help you think and talk about what is needed, wanted, and possible in the care arrangement at home.
Step 3	Family meeting	Hold a family meeting	Using written guidelines, the family will share completed tools and talk about what's needed, wanted and possible as you create a family care and support plan. Long distance family members can attend by phone. The researcher will not be present.
Step 4	Within two weeks after family meeting	60 minute phone interview	The researcher will conduct a second phone interview with each participating family member.
		OPTIONAL: Family interview	The researcher will conduct an optional family interview, in-home, with all participating family members who are able to be there . The interview will last approximately one hour.
Step 5	4-6 weeks after family meeting	Brief 15 minute phone interview	The researcher will conduct a final brief phone interview with each participating family member.

Time 1 and 2 evaluation tools and interviews

Because we were exploring so many domains of communication and the care experience, in the interest of keeping the length of our interviews manageable, the evaluation tools were limited to as few items as possible. Time 1 and Time 2 interviews included scales adapted or constructed to measure perceptual congruence; explicitness of family planning and decision making; inclusiveness of family planning and decision making; perception of overall fairness (equity) (adapted from Grote & Clark, 2001); perception of over- or under-benefitting from inequity; distress appraisals related to fairness; and perception of family efficacy, using guidelines and some language from Bandura (2006). Most of the scales were followed with brief probes, generally, “Can you say a bit more about that?” In addition, multiple semi-structured and open-ended questions and probes were included, for example “Can you give me an example of the kinds of conversations that don’t include all of you?”⁹

All scales were repeated verbatim at Time 2 interviews; several additional questions were added to Time 2 interviews to explore the Our Family, Our Way intervention experience. These questions were designed to identify: the individual’s process of completing the individual tools; the individual’s and family’s process of conducting the family meeting, including the tools exchange, the shared assessment, the goals statement, and the family care and support plan; the individual’s or family’s use of resources in the Guide; changes in the care and support arrangement; effects on communication; the feasibility of the Guide and process; any final comments or questions from the participant.

At Time 2, in addition to the scales and standardized questions, each researcher added questions specific to her assigned family(ies) based on a review of their completed materials after the family meeting and before the Time 2 interview. For example, a researcher noted that two different colors of ink were used in her individual tools; she asked if those different colors reflected different times of data entry, for example before, during or after the family meeting. As another example, in the case of missing items or incomplete individual or family tools, the researcher explored the reasons for those. In some cases, participants had made notes on the ruled paper and post-it notes in the Guide; the researcher clarified the meaning of those notes in the Time 2 interview.

Finally, as we conducted individual Time 2 interviews one by one, we incorporated insights or questions gained from each interview into the open-ended components of subsequent interviews.

⁹We conducted cognitive interviews for the Time 1 evaluation tools with three individuals, two secondary caregivers, and one PWCN.

The Time 1 and Time 2 evaluation tools are found in Appendix B.

Time 3 interviews

Time 3 interviews were brief follow-up interviews with individuals who were available to participate within our time frame. Twenty-four individuals completed the Time 3 interview. The time between the first Time 1 interview and the last Time 3 interview (or the optional family interview, whichever came later) ranged from 12 weeks to 14 weeks. We prepared for the Time 3 interviews by reviewing the family's tools and Time 2 interviews to identify changes in the care and support arrangement attributed to the Our Family, Our Way process and the degree to which family communication and the arrangement had been reported as improved or worsened. We asked for updates on those changes and then asked two basic questions: "Since I last spoke with you, have you had any new insights about your participation or your experience in the Our Family, Our Way process?" And: "Have you or your family had any conversations or made any decisions or changes as a result of your family meeting or because of your participation in Our Family, Our Way?" We sought elaboration when responses were inconsistent with our review of the materials and the Time 2 interviews, and we allowed for any final comments or questions from the participant. We incorporate findings from the Time 3 interviews primarily into our discussion about sustainability, later in the report.

Family interviews

Three optional family interviews were conducted a few weeks after the family meeting, after the Time 2 interviews. In one family interview, all participating members were present; in the other two interviews, only two family members were present, and in the third interview. Although we were prepared with a family interview guide (See Appendix B), the family interviews were quite unstructured. Families told the stories of their family meetings and provided updates and impressions. These interviews enhanced the researcher's construction of the family experience as the unit of analysis. They served as an opportunity to observe family dynamics, to clarify contradictory information and to fill gaps in understanding. Obviously the issue of network confidentiality affected the researcher's decisions about questions, prompts, and probes. Information and data gathered from individuals were excluded from the family interview process.

Intervention evaluation and analysis

The family as unit of analysis: Data gathering, analysis, and reporting

Only two of our measures at Time 1 and Time 2 were individual measures: perceived equity and distress appraisals. The remaining measures, although gathered from individuals, were collected and analyzed as family measures. Our Family, Our Way is a family intervention and our

aim was to explore the impact of the intervention on the *family* experience and dynamic. We investigated the family processes of perceptual congruence; communication; decision making; the distribution of care in the family's care and support arrangement; and collectively perceived family efficacy. This calls for treating the family as the unit of analysis, an uncommon and complex method, made more complex by using *individual* family members as our data sources (Warin, Solomon, & Lewis, 2007). This requires a co-construction of a shared family reality by integrating the perspectives of individual family members (Van Parys, Provoost, De Sutter, Pennings, & Buysse, 2017). (Only two sources of actual *family* data were used: the optional family interviews with three families and data from the common recorder version of the family meeting tools.)

Methodological approaches to family as unit of analysis are limited and pose their difficulties. We used "multi-family member interview studies" (MFMIS), an approach that does not seek a 'truth' in the integration of multiple perspectives, but instead a "threading" of individual accounts into a more comprehensive, systemic account. (Reczek, 2014) The development of a comprehensive account in MFMIS borrows from the dyadic interview conceptualization by analyzing the individual interviews and then searching for overlaps and contrasts between the individual accounts (Eiskovits & Koren, 2010).

While the constructed account may be somewhat generalized, the family itself is not a homogenous, static unit, but a group of individuals coexisting in complex and fluid relationships (Scott, 1997). In our evaluation, we recognize the need for a comprehensive story through MFMIS analysis, while addressing the heterogeneous nuances that arise in individual accounts.

Throughout our analysis, we asked, "What meaning can we create from individual experiences when we regard the family as unit of analysis?" and "When can we describe an experience as a family experience and an outcome as a family outcome?" We used a set of strategies to organize and analyze our data with a focus on the family. Each of the four project researchers was assigned a participating family or families. The lead researcher for each family did all of the logistics (communications, Guide deliveries, and pick-up) and all data gathering (Time 1, 2, and 3 interviews; and family interviews where applicable) with that family. This strategy allowed the researcher to construct a coherent story about the family's experience; it also provided step-by-step continuity for the families. In organizing and analyzing data, first, we constructed a demographic data table for each family. Next, we organized all other data (scales/ratings and verbatim interview text) on a spreadsheet by family. Then, we organized ratings in tables, (e.g., inclusiveness of decision making) for each family, at Time 1 and at Time 2. All individual interviews were audio-recorded and qualitative, open-ended responses were transcribed verbatim. We identified themes and salient text in the qualitative data. We attached relevant, elucidating text from the interview probes or open-ended questions to the ratings tables. We connected those tables and their corresponding texts to each other, by family. We did a quantitative analysis to identify frequencies and patterns, including changes and directions of changes from Time 1 to Time 2, within each table and across tables, still by family. Using these data and our analyses, we constructed a long narrative for each family, organized by our research questions. We

then summarized major features of each family's experience in a short family summary (Appendix A). In our long narratives and short family summaries, we worked to account for contradictions and outliers in individual experiences as well as for changing events and circumstances over the family's course of the project.

To determine whether particular family characteristics corresponded with other characteristics and/or appeared to have an effect on the level and nature of intervention outcome, we rated each family as high, middle, or low on the following characteristics: level of care (PADL/IADL impairment and/or self-imposed care demands, from the Guide individual tools); level of strain (self-rated physical strain, emotional stress, social loss, and financial burden, from the Guide individual tools); perceptual congruence (level of agreement in the Guide individual tools), "going-in" family efficacy (collective rating of family efficacy by family, in Time 1 interviews), and intervention fidelity (using a set of indicators about adherence to the guidelines.). We also considered family size and the composition of caregiver roles, for example, spousal vs. filial primary caregivers. The high/middle/low ratings for each family were negotiated as a research team, establishing demarcations and comparing each family to the others, by characteristic.

Finally, in a purely exploratory approach, we were constantly attentive to unique individual or family characteristics or experiences that might elucidate or explain a family's particular outcomes. In all, we strived to construct accounts and characterizations that reflected the overall family experience and outcomes while accommodating the unique experiences of individuals. Over the course of the project, we held weekly meetings during which each of the four researchers provided family updates with a focus on noteworthy issues or insights. This process clearly informed our analysis.

The constraint of network confidentiality

Studying the family through individual perspectives clearly poses analytical challenges, but the reporting challenges are arguably even greater. Individuals, not families, consented to participation in our study and the guarantee of confidentiality was made to individuals. Our consent form states, "The project is confidential. Neither your name nor any identifying information will be used in the formal or informal reporting of this study. That said, because only 10 families are participating, you might be able to recognize yourself and your family in reports about the project that include informative experiences related to your unique family configuration and/or circumstances. Being aware of this should help you decide whether to answer specific questions or share specific information." In the Time 1 and Time 2 individual interviews, we began the interviews by saying, "First, it's important that you know that anything you share with me during our telephone [or face-to-face] interviews is confidential and will not be shared with your family members." The constraint of "network" confidentiality has a significant impact on our ability to

include some of our data (both quantitative and qualitative) in our written reports or other public communications. Van Parys et al., (2017) summarize this challenge well:

“[R]ecognizability of participants increases when their perspectives are linked to their family members’ perspectives. In order to assure ‘network confidentiality,’ when doing research with families, one needs to balance anonymizing details and maintaining authenticity (Harden, Brackett-Milburn, Hill, & MacLean, 2010, p. 447). Thus, for ethical reasons, the dissemination of research results should be at a general level, rather than at a dyadic or systemic level (Ummel & Achille, 2016). This means that the strength of this analysis (being able to offer an in-depth understanding of shared family realities) at the same time encompasses the method's main limitation: we simply cannot exemplify all new insights at a systemic level when seriously considering our responsibility to protect (network) confidentiality” (p. 399).

In reporting the experiences of the participating families, we have worked to protect individual family members while striving to capture and relate the complexity and authenticity of the family dynamic and experience. It was necessary to exclude some information and experiences shared with us by individuals about themselves or about each other. Information was often shared by one family member about another family member who did not disclose that information him or herself. Examples include legal, financial or health events, or circumstances. We also are not able to report scale ratings, including averages, by family, because of inferences that can be made about others’ ratings in relation to one’s own. Rich responses to interview probes about family communication and the care arrangement were left unused when they could not be de-identified to a satisfactory degree.

In summary, we have an understanding of each family’s dynamics and circumstances that is deeper than what we are able to communicate in our report, for reasons of confidentiality. Therefore, we have withheld information that nevertheless has influenced our perspective on many aspects of many areas of our findings. With these constraints, we report some findings at the individual level and some at the family level, but we do not link individual data to particular families. That said, in our conclusion, we do identify characteristics of families that had better and worse outcomes than others. In this way, we attempt to provide an understanding of the range of Our Family, Our Way experiences, their underlying features, and their implications for further study and design.

FINDINGS

In reporting our findings we examine outcomes to determine the value and risks of the intervention. We then assess the feasibility of the Guide and process with a focus on fidelity and acceptability. Finally, we consider the implications of our findings for modifications to the Guide and process and for proposed next steps for implementation and evaluation. We conclude that the Our Family, Our Way Guide has value; that the Guide is feasible; and that the Guide has a promising future through multiple potential iterations, formats, and applications.

TWO FINDINGS AS CONTEXT

We begin with two major findings that provide important context for some of our analysis and other findings. *First*, there was a wide range of adherence to the Our Family, Our Way guidelines. As a reminder, the Guide is divided into basic two components: the Shared Assessment and the Family Care and Support Plan (to be based on the Shared Assessment). The Shared Assessment comprises three tools and processes: the individual tools (pre-family meeting) including what's needed, what's happening now, what's wanted, and what's possible; the individual tools exchange at the family meeting; and a negotiated assessment at the family meeting. Three families completed the entire process: the Shared Assessment *and* the Family Care and Support Plan. Five families completed the Shared Assessment (although one of these families did not record their negotiated assessment), and although three of these families made changes to their care and support arrangement, they did not complete the formal Family Care and Support Plan. Finally, one family (the "Chase" family¹⁰) completed the Shared Assessment in one meeting, but abruptly ended a second meeting in the early steps of discussing the Family Care and Support Plan. (*All families remained in the study through Time 3.*)

Because all nine families completed the Shared Assessment and related processes, our strongest findings are related to Research Questions 1 and 2. To the degree we are able, we analyze Research Questions 3 through 5. We conclude that the Shared Assessment section of the OFOW Guide clearly has value and is feasible and we speak more to these intervention fidelity issues later in the report.

Second, there is strong evidence that a heightened individual consciousness of the family's issues of incongruence, implicitness, exclusiveness, and inequities was brought about by the process of the tools exchange and other parts of the family meeting. That consciousness was intended by the intervention and regarded as instrumental for change. While it often *was* the impetus for changes in the care and support arrangement and in actual equity, it also led to complicated Time 2 ratings in our quantitative measures. We had hypothesized improved perceptual congruence, explicitness, and inclusiveness among family members, from Time 1 to Time 2. We also hypothesized improvement in equity ratings, distress appraisals and family efficacy ratings based on improved communication and change in or affirmation of the care and support arrangement. Instead, in many cases, what our Time 2 measures apparently captured were individuals' idiosyncratic, complex—and sometimes negative—reactions to newly confronted awareness of family dynamics and concerns. For example, in grading family efficacy at Time 2, one secondary caregiver said, "Well, I would have said A, but I think after the [family meeting] maybe I would give us more like a B. We -- we -- we seem to not be on the same page..." In other cases, ratings held constant, and it is possible that they may have done so because a heightened

¹⁰ The "Chase" family had a complicated experience with the project and is an outlier in many areas of analysis. We identify them by name (their pseudonym) when that status is relevant. Their family summary is found in Appendix A.

consciousness about a problem area was offset by some perceived progress during the family meeting in that domain. Finally, in yet other cases, improved ratings may have reflected a perception of net progress in that domain. For example, one secondary caregiver who changed her “inclusiveness” rating from Mostly false at Time 1 to Somewhat true at Time 2, said “[There were] some things that [PWCN] had problems with that I didn't know she had problems with...and I was like, 'Wow. When were you all gonna tell me?' So it kind of got into where I was getting upset because they were saying things that were going on with her and I talk to them all the time and these are things you're not telling me.... So doing this helped, I learned a whole lot of stuff.” As an illustration of this phenomenon, the following table (Figure 4) presents hypothetical individual Time 2 reactions to the intervention process, using the inclusiveness scale as an example.

Figure 4. The Effect of Heightened Consciousness at Time 2: Hypothetical Individual Reactions

Time 1	Time 2
<p>Inclusiveness question:</p> <p>“All of us are included in important conversations about who does what, when, where, and how in the care and support arrangement.”</p> <p>Is that: Mostly true, Somewhat true, Mostly false, or Not sure?</p> <p>At T1: ALL family members responded: Somewhat true</p>	<p>Family member 1: “I found out that I’m being left out of important decisions. It made me angry.” T2 Response: Mostly false</p> <p>Family member 2: “At the family meeting, I found out that I had been left out of some important discussions, but I also felt especially included in the decisions we made in the meeting.” T2 Response: (Still) Somewhat true</p> <p>Family member 3: “At the family meeting, we all got together and talked about important decisions. It felt good.” T2 Response: Mostly true</p> <p>Family member 4: “My sister felt angry when she found out that she had been left out of some decisions. I hadn’t thought to include her; it was a mistake.” T2 Response: Mostly false</p>

Importantly, a heightened consciousness does not appear to be the only factor in complicating our analysis of T1/T2 data. Sometimes, when ratings *did* change, the changes were not always reflected in the interview probes. For example, one participant, a primary caregiver, reported that a statement about the explicitness of family care decisions was “mostly true” at Time 1 and “somewhat true” at Time 2. Yet her explanations for her ratings were nearly identical at Time 1 (“It just falls into place. We do what's needed.”) and at Time 2 (“We don't really discuss it much. We just kinda do what needs done.”).

Essentially, we believe that we over-estimated the power of one family meeting to achieve a net perceived improvement in our targeted dynamics (fairness, inclusiveness, etc.) that would be reflected in significant ratings changes. At the same time, we underestimated the often mixed effect that the tools exchange and the meeting would have on individual participants' Time 2 appraisals of their family's communication about care and about the care arrangement itself. Those effects were best captured in the qualitative portions of our Time 2 interviews. We conclude that our Time 2 quantitative measures should be interpreted cautiously. We provide summaries of the quantitative T1/T2 findings, but for a more meaningful analysis we focus and rely on the many examples of the effects (positive and negative) of the tools exchange, the family meeting, and consequent raised consciousness reported in the semi-structured or open-ended components of our Time 2 interviews. Overall, these many examples—even without logically related ratings—do demonstrate the wide-ranging positive impact of heightened consciousness, brought about by direct communication in these families.

OUTCOMES

The intervention (the Guide and process) itself was designed to *directly* achieve the proximal outcomes of improved family communication processes and changes in (or consensus affirmation of) the care arrangement. These outcomes are examined in Research Questions 1 and 2 (See Figure 1). The intervention was designed to *indirectly* produce—through the achievement of the proximal outcomes—the intermediate outcome of a more equitable actual and perceived care and support arrangement (Research Question 3) and the distal outcomes of reduced individual distress and improved perceived family efficacy (Research Questions 4 and 5, respectively).

The intervention very clearly achieved the first proximal outcome, improved family communication, for all but one of the families. The intervention also achieved the second proximal outcome, changes in (or consensus affirmation of) the care and support arrangement for eight families. In terms of intermediate outcomes, changes in the care and support arrangement improved the actual equity of the arrangement in five families. There was slight improvement in perceived family efficacy in five families, significant improvement in one family, slight decrease in two families, and significant decrease in one family. These are all measures of family processes and outcomes. In analyzing the individual outcomes of perceived equity and equity-related distress, individuals in families responded in unique ways to the experience. We discuss the complexity of individual reactions throughout our findings.

Effects on communication and decision-making processes

RESEARCH QUESTION 1: What are the effects of the intervention on family **communication and decision-making processes** related to care and support?

In looking at communication and decision making, we focused on the following underlying characteristics and particular dynamics: the level of congruence about what is needed, wanted and happening now; the recognition (or not) of areas of incongruence; recognition (or not) of decision interdependence; reconciliation of areas of incongruence; explicitness of decision making; and inclusiveness of decision making. We examined each of these processes or characteristics separately, both quantitatively and qualitatively at Time 1 and Time 2.

The following two sets of quotes encompass many of the family communication processes targeted in our project. A person with care needs and her primary caregiver (her son) talk in separate interviews about the care and support arrangement at Time 1 and Time 2.

Time 1 Pre-intervention:

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.*

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.*

Time 2 Post-intervention:

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.*

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.*

Perceptual incongruence in family communication about care

As presented in our literature review, family communication and decision making about who does what, where, when, how, and even why in the care and support arrangement can be significantly impeded by perceptual incongruence about *what is needed, what is wanted, and what is possible*. This issue has been well-studied and argued in the literature for three decades. Our findings reinforce the significance of this issue, and they also support the viability of the Our Family, Our Way Shared Assessment as a strategy for recognizing and reconciling perceptual incongruence.

Perceptual incongruence about what is needed

We first describe the level of perceptual incongruence within our participating families “going in,” that is, pre-family meeting. We measured perceptual congruence about what was needed and what was happening in the care arrangement by using the individual tools completed by participants in each of these areas. In terms of what is needed, the tools require the participants to: report the degree to which underlying health conditions limit the PWCN’s ability to carry out daily living and self-care activities; identify problem areas in the PWCN’s physical environment; and indicate what help and support is required by the PWCN, and to what degree.

Perceptions about underlying health conditions

Regarding the limitations caused by underlying health conditions, family members indicated, by checking boxes in their individual tools, whether or to what degree each in a list of health conditions (e.g., hearing, balance, bladder or bowel control, depression or anxiety) limited the PWCN’s ability to carry out daily living and self-care activities. Degrees included: no limitation, some limitation, or major limitation (with an option to indicate “I am not sure”). Using this tool, we identified three levels of congruence:

Full congruence: All family members checked the same box (either no limitation, some limitation, or major limitation).

Degree-of-limitation incongruence: All family members agreed there was a limitation but some checked “some” limitation and others checked “major” limitation.

Limitation-or-not incongruence: At least one family member indicated “no limitation” while at least one indicated “some” or “major” limitation.

For example, in one family, there was limitation-or-not incongruence on 6 of the 14 items; degree-of-limitation incongruence on 4 of the 14 items; and full congruence on 4 of the 14 items. We used these (and the other congruence calculations and descriptions that follow) to rate families

as high, middle, and low-congruence families. **We rated eight families, including this family who was fairly typical, as middle-congruence families. There were no high-congruence families and there was one low-congruence family.**

Perceptions about environmental considerations

Regarding environmental considerations, family members indicated, by checking boxes and making notes in their individual tools, their perceptions about whether an environmental condition (e.g., safe stairways) was in place or not. Options, were: Not applicable (for example, there are no stairs); yes, no, or not sure.

In general, there was greater congruence in the area of environmental considerations than in any other tool. Although there is some unsurprising evidence that the PWCN and primary caregiver were more aware of environmental issues than were secondary caregivers, this tool was less useful in identifying incongruence than it was in identifying commonly perceived areas for attention and action. For example, in one family, all members had noted safety issues in the home related to rugs and flooring; this became part of the changes in their care and support arrangement. Because there was minimal incongruence, we did not conduct “counts” of areas of incongruence in this tool.

Perceptions about what help is required

Regarding what help is needed, family members indicated, by checking boxes, the PWCN’s ability to carry out daily living and self-care activities. Individuals indicated whether and to what degree each in a list of PADLs (e.g., bathing, dressing, or transferring) and IPADLs (e.g., transportation and laundry) created a need for personal care or support. Also included in this tool were pet care, socialization contact, and emotional support. Options were: requires no help, requires some help, and requires much help, with an option to indicate not applicable (e.g., there are no pets) or “I’m not sure.”¹¹ Using this tool, we identified three levels of congruence:

Full congruence: All family members checked the same box.

Degree-of-limitation incongruence: All family members agreed that help was required but some checked “requires some help” and others checked “requires much help.”

Limitation-or-not incongruence: At least one family member indicated “no limitation” while at least one indicated “some” or “major” limitation.

For example, in the same family as above, there was need-or-not incongruence on four of nine PADLs; degree-of-need incongruence on two of nine PADLs; and full congruence on three of the nine PADLs. There was much better congruence on what help was required for IPADLs.

¹¹ In this report we are using language from the caregiver version of the individual tools. The language in the PWCN individual tools and in the caregiver tools is different for parallel items. For example, the caregiver version “requires much help” becomes “I require much help” in the PWCN version.

There was no need-or-not incongruence of the 13 applicable¹² IPADLs; degree-of-need incongruence on 1 of 13 IPADLs; and full congruence (“needs much help”) on 12. Finally, there was need-or-not incongruence on one of two social and emotional care activities; and full congruence on the other social and emotional care activity.

Perceptions about what is happening (who is helping) now

In terms of what is happening and who is helping now, the tools require the participants to indicate, by checking boxes and filling in a calendar, what individuals are providing specific care or support. Consistent with earlier research (Matthews, 1987; Pillemer & Suito, 2006; Suito & Pillemer, 2007), there was perceptual incongruence within families about who is actually providing which care and support tasks. Interestingly, but perhaps not surprisingly, primary caregivers tended to list themselves without listing secondary caregivers (who *had* listed themselves) in many tasks. This area of incongruence was more complex and difficult to quantify than the other areas but its importance is reflected in Time 2 interview texts that reflect surprise or appreciation about the efforts of the primary caregiver. For example, one secondary caregiver said, “There were times I was surprised how much more [primary caregiver] is doing than I had any idea.” And, in another family, one primary caregiver said, “I was surprised [secondary caregiver] recognized I carried the load. Didn't think he did.”

Congruence about what is wanted

In terms of what is wanted, the individual tools invite individuals to record what matters most to them in their daily lives; to indicate what hopes they have for themselves and each other when it comes to the care and support arrangement; and to identify “what would really help” from others. There was inconsistent interpretation of the questions among participants in the “what is wanted” tools; this section of the Guide clearly needs revision. Because of this, we did not attempt to measure family congruence about what is wanted in any quantitative way, but did look for glaring incongruence or general congruence or common ground among family members.

Primary: [PWCN] won't let me do some of the things she needs. It's hard because she wants to do as much as possible [but] she doesn't really give me an option at times. So it's kinda like I am caught between a rock and a hard place.

Primary: Sometimes [PWCN] doesn't even want me to say anything. So when I do, it's because I made the choice to make them aware and keep them in the loop [even] when she says otherwise.

¹² There were not pets in this household, so 1 of the 14 potential IADLs was not applicable.

Secondary: *Just because [PWCN] not doing it doesn't mean that he can't be involved kind of thing.*

PWCN: *I think some of the pages that dealt with how the caregiver looked at things is important to keep in mind and for me because I don't want it to be everything revolves around me and my illness and I just don't want that. And so I've got to be constantly aware of what their needs are and so I think that can help out a lot. Look again at what they've written and what their desires are.*

Congruence about what is possible

In terms of what is possible, the individual tools require the participants to indicate their ability, willingness, availability, and preferences for each care and support task. It also invites participants to indicate whether they would be willing to learn to do a task or could contribute or other resources toward meeting that need. In terms of what is possible, we considered the degree to which individual sharing of what is possible was congruent with other's expectations of them as expressed in the "what is wanted" tools, particularly the tool that asks the family member to indicate "what would really help" from other family members, specifically or generally. We identified discrepancies in these tools and also looked for references to these issues in the interview responses. Examples of perceptions about what is possible include: Secondary, "I wish my brother would just make himself more available." and Co-caregiver, "I think we all do what we can in our own ways...I feel everyone's doing the best they can." These notes and observations were included in the high/middle/low congruence rating of each family.

A second part of the "what is possible" tool invites individuals to identify extended family or friends or community services who might be able to provide some of the care and support ("Who else might be able to provide care and support?") and what they might do. Again, we did not measure congruence quantitatively in this section, but looked for remarkable inconsistencies in the tools or interviews. For example, in one family, some members indicated that the grandchildren of the PWCN could perform some of the care tasks, but the parent of those grandchildren did not indicate that possibility.

Our observations about perceptual congruence in each family about what is possible were the final factors included in the high/middle/low congruence rating of the family. As we indicated above, in the final analysis, none of the nine families was rated high congruence; one was rated low; and the remaining eight—similar overall—were rated middle congruence. Perceptual incongruence about what is needed, wanted, happening now, and possible was clearly evident among all families. This was a core feature of the Our Family, Our Way experience as the families recognized and worked to reconcile their areas of incongruence in the family meeting.

Recognizing and reconciling perceptual incongruence: The role of the individual tools and the tools exchange

The tools exchange was designed to help families identify and confront perceptual incongruence as an essential process for honest and effective communication going forward. It was designed to give each family member's perception equal time and weight, giving voice to family members who may have gone unheard or less heard in earlier family communications. The individual tools, completed before the family meeting, required the family members to own and record their individual perceptions. By sharing those perceptions in the tools exchange in the beginning of the family meeting, areas of incongruence are revealed and recognized. According to the participants, the process of recognizing—and reconciling—areas of incongruence was among the most valued parts of the Our Family, Our Way experience. As one caregiver said, "I think that you have to have a starting point...because everybody does have different ideas and awareness. And I think it helps just to bring that into focus and choose what you're going to do with it." The tools exchange was described by participants as "eye-opening," "helpful," "thought-provoking," "productive," and "rewarding," but also "heartbreaking," "sad," and "emotional." There was overwhelming qualitative evidence of the impact of the tools exchange and related family discussion on the recognition of perceptual incongruence.

Primary: I found that [Secondary] got more insight into our daily lives than she had before and she was appreciative of that.

Secondary: The one part where, the assessment, we each had an individual assessment, I thought that was helpful because you got to hear from what each individual person would think or what they would want to happen.

Secondary: Well, I think the most helpful thing was to have [Primary] speak up a little bit and us talk about what is needed on his end for his happiness in the house and then for us to kind of hear my mom's [perspective]. And so what can we do about that also? So yeah, I mean it just brought out some things that I wasn't aware of.

Secondary: I appreciated having the chance to read for myself and to myself what each of my parents had written... [M]y dad was very honest. My mother was honest...it was funny...she was honest from her perspective, but once we had to start having the discussion, she started realizing she was kind of making things a little better than they are [laughter] in some ways. That was interesting to read their stuff and for me to realize, 'Oh there's some things that are going on that I didn't realize were going on'...[I]t was just interesting to know that there's some things that she actually needed some help that I didn't realize she did.

Secondary: [I]t was good to go through and very eye-opening, um, once we exchanged [the individual tools]. I think having us answer the questions on our own first allowed us to be pretty honest and open with, you know, our thoughts and feelings...

Do family members recognize perceptual incongruence? Recognition of perceptual incongruence from Time 1 to Time 2

We also wanted to understand whether and to what degree families *believed* there was agreement among themselves about what was needed in the care arrangement both before and after the intervention. In our T1/T2 interviews, we asked participants to answer the following question: *We see eye-to-eye when it comes to what care and support is needed (or, for the PWCN, What care and support I need)*, and we asked for examples of that care and support.

We see eye-to-eye @T1	ALL Mostly true	Mostly or somewhat true	Mostly/somewhat true plus one Not sure	Range from mostly true to mostly false	Somewhat or mostly false
Number of families	3	3	1	2	0

In spite of a notable level of perceptual incongruence evident in all families at Time 1, participants generally reported that their families see eye-to-eye. In three families, all members responded that it was mostly true that they see eye-to-eye. In another three families, members responded that it was either mostly or somewhat true. In one family, all but one of six members responded mostly or somewhat true, while the sixth person was not sure. Finally, in two families, there was a mixture of responses, from mostly true to mostly false.

At Time 2, there were no changes in the eye-to-eye ratings in three families. (Two of these three families had rated their eye-to-eye perceptions very high at Time 1. In the third family, the members' very mixed ratings did not change.) In three other families, at least one member reported an increase in eye-to-eye rating, from somewhat true to mostly true. And in the final three families, at least one or two members reported a lower eye-to-eye rating, from mostly true to somewhat true. There are no discernible patterns to these T1/T2 changes or lack of change. We could not identify family characteristics or individual roles, e.g., PWCN, primary or secondary caregiver, that would explain these changes. Again, unique individual reactions to heightened consciousness about incongruence appear to be at play, as opposed to any identifiable collective family response.

Do family members reconcile perceptual incongruence? The Shared Assessment

Families confronting areas of perceptual incongruence worked to reconcile those areas by working through them in their discussions and by negotiating and completing the Shared Assessment. In analyzing the reconciliation of perceptual incongruence we used data from the completed Guides and our semi-structured or open-ended Time 2 interview questions. We also referred to T1/T2 changes in the “We see eye-to-eye” scale although, again, these were not instructive.

Not all families completed the formal Shared Assessment in the family’s “master” Shared Assessment (the recorder version); some families used one individual’s tools to record discrepancies and resolution of those discrepancies. In other families, all individuals recorded the “final” shared perception in each member’s own Guide, for example, by scratching out their first perception and changing it according to the discussion from the tools exchange. In each of these approaches we identified a process of reconciling incongruence. We also learned about the process through the Time 2 interviews. Participants described many paths to reconciling areas of incongruence, or what several participants described as “getting on the same page.”

Secondary: We just talked about them. As we were talking about the tool, we had all read each other's at that point and then we would just go one by one through each of those limitations and remind each other what we each put and if there was a discrepancy...and a lot of times the discrepancy was me being different than the two of them, but sometimes it was my dad being different than my mom. And that's where the most conversation was, if it was me that was different, the conversation was usually the two of them saying, 'Oh no, this is what this is really like.' [Laughter] and I'd go, 'Oh, I didn't know that.' [Laughter] But when it was a difference between my mom and dad, then there would be a conversation and the three of us would talk about it. They're really good about being very...compassionately direct with each other. So it wasn't a problem, it was just tiring dad. It was draining for my dad. It was emotionally draining for him.

Primary: Because my mom is such a strong willed person it's like almost every answer she was like, No, no, but then [Secondary] had to remind her or whatever, like well [Primary] fills your checks out when you are having a hard time, and then [mom says] oh, yeah, yeah she does that, you're right, so sometimes it's like my mom is so independent she is almost in denial when we do help her.

Secondary: We went over the questions together and that's when I found out 'Hey mom does have a problem with this.' and then I took and circled it when I realized I was totally wrong.

Secondary: *[I]t did kind of provoke some good discussion... [P]eople had a chance to say this is why they responded that way. And I, in general, we all kind of moved along, you know, with a sense of, "Yeah, okay. We can...we're basically seeing it the same."*

PWCN: *Separately, I think the children have their own opinions and ideas, a lot of times they will throw them to me. But this time they were able to discuss what came to the forefront.*

Secondary: *The most helpful was, um, probably I think feeling that you...were starting the process with your own personal opinion and then were asked to...move into a group setting with very similar questions. So...as you were making a group decision or group assessment you had the perspective from your original personal one to kind of, uh, get the ball rolling...I guess I never felt like I got caught off guard with questions. Because you were gradually working into those questions as you went through the process.*

PWCN: *We're pretty forthcoming with each other and our daughter and my husband, in particular, and so if there was a disagreement or a 'I don't see it that way, this is the way I see it.' we were able to come to a decision that we could all live with.*

Primary: *[W]hen there was difference, in many cases it would either be [PWCN] evaluated things differently than I and [Secondary] didn't know because it was something you'd have to be involved on our daily basis. And when we came to those, I would give my reasons for saying it was this way and she would either agree or disagree and if she disagreed, we would talk it out and come to an agreement.*

As the above quotes indicate, these families were able to reconcile areas of incongruence by referencing their own and each other's individual assessment tools and negotiating a shared perspective.

Do family members acknowledge decision interdependence?

As we stated earlier, the negotiation of change in the care arrangement requires an acknowledgement of tradeoffs and exchanges inherent in individual choices. What one individual chooses to do or not to do affects what the others do. We examined whether and how family members acknowledge the interdependence of their behaviors and decisions. We used a qualitative approach, identifying acknowledgements of interdependence in the open-ended portions of the interview. Examples of acknowledgement include:

Primary: *[Secondary] just kind of stands back and lets me do a lot of things.*

Secondary: *[Sibling] tends to stay away when caregiving is needed and I tend to go in and work there...to pick up the pieces.*

Secondary: *Since so much of it falls on [Primary's] shoulders, and he takes it on his shoulders, he doesn't leave a lot for the rest.*

Primary: *I've found that when I am here, she won't do things, but if I don't come she will do it.*

Primary: *I mean I'm going to take care of her so it's like, it kind of irrelevant. I mean, what they contribute.*

Secondary: *My mom [primary caregiver] just takes over and does everything.*

There was some evidence that consciousness of decision interdependence raised in the family meeting influenced the thinking of some participants. For example:

Secondary: *My sister is just more involved...She's more of a proactive person and I am more of a "you need to tell me what to do" kind of person.*

Primary: *I'd delegate more of the duties, I guess. After me and my sister had a conversation, I guess she wants to be involved in more and learn more, cause she said, 'I don't think I'm aware of a lot.' So, I guess [I would do] less so they can be more involved.*

Do family members engage in explicit decision making?

We asked participants to respond to this statement: “Generally, we don’t have explicit conversations about who will do what, where, when and how in the care arrangement. Instead, the care arrangement just happens.” Response categories were “Mostly true,” “Somewhat true,” “Mostly false,” or “Not sure.” Positive responses to this statement (mostly true or somewhat true) were an indication of implicit or de facto decision making, while negative responses were an indication of explicit decision making. Going into the intervention, the family with four co-caregivers had a very structured system of explicit communication about the care arrangement. This family had committed that someone would visit the PWCN each day for a few hours and they utilized a monthly calendar to coordinate these visits. One sibling took responsibility for the calendar, which involved gathering information about each sibling’s availability and distributing the calendar to all those involved. Within and across the *other* families, however, there was a

remarkable level of agreement that much of the care and support arrangement “just happens.” The care arrangement is an implicit, tacit “agreement” based on assumptions, without conversation.

Secondary: *We just take it as it comes and we just go with the flow pretty much...It just goes as it goes.*

Primary: *I think that most things are done spontaneously. Not a lot of planning. Especially my [adult children] who are active and have families, they cannot really plan.*

Secondary: *We always just kind of make it happen in time and split it up the best we can.*

Secondary: *A lot of it's...It's situation by situation...*

Secondary: *Things kind of fall into place as needed.*

There was some evidence of using implicit decisions as a way to avoid conflict (Radina, Gibbons, & Lim, 2009), for example:

Secondary: *[Primary] tends to not want to have any conflict so he doesn't always say what he thinks.*

Effects of the family meeting on explicitness of decision making

The family meeting Guide created a structure to facilitate explicit decision making in the meeting, in real time, and although explicit decision making about care and support did indeed happen in most of these meetings, participants' ratings about explicitness of decision making did not change much from Time 1 to Time 2. We consider several possibilities here. Is the tacit agreement working, and therefore there is little perceived need to be more explicit about it? Is there an underlying resistance to having more explicit conversations about the care arrangement? Did the family meeting raise consciousness about the lack of explicitness? There is some evidence from the interviews that families became more sensitive to the implicit nature of the “decisions.”

Primary: *My [sibling] kept saying like “I can't read your minds. I don't know where you need help. I need you to tell me what you need help with.” It...confirmed and reassured me why things are the way that they are...Um, cause if you don't tell somebody and they don't know then why should they be expected to help...but it's something that we need to think about in how we need to communicate.*

PWCN: *Well, we hadn't discussed much of anything before that. We were just kinda goin' along taking things for granted.*

Secondary: *This is still in the area of just wing it because of so many changes...nothing is structured because no one is reliable.*

Secondary: *Well, we never actually plan...we don't plan out and say, 'Hey, this is what we're gonna do.'...We don't plan ahead of time.*

In summary, it appears that the families' tendency to assume tasks and roles without communicating about them is strong, but, as we will explain, reports of overall improvement in communication suggest that the exercise of explicit conversation and decision making did impact the family's outcome.

Do family members engage in inclusive decision making?

A family can engage in explicit communication, but not necessarily do so inclusively. Some families are “good at” one but not the other, some families are good at both, and some are good at neither. As we stated in our background section, a major goal of this project was to enhance the inclusiveness of decision making and especially the inclusion of the person with care needs. And as we noted in our methods section, challenges with inclusiveness of decision making began with the families' decisions about who would participate in the project (both the study and the Guide and process itself) from the start. The marginalized and underutilized were in many cases marginalized in the very experience of inclusiveness intended in the project design. While it was a requirement of the study that the person with care needs and at least two caregivers participate, inclusion in the experience was left to the families. Again, those most likely to be excluded were children living at a distance, children-in-law, and step-children.

It is important to consider whether **full inclusion** is always best. Participants identified multiple rationales for limiting some discussions and decisions to a selected few; these were not inherently detrimental choices. How do families decide who to include in family communications? The following interview excerpts illustrate different reasons for limiting the involvement of some family members in some communications:

Efficiency issues. Primary: *But when I'm helping her out the bed, I'm not gonna call and say, 'Okay, I'm helping mom out the bed.' That's just not realistic for me and it's a waste of time to call her and say, 'Okay, I'm doing this.' I just don't do that.*

Need-to-know inclusion. Primary: *When we have those conversations, all who need to be included are included. When she needs help or when something new is on the horizon that they feel they need additional input about, they call me or my brothers or all of us.*

“Legitimate” exclusion. Secondary: *My own husband, he's been really good about going along with things, but he has a 94 year old mother also. He was legitimately excused.*

Division-of-labor considerations. Secondary: *As far as financial, [my sibling, another Secondary] does that. [My sibling] and I will discuss [financial matters] and he does most of it but then we usually concur and share costs.*

Effects of proximity. Secondary: *Well, because I'm not there. I do get included eventually, but after it's done. So I do get included eventually, but I'm not usually there when they're discussing this and discussing that. I'm always at work, of course.*

Preference for inclusion. Primary: *[Sibling] is busy, we always tell her later and have her call us back at her convenience, but she never does.*

“Earned” inclusion. Secondary: *I've been so angry that, you know, there's [out-of-state sibling], I know if she were here she would do more, but she wants to weigh in and she wants to, you know, I think, say more...and she can't do a doggone thing. (One of the agreements this family made in their family meeting was that because some of the family members were very minimally involved in the care, they should not expect to have equal voice in the decision making. They would be “informed” but not “consulted.”)*

Conflict avoidance. There were examples of excluding some family members because of mental health or other issues, or because of unresolved disturbances in communication attributed to those family members from past experiences.

Effects of the family meeting on inclusiveness of decision making

At Time 1 and Time 2, we asked family members to respond to the following statement: “All of us are included in important conversations about who does what, where, when, and how in the care and support arrangement.” Response categories were “Mostly true,” “Somewhat true,” “Mostly false,” or “Not sure.” This was followed by probes to identify who in the family was less likely to be included, and in what kinds of conversations. In rating the inclusiveness of family communication about care, for most families there was very little within-family consistency at either Time 1 or Time 2 and there were no patterns to the inconsistencies across families or across time within families. At Time 1, only one family reported the statement as mostly true across the board, and that consistency did not hold at Time 2. In one other family, near consistency (mostly and somewhat true) was reported at Time 1 and that range held at Time 2, although with flip-flopping among members. In six families, at both Time 1 and Time 2, both false and true responses were given at both Time 1 and Time 2; within-individual changes were not explained by qualitative probes. In one notable family, all members responded mostly true at Time 2, a shift from a range of mostly true to mostly false at Time 1. These were not well explained by qualitative probes. Again, we argue that these mixed responses represent individual reactions to heightened consciousness as illustrated in Figure 4.

The importance of the **inclusion of the person with care needs** is unquestionable. There was a general embrace of the person with care needs' role in discussion about care and support in the family meeting, and parents/partners with care needs reported feeling heard and affirmed.

PWCN: I think the part where my daughters shared about my care and [Primary Caregiver adult child] made [Secondary Caregiver adult child] more aware of some of the things that I struggle with...their getting to know or actually discussing what my needs are [and] getting to really know actually what I need and what I need to do... [T]hat was the most helpful thing I think for me.

PWCN: 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.

PWCN: For me, it was feeling a little freer to say something that I had read there (in the tools) or talked about.

One PWCN was notably indifferent to issues of inclusiveness, however. When asked about not being involved in the family meeting by choice, the PWCN said, "I let them decide and they let me know...They just know what to do and figure it out between them."

Caregivers also valued the engagement of the person with care needs in the Our Family, Our Way process.

Primary: [T]he communication has changed and I feel like my mom might not be quite as stressed just getting some of that off of her chest probably helped. Just not necessarily that anything has come out of it, but she's not holding those feelings back anymore...

Co-caregiver: [T]he family meeting was helpful because it was interesting because we all talk about this but we don't generally have my dad there. So I guess if I had to pick one [helpful thing about the process] that would be it, just because of his presence and being a part of it.

Primary: We need to talk more often amongst ourselves about that—including mom. How she's doing? Is she getting what she needs?

Inclusion in the Our Family, Our Way experience: What participants' hindsight tells us about inclusive communication and decision making

Perhaps the most striking thing we learned about inclusiveness was that at least one and often multiple persons in each family said that, were they to start the experience again, they would include family members (especially other siblings, spouses and in one case, step-siblings) who had

been left out. Some participants reported that had they fully understood what the project entailed before beginning it, they would have made different choices about inclusion. Interestingly, in addition, at least some members of two families said that they would have included the formal caregivers in the process. Although the inclusion of formal caregivers in the Our Family, Our Way process is beyond the target of intervention and analysis, we believe it has implications for future iterations and variations of the Guide and its uses.

Primary: *[My sister] because [she] would be the one to step up the most and help with anything.*

PWCN: *[My daughter because] she basically would probably be helpful if [Primary CG] runs into problems...she might give [Primary CG] a break.*

Secondary: *At some of the very beginning [my husband and my sister-in-law]. We brought them in later on for the actual family interview and I think they felt a little bit lost as far as what they needed to provide. I think if we **involved them earlier on** that would have been good.*

Secondary: *[My three siblings] that still live in town...They are close enough that **they could handle certain responsibilities when they arise**. It would alleviate some of the pressure.*

Primary: *...all of my siblings, I wouldn't just involve me and my older sister. I would involve everybody, to **keep them all in the loop of** what's going on with my mom.*

Secondary: *...all of my sibling so they could know...I learned some things about mom that I didn't even know, cause I'm not there...and **the other siblings need to know that as well**.*

Secondary: *Certainly all of the siblings should've been there. They would have **had a sense of decisions that were made that would affect them**. In terms of the spouses you know...I don't think so.*

Primary: *[O]ur sons just so they would have the benefit of that discussion and **be more tuned in to what's going on in our daily lives and how their sister's been interacting**. And she would find out what they've been doing that she might not know.*

Secondary: *I think I would probably have invited my brothers...I also think it would have been interesting **to get their perspective**.*

Secondary: *[My other brother and my other sister] should have been involved as well and **we could have all been in one accord.***

In some cases, an inclination to include others was followed by some sort of qualifier.

Secondary: *I would definitely consider having [sibling] but that was another situation where it was out of the question, so it wasn't even a situation.*

PWCN: *If [the sons-in-law] were not as busy as they are I would have invited them.*

Secondary: *Maybe our husbands, but I don't know if they would have wanted to be included.*

At Time 3, one participant (a secondary caregiver) said, *I think it was awesome. And I don't know about other families, but it helped me learn a lot and it helped me help my other siblings. But again, I say that this shouldn't be who some people think should be involved, I think the whole family should be included. I don't think anybody should be telling who should be included and who shouldn't. I think all siblings should be included because we're kinda close, our brothers and sisters, and all of them are included at this point.*

Reported overall impact on family communication from Time 1 to Time 2

We asked participants to describe the impact of using the Our Family, Our Way Guide on their family's communication, on a 5-point scale from "greatly improved" to "greatly worsened." In four of the nine families, all participants reported that their family communication greatly or somewhat improved, although the PWCN in one of these families did not respond to this question. In four other families, some members reported that their communication had greatly or somewhat improved while one or two members said that there had been no effect on their communication. (All participants who reported that there had been no effect were from high-"going-in"-efficacy families.) Finally, in one family¹³, response to this question ranged from somewhat improved to greatly worsened; three members responded somewhat or greatly worsened and one responded somewhat improved.

At the individual level, of the 34¹⁴ total individual responses to this question, 21 participants reported that their family communication had somewhat improved; three (all primary caregivers) reported that it had greatly improved; and seven reported that there had been no effect. It is worth noting that one of the participants who reported that the intervention had "no effect" on communication, later said, "We do know that we can rely on each other and maybe...we would

¹³ This is the family whose second family meeting, after a successful first family meeting, "blew up" over a legal matter raised during the first steps of negotiating the Family Care and Support Plan.

¹⁴ Two missing responses.

maybe pick up the phone and call each other...maybe it would be more likely that we would do that now than prior to...going through this process.” And, as noted above, three members of one family reported that communication had greatly or somewhat worsened.

Communication improvements were characterized by participants in a variety of ways by multiple participants: *It opened up topics that we never talked about before...it helps you get to know things and actually it kind of helps to plan and order. Don't wait until something happens...I think I made [PWCN] talk a little bit...it's good if you just sit down and just really get into it and understand it...it gives everyone a chance to, you know, to speak up about their opinions...the fact that we got the family together to think and talk and we had some guidelines for the conversation on what we should be doing or could be doing...it gets everybody sitting down at the same time to voice their opinions on each individual thing...our communication was pretty good to begin with, but I saw a change for the better...I think I understand better now how deeply she feels...it did open up the channels of communication and it got us thinking along those lines...it brought some things on the table that I don't know that would have otherwise...just getting people to sit down, have a conversation so everyone knows kind of where everyone's coming from.*

There was also evidence of plans or expectations to sustain or improve communication ahead.

Secondary: *[S]ome emerging things that I wasn't aware of really until yesterday...will bring us to having a conversation a little more proactively to start getting in front of it so...*

Primary: *[Sibling] answers his phone more. Well...he carries his cell with him more.*

Primary: *It's something that we can't just assume, as mom ages the situation becomes dynamic and things are going to change. And you just can't assume well this is what's being done right now so it's always going to be. You kind of have to be flexible and know that she's going to require more care.*

Secondary: *Well, you know...I'm not very good at like reaching out...I'm very much a 'whatever's right in front of me' is what I'm, you know? So, if I'm not like coming over here or we don't have a plan already, I'm just like doing my stuff. And so I said "What...would help me is if you called me and say like "In the next two weeks, I would like to get together." And then I...Great! Yeah, I'm gonna be less likely to initiate it because it's...It's not going to be on my radar as much as it is gonna be on your radar...*

Primary: *It hasn't changed just yet, [Secondary] will go pick up my mom's medicine from the pharmacy, she does do that more...It hasn't changed drastically just yet, but it will because I will make them aware of when I need them.* **Note:** At Time 3, the secondary caregiver referred to here said, *Oh my god, everything's different. I know everything [laughter]! I think I kind of hurt [Primary caregiver's] feelings [at the family meeting] cause I was just kind of upset about some things that I didn't know. But we discussed that before. And now I'm tired of her telling me everything [laughter] but, it's awesome. A lot of things have changed, I know a lot about what's going on and I can jump in and help.*

Clearly, a major benefit of the Our Family, Our Way process is the generally positive impact that the tools completion, exchange, and related discussion had on communication within participating families. It could be argued that improved communication alone was sufficient to elicit overall positive responses to participation in the project. Our answer to Research Question 1 (What are the effects of the intervention on family **communication and decision making** processes related to care and support?) is that the intervention achieved generally positive intended effects. We now examine whether improved communication led to changes in the care and support arrangement.

Changes in the care and support arrangement

RESEARCH QUESTION 2. What is effect of the intervention on **changes** in PWCN self-care; caregiver involvement; indirect support and resource transfers; and use of formal services or other informal supports?

Although only three families engaged in the process of formally completing the Family Care and Support Plan (to record changes in the care and support arrangement), five of the other six families either made changes to the care and support arrangement or affirmed the arrangement already in place.

In our Time 2 interviews, we asked participants to answer the following question: *As a result of your family meeting, did your family's care and support arrangement change in any way?* (Yes, No, or Not Sure.) In one family, all members reported that they had made a change or changes in the care and support arrangement. In two families, all members reported that the care arrangement had not changed. In another family, all but one member (who was Not sure) reported it had not. In the remaining five families, at least one member reported that the care and support arrangement had changed and at least one reported that it had not. Importantly, in four of the five families with mixed responses, *at least one specific change was noted in other parts of the interviews.* This discrepancy suggests to us that there was ambiguity about the definitions of both *change* and *arrangement*. It appears that most participants interpreted changes in “who does what, where, when, and how” to mean major decisions about care (such as changes in roles, or changes in living arrangements). We believe that our research questions did not sufficiently invite participants to regard small changes in care and support as changes in the *arrangement*. Relatively

small or subtle changes that were prompted by the family meeting were under-acknowledged. The participants' narrower definition appear to indicate our failure to sufficiently communicate a broader conception of the care and support arrangement¹⁵.

In addition, *plans* to change something in the care arrangement were not acknowledged at the Time 2 interview if those plans hadn't actually been executed by then. In two of the five families with mixed responses, the "No" response was accompanied by a "Not yet." For example, a secondary caregiver agreed in the family meeting to provide a respite holiday for the primary caregiver, but that had not yet happened by the Time 2 interview.

In the final analysis, five of the nine families made "positive" changes to the care and support arrangement as a result of the family meeting. Three families made no changes, and in the ninth family (whose family meeting had "blown up"), one secondary caregiver was for the time being no longer involved in care and support, which at least two family members experienced as a negative change.

Managing expectations

We learned that it is important to manage expectations about how much can change, how fast, and whether some change can happen at all. In fact, we learned that in this sense our intervention and evaluation aims were arguably too high. As one of the secondary caregivers said, "[O]ne of the things we proposed is let's...let's start small. Let's not try to say, "Let's turn everything upside-down." So, it's like, "[Primary caregiver], what can we do to help you? Well, you need some time away. So, let's set up at least a day a week where someone's going to come in to be with [PWCN] and you can go leave, you can do something else, you can...or we'll take her...take her out so you can just have the house to yourself and quiet." A primary caregiver said, "Well, we felt that, uh, not a whole lot would change...with me being home all the time...just maybe some little things to keep the children more involved."

We also learned that even the smallest changes in the care and support arrangement can make a powerful difference. As we have said, many participants responded that there had been no change in the care and support arrangement when in fact they had agreed to changes at the family meeting. Sometimes the change was simply hard to imagine: (Primary) *Feeling a need for respite time, but don't know what it would be*. One participant reported that the biggest change in the family's care and support arrangement was that "We have one now."

Affirmation of the status quo

For some participants, the care arrangement was affirmed, status quo, without any identified changes. In families who made changes but regarded the fundamental arrangement as

¹⁵ In introducing the expression "care and support arrangement," we continued, "that is, the who does what, when, where, and how to support you (for PWCN's) or your [parent/spouse] (for caregivers)." We frequently repeated that definition as a reminder throughout our interviews. (See Evaluation Tools in Appendix B.)

unchanged, that fundamental arrangement was affirmed by some participants. We note three different kinds of affirmation: **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,” and “They’re saving my spirit for when it actually becomes more critical.”); and **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.”) Importantly, as we will discuss later, we have some concern that affirmation of the care and support arrangement not become “locked in” as an effect of the family meeting. All three kinds of affirmation call for ongoing shared assessment of the situation at hand.

What is effect of the intervention on changes in PWCN self-care?

Changes in self-care were identified in four families, and we were reminded that many tasks in the care and support arrangement invite collaboration between two or more members. This was especially true of PWCN partnerships with their caregivers. In one family, the PWCN and spouse agreed to join a gym and to begin attending the community senior center. In the same family, the PWCN, who had lost his involvement in taking care of family finances, negotiated a change. As a secondary caregiver in that family reports, “What really opened my eyes and...really hit home was reading my dad’s responses on how he feels he is different, treated differently...because he wants to be more involved in the finances. My mom just took on that as responsibility cause she assumed that it, you know, she needed to do it. It needed to be taken on, but in doing so it was easier for her to just kind of take the reins away and do it at 100%...[I]t doesn’t give him the opportunity to try.” As part of the care and support plan, it was agreed that the PWCN will collaborate with his wife on the parts of bill paying with which he can help. This PWCN and primary caregiver also agreed to take care of some legal and financial end-of-life issues together. Finally, they will attend Parkinson’s seminars together.

Some changes in self-care correspond with the ups and downs of a chronic condition and we are reminded of yet another reason for ongoing communication about the care arrangement. PWCN, “I’m doing better and so I started to do a lot of stuff by myself.”

In one family, a plan was made to repair the smoke alarm and get new rugs, for safety reasons. This is a family collaboration, but the PWCN will contribute resources toward this change.

In another family, several changes were made that rely heavily on the PWCN’s efforts. According to their care and support plan, she will seek assistance with a review of her medication, look into possible counseling, pursue an exam for hearing aids, and move or remove items in her home for easier accessibility and increased independence.

*What is effect of the intervention on changes in **caregiver involvement**?*

Several participants remarked about their own efforts or the efforts of others to “step up” in the care arrangement.

Secondary: Just since the...the round table I'll call it [the family held their meeting around the PWCN's round kitchen table], [another secondary caregiver] has stepped up [by giving the primary caregiver a break and providing more companionship and emotional support to the PWCN]. And it's been wonderful and it's been appropriate and I'm truly appreciative of it. That has been a true gift.

PWCN: [Three secondary caregivers] and I went off and [primary caregiver] had the house to himself to do what he wanted to. And just the feeling...What he did...may not be very exciting. But it gave the feeling that this could happen again. It's better for [primary caregiver], and it's better for me I know. The feeling that he was able to get away and not be tied to the house.

Primary: Up until we had that meeting and we discussed things more openly with [secondary caregiver], I hadn't known that she was gonna be very supportive of [providing some respite]. I was always thinking I would like to do that, but I felt guilty, I didn't want to leave [PWCN] home alone...just kind of like deserting her...I didn't want to do that. But [secondary caregiver] just volunteered.

Secondary: I think the most important decision we made was giving [primary caregiver] a break and allowing him to get out if he chose to do so, and just get away from the house and do whatever he wanted to do for a while. The outcome was the appreciation for what he is doing.

Primary: It got us thinking about, through that tool, about [the PWCN] being safe, and [secondary caregiver] is going to move some stuff around for her to reach...that was another thing that was discussed in our meeting...We discussed how we need to have things safe here.

*What is effect of the intervention on changes in use of **formal services or other informal supports**?*

In the individual tools and the Shared Assessment, we provided a place for family members to indicate who else might help. (What's Possible Part 2: “Who else might be able to provide care and support?”) All members of three families completed the individual who-else-might-help tool, while some family members completed the tool in five. Among the nine families, two families completed the family tool in the recorded Shared Assessment. When combining individual tools, all families were able to identify, as a collective, at least three extended family members or friends who might be available to provide care and support. This group included neighbors, children, grandchildren, friends, and other extended family. The most common potential care areas identified were transportation (from neighbors, children, or friends) and social and emotional

support (visits, calls, or emails from friends or grandchildren). Forms of other potential help less often identified were household work and meal preparation.

In terms of formal services, although seven of the eight families who completed this section of the tool identified at least one service that might help, there was no evidence of actual decisions to add formal services to change the care and support arrangement. As noted earlier, four of the nine participating families already use formal services to augment their care arrangements. One family indicated an intention to explore services listed in the Family Resources Booklet provided with the Guide; another family listed several area services as “look-into” possibilities. The families who use formal services appear to conceptualize the care and support arrangement to include the formal caregivers and therefore sources of change. Among those families who are not using formal services, this idea was not at the forefront of their thinking. In summary, the intervention did not immediately lead to changes in the use of formal services.

*What is effect of the intervention on changes on indirect supports or **resource transfers?***

In two families, decisions about resource transfers were mentioned as part of the Family Care and Support Plan. In one family, a secondary caregiver will help with the financial cost of respite. Secondary: “I was like, ‘Don’t let money be the reason you don’t do this.’”

At the beginning of the Guide, is a page titled, “Before You Begin.....Did You Know?” This page includes a reminder that family care and support has an economic value; it provides the general costs of in-home care and a reference to a cost-of-care calculator by geographic region, in the Family Resources Booklet accompanying the Guide. One of the families used that reference to calculate the value of care being provided by the primary caregiver. At the family meeting an agreement was reached that the house in which the primary caregiver and his mother, the PWCN, co-reside would be left to the primary caregiver as some compensation assuming so much of the responsibility of care. By the Time 3 interviews, all of the legal documents had been completed.

Although these were the only two resource transfers mentioned among these families, they serve as good examples of the many possible paths to a more equitable care and support arrangement.

The prospects and hope of change

As we have said, some changes discussed at the family meeting are merely “in the wind” and not yet executed. Some are perceived as standing offers or general impressions of support.

Primary: I feel like I can lean on my kids more than I thought, you know, prior. So, I think, it was helpful in that way and they both know that I can lean on them so....And they're very receptive to that.

Secondary: *[F]or us, it was easier to say, um, you know, like “if you want to go somewhere, let me know and let’s try to plan it on a weekend and I can help you on weekends.” “If there’s something that you need to do, um, let’s look at our calendars and see if, you know, Wednesday night I might be free and I can take you then.”*

Primary: *It hasn't changed just yet, but when I need them, I need to pick up the phone and call them a little more often.*

Co-caregiver: *...there are a couple things that I know that we were going to do... we didn't designate who, um, but when [out of town siblings] come to town they frequently just kind of show up and nobody knows that they're going to be there and we need to have a conversation [giving] somebody a day off...So, I think that conversation was going to be had.*

Primary: *[T]he biggest realization was how deeply [Secondary]...wants to be involved and...she's just so busy that we just, you know, it just, um, I'm reticent and I won't be. I won't be, I promise...She opened that door for me. I was very, very pleased and gratified.*

Changes in actual and perceived equality research question 3: What is the impact of changes in the care and support arrangement, including indirect support and resource transfers, on actual and perceived equity?

The impact of the tools exchange and the family meeting on actual equity

We would argue that none of the care and support arrangements in the nine families was equitable on face value at Time 1. In fact, it is difficult to imagine describing any family care and support arrangement as perfectly equitable; there are simply too many fluid and unidentifiable variables. We ask, was there an *improvement* in equity at Time 2? As an individual cost-benefit appraisal, it is not ours to determine whether a change in the care and support arrangement is actually more or less equitable because we can't fully know what are experienced as costs and what are experienced as benefits by the individual participants. Furthermore, we cannot say what a child “owes” her parent when it comes to care and support, as in the cost-*obligation*-benefit ratio we suggested earlier.

That said, in looking at each family picture, we are able to identify over-providers and under-providers of care and support in the participating families. Importantly, we do this with the help of the participants themselves who were asked at Time 1 and Time 2 if they would do more, if they would do less, or if they do the right amount when it comes to the care and support arrangement. Although an admittedly crude measure, secondary caregivers who said they would do more were regarded as under-providers and primary caregivers in those families were regarded

as over-providers. Technically secondary caregivers can be over-providers, too, as long as there is a corresponding under-provider. Also, as noted earlier, persons with care needs also affect the equity of the care arrangement when they assume more self-care or when they contribute resources toward some of their own care and support. (To complicate matters, it is possible for a primary caregiver to say they would do more, and indeed, one primary caregiver gave that response.)

We calculated that there was improvement in actual equity if at least one under-provider or the PWCN took on more of the care and support and at least one over-provider took on less. Of course, we were especially interested if it was the primary caregiver who took on less, a major aim of the intervention.

The changes identified in the care arrangement above indicate that there was at least some adjustment toward a more equitable arrangement in five of the nine families. In three families the existing arrangement was affirmed and in one family the arrangement was less equitable due to the loss of involvement of one secondary caregiver.

Perceived equity: Changes from Time 1 to Time 2

We regarded changes in perceived equity as an individual measure, but were also interested in any collective effects of the intervention on individuals' perceived equity within families. At Time 1 and Time 2, we asked participants to rate the fairness of the care and support arrangement. (*When it comes to everyone's involvement in the care and support arrangement how fair do you think it is?*) (Not very fair, Somewhat fair, Very fair) In one of the nine families (the co-caregiver family), all five members reported that the care arrangement was somewhat fair at both Time 1 and Time 2. In five of the other eight families, all members reported that the care arrangement at Time 1 was very or somewhat fair; in three families, members reported a range of fairness (from not fair to somewhat fair in two families, and from not fair to very fair in the remaining family). In these eight families, there were individual changes in reports of fairness (both up and down) at Time 2, but the ratings across the family members remained mixed. There were no identifiable patterns in categories of care, that is, PWCNs, primary caregivers, co-caregivers, and secondary caregivers.

These mixed responses within families (at both Time 1 and Time 2) point very clearly to the individual nature of perceived equity and to unique individual reactions to the intervention. When we examined the changes in individuals, their ratings did not appear to reflect actual changes in equity. We again point to the suspected effects of heightened consciousness experienced in the family meetings, and the individual responses to that experience. That is, a rating may have gone up or down because of new information calculated in the cost-benefit appraisal; our interviews did not allow for clear confirmation of this possibility. For example: After the family meeting in which the secondary caregiver expressed irritation and displeasure about not knowing details of [PWCN]'s care, both this caregiver and the PWCN perceived the arrangement as less fair. The PWCN went from thinking the arrangement was "very fair" to thinking it was "somewhat fair." In

fact, at Time 2, she commented, “Because a lot of this falls on [primary caregiver].” The primary caregiver’s perception had a more dramatic shift. She went from thinking the arrangement was “very fair” to thinking it was “not very fair.” She attributed this to her own lack of communication with her siblings.

One of the more striking findings in a study full of elusive T1/T2 patterns is the changes in response to the “would-do-more/less or do-the-right-amount” question among primary caregivers. As a frame of reference, there were nine PWCNS, eight primary caregivers, four co-caregivers (in one family), and 15 secondary caregivers in this study. Four PWCNs said they “do the right amount” at both Time 1 and Time 2; four said they “would do more” at both Time 1 and Time 2; and one changed the response from “more” at Time 1 to “right amount” at Time 2. Of the 15 secondary caregivers, perhaps not surprisingly, 13 said they “would do more,” at both Time 1 and Time 2. Only seven of the 36 participants in the entire sample reported a change in the amount they would do, from Time 1 to Time 2, and *four of those seven* were primary caregivers. The four primary caregivers (one spouse and three adult children) had responded at Time 1 that they “do the right amount,” but at Time 2 they responded that they “would do less.” Interestingly, however, of those four primary caregivers, only one changed the fairness response at Time 2, from “very fair” to “not very fair.” Two of the other three responded “very fair” at both Time 1 and Time 2 and one responded “somewhat fair” at both Time 1 and Time 2. Clearly there is room within each of the broad fairness categories for adjustment of amounts one would do without changing the fairness rating. We are struck, though, with the evident impact of the intervention on four primary caregivers’ change in perception about their contribution to the care and support arrangement. This phenomenon clearly compels further study.

The family of four co-caregivers also stood out, because of mixed responses; at Time 2, two co-caregivers had unchanged responses and two had changed responses. One co-caregiver responded “right amount” at Time 1 and Time 2, one responded “more” at Time 1 and Time 2; one changed from “less” to “right amount;” and the fourth changed from “right amount” to “more.” This suggests that “co”-caregiving may not have been perceived as equitable in this family; all members rated the care and support arrangement as “somewhat fair” at both Time 1 and Time 2.

Several participants pointed to specific ways they would like to see equity improved in their families.

Secondary: I want [my mom] to be able to share with us when she needs help and what she needs.

Primary: Well, we felt that, uh, not a whole lot would change...with me being home all the time...just maybe some little things to keep the children more involved. That was the main thing, I think...just, you know, share with them when I need help, you know?

PWCN: *I think that [the secondary caregivers] should share more of the load with [primary caregiver] ...I'm not sure how easily [she] would give up any of the things she's doing but they could help her.*

Secondary: *I think [primary caregiver]'s voicing or verbalizing that he's willing to do a lot but, you know, there are limits to what he can do so...*

PWCN: *It's not very fair because it gets down to one person and that is [primary caregiver]. I would like to see him get a break every now and then...I am not happy in the sense that it is lopsided.*

PWCN: *I don't want to become a burden. I don't want to take...if I need to have some help, then I'll ask for it. But if I don't need it, I want this independence to last as long as it possibly can.*

Even when grand changes in the care and support arrangement are not made, expressions of acknowledgment and gratitude toward the primary caregiver have a positive impact. As we stated earlier “The perception of equity may be influenced by rather small gestures of exchange or support; it is notable that simple expressions of gratitude from siblings can go a long way in compensating for perceived inequity (Amaro & Miller, 2016).” This was achieved in most of the family meetings.

Secondary: *The most important one is the appreciation that [primary caregiver] didn't get enough appreciation for what he was doing and the sacrifices he was making. We all knew in the back of our mind, but we never brought it up to him.*

Secondary: *I think better the new arrangement is better for [primary caregiver] in a sense that he knows people see what he's doing and appreciate it and that...that counts. That counts for something.*

Co-caregiver: *For myself, I feel like those that live close by are doing amazing amounts of support and I'm eternally grateful...I feel everyone's doing the best they can.*

Secondary: *I'm happy with the quality of care that she is getting with the ones who are participating. But it also makes me angry that the others don't step up and do more.*

Secondary: *I think better the new arrangement is better for [primary caregiver] in a sense that he knows people see what he's doing and appreciate it and that...that counts. That counts for something.*

It is important to note that in examining perceived equity, we focused on the *amount* of care and how it is divided in the family. This was a limited approach in that it did not take into account the *nature* of some tasks which might “weight” time spent on, or frequency, of tasks.

PWCN: *I don't like watching my husband do things that I used to do. And it feels to me that there's too much on his plate sometimes.*

Secondary: *I had NO idea [primary caregiver] was doing so much very personal hands-on care, so there's that!*

Sometimes the perception of equity was impacted by issues of reciprocity or obligation, that is, equity over the family life course. For example:

Primary: *Let me tell you something. Where I'm at, my own arc of my life, has been affected by...I have [my own chronic condition] so [for over 50 years] years [PWCN] has been supporting me in that regard. But during that time, there were times I'm sure when she thought...I'm getting out of here.' But she didn't do it. She stayed and we worked it out and so, I guess the summary of what I'm saying is: I won't live long enough to [make it] even.*

Primary: *She's my mother. That's what you do for your mother.*

Finally, it appears that psychological equity may be at play:

Primary: *Because I don't mind doing it because I live here, but I'm here and so I don't usually call my siblings and ask them for help unless I just need to. Which is often times, I just handle it. I don't call for help and I guess that's where the problem is because I'm not informing them.*

PWCN: *I'm trying to give the benefit of the doubt to the people because they are all in different circumstances.*

Changes in distress

RESEARCH QUESTION 4: What is the impact of changes in equity on appraisals of **distress**?

Because there were no significant changes in equity (or fairness) ratings among families, we cannot discuss correlations with, let alone impact on, appraisals of distress. The distress ratings are individual ratings, that is, they are appraisals of individual not family distress about the how the amount of care is divided in the family. By comments made during the administration of the distress appraisal scale, it appears that many participants responded according to a broader state of distress than that related to how care and support is divided. We conclude that the ratings should not be regarded as a measure of distress related to perceived equity in the family's care and support arrangement. Additionally, there appears to be no discernible pattern of change in distress ratings.

Changes in family efficacy

RESEARCH QUESTION 5: What is the impact of the intervention process and related changes on perceived **family efficacy** about care and support decision making and planning?

The Our Family, Our Way intervention was designed to provide the family with a carefully constructed mastery experience in communicating about care. A sense of mastery is one of the four major criteria for self (or family) efficacy (Bandura, 1998). Following guidelines from Bandura, Caprara, Barbaranelli, Regalia, and Scabini (2011), we asked participants to rate family efficacy using a grading system, i.e., A is excellent, B is Good...to F is Failing, on 11 items related to how well the family works together when it comes to the care and support arrangement. For example, “Working together, as a whole, how well can your family resolve differences of opinion about the care and support arrangement?” or “...support each other in times of stress?” or “...get each other to share in care and support activities?” To establish a “holistic efficacy appraisal” (p. 429) from individual judgements, we assigned weighted points for each grade on the 11 item scale and averaged the family scores. Thus, we had both individual efficacy appraisals and family efficacy appraisals at Time 1 and Time 2.

It is essential to consider how easily a family average can be skewed by one rating in a small group, so it is important for this and other reasons that we not read too much into these ratings. For example, in one family the rating was skewed especially high by one member. In another family, there was a very wide split in perceived efficacy between the PWCN/primary caregiver and the secondary caregivers. Their “family” score loses its meaning without this understanding.

Essentially, though, using these considerations and with the benefit of knowing individual scores and their sources, we were able to rate perceived family efficacy at Time 1 (going-in efficacy) and at Time 2, as high, middle, and low efficacy for each family. Using cut-offs decided by the researchers in a team review of all family scores and in comparing families with each other, we rated five families as high going-in (T1) efficacy families, that is, their scores were internally consistent and high. Two families were rated middle-efficacy going in; one family was rated mid-to-high, and another family was mid-to-low.

At Time 2, of the five high going-in efficacy families, three family efficacy ratings increased and two decreased. These changes were all slight, however. (It is also important to note that high going-in efficacy families did not have much room for improvement in their ratings.) Of the two middle-efficacy families, one rating increased significantly and one decreased slightly. The mid-to-high family increased their rating slightly at Time 2 and the mid-to-low family decreased significantly at Time 2. Two families, therefore, appeared to have significant changes in ratings (one higher and one lower), and these changes are consistent with the narratives of these two families’ experiences. We explore these findings in our conclusions below.

Outcome conclusions

We conclude that positive intervention outcomes were experienced by eight of the nine families, with a mixed experience reported in the “Chase” family. Positive outcomes included

improved communication and changes or promise of changes in the care and support arrangement that led to improved actual equity to varying degrees. We have less evidence about the effect of the intervention on perceived equity, on appraisals of equity-related distress and on family efficacy.

In conducting our analysis, we asked, *Do particular family characteristics or experiences appear to have an effect on the level or nature of intended outcomes?* Or put another way, *Which families had the best and worst outcomes, and why?* We considered the effect of family size and the composition of caregiver roles, for example, spousal vs. filial primary caregivers. And as we said earlier, we rated each family as high, middle, or low on the following characteristics: PWCN level of care (PADL/IADL impairment and/or family-imposed care demands); collective level of strain (physical, emotional, social, and financial); perceptual congruence (level of agreement in individual tools); “going-in” family efficacy (collective rating of family efficacy by family, pre-intervention); and intervention fidelity (using a set of indicators about adherence to the guidelines.)

Importantly, there does not appear to be an isolated directional relationship between the high/middle/low family characteristics and outcomes. The strongest outcomes were not linked to one characteristic by care intensity; family function going in; level of agreement going in about what is needed, wanted, happening, or possible; or the degree to which the family followed the guidelines. We conclude that the combination of the family’s *perceived need or motivation to change* and the *family’s readiness and capacity to negotiate change* using the Our Family, Our Way tools and basic guidelines had the greatest impact on outcomes. We examine three of the families more closely to make this argument.

The “Chase” family was rated high in care intensity; high in strain; low in perceptual congruence; and mid-to-low in going-in family efficacy. The family’s motivation to change was especially high among the two secondary caregivers who had struggled painfully to cooperate and communicate about care. The family made very good progress in the first of two family meetings, completing the Shared Assessment and adhering closely to guidelines. As one of the secondary caregivers said, “I was psyched that things were actually going to change.” However, early in the second meeting as the family began its work on the care and support plan, a legal issue was raised, conflict ensued, and the family meeting “blew up.” The fidelity of the intervention went from high to low, and the outcome, according to the two secondary caregivers, was worsened communication and worsened family efficacy. The PWCN and primary caregiver were shaken by the disturbance at the second family meeting. We regard this family’s outcome as mixed, however, because of hints of the family’s interest in attempting to meet again and also because, at their Time 3 interviews, the PWCN and primary caregiver pointedly credited the entire process for overall improvements in their situation. However, at her Time 3 interview, one of the secondary caregivers had still not restored her communication and care with her family, a situation confirmed by the other secondary caregiver. We believe that this family’s strong need and motivation to improve the care and support arrangement might have gone a long way toward achieving their goals had

there been a facilitator present to mediate the conflict that arose during the meeting and to help the family navigate some of their more troublesome areas of incongruence. In fact, the family briefly considered bringing in an outside professional to mediate another meeting. It did not happen. In the end, in the absence of the family's capacity to withstand a communication crisis and negotiate change, their strong motivation was not enough for a successful outcome.

The second family, the "Knox" family, experienced positive outcomes in most areas of the intervention: multiple and significant changes in the care and support arrangement; reports of improved communication; and significantly higher efficacy ratings at Time 2. The family's going-in efficacy was rated middle, their perceptual congruence was middle and their intervention fidelity was low. The PWCN's care level was high, however, and the primary caregiver was providing 24/7 care. The family's motivation and need for change was very high, especially among the PWCN, the primary caregiver, and two of the four secondary caregivers. In addition, two of the motivated secondary caregivers were able to facilitate an effective family meeting, although they took significant (usually adaptive) liberties with the guidelines. We attribute this family's significant positive outcomes to this combination of high motivation and need for change, and clear family readiness and capacity to negotiate change in the family meeting, using the basic structure of the tools and process. In their Time 3 interviews, the family members attribute their success to the intervention. As one caregiver said, "If we had not gone through this meeting and built this new kind of relationship none of these things would have happened."

The third family, the "Hefner" family, experienced unexpected positive outcomes from the intervention. At his Time 2 interview, the primary caregiver said, "To be frank, I felt going in that we were really inappropriate subjects because I didn't think that we had any problems that were worth being concerned about, so I was kind of cavalier going into it. But as a result of the family meeting, I changed my mind completely." This family developed what we would describe as an *acquired* motivation during the process. Their care intensity level was low to middle and their reported individual strain was low. However, the tools exchange and the family meeting produced insight about the primary caregiver's need for respite and the capacity and willingness of the secondary caregiver to provide it. The family members *became* motivated to make changes in the care and support arrangement during the Our Family, Our Way process. They also had the capacity to negotiate and reconcile areas of incongruence and to agree to some changes through completing the family tools. As the PWCN said, "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."

We have learned that **essential core features** of the intervention go a long way in facilitating positive outcomes, even when families deviate from scripted guidelines and even without formally completing a formal Family Care and Support Plan. The first of these core features is the individual owning of perspectives about what's needed, what's happening now,

what's wanted, and what's possible, using the individual tools. Second is the family's simple coming together, *including the parent or partner with care needs*, in a structured way to pay attention to the shared situation at hand. Third is the process of engaging in a negotiated assessment by confronting and reconciling areas of incongruence. All of these features are the foundation of the Shared Assessment. A fourth core feature is the built-in expectation that something positive and helpful will happen as a result of the meeting; for families with a strong need and motivation to change, this appears to be especially powerful. The final core feature is the family's capacity to withstand and work through unanticipated differences or unwelcome information, in the interest of the greater good. In summary, by facilitating inclusiveness, explicitness, and a recognition and reconciliation of individual perceptions, wants, and capacities, successful outcomes can be achieved. Our task going forward is to maintain and address these core features in subsequent modifications to the Guide and process.

Risks

Although the Our Family, Our Way process shows significant promise as a communication and care coordination strategy for families, it is not without risks, as we have reported. First, we argue that the option of a family-directed process is important; it is not only simpler, less intrusive and less costly than a professionally facilitated process would be, but it is also empowering to families who experience success on their own. That said, without an outside facilitator or mediator, the essential structure of the family meeting may not be followed; tools may be poorly completed, voices may go unheard, and and/or conflicts may go unmediated. We explore these issues further in our assessment of fidelity and implications for the future of the project.

We are also concerned that inequitable care and support arrangements may become “locked in”—or essentially certified—as an effect of the family meeting when thoughts or feelings go unexpressed and issues go unresolved. A false consensus about an inequitable arrangement clearly contradicts the goals of this project. Although the Our Family, Our Way guidelines provide multiple opportunities for “reality checks,” if you will, these guidelines are only as effective as the family's adherence to them.

Feasibility

RESEARCH QUESTION 6: What is the **feasibility** of the intervention (Guide content and process) for all family members?

It is important to begin the discussion of our findings with our analysis of the fidelity of the intervention. Here we apply a definition of intervention fidelity as “the adherent and competent delivery of an intervention by the interventionists” (Ahn, Smith, Altpeter, Belza, Post, & Ory, 2014). As a family-guided process, our participating families were themselves the interventionists, and the fidelity of the Our Family, Our Way implementation was fundamentally in their hands.

Overall, compliance with the completion of individual tools by individual participants was high. Family members generally completed all of their individual tools, adhering well to instructions with some minor, practical deviations. Also as instructed, participants completed their individual tools before their family meeting. Guideline adherence was weaker when it came to conducting the family meeting itself.

Assessing fidelity

“Adherence is essentially the bottom-line measurement of implementation fidelity. If an implemented intervention adheres completely to the content, frequency, duration, and coverage prescribed by its designers, then fidelity can be said to be high. Measuring implementation fidelity means evaluating whether the result of the implementation process is an effective realisation of the intervention as planned by its designers” Carroll, Patterson, Wood, Booth, Rick, and Balain (2007).

According to Zarit, Lee, Barrineau, Whitlatch, and Femia (2013), “The gold standard for assessing fidelity is ratings of audio or video recordings of the sessions” (p. 3). We do not have recordings or observations of the family meetings and instead we relied on the reports of the participants and the evidence of fidelity in degree and quality of the family tools completion, particularly the Shared Assessment and the Family Care and Support Plan.

As we have noted, ALL families completed the sharing of information from the individual tools and engaged in the work toward a shared assessment, and this process alone had a significant impact. However, to varying degrees, families deviated from the highly scripted family meeting guidelines by improvising and adapting, beginning with the tools exchange. For better or worse, they created their own adaptive interventions (Zarit et al., 2013) according to their own circumstances and dynamics. Some adaptations were minor, practical and needed; others were more substantial deviations from the protocol. Other adaptations were offered as part of the guidelines, including options for taking a break.

Some families departed significantly from the guidelines by abbreviating certain steps or completing only some of the sections of the process. Some ended their meetings before completing the Family Care and Support Plan even though they may have agreed to significant changes in the care and support arrangement. Our participating families ranged from high to low fidelity. This wide range was helpful to us in assessing feasibility and in informing modifications to the Guide and process. We regard these deviations from the Guide, particularly stopping after engaging in the shared assessment process, as important signals for modifications to the Guide and surrounding processes; they have implications for both content and structure. The deviations also have implications for the processes surrounding the Guide, including greater clarity about suitability.

To assess fidelity, we first identified points of non-adherence among families. Reflecting those points, we then rated families as high, middle, and low fidelity, using the following criteria: Were all participating family members fully present? Did family members complete their individual tools before the family meeting? Did the family assign roles in the meeting (reader, recorder, and timer) that were designed to diffuse power in communication? Did the family follow the tools exchange protocol? Did the family stick to the topic? Did the family complete the process in one or multiple meetings? (Families who met in more than one meeting were assigned “extra points” for tenacity.) Did the family complete a written Family Care and Support Plan? (Minor adaptations to the protocol did not affect the family rating.) Families who met all of the criteria were identified as high fidelity (three of the nine families); families who met three or fewer of the criteria were identified as low fidelity (four of the nine families); all others (two of the nine families) were rated as middle fidelity families.

Finally, we raise these fidelity issues here as a lens through which to regard the analysis of intervention outcomes. That is, our findings should be considered from a recognition of the differences between the scripted, intended intervention and the actual, varied interventions that took place. The outcomes of the family meeting and surrounding processes should be regarded as outcomes of the basic structure as altered by the families’ improvisations. That said, even with such improvisations—or in some cases perhaps because of them—our findings suggest that the intervention clearly holds promise and compels further development and testing.

Adaptations and deviations: Individual tools

Some adaptations were practical. Although the individual tools were designed to be completed privately, ahead of the family meeting, the PWCN in four of the nine families required assistance with completing their individual tools. The barrier in most cases was difficulty with hand-writing; in three cases, one of the caregivers recorded the responses of the PWCN; in one case, a family friend provided this help.

Adaptations and deviations: Family meeting guidelines

The family meeting guidelines ask families to conduct their tools exchange by systematically passing the tools to the right and allowing 10 minutes per tool, etc. There was a range of adherence to the tools exchange guidelines. Three families followed the guidelines very closely. Other families adapted or deviated in a variety of ways, for example:

Secondary: [We] chose, *as we sat down to, um, to take Mom’s book and what we did was, we said “Let’s go through Mom’s book. This is what she feels.” And then... “Look at your own book and if you don’t agree or you have an outlier then let’s talk about it.” And that worked really well because shifting books around and everybody trying to read everybody’s and then people were done at different times,*

um, and they're sitting there waiting to shift a book. We just found this to be a cleaner process than...than one trying to read and then also waiting for someone to finish who doesn't read as fast.

Primary: We held one meeting, but toward the end, um, we kind of started skipping around.

Secondary: I think there were pieces of it that were really helpful. The parts that weren't, we just kind of blew past. The ones that weren't helpful weren't helpful just because they didn't apply to us, not that they were unhelpful.

Primary: [Secondary caregiver] was the recorder, I think, and some of the...according to your instructions some of us was supposed to be a timer and we opted to not have a timer and we just felt like we could talk as long as we needed to...cause we took a lot more than 10 minutes with each...We didn't look at the time at all...And it seemed to flow pretty well.

Secondary: [Primary] was reading each question out loud. She was saying, 'This is what I put for this,' and then we would comment on it as well...

She just took the lead role I guess... [W]e didn't pass them or take the papers out the binder, we just talked about each one. We went down each point and talked about it.

Families pointed to what adaptations worked especially well for them:

Secondary: [Re completing the Shared Assessment form] Instead of having one person as the recorder, having each person mark each thing down made [the primary caregiver] keep up with all of us. Right? [It] also made us all kind of agree, and what are we agreeing on in this and this, and this. And so I kind of liked that each marking our own and making it kind of, um, an agreement as we marked them. Because I think someone could disengage pretty easily if they were not the recorder or the reader.

Primary: I think just having somebody recording it, it helped everyone else focus on the conversation. Um, like I said everyone having the conversation. Everyone stopping, jotting down notes and then going back to the next question. So that helps kind of it to flow.

Secondary: Some things we didn't dwell on, somethings we had some discussion on. But I think you were concise in having certain areas identified and then we quickly

went over those and spent time where we needed. Otherwise, we just quickly went over them.

In some cases, families may have taken cues from us as permission to take liberties with the Guide instructions. For example, during some of the communications with families who inquired with their assigned researcher about deadlines or other logistical matters, we generally implied the following message, *We don't want to impose too many rules on your family, because although we have an interest in completing our project on time, we are primarily interested in how your family naturally experiences the Our Family, Our Way experience.* It appears that participants took to heart the title of the project, "Our Family, Our Way."

Acceptability

Acceptability is a central component of the feasibility of an intervention. Sekhon, Cartwright, and Francis (2017) define acceptability as a "multi-faceted construct that reflects the extent to which people delivering or receiving [an] intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention. The theoretical framework of acceptability consists of seven component constructs: affective attitude, burden, perceived effectiveness, ethicality, intervention coherence, opportunity costs, and self-efficacy" (p. 9). We add *suitability* (Bowen, Kreuter, Spring, Cofta-Woerpel, Linnan, Weiner, & Fernandez, 2009) to this list, with a focus on the family's suitability to conduct a self-guided process.

Following most of these constructs and adding some of our own, we analyzed the following in our assessment of acceptability: recruitment response; likeliness of re-using the Guide; likeliness of recommending the Guide to others; perceived benefit (helpfulness); perceived burden; perceived effectiveness; ethical issues; overall fit for a self-guided process; and suggestions for improving the Guide or process. We used a combination of quantitative and qualitative data in this analysis.

Ease of individual tools

All members of the nine families completed their individual tools prior to the family meeting. However, in one of the families, there was confusion with the tools and the PWCN ended up filling out a caregiver version, while the secondary caregiver filled out the PWCN version. Due to this, the responses of that family regarding the ease of completing the tools were not included in analysis. Of the eight families whose responses were analyzed, the individual family members varied in their opinions of how difficult the tools were to complete. Among the 25 caregivers whose responses were analyzed, 15 found the individual tools "very easy" or "somewhat easy," five found them "somewhat difficult," and five found them "neither easy nor difficult."

Because the inclusion of the PWCN is a main feature of the project, we were particularly interested in how PWCNs experienced the individual tools. Of the eight PWCNs whose responses were analyzed, three found the tools “somewhat difficult,” three found them “very easy” or “somewhat easy,” and one found them “neither easy nor difficult.” It is important to reiterate here that out of the nine PWCNs who participated in the project, four of them received the assistance of another person in completing their tools. One of those PWCNs reported the tools as “somewhat easy,” but noted that “If [daughter-in-law] was not here it would've been difficult.”

We found that when participants responded to this question, they thought about the ease or difficulty of the tools in different ways. Some responded in regard to the logistical aspects of the tools themselves: “the boxes and checking boxes...that was fairly easy” or “They seemed very redundant.” Others responded in regard to the cognitive effort required: “It made me think about things that I hadn’t thought about.” “Some things took more thought than others.” Still others responded to the emotional work involved with completing the tools: “I was kind of, uh, empty at the end. I was tired. Emotionally tired because I put so much effort into that and wanting to be so accurate.”

Ease of the Shared Assessment

The process of completing the Shared Assessment was addressed earlier as a mechanism for reconciling areas of incongruence. As a reminder, all nine families completed the Shared Assessment portion of the process. Here again, participant responses to ease of completing the Shared Assessment reflected the ease or difficulty of both the tools themselves and also how their families navigated the emotions and differences of opinion that arose during the process. Six families reported that the Shared Assessment was “very easy,” “somewhat easy,” or “neither easy nor difficult” to complete.

Primary: I felt like it was kind of repetitive but it wasn't hard at all to do that section.

Secondary: We were very open and frank. We were open to opinions. There was not a lot of disagreement.

Secondary: [in regard to Shared Assessment] [T]hat's the part that may have been more emotionally difficult for my dad, because he, a few times, had to say to my mom, 'No, honey, you really do have a major impairment in this area. This is a major problem. This is something that's more of a limitation.' And sometimes it was stuff that mom didn't want to see that way, but what I was really glad about was that she didn't get real upset, she didn't get defensive, she just said, 'Oh, I never really thought about it like that, I guess you're right. It really does. It is more of a limitation than I want to realize.' But I think that's hard on my dad because it's hard for him to have to kind of put a mirror up in front of her and to have her see things

the way she sees them. I think that was hard on him, so that's why I'm saying neither easy nor difficult.

In three families, at least one of the family members reported the Shared Assessment as “somewhat difficult” to complete. This difficulty was related to both the tools themselves and emotions experienced during the process.

Primary: It's so much repetition you lose interest of others. Environment should be more about does everyone agree it is safe, and if not, what isn't safe?

Ease of family goal statement

The same six of nine families above completed this section of the Guide, and even within the families who did complete this section, there was some non-response to this question. This makes it difficult to report their experience at the family level. Of the six families who completed a family goal statement, all the responding members of five families reported that the goal statement was “very easy,” “somewhat easy,” or “neither easy nor difficult” to complete.

Secondary: Because by then there had been such rich, good discussion that everybody was in agreement. It's all about [PWCN]. Let's do what's right for [PWCN] and...and so that was the easy part.

PWCN: Because we're on the same page when it comes to that.

Primary: I believed it was very easy cause we were very focused on, you know, and having the same goal in mind and that was the comfort of [PWCN].

Primary: It was like, are we supposed to make this something extravagant or is this basically what we all agree on. We kind of made it very simple.

Secondary: That's the part where we came up with the goal of what we all wanted was to keep her healthy and at home rather than going into a nursing home.

In one family at least one of the family members reported the family goal statement as “somewhat difficult” or “very difficult” to complete.

Secondary: It was difficult. We ran into the same thing, that [secondary caregiver] thinks [PWCN] can drive still, and there's absolutely no way that she could drive. There were way too many things that we disagreed on.

Primary: It was like, are we supposed to make this something extravagant or is this basically what we all agree on. We kind of made it very simple.

Ease of completing the Family Care and Support Plan

Again, the same six of nine families completed or attempted to complete the Family Care and Support Plan section of the Guide, and again, within the families that *did* complete this section, there was some non-response within families to this question. This makes it difficult to report their experience at the family level. In three families, all responding family members reported the Family Care and Support Plan as “very easy,” “somewhat easy,” or “neither easy nor difficult” to complete. In some cases, the family felt that the care and support arrangement did not require much adjustment at the present time. In others, the family felt that they could easily adjust the plan based on their shared assessment conversation.

Secondary: [B]y that time, we kinda knew what we needed to change about the plan and so it wasn't difficult at all to come up with that.

Secondary: Pretty much what we set up was pretty much what we do now. If it's something personal, [primary caregiver] will handle it, if it's something that's needed around the house, mechanical or electrical, then I usually take care of that and that's how we had it set up.

Secondary: [Other secondary caregiver] and I think it was very easy because I mean, again we're in a unique situation in that [the primary caregiver] is very capable of taking care of [the PWCN] 90% of the time...with [the secondary caregivers] coming in as kind of the back-up players.

In three families, at least one of the family members reported the Family Care and Support Plan as “somewhat difficult” or “very difficult” to complete.

Secondary: That was really hard for us. Just because...both my brother and I work and we both have families...so in order to assign somebody shift work, it was difficult for us.

Secondary: I would say that it started out somewhat easy and then it turned into very difficult. We didn't complete it.

How likely to are participants to use the Guide again?

Participants reported a likelihood of using the Guide in their families again. In six of the nine families, all members reported that they would be very likely or somewhat likely to use the Guide again in their families. In the remaining three families, some members reported that they were not sure (two of five members; two of four members, and two of three members), while the other members in those families reported that they would be very or somewhat likely to use the Guide again. No participants reported that they would be unlikely to use the Guide again in their families.

PWCN: *[I]t's good to have some guidelines around, basically it wouldn't hurt to have it around.*

Primary: *It is something where it would get us communicating with each other, for me to say, "By the way I feel like I am doing everything and you're doing nothing kind thing," so I guess that's where I think it would be helpful.*

Secondary: *I think it would come in handy later on down the line if something comes up, sitting down and having the meetings, that would be something too good to do, even if you do it every six months or whatever.*

Primary: *If we realized that things weren't going right maybe we would get back together and say, "Let's go over this one more time."*

Primary: *[W]e did agree that we would get together quarterly so that is something we will need to do probably in the next month or so.*

Likelihood of recommending the Guide to others

Participants reported a strong likelihood to recommend the Our Family, Our Way Guide to others in situations like theirs. In two of the nine families all members reported that they would be very likely to recommend the Guide to others. In four of the families, all members reported that they would be very or somewhat likely to recommend the Guide to others. In the remaining three families, all but one of the members reported that they would be very or somewhat likely to recommend the Guide to others; in those three cases, the one member reported "Not sure." No participants reported that they would be unlikely to recommend the Guide to others. It is noteworthy that, even in the "Chase" family, whose meeting abruptly ended, three of the four members said they would be very or somewhat likely to recommend the Guide (the fourth responded, "Not sure").

Some participants offered qualifiers, for example:

Secondary: *I think that most families would find some aspects of it really helpful. I think it could be really tough for families who don't have relatively good communication already though.*

Primary: *[W]hen I think of that set of tools I think of somebody that is very loaded down with taking care of their loved one and I feel that tool particularly helps shine a light to their other family members or even maybe to the person receiving care to understand where that person's coming from.*

Secondary: *I'd say that the Guide can help families out in the situation where they're taking care of somebody and everyone has the same goal in mind to get everybody talking and get everybody on the same page.*

Recruitment response

As noted earlier, we experienced recruitment challenges in this project, but are reluctant to make too much of this as a measure of acceptability, for several reasons. First, families who participated in this project were signing on to participate not only in the Our Family, Our Way process, but also in extra, time-consuming and intrusive activities: two or three months of involvement with two long interviews and one short interview with an optional family interview and all of the consent and logistical components of that. Our recruitment challenges were also an apparent effect of our narrow eligibility requirements (particularly the exclusion of PWCNs with dementia).

Perceived benefit (helpfulness)

We asked participants to identify what was most helpful about the OFOW experience. Nearly all participants found the Guide helpful in some way. We have provided examples of benefits throughout this report, but we share additional evidence here. The benefits reported were especially focused on the value of heightened consciousness or awareness and on improved communication.

Secondary: Um, I think it was very beneficial just to see everyone's thoughts and opinions and just to know kind of how the person is dealing with this every day. And how he feels and how we can be more helpful. It's not something that I feel like you go through on a daily basis... [Y]ou don't know what to ask. You just don't know what's going on.

Primary: [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.

Primary: I would say I was pleased - surprised and pleased - that we did get some significant benefit out of it. As things progress, now that we've been exposed to all these potential areas of confrontation...not confrontation, but disagreement maybe, or misunderstanding, as we progress through this path if I see, or [PWCN] sees, that there are areas that need some attention and that we need to get [Daughter] involved more or maybe even our boys at that time, I think that would be a good way to start.

PWCN: Being able to see how the caregivers look at the same situation I'm looking at.

Primary: It opened up the channels of communication and got us talking and discussing.

Secondary: *Um, it was beneficial. It was eye opening. Uh, you know, kind of sad and frustrating, all at the same time.*

PWCN: *For the first time, I think it open their eyes to the fact that they could talk openly and talk about different things. There was no anger or animosity or raised voices. It was a very pleasant experience.*

Perceived burden

Very clearly, the length and detail of the tools and Guide can be perceived as burdensome, even though participants were usually hard pressed to identify what they would have left out. Many participants described the tools as “repetitive” or “redundant.”

I thought it was very repetitive. And then maybe I'd get a little frustrated. Didn't I just answer that? It was quite daunting at first...It seems like there were a lot of questions that I don't know if were useful... [I]it seems like there was a lot of the dog chasing the tail...I just remember thinking at the time, This is the same...The more open ended questions were redundant...Some things didn't apply...It took two to three times longer than I thought it was gonna take...

Some participants described the family meeting as exhausting or draining. “Sitting down to do this in a more formalized way was a little bit exhausting, quite honestly...It was draining.” Aside from the obvious implications for revising the Guide and tools, these areas of perceived burden (length and level of detail) could be eased to a degree by an option to break the process down into more than one meeting.

Perceived effectiveness

Perceived effectiveness is closely linked to perceived benefit, but we focus here on what participants reported to be the effective features of the process—particularly the structure.

Secondary: *That last part [the Family Care and Support Plan] where you actually put a time stamp on when you are going to address things and that kind of call to action and who's in charge of doing what. That was, I think, really helpful because it's easy to talk about things in the abstract... [N]o one was taking the initiative and there certainly wasn't a timeline. So, I think that really helped that we had more of a roadmap on things.*

Secondary: *It gave us a structured way of being able to talk about some things that we just weren't talking about. Not because we were avoiding them, we just didn't think to talk about them.*

Primary: *I think that the structure that it brings to the family bring some of these issue to light that may normally not be talked about. Like I said, the structure and some of the material, like the Guide.*

Secondary: *I thought that part of all of [the Family Meeting Guide sections] were useful. It'd help keep us on task by having the Guide and brought up some questions and concerns that we probably would not have considered.*

Secondary: *It forces you in a structured process which that's what I think is critical. 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.*

Secondary: *I mean really, [PWCN] being able to kind of crystalize all of her needs in one place...a way of kind of gathering all issues into one place.*

Secondary: *[Having] a way of kind of methodically going through all the different aspects that need attending to.*

Primary: *Just getting us together and sitting down and realizing that we were all in it together and we had to figure out how we were going to operate as a unit to give the care that's, you know, that's necessary...*

PWCN: *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.*

Ethical issues

One of our concerns going in to this project was the potential of placing families already at risk for negative outcomes in a situation that could cause them harm. Families with histories of abuse, maladaptive coping mechanisms, or poor communication are likely to bring those patterns into their caregiving arrangements and conversations. In such circumstances, a process that includes the potential for conflict could be damaging. We attempted to address this concern up front with the page, "Is This Guide Right for Your Family?" We used accessible language to help potential families self-select, for example: "You might worry that, without a professional involved, your family could not handle the 'can of worms' that topics of care and support might open." We suggested that families who may not feel ready to go through a self-guided process consult a family counselor, mediator, or geriatric care manager to help them navigate their care and support arrangement. Resources for such professionals were included in the Family Resources Booklet which was made available to participants along with the Guide.

We included checkpoints in the Guide itself to encourage families to pause and take stock of how things were going and how they were feeling as they went through the process. The family is instructed to stop and consider their readiness to move on to the next section. “How ready do you feel to move on to [the next section]? Do you need to stop and take a break?...a few minutes?...a few days? Is it time to call in a professional counselor or mediator?”

Overall fit for a self-guided process

As their own interventionists, families self-directing the Our Family, Our Way process must be able to accomplish the following: decide who should be included in the process; articulate and clarify the objectives of the process; articulate and clarify the purpose of the tools; identify common ground; identify and reconcile perceptual incongruence; mediate power imbalances, making sure all voices get heard; keep the family on topic; resolve crisis moments in the family meeting; facilitate logistics for individuals with limitations (literacy, vision, hearing, hand-writing); and assure follow-up and follow-through accountability. These are no small tasks and we strived to provide guidelines that address each of these issues for the family.

Some participants readily saw the potential value of an outside facilitator.

Secondary: I think it's very helpful. I just don't know if I would openly go out and just do it on my own. I would need some guidance or somebody taking charge to say, "Here's what we need to do to figure out the next step...or even if honestly it came from a doctor...just somebody...I feel like higher up or you know, um...Yeah, a counselor or even if it came from a, uh, what do you call it family services? Or, you know, something like that. If we were to reach out and needed help."

Secondary: I know I was sitting during this family meeting thinking "Man, if this...If a family that was less functional was doing this, I wouldn't want to be in that family meeting...Cause I could see all kinds of places where this could go way off the rails."

Some families rode out difficult moments well and demonstrated a solid capacity to navigate the process by themselves. For example:

Secondary: And [primary] got up and walked away. He was so uncomfortable at that point and when he came back I said, "I don't want to speak for you but I want to...I want to revisit what I just said and make sure that I'm not speaking out of turn. Is that something you agree with?" And he said, "Yes." So, for the most part I think there was maybe some moments that actually made sense to [PWCN] as well as to all of us when we went through the process of...of a couple of heated discussions.

Finally, as we have indicated throughout this report and as illustrated by the “Chase” family’s experience, some families—no matter how highly motivated and determined—do not have the readiness or capacity to confront the often highly sensitive matters of care without some outside facilitation.

Sustainability of communication and changes in the care and support arrangement

Our intervention required participants to participate in one family meeting with built-in tools and high expectations for communication and change. We asked a lot of these participants, and as we have said, we learned from them that it is important to manage expectations and to acknowledge and affirm even the smallest changes. It is also essential that we consider mechanisms to sustain the improvements and changes experienced by families who complete the process. As one participant said, “I think that people tend to slip back into the old habits and the old idea. So I think you need to keep it fresh and up to date from time to time.”

The final section of the Our Family, Our Way Guide provides a place for the family to think and talk about their next steps: a plan for ongoing communication and care coordination; a plan for ongoing revision to what’s needed, wanted, and possible; a plan for meeting again; and a plan for revisiting unresolved areas. The Guide also provides a sample follow-up meeting agenda. One of the three high-fidelity families made a plan to meet four times a year. Others left their follow-up plans more wide open.

T3 interview updates: Implications for sustainability

In our brief, Time 3 follow-up interviews, we learned that most families who reported an improvement in communication at Time 2 are seeing that improvement continue and build. We also learned that it can take a while to execute a new plan or decision and that sustainability may mean starting with a trial run of a new care and support arrangement. One primary caregiver is learning how to take a break and how to teach and trust others to provide the kind of care he has been providing. We conclude that “booster” mechanisms could be helpful to all families, either in the form of a family-managed checklist or by outside facilitator check-ins. The outcomes of the Our Family, Our Way process are only as strong as the hope of sustaining them.

LIMITATIONS

Our findings should be considered in the context of the following limitations.

Network confidentiality

We have discussed the issue of network confidentiality in detail, but identify it here as the first research limitation, especially in the reporting of our project. We have attempted to describe family experiences using primarily individual data. We have drawn conclusions and made broad statements about family units without the capacity to support and report those conclusions and statements with directly linked individual data. Without the constraint of network confidentiality, we could have told each family's story intact, with an open reporting of the pieces and analysis of quantitative and qualitative individual data, by family.

Intervention adherence issues

We have also discussed the issue of intervention fidelity in detail, and while the range of intervention adherence by these families is a central finding, it is also a limitation, especially because we did not observe family meetings and must rely on participant reports about the experience. We cannot say with confidence how a strictly followed Guide would affect our target outcomes because no families strictly followed the scripted guidelines.

Effects of study participation on OFOW experience and outcomes

Participants in this project participated not only in the Our Family, Our Way experience, but in somewhat demanding and intimate interviews. We are not sure to what extent the researcher's engagement with each family functioned as facilitation or mediation. That is, we do not know how our research needs intruded themselves on the family's natural experience, or to what extent our communications with the participants intruded itself on the natural dynamic and experience of the family. We are also unable to know to what extent the burden of the interviews was conflated with the perceived burden or cost of engaging in the Our Family, Our Way process only.

Furthermore, we don't know what artificial effect participation in the study may have had on participation at all. Might family members have participated had there been no attached study requirements, and did some participate in order to help the family qualify for study participation but would not normally have agreed to participate in the natural process?

There was a persistent tension between the *study* protocol and the *Guide* protocol in our work with these families. We walked a fine line between facilitating the details of participation in the study and allowing the natural processes of the family's self-directed experience to play out. At most of these points, we opted to allow families to do what came naturally to them. Examples included communicating with the members of the family whose meeting "blew up" about their interest in continuing their participation in the study. This included responding to their questions about whether they should try meeting again with a "third party" involved. (They did choose to continue in the study but decided not to try the family meeting again within our timeframe.)

In another family, enrolled several weeks after others had started (in a rolling start), the timeline of the project imposed some artificial pressure. The one area where the needs of the study generally overrode the natural process of the family was in our requests to keep their experience within a certain timeframe.

Effect of payment?

While we do not believe that a \$300 participation payment to families was coercive, families who chose to enroll were not able to know or predict how much time they would spend in the total process. That was dependent on individual and family choices about how much time to invest in the tools and the family meeting. We suspect that one of the nine families was enticed by the payment and had relatively low motivation and low expectations related to change in communication or the care and support arrangement. This may have affected their outcome to some degree.

DISCUSSION AND IMPLICATIONS FOR FURTHER DEVELOPMENT AND STUDY

As a pilot study, we sought to answer three broad questions about the promise of the intervention:

- 1) Does the intervention have value and does its value outweigh its risks and costs?
- 2) Is the intervention feasible?
- 3) What are the implications of our findings for enhanced value and feasibility and the next iterations of the project?

This projects extends our understanding of caregiving in families with its focus on the family as the primary unit of analysis and concern. It is inclusive of the parent or partner with the need for care and support and both active and prospective secondary caregivers. It follows principles of both person-centered and family-centered care. Much of the existing caregiving research, including intervention research, focuses on dyads and on the primary caregiver only. Much of the existing research also focuses heavily on stress, strain and burden as outcomes of caregiving. Although we address individual distress related to the equity or inequity of the care situation we broaden the conventional stress emphasis through our attention to the prospects of more equitable care and support distribution and the possibility of improving actual and perceived family efficacy.

This intervention has value. It adds to our understanding of family processes of communication, decision making, and planning that suggest important areas for future research, including our own. We have a better understanding of the possibilities of family-directed tools and understand which families are suitable for such an approach. We have laid the groundwork for future study of the process and intended outcomes proposed in our theoretical framework. And finally, we are a step closer to providing a tested tool for dissemination in programs serving older adults and their families and available to families not connected to service systems.

While we did not go so far as to examine impact on health outcomes, nursing home diversion, or quality of life and the like, we believe that such outcomes may be achieved with more equitable care and support arrangements, and in fact, argue that future iterations of our work might include such aims and their measurement.

The current work has provided us with rich information about the experiences of the participating families and has affirmed our belief that Our Family, Our Way could prove to be a powerful resource for caregiving families. Building from this foundation, we intend to conduct an evaluation with revised tools and guidelines, implemented with a larger, more diverse sample. We will expand our work to explore several promising areas for further development and study, as follows.

SELF-GUIDED VS. PROFESSIONALLY FACILITATED PROCESS

Although we conclude that many families can achieve the goals of the Our Family, Our Way process without the facilitation of a professional, and while we assert the importance of a family-directed option, we also conclude that a professional facilitator or mediator would—with the right training—achieve more goals to a greater degree by assuring the fidelity of the process and correcting some of the power inequities in the family dynamic and communication process. The involvement of a professional could provide screening to assess families’ risks of participation and help determine if they would be better-suited for a self-guided or facilitated process. Additionally, professional involvement could allow for quick intervention and access to needed resources if a family experiences significant problems with the process, or a disruptive event, as was the experience in one of our families. Finally, a professional facilitator could serve a boosting role in sustaining the outcomes of the process.

We propose the development of a facilitator’s manual and training materials for professionals, as well as additional self-guided resources for families, such as videos to accompany the materials (e.g., “How to Hold a Family Meeting”). We believe that the option of either a self-guided or facilitated process would provide caregiving families with more choices in addressing their unique care and support arrangements *and* provide an opportunity for more rigorous testing of the tools and process. The ability to compare the experiences of self-guided versus facilitated families would contribute to better understanding of the impact and outcomes of Our Family, Our Way.

REVISIONS TO THE TOOLS

It was clear from the feedback provided by participants that issues of redundancies and bulk must be addressed prior to another test of the materials. At the same time, participants pointed out *additional* areas such as nutrition, addiction, and mental health issues that can have profound effects on the care and support arrangement but were not included in this first iteration. Further

clarification of guide and tool instructions and the ability of families to “opt out” of sections of the guide that do not apply to their particular care and support arrangement should also be considered.

Based upon participant feedback, we are also interested in exploring formats of the tools which may allow for greater flexibility in how families complete and share them (e.g., electronic versions, the ability to view all family members’ responses together). As pointed out by some participants, electronic versions of the tools could assist with inclusion of family members who live remotely and potentially save time during the family meeting.

REVISIONS TO THE PROCESS

It is clear that experiences of using the individual tools, the individual tools exchange, and the shared assessment process had the greatest impact on our families. Some stopped the process after the shared assessment process because they already felt a sense of accomplishment simply from addressing their different perspectives. Others found these early parts of the process to be emotionally draining and decided that they had reached their capacity. The process in its current form may be too overwhelming for some families, especially those at greater risk for communication problems and for falling back into old family dynamics or patterns.

The fact that some families did not reach the point of creating a family goal statement or family care and support plan may suggest that the process needs to be broken down into smaller, more manageable segments which allow families to work at their own pace. The involvement of a service professional could also assist in this regard. The professional could walk families through the process in sequential steps, helping to assure fidelity to the process, yet providing opportunities for families to process, address problems, and respond before moving on to the next step.

INCLUSIVENESS

Many participants stated in hindsight that they would have made different decisions about whom to include in the process. We would like to explore how recruitment and guide materials could be adapted to give families a clearer idea of how Our Family, Our Way may benefit them and help them make decisions about who to involve. Participants also shared that the process should not be focused solely on aging parents and their adult children, but could be expanded to include less immediate family members, such as grandchildren, and others, such as friends, neighbors, and paid caregivers.

The value of requiring the inclusion of the person with care needs is unquestionable and will remain a core feature of Our Family, Our Way. At the same time, there are many families who could benefit from Our Family, Our Way that have members with cognitive and/or developmental limitations that do not allow them to utilize the tools and process in their current formats. Considering the growing numbers of individuals living with these challenges and the numbers of caregivers supporting them, future iterations of this work must explore how these individuals can

be given a voice and meaningfully participate in the process. The Our Family, Our Way research team has already begun exploring partnerships that will lead us closer to that possibility.

We also recognize that there will be circumstances where the person with care needs cannot or chooses not to participate in the process, but his or her caregivers could benefit from using Our Family, Our Way. This scenario and others, such as couples with no adult children, or persons with care needs residing in long-term care settings, present important challenges, and we believe that with some customization, Our Family, Our Way could be made available for a wide variety of arrangements and settings.

REFERENCES

- Ahn, S., Smith, M. L., Altpeter, M., Belza, B., Post, L., & Ory, M. G. (2014). Methods for streamlining intervention fidelity checklists: An example from the Chronic Disease Self-Management program. *Frontiers in Public Health*, 2, 294. Retrieved from: <http://doi.org/10.3389/fpubh.2014.00294>
- Amaro, L. M., & Miller, K. I. (2016). Discussion of care, contribution, and perceived gratitude in the family caregiver and sibling relationship. *Personal Relationships*, 23(1), 98-110.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. *Psychological review*, 84(2), 191.
- Bandura, A. (1998). Personal and collective efficacy in human adaptation and change. *Advances in Science*, 1, 51-71.
- Bandura, A. (2000). Exercise of human agency through collective efficacy. *Current Directions in Psychological Science*, 9(3), 75-78.
- Bandura, A. (2006). Guide for constructing self-efficacy scales. *Self-Efficacy Beliefs of Adolescents*, 5, 307-337.
- Bandura, A., Caprara, G. V., Barbaranelli, C., Regalia, C., & Scabini, E. (2011). Impact of family efficacy beliefs on quality of family functioning and satisfaction with family life. *Applied Psychology*, 60(3), 421-448.
- Beatty, P. C., & Willis, G. B. (2007). Research synthesis: The practice of cognitive interviewing. *Public Opinion Quarterly*, 71(2), 287-311.
- Becker, G. S. (1976). Altruism, egoism, and genetic fitness: Economics and sociobiology. *Journal of Economic Literature*, 14(3), 817-826.
- Becker, G. S. (1974). A theory of social interactions. *Journal of Political Economy*, 82(6), 1063-1093.
- Blau, Z. (1973). *Old age in a changing society*. New York, NY: Viewpoints Press.
- Bowen, D. J., Kreuter, M., Spring, B., Cofta-Woerpel, L., Linnan, L., Weiner, D., & Fernandez, M. (2009). How we design feasibility studies. *American Journal of Preventive Medicine*, 36(5), 452-457. Retrieved from: <http://doi.org/10.1016/j.amepre.2009.02.002>
- Bravell, M. E., Zarit, S. H., & Johansson, B. (2011). Self-reported activities of daily living and performance-based functional ability: A study of congruence among the oldest old. *European Journal of Ageing*, 8(3), 199-209.
- Brody, E. M. (1990). Role reversal: An inaccurate and destructive concept. *Journal of Gerontological Social Work*, 15(1-2), 15-22.

- Buhr, G. T., Kuchibhatla, M., & Clipp, E. C. (2006). Caregivers' reasons for nursing home placement: Clues for improving discussions with families prior to the transition. *The Gerontologist*, 46(1), 52-61.
- Byrne, D., Goeree, M. S., Hiedemann, B., & Stern, S. (2009). Formal home health care, informal care, and family decision making. *International Economic Review*, 50(9), 1205-1226.
- Carroll, C., Patterson, M., Wood, S., Booth, A., Rick, J., & Balain, S. (2007). A conceptual framework for implementation fidelity. *Implementation Science*, 2(1), 40.
- Caron, C. D., & Bowers, B. J. (2003). Deciding whether to continue, share, or relinquish caregiving: Caregiver views. *Qualitative Health Research*, 13(9), 1252-1271.
- Cicirelli, V. G. (1983). Adult children and their elderly parents. In T.H. Brubaker (Ed.) *Family relationships in later life* (pp. 229-242). Beverly Hills, CA: Sage Publications.
- Cicirelli, V. G. (1992). *Family caregiving: Autonomous and paternalistic decision making*. Newbury Park: Sage Publications.
- Cicirelli, V. G. (1993). Attachment and obligation as daughters' motives for caregiving behavior and subsequent effect on subjective burden. *Psychology and Aging*, 8(2), 144.
- Connidis, I. A., & Kemp, C. L. (2008). Negotiating actual and anticipated parental support: Multiple sibling voices in three-generation families. *Journal of Aging Studies*, 22(3), 229-238.
- Davey, A., Janke, M., & Savla, J. (2005). Antecedents of intergenerational support: Families in context and families as context. *Annual Review of Gerontology and Geriatrics*, 24, 29-54.
- Davey, A., & Szinovacz, M. E. (2008). Division of care among adult children. In M. E. Szinovacz & A. Davey (Eds.), *Caregiving contexts: Cultural, familial, and societal implications* (pp. 35-70). New York, NY: Springer Publishing Company.
- Dwyer, J. W., Lee, G. R., & Jankowski, T. B. (1994). Reciprocity, elder satisfaction, and caregiver stress and burden: The exchange of aid in the family caregiving relationship. *Journal of Marriage and the Family*, 56(1), 35-43.
- Eiskovits, Z., & Koren, C. (2010). Approaches to and outcomes of dyadic interview analysis. *Qualitative Health Research*, 20(12), 1642-1655.
- Emerson, R. M. (1976). Social exchange theory. *Annual Review of Sociology*, 2(1), 335-362.
- Engers, M., & Stern, S. (2002). Long-term care and family bargaining. *International Economic Review*, 43(1), 73-114.
- Feinberg, L. F. (2014). Moving toward person-and family-centered care. *Public Policy & Aging Report*, 24(3), 97-101.

- Feinberg, L. F., & Whitlatch, C. J. (2002). Decision making for persons with cognitive impairment and their family caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 17(4), 237-244.
- Finch, J., & Mason, J. (1993). *Negotiating family responsibilities*. New York, NY: Routledge Publishing.
- Fingerman, K. L., Pitzer, L. M., Chan, W., Birditt, K. S., Franks, M. M., & Zarit, S. H. (2011). Who gets what and why? Help middle-aged adults provide to parents and grown children. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 66B, 87-98.
- Fitzpatrick, M. A. (2013). Health, aging, and family paradigms: A theoretical perspective 14. In D. O'Hair & G. Kreps (Eds.), *Applied Communication Theory and Research* (p. 232). New York, NY: Routledge.
- Fontaine, R., Gramain, A., & Wittwer, J. (2009). Providing care for an elderly parent: Interactions among siblings? *Health Economics*, 18(9), 1011-1029.
- Fried, T. R., Bradley, E. H., O'Leary, J. R., & Byers, A. L. (2005). Unmet desire for caregiver-patient communication and increased caregiver burden. *Journal of the American Geriatrics Society*, 53, 59-65.
- Galvin, K. M., & Brommel, B. J. (1991). *Family Communication: Cohesion and Change*. New York: HarperCollins.
- Ganong, L. H., & Coleman, M. (2006). Obligations to stepparents acquired in later life: Relationship quality and acuity of needs. *Journals of Gerontology: Social Sciences*, 61B(2), 80-88.
- Ganong, L., Coleman, M., Killian, T., & McDaniel, A. K. (1998). Attitudes toward obligations to assist an elderly parent or stepparent after later-life remarriage. *Journal of Marriage and the Family*, 60(3), 595-610.
- Gans, D., & Silverstein, M. (2006). Norms of filial responsibility for aging parents across time and generations. *Journal of Marriage and the Family*, 68(4), 961-976.
- Grote, N. K., & Clark, M. S. (2001). Perceiving unfairness in the family: Cause or consequence of marital distress? *Journal of Personality and Social Psychology*, 80(2), 281.
- Grundy, E., & Henretta, J. C. (2006). Between elderly parents and adult children: A new look at the intergenerational care provided by the "Sandwich Generation." *Ageing & Society*, 26(5), 707-722.
- Harden, J., Backett-Milburn, K., Hill, M., & MacLean, A. (2010). Oh, what a tangled web we weave: Experiences of doing 'multiple perspectives' research in families. *International Journal of Social Research Methodology*, 13(5), 441-452.

- Hatfield, E., Traupmann, J., Sprecher, S., Utne, M., & Hay, J. (1985). Equity and intimate relations: Recent research. *Incompatible and incompatible relationships* (pp. 91-117). Springer: New York.
- Hauser, B. B., & Beckman, S. L. (1984). Aging parent/mature child relationships. *Journal of Marriage and the Family*, 46, 295-299.
- Henretta, J. C., Soldo, B. J., & Van Voorhis, M. F. (2011). Why do families differ? Children's care for an unmarried mother. *Journal of Marriage and Family*, 73, 383-395.
- Hequembourg, A., & Brallier, S. (2005). Gendered stories of parental caregiving among siblings. *Journal of Aging Studies*, 19(1), 53-71.
- Hiedemann, B., & Stern, S. (1999). Strategic play among family members when making long-term care decisions. *Journal of Economic Behavior & Organization*, 40(1), 29-57.
- Horowitz, A., Goodman, C. R., & Reinhardt, J. P. (2004). Congruence between disabled elders and their primary caregivers. *The Gerontologist*, 44(4), 532-542.
- Ingersoll-Dayton, B., Neal, M. B., Ha, J. H., & Hammer, L. B. (2003). Redressing inequity in parent care among siblings. *Journal of Marriage and Family*, 65(1), 201-212.
- Johnson, R. W. (2008). Choosing between paid elder care and unpaid help from adult children: The role of relative prices in the care decision. In M. E. Szinovacz & A. Davey (Eds.), *Caregiving contexts: Cultural, familial, and societal implications* (pp. 35-70). New York: Springer.
- Karantzas, G. C., Evans, L., & Foddy, M. (2010). The role of attachment in current and future parent caregiving. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 65(5), 573-580.
- Kemp, C. L., Ball, M. M., & Perkins, M. M. (2013). *Journal of Aging Studies*, 27(1), 15-29.
- Kwak, M., Ingersoll-Dayton, B., & Kim, J. (2012). *Journal of Social and Personal Relationships*, 29(4), 470-487.
- Lawrence, J. A., Goodnow, J. J., Woods, K., & Karantzas, G. (2002). Distributions of caregiving tasks among family members: The place of gender and availability. *Journal of Family Psychology*, 16(4), 493-509.
- Leopold, T., Raab, M., & Engelhardt, H. (2014). The transition to parent care: Costs, commitments, and caregiver selection among children. *Journal of Marriage and Family*, 76(2), 300-318.
- Lerner, M. J., Somers, D. G., Reid, D., Chiriboga, D., & Tierney, M. (1991). Adult children as caregivers: Egocentric biases in judgments of sibling contributions. *The Gerontologist*, 31(6), 746-755.

- Magaziner, J., Simonsick, E. M., & Hebel, J. R. (1988). Patient-proxy response comparability on measures of patient health and functional status. *Journal of Clinical Epidemiology*, 41(11), 1065-1074.
- Matthews, S. H. (1987). Provision of care to old parents: Division of responsibility among adult children. *Research on Aging*, 9(1), 45-60.
- Matthews, S. H., & Rosner, T. T. (1988). Shared filial responsibility: The family as the primary caregiver. *Journal of Marriage and the Family*, 50(1), 185-195.
- McGraw, L. A., & Walker, A. J. (2004). Negotiating care: Ties between aging mothers and their caregiving daughters. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 59(6), 5324-5332.
- McPherson, C. J., Wilson, K. G., Chyurlia, L., & Leclerc, C. (2010). The balance of give and take in caregiver-partner relationships: An examination of self-perceived burden, relationship equity, and quality of life from the perspective of care recipients following stroke. *Rehabilitation Psychology*, 55(2), 194-203.
- National Alliance for Caregiving and AARP. (2004). *Caregiving in the U.S.* Washington, D.C.
- National Alliance for Caregiving and AARP. (2015). *Caregiving in the U.S.* Washington, D.C.
- National Alliance for Family Caregiving in the U.S. (1997). *Findings from a National Survey*. Washington, DC. Retrieved from http://assets.aarp.org/rgcenter/il/caregiving_97.pdf
- Neufeld, A., & Harrison, M. J. (1995). Reciprocity and social support in caregivers' relationships: Variations and consequences. *Qualitative Health Research*, 5(3), 348-365.
- Neuharth T. J., & Stern S. (2002). Shared caregiving responsibilities of adult siblings with elderly parents. *Journal of Human Resources*. 37, 441-478.
- Noelker, L., & Poulshock, S. W. (1983). Elder family care recipients perceptions of caregiving and caregivers. *The Gerontologist*, 23(1), 242-242.
- Pearlin, L. I., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30(5), 583-594.
- Pecchioni, L. L. (2001). Implicit decision making in family caregiving. *Journal of Social and Personal Relationships*, 18(2), 219-237.
- Pezzin, L. E., Pollak, R. A., & Schone, B. S. (2007). Efficiency in family bargaining: Living arrangements and caregiving decisions of adult children and disabled elderly parents. *CESifo Economic Studies*, 53(1), 69-96.
- Pezzin, L. E., Pollak, R. A., & Schone, B. S. (2015). Bargaining power, parental caregiving, and intergenerational coresidence. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 70(6), 969-980.

- Pezzin, L. E., & Schone, B. S. (1999). Intergenerational household formation, female labor supply and informal caregiving: A bargaining approach. *The Journal of Human Resources*, 34(3), 475–503.
- Pillemer, K., & Suito, J. J. (2006). Making choices: A within-family study of caregiver selection. *The Gerontologist*, 46(4), 439–448.
- Pillemer, K., & Suito, J. J. (2008). Collective ambivalence: Considering new approaches to the complexity of intergenerational relations. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 63(6), 5394-5396.
- Pillemer, K., & Suito, J. J. (2013). Who provides care? A prospective study of caregiving among adult siblings. *The Gerontologist*, 54(4), 589-598.
- Pillemer, K., & Suito, J. J. (2014). Who provides care? A prospective study of caregiving among adult siblings. *The Gerontologist*, 54(4), 589-598.
- Pillemer, K., Suito, J. J., Mock, S. E., Sabir, M., Pardo, T. B., & Sechrist, J. (2007). Capturing the complexity of intergenerational relations: Exploring ambivalence within later-life families. *Journal of Social Issues*, 63(4), 775-791.
- Pruchno, R. A., Burant, C. J., & Peters, N. D. (1997). Typologies of caregiving families: Family congruence and individual well-being. *The Gerontologist*, 37(2), 157-168.
- Pyke, K. (1999). The micropolitics of care in relationships between aging parents and adult children: Individualism, collectivism, and power. *Journal of Marriage and Family*, 61(3), 661–672.
- Radina, M. E., Gibbons, H. M., & Lim, J. Y. (2009). Explicit versus implicit family decision-making strategies among Mexican American caregiving adult children. *Marriage & Family Review*, 45(4), 392-411.
- Reczek, C. (2014). Conducting a multi-family member interview study. *Family Process*, 53(2): 318-335.
- Reamy, A. M., Kim, K., Zarit, S. H., & Whitlatch, C. J. (2012). Values and preferences of individuals with dementia: Perceptions of family caregivers over time. *The Gerontologist*, 53(2), 293-302.
- Reinhardt, S. C., Feinberg, L. F., Choula, R., & Houser, A. (2015). *Valuing the Invaluable: 2015 Update*. AARP Public Policy Institute, July, 2015.
- Richlin-Klonsky, Judith, and Vern L. Bengtson. (1996). "Pulling together, drifting apart: A longitudinal case study of a four-generation family." *Journal of Aging Studies* 10, (4), 255-279.
- Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, 55(2), 309-319.

- Schulz, R., Beach, S. R., Cook, T. B., Martire, L. M., Tomlinson, J. M., & Monin, J. K. (2012). Predictors and consequences of perceived lack of choice in becoming an informal caregiver. *Aging & Mental Health, 16*(6), 712–721.
- Scott, J. (1997). Changing households in Britain: Do families still matter? *The Sociological Review, 45*(4), 591-620.
- Sekhon, M., Cartwright, M., & Francis, J. J. (2017). Acceptability of healthcare interventions: An overview of reviews and development of a theoretical framework. *BMC Health Services Research, 17*, 88. Retrieved from: <http://doi.org/10.1186/s12913-017-2031-8>
- Seltzer, M. M., & Li, L. W. (2000). The dynamics of caregiving: Transitions during a three-year prospective study. *The Gerontologist, 40*(2), 165-178.
- Shuey, K., & Hardy, M. A. (2003). Assistance to aging parents-in-law: Does lineage affect family allocation decisions? *Journal of Marriage and Family, 65*(2), 418–431.
- Silverstein, M., Conroy, S. J., & Gans, D. (2008). Commitment to caring: Filial responsibility and the allocation of support by adult children to older mothers. In M. E. Szinovacz & A. Davey (Eds.), *Caregiving contexts: Cultural, familial, and societal implications* (71-91). New York, NY: Springer.
- Silverstein, M., Conroy, S. J., Wang, H., Giarrusso, R., & Bengtson, V. L. (2002). Reciprocity in parent-child relations over the adult life course. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 57*(1), S3-S13.
- Smerglia, V. L., & Deimling, G. T. (1997). Care-related decision-making satisfaction and caregiver well-being in families caring for older members. *The Gerontologist, 37*(5), 658-665.
- Sprecher, S. (2001). A comparison of emotional consequences of and changes in equity over time using global and domain-specific measures of equity. *Journal of Social and Personal Relationships, 18*(4), 477-501.
- Sprecher, S. (2016). Inequity Leads to Distress and a Reduction in Satisfaction: Evidence From a Priming Experiment. *Journal of Family Issues, 39*(1), 230-244.
doi:10.1177/0192513x16637098.
- Strawbridge, W. J., & Wallhagen, M. I. (1991). Impact of family conflict on adult child caregivers. *The Gerontologist, 31*(6), 770-777.
- Suitor, J. J., Gilligan, M., Pillemer, K., & Pruchno, R. (2013). The role of violated caregiver preferences in psychological well-being when older mothers need assistance. *The Gerontologist, 53*(1), 388–396.
- Suitor, J. J., & Pillemer, K. (2007). Mothers' favoritism in later life: The role of children's birth order. *Research on Aging, 29*(1), 32–55.

- Szinovacz, M. E., & Davey, A. (2007). Changes in adult child caregiver networks. *The Gerontologist*, 47(3), 280-295.
- Szinovacz, M. E., & Davey, A. (2008). The division of parent care between spouses. *Ageing and Society*, 28(04), 571-597.
- Szinovacz, M. E., & Davey, A. (2013). Changes in adult children's participation in parent care. *Ageing & Society*, 33, 667-697.
- Szinovacz, M. E., & Davey, A. (2013). Prevalence and predictors of change in adult-child primary caregivers. *The International Journal of Aging and Human Development*, 76(3), 227-249.
- Tennstedt, S. L., McKinley, J., & Sullivan, L. M. (1989). Informal care for frail older persons: The role of secondary caregivers. *The Gerontologist*, 29, 677-683.
- Tolkacheva, N., van Groenou, M. B., & van Tilburg, T. (2010). Sibling influence on care given by children to older parents. *Research on Aging*, 32(6), 739-759.
- Tolkacheva, N., van Groenou, M. B., & van Tilburg, T. (2011). The impact of informal caregiving networks on adult children's care-giver burden. *Ageing and Society*, 31(01), 34-51.
- Tolkacheva, N., van Groenou, M. B., & van Tilburg, T. (2014). Sibling similarities and sharing the care of older parents. *Journal of Family Issues*, 35(3), 312-330.
- Ummel, D., & Achille, M. (2016). How not to let secrets out when conducting qualitative research with dyads. *Qualitative Health Research*, 26(6), 807-815.
- Van Parys, H., Provoost, V., De Sutter, P., Pennings, G., & Buysse A. (2017). Multi family member interview studies: A focus on data analysis. *Journal of Family Therapy*, 39(3), 386-401.
- Volkom, M. V. (2006). Sibling relationships in middle and older adulthood: A review of the literature. *Marriage & Family Review*, 40(2-3), 151-170.
- Walster, E., Walster, G. W., & Berscheid, E. (1978). *Equity: Theory and research*. Boston, MA: Allyn and Bacon.
- Warin, J., Solomon, Y., & Lewis, C. (2007). Swapping stories: Comparing plots: Triangulating individual narratives within families. *International Journal of Social Research Methodology*, 10(2), 121-134.
- Whitlatch, C. J., & Menne, H. (2009). Don't forget about me! Decision making by people with dementia. *Generations*, 33(1), 66-73.
- Whitlatch, C. J., Piiparinen, R., & Friss Feinberg, L. (2009). How well do family caregivers know their relatives' care values and preferences? *Dementia*, 8(2), 223-243.

- Wiesmann, S., Boeije, H., van Doorne-Huiskes, A., & Den Dulk, L. (2008). 'Not worth mentioning': The implicit and explicit nature of decision making about the division of paid and domestic work. *Community, Work & Family, 11*(4), 341-363.
- Wolf, D. A. (2014). Getting help from others: The effects of demand and supply. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 69*(1), 559-564.
- Wolf, D. A., Freedman, V., & Soldo, B. J. (1997). The division of family labor: Care for elder parents. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 52B*(Special Issue), 102–109.
- Wolff, J. L., & Kasper, J. D. (2006). Caregivers of frail elders: Updating a national profile. *The Gerontologist, 46*(3), 344–356.
- Zarit, S. H., Lee, J. E., Barrineau, M. J., Whitlatch, C. J., & Femia, E. E. (2013). Fidelity and Acceptability of an Adaptive Intervention for Caregivers: An Exploratory Study. *Aging & Mental Health, 17*(2), 197–206. Retrieved from: <http://doi.org/10.1080/13607863.2012.717252>
- Zweibel, N. & Lydens, L. A. (1990). Incongruent perceptions of older adult/caregiver dyads. *Family Relations, 39*(1), 63-67.

CONTACT INFORMATION:

For more information about this project or for access to Guide contents, Individual Tools, Family Tools, and Family Resources Booklet, please contact Jennifer L. Heston, PhD, LISW, Scripps Gerontology Center, Miami University, Oxford, OH, 45056.

hestonjl@MiamiOH.edu

513-529-1858

APPENDIX A FAMILY SUMMARIES

(All family names are fictitious.)

The “North” Family

Participating Family Members	Relationship to PWCN	Housing or Living Arrangement	Gender	Age	Marital Status	Education	Employment	Household Income	Self-Rated Health
PWCN Eleanor	Self	House	F	81	D	High School	PT	25-50,000	Good
Primary Caregiver Janet	Daughter	Lives with PWCN	F	42	M	Some College	FT	50-100,000	Good
Caregiver 2 Don	Son-in-law	Lives with PWCN	M	51	M	High School /GED	FT	100,000+	Excellent

PROFILE: The “North” family lives together in a one-story house in a small rural community. The PWCN, Eleanor, age 81, is divorced and shares the expenses of the home with her daughter Janet, age 42, and son-in-law, Don, age 51. Janet and Don have three school-age children living at home and Don has two children from a previous marriage, living outside the home. The PWCN has relatively minimal IADL limitations; she lives with the least impairments of all the PWCNs in this study. In fact, she works a menial job outside the home for two hours each week; it’s a small job that she is determined to hang onto. She is fiercely independent but needs help with at least three IADLs and the family is quite concerned about the risks she takes in getting around inside and outside the home. She becomes easily tired and depends on her family for most of the day-to-day tasks of meals, transportation, and housekeeping. Janet works from home and has an office in the basement of the home. Thus, she is on hand if Eleanor needs her. Don is quite handy with household repairs and projects and the entire family has come to rely on his willingness to step in and take on large tasks. However, he does not engage in any hands-on care with Eleanor. Aside from being fiercely independent, Eleanor is intensely private. Because of this, most conversations about care take place between Eleanor and Janet. According to Janet, Don just “does what he’s told,” and all agree that the care and support arrangement works well for now. Don is often out of the home for a job on the road, and the school-age children

take up a lot of Janet's time. This family reports very little strain related to the care and support arrangement. Their greatest concerns are about the future; all agree that they have to be vigilant for changes in Eleanor's functional health.

PROCESS: This family made quite a few errors in following the Our Family, Our Way guidelines. Most particularly, Don and Eleanor mixed up their color-coded, clearly marked individual tools. Don attempted to fill out the caregiver version of the tools and Eleanor attempted to fill out the caregiver version. This was not discovered until the tools exchange at the family meeting, and although they had adapted their responses and they muddled through the tools exchange, it did affect their experience with the process.

OUTCOME: Eleanor, Janet, and Don all report that they are glad that they completed the Guide and process this early in the Eleanor's aging process because they now have a heads up on what's ahead and how to talk about it. They made several changes in their house to enhance the safety of the environment, precipitated especially by the "Environmental Considerations" tool. They report improved communication, would use the Guide again and would recommend it to others.

Care Intensity Level: LOW

Strain: LOW

Congruence: MIDDLE

Going-in Efficacy: MIDDLE

Fidelity: LOW

Impact: LOW

The “Woods” Family

Participating Family Members	Relationship to PWCN	Housing or Living Arrangement	Gender	Age	Marital Status	Education	Employment	Household Income	Self-Rated Health
PWCN Thomas	Self	House	M	67	M	College	No	50-100,000	Good
Primary Caregiver Miranda	Spouse	Lives with PWCN	F	66	M	High School	Retired	50-100,000	Good
Caregiver 2 Tracey	Son	20 minutes from PWCN	M	37	M	College	FT	50-100,000	Fair
Caregiver 3 Thomas Jr. (TJ)	Daughter	10 minutes from PWCN	F	34	M	Some College	PT	50-100,000	Good

PROFILE: Thomas, the person with care needs, is 67. Thomas requires the most help with managing medications, medical or nursing tasks, transportation, doing house or yard work, coordinating health care and appointments, and managing money and legal matters. Thomas lives with his recently retired wife, Miranda. Miranda retired from her job as an administrative assistant in order to be a full-time caregiver to Thomas. Their daughter, Tracey, age 34, lives 10 minutes away and plays an active role in the care arrangement and is often included in decision making conversations as the secondary caregiver. Tracey works in business administration part time, and is married with two small children. In addition to Tracey, Thomas and Miranda have a 37 year old son, Thomas Junior (TJ). TJ lives 20 minutes away and is also married with two children. TJ generally provides limited assistance and is often uninformed about the care situation. None of the family members report significant financial strains.

PROCESS: Participating in the project were Thomas (PWCN), Miranda, Tracey, and TJ. Although some tools were not completed in their entirety, the family adhered to the remaining guidelines of the process; in the family meeting, Joanne and Julie assumed leadership roles in the family meeting and strictly stood by the guidelines. All things considered, the family participants reported a positive response to the experience and would recommend it to others.

OUTCOME: The “Woods” family reported three major outcomes of the Our Family, Our Way process: the family agreed to, with supervision, include Thomas more in day-to-day self-care activities like managing finances and cooking; they agreed to include TJ in all communication via text or phone; and they agreed to meet formally four times a year to revisit the care and support plan.

Care Intensity Level: MIDDLE

Strain: MIDDLE

Congruence: MIDDLE

Going-in Efficacy: HIGH

Fidelity: HIGH

Impact: MIDDLE

The “Kohl” Family

Participating Family Members	Relationship to PWCN	Housing or Living Arrangement	Gender	Age	Marital Status	Education	Employment	Household Income	Self-Rated Health
PWCN Susan	Self	House	F	78	W	Some College	No	<25,000	Good
Primary Caregiver Mandy	Daughter	3 minutes from PWCN	F	54	W	Some College	No	<25,000	Fair
Caregiver 2 Brad	Son	3 minutes from PWCN	M	52	M	High School	FT	50-100,000	Excellent
Caregiver 3 Nicole	Daughter-in-law	3 minutes from PWCN	F	49	M	Some College	FT	50-100,000	Good

PROFILE: Susan, the PWCN, recently became a widow. She lives on a limited income in a home that she owns. Her daughter, and primary caregiver, Mandy, left her job when her father became ill and when funding for in-home care had been expended. Mandy has limited income and health issues of her own. She provides most of the direct care and has been trusted to do so due to her background in nursing, work history in nursing facilities, and for her assignment as Power of Attorney. In addition to Mandy, Susan has two other children. Her only son, Brad, and his wife, Nicole, live three minutes from Susan. They each work full-time and act as secondary caregivers for Susan. They have adult children of their own, Brad having four biological children and three step-children from his marriage to Nicole. Susan has another daughter, Gloria, who lives in town. She did not participate in the project. Family reported that while Gloria has provided limited assistance in caregiving both in the past and currently, she is not a decision maker and helps at her convenience. She is experiencing health issues of her own and is not confident in her ability to care for her mother.

PROCESS: The family did not fully adhere to the guidelines of the process; for completion of individual tools, the primary caregiver assisted the PWCN her individual tools due to difficulty in reading and completion. For the family meeting, the PWCN did not attend or participate, despite being present in the home. This was the PWCN’s choice. The family did not exchange the tools, but instead sat at the table close to one another and viewed each other’s tools together.

OUTCOME: The “Kohl” family reported that their family did not make any changes as a result of the Our Family, Our Way process. Each of them individually identified shared goals, but none of those goals matched. They all reported that the goal was to keep Susan

safe and at home for as long as possible. Despite change not happening, it was clear that for the primary caregiver, change was desired as everyone recognized that a significant caregiving burden fell on the primary caregiver; the primary caregiver identifying negative effects on her social life, health, and income. The primary caregiver reported that the sacrifice was worth the preservation of the familial relationships. In general, the family reported that the process was helpful, but reported that it may have been more helpful at the onset of caregiving planning when their father fell ill. They would recommend the tools to others.

Care Intensity Level: LOW

Strain: HIGH

Congruence: MIDDLE

Going-in Efficacy: MIDDLE

Fidelity: LOW

Impact: LOW

The “Franklin” Family

Participating Family Members	Relationship to PWCN	Housing or Living Arrangement	Gender	Age	Marital Status	Education	Employment	Household Income	Self-Rated Health
PWCN Rosie	Self	House	F	71	W	Some College	PT	<25,000	Good
Primary Caregiver Sherese	Daughter	Lives with PWCN	F	47	S	Some College	NO	<25,000	Good
Caregiver 2 Jeannette	Daughter	3 to 5 minutes from PWCN	F	51	D	High School	FT & PT	25-50,000	Fair

PROFILE: The participating family members of the “Franklin” family were Rosie, her daughter Sherese, and her daughter Jeannette. Rosie (age 71) is undergoing treatment for stomach cancer and also lives with rheumatoid arthritis which can greatly affect her functioning, however, she experiences a remission from her arthritis when she is receiving chemotherapy. Rosie is currently enrolled in a training program through Goodwill Industries and does part-time clerical work for about 18 to 20 hours a week. She is able to drive, but she does not drive when she’s not feeling well. Sherese (age 47), has never married and has one adult child. She is currently not employed and is attending college to earn her bachelor’s degree. Rosie and Sherese live in Rosie’s home along with Sherese’s six year old grandchild for whom Sherese is responsible. Rosie and Sherese have limited household income and Rosie expresses concerns about finances and the costs of her medications. Sherese provides all hands-on help that Rosie requires and also cooks, runs errands, and accompanies Rosie to medical appointments and treatments. Jeannette (age 51) lives in her own home about five minutes away from Rosie and Sherese. She has six grown children and works both a full-time (35 hours per week) and part-time job (23 hours per week.) She also expresses concerns about finances and some concerns about her own health. Jeannette is a frequent visitor to Rosie and Sherese’s home and also assists with picking up medications, running errands, and accompanying Rosie to medical appointments and treatments when her work schedule allows. She often states that she wishes she could “do more”, but that her work schedule limits her ability to care for Rosie.

PROCESS: There are two other sons and a daughter, Janice, who live in the area, all within 20 minutes of Rosie. It is unclear how much contact they have with Rosie, Sherese, and Jeannette, but they are frequently mentioned by all three and they seem to enjoy positive relationships between them. Rosie speaks fondly of her family members and frequently mentions their good humor. She expresses that

if she needs anything, they'll take care of it. The two sons and Janice did not participate in the project, but that seems to be a result of a misunderstanding in which Rosie told Sherese and Jeannette that only the three of them could participate (possibly because the recruitment information stated a minimum of three participating family members), even though the researcher working with the family did inform Rosie in their early contacts that all adult children and children-in-law were invited to participate. Both Sherese and Jeannette expressed that they wished their other siblings had been included in the process.

The "Franklin" family did not fully adhere to the guidelines of the family meeting, again, due in part to a misunderstanding in which Rosie told Sherese and Jeannette that the researcher would be meeting with them in person to go through the tools. Perhaps because of this, it appears that they did not thoroughly read through the materials and guidelines provided to them, and did not complete a Shared Assessment or Family Care and Support Plan during their family meeting.

OUTCOME: All three reported that it was very helpful for them to compare and discuss the individual tools with each other. They agreed to changes in their communication processes but made no changes in the care and support arrangement. All three reported a positive experience with the process and stated they would recommend it to others.

Care Intensity Level: LOW

Strain: LOW

Congruence: MIDDLE

Going-in Efficacy: HIGH

Fidelity: LOW

Impact: MIDDLE

The “Knox” Family

Participating Family Members	Relationship to PWCN	Housing or living arrangement	Gender	Age	Marital Status	Education	Employment	Household Income	Self-Rated Health
PWCN Dora	Self	House	F	94	W	High School	No	<25,000	(Missing)
Primary Caregiver Stan	Son	Lives with PWCN	M	65	S/NM	Some College	No	<25,000	Good
Caregiver 2 Kate	Daughter-in-law	20 minutes from PWCN	F	70	M	Post-Graduate	FT	100,000+	Good
Caregiver 3 Roger	Son	20 minutes from PWCN	M	70	M	Post-Graduate	PT	100,000+	Excellent
Caregiver 4 Julius	Son	15 minutes from PWCN	M	74	S/NM	Post-Graduate	No	<25,000	Excellent
Caregiver 5 Violet	Daughter	30 minutes from PWCN	F	72	M	Post-Graduate	No	50-100,000	Excellent

PROFILE: A striking characteristic of the “Knox” family is its wide diversity of household incomes, educational attainment, employment history, and health status. All of these come into play in the care and support arrangement as well as in the family’s decision making processes. Dora, the parent with care needs, is 94. Dora requires significant help with all IADLs and requires hands on help with bathing and some help with dressing. Dora’s retirement income is quite limited. She and Stan co-reside in a one-story home in a small mid-sized town. Her 65 year old son Stan left his job and moved in with his mother four years ago to assume full-time caregiving responsibilities. Stan has had a spotty work history and has a very limited Social Security income. In addition to Stan, Dora has four other children. One son, Roger, and his wife Kate live 20 minutes away and have assumed a major role in the management of Dora’s care arrangement, although Chuck does nearly all of the direct care. Dora receives formal services for assistance primarily with bathing. Roger and Kate have advanced degrees in organizational management and are nearing full retirement from their successful consulting business. Dora has another son, Julius, the oldest in the family, who lives alone, about 15 minutes from Dora; he also has a spotty work history, limited income, and has many health issues of his own. Dora has two daughters. For five months of the year, daughter Violet,

age 72 lives with her husband Randy about 30 minutes from Dora; for the other seven months, she lives several states away and rarely comes home.

PROCESS: Participating in the project were Dora (PWCN), Stan, Roger, Kate, Julius, and Violet. The family did not fully adhere to the guidelines of the process; in the family meeting, Roger and Kate assumed leadership roles in the family meeting and departed in several ways from the guidelines. They completed the Shared Assessment and although they did not formally complete the Family Care and Support Plan, they made several significant changes in the care and support arrangement.

OUTCOMES: The “Knox” family reported improved communication and three major outcomes of the process: the secondary caregivers agreed to increase their time with Dora and provide Stan a day off each week; they agreed that the primary caregiver would receive “the lion’s share” of assets upon Dora’s death; and they agreed that family members least involved in the care would be informed about, but not included in, the day-to-day decisions about care. By the Time 3 interview, the legal documents had been executed to leave the house to Stan upon Dora’s death. The family reported improved communication and would be very likely to recommend the Guide to others.

Care Intensity Level: HIGH

Strain: MIDDLE

Congruence: MIDDLE

Going-in Efficacy: MIDDLE

Fidelity: MIDDLE

Impact: HIGH

The “Bellin” Family

Participating Family Members	Relationship to PWCN	Housing or Living Arrangement	Gender	Age	Marital Status	Education	Employment	Household Income	Self-Rated Health
PWCN Robin	Self	Independent Living	F	79	M	College	No	50-100,000	Fair
Primary Caregiver David	Spouse	Lives with PWCN	M	82	M	Post-Graduate	No	50-100,000	Good
Caregiver 2 Lynn	Daughter	3 minutes from PWCN	F	52	M	College	FT	100,000+	Excellent
Caregiver 3 Marie	Daughter	70 minutes from PWCN	F	54	M	College	FT	100,000+	Good

PROFILE: In the “Bellin” family, proximity to the PWCN as far as living arrangement appeared to have the largest effect on the caregiving arrangement. All participating family members recognized that the primary caregiver, David, the spouse of Robin, carried the largest load of caregiving responsibility. Robin and David are fairly involved in their living community through the senior center and meals on wheels. In addition, their living community provides assistance with maintenance and cleaning. The PWCN and primary caregiver have two daughters together. The first, Lynn, lives in the same town as her parents. She works full time and has three children of her own. She does provide assistance as needed and is available for emergencies. She more frequently has leisure time with her mother and father, in which her time is not structured with them. Lynn’s husband acts as a secondary contact in the case of an emergency. The second daughter, Marie, lives a little over an hour away. She also works full time and has two children of her own. She is available as needed, but requires advanced planning for visits. She visits every other weekend for a day. The primary caregiver and daughters enjoy fitness and rank their health either good or excellent. At times, this can be a contentious point for the family, as Robin prefers to sleep, or sit with family at home, due to pain she experiences. Participating family would like her to try and engage in physical therapy to regain her strength and activity to promote independence. The primary caregiver and daughters are protective of their time in maintaining their health in order to best care for Robin for as long as possible.

PROCESS: The family did not fully adhere to the guidelines of the process in the context that they required more than one meeting to complete the Guide, and they did not assign roles during the family meeting. The family reported that they used the roles loosely, with

one daughter managing time, and the rest taking turns in reading and encouraging participation. They also did not complete the recorder version of the Shared Assessment and Family Care and Support Plan. However, they reported that tracking the conversation in their individual binders in the shared assessment enforced continued involvement and did not allow for members to disengage, so they preferred it. All reported that the process was repetitive, with one indicating that the repetition was helpful in reinforcing their thoughts and discussions.

OUTCOMES: The “Bellin” family reported that their family did not make any immediate changes as a result of the Our Family, Our Way process, yet several changes were in fact indicated. Robin reported that she felt she had the most work to do as far as follow up to their family meeting, including: physician follow up for medications, emotional and physical therapy follow ups, and looking for community resources. This was a surprise to her as she said that, “this process was supposed to be about me and my needs, and I have the most to do.” The family agreed that the goal was for Robin and David to stay together in independent living for as long as possible and to maintain their health. The daughters also recognized that while the primary caregiver may not ask for breaks, that he does need them and they are more aware of that and he is more willing to ask for a break as a result of their discussions. In general, the family reported that the process was helpful as it allowed their family to talk about things that they do not usually address and got them thinking about things they had not thought about. They reported improved communication and would recommend the Guide to others.

Care Intensity Level: LOW

Strain: LOW

Congruence: MIDDLE

Going-in Efficacy: HIGH

Fidelity: MIDDLE

Impact: LOW

The “Chase” Family

Participating Family Members	Relationship to PWCN	Housing or Living Arrangement	Gender	Age	Marital Status	Education	Employment	Household Income	Self-Rated Health
PWCN Joan	Self	House	F	81	M	Post-Graduate	No	50-100,000	Poor
Primary Caregiver George	Spouse	Lives with PWCN	M	84	M	College	No	50-100,000	Good
Caregiver 2 Ellen	Daughter	25 minutes from PWCN	F	56	D	Post-Graduate	FT	50-100,000	Fair
Caregiver 3 Beth	Daughter	2 minutes from PWCN	F	54	P	College Graduate	PT	50-100,000	Fair

PROFILE: The “Chase” family is highly educated and has sufficient resources to afford formal services to assist Joan, the PWCN, with some of her PADLs and IADLs. Joan is 81 and lives with Parkinson’s disease. Joan has limitations in mobility, fine motor skills, speech, hearing, and cognition. She no longer drives and feels quite isolated. In very recent years she lost her only son to a sudden illness. She has been married to George, age 84, the primary caregiver for approximately 20 years; George is the stepfather to Joan’s daughters, Ellen, age 56 and Beth, age 54. Joan and George live in a large, old two-story rambling house in an established neighborhood in a large city. The master bedroom and bath are on the first level. Ellen lives about a half hour from Joan and Beth lives just blocks away. Ellen and Beth are professional women. Beth gave up one full-time job to take more flexible contract jobs to be “on call” for her mother. Ellen has an adult daughter who lives with a significant developmental disability and chronic health problems. Ellen and Joan have had a stormy relationship since childhood and they have had many conflicts related to the care of their mother. This was part of their strong motivation to participate in the Our Family, Our Way process but was also part of their struggle in the project.

PROCESS: The “Chase” family began the Our Family, Our Way project in earnest, with very strong adherence to the protocol and detailed responses to the individual tools. (Beth helped Joan complete her tools because of Joan’s hand-writing limitations.) At the first of two family meetings, they successfully engaged in the tools exchange although there was significant perceptual incongruence about what was needed and wanted in the care arrangement. Because Joan was weary and time was running out, the family decided to hold a

second meeting to complete the Family Care and Support Plan. Very early into this meeting a legal issue arose that was surprising and disturbing to one of the family members and the meeting ended abruptly and with a great deal of tension. The family did not complete the Guide but remained in the study through Time 3. Two of the family members describe this event as “blowing up.”

OUTCOME: It is difficult to report the outcome from this family’s process because the individual Time 3 reports of the outcome are mixed and contradictory. As of the time of this report, one of the daughters remains essentially estranged from the family, yet the parents report a quite positive outcome from the experience. In spite of this family’s challenges in the project, three of the four reported that they would recommend the Our Family, Our Way Guide to others; the fourth is not sure.

Care Intensity Level: HIGH

Strain: HIGH

Congruence: LOW

Going-in Efficacy: MID- to-LOW

Fidelity: LOW*

Impact: LOW

* Very high fidelity up to and through the first meeting of two meetings. Very low fidelity at second meeting.

The “Hefner” Family

Participating Family Members	Relationship to PWCN	Housing or Living Arrangement	Gender	Age	Marital Status	Education	Employment	Household Income	Self-Rated health
PWCN Elizabeth	Self	House	F	78	M	College	No	25-50,000	Good
Primary Caregiver Sam	Spouse	Lives with PWCN	M	78	M	College	No	25-50,000	Excellent
Caregiver 2 Lily	Daughter	15 minutes from PWCN	F	52	M	Post-Graduate	FT	100,000+	Excellent

PROFILE: The participating family members of the “Hefner” family were Elizabeth, her husband Sam, and their daughter, Lily. Elizabeth and Sam have been married for 55 years. Elizabeth (age 78) was diagnosed with Parkinson’s disease nine years ago. At that time, she and Sam relocated from their home 3.5 hours away to be near Lily. Elizabeth is a retired teacher. She is very concerned about becoming a burden to her family and works hard to maintain her physical abilities by participating in physical therapy and doing as much as she can around the house. She is able to drive. Because of the physical challenges of Parkinson’s Disease and decreased energy, she tends to limit her activities outside of the house, and typically doesn’t attend evening events or events held in places where a great deal of walking is involved. Sam (age 78) is a retired small business owner. In the early years of his retirement, he experience sadness about having no worthwhile things to do. He says becoming a caregiver renewed his feelings of self-worth. He asked Elizabeth to teach him to cook and bake and really enjoys doing these things. Sam is a very social person and enjoys spending time with friends, attending local events, traveling, and sightseeing. Elizabeth’s decreased ability to tolerate outings has been difficult for Sam and he’s expressed a need for more time to socialize and spend time with others. About a year ago, Lily connected Sam with a local retired man in her social circle and the two of them have been meeting weekly for breakfast. They recently added a third man to their group and are now also meeting weekly to exercise at the local rec center. Elizabeth and Sam report a moderate income, but express some concerns about finances—particularly for Elizabeth’s therapies which are not covered by insurance. Lily (age 52) lives about 15 minutes from Elizabeth and Sam. She is married and has three children ages 20, 18, and 17. She holds a doctorate in psychology and works full-time in a high-level position. Lily reports a high level of financial security and she willingly provides financial assistance for Elizabeth and Sam when needed. Elizabeth, Sam, and Lily report that they have always enjoyed close relationships and good communication with each other.

PROCESS: Elizabeth and Sam have two sons who did not participate in the project. Elizabeth and Sam report that they also enjoy a positive relationship with their sons, but made the decision not include them in the project because they live at some distance and are not involved in the day-to-day care arrangement. Ian (age 50) is married and lives about two hours away. Recently, Ian has also started to provide some financial assistance to Elizabeth and Sam. Ben (age 48) is also married and lives about 3.5 hours from them.

The “Hefner” family adhered relatively closely to the guidelines of the family meeting, although they made minor adaptations to the individual tools exchange (they did not limit themselves to 10 minutes and took as long as they needed to review the tools).

OUTCOMES: All three reported a positive experience with the process. They expressed surprise at the effectiveness of the intervention and reported improved communication. They made plans for Lily to provide respite for Sam; Lily was also provide some financial support for respite outings.

Care Intensity Level: L/M

Strain: LOW

Congruence: MIDDLE

Going-in Efficacy: HIGH

Fidelity: HIGH

Impact: MIDDLE

The “Star” Family

Participating Family Members	Relationship to PWCN	Housing or living arrangement	Gender	Age	Marital Status	Education	Employment	Household Income	Self-Rated Health
PWCN John	Self	Assisted Living	M	90	M	Post-Graduate	No	100,000+	Good
Caregiver 1 Marilyn	Daughter	10 to 12 minutes from PWCN	F	52	D	College	FT	100,000+	Excellent
Caregiver 2 Joanne	Daughter	10 minutes from PWCN	F	54	M	College	FT	100,000+	Excellent
Caregiver 3 David	Son	12 minutes from PWCN	M	57	M	GED and Tech School	FT	100,000+	Fair
Caregiver 4 Lisa	Daughter	4.5 hours from PWCN	F	62	D	Post-Graduate	FT	50-100,000	Good

PROFILE: The “Star” family stands out for its size and the decision to focus on the father as the PWCN. The family consists of John (age 90) his wife Laurel, and their nine children. Because Laurel lives with advanced Alzheimer’s disease and could not participate in the project, the decision was made for the process to focus on John. John is a retired physician and is quite independent, but needs extensive assistance with several IADLs, such as meals, laundry, housework, and transportation. John and Laurel live in a facility where Laurel can receive the care she needs and John has support from the staff and his children in caring for her. John is very devoted to Laurel and oversees all her care needs. This is the third care facility they have resided in within the last six years. As Laurel’s care needs have changed, the family has worked to find a setting for them that allows John and Laurel to be together while at the same time providing the total care needed by Laurel.

An interesting feature of this family is their communication system. Via email and group texts, all nine children are typically informed of changes in Laurel and John’s care and other important family news. However, a more frequent level of communication occurs between the “core group” of local children regarding day-to-day needs and changes to the visitation schedule. The visitation schedule is maintained by Joanne, and all siblings report that this is in tune with Joanne’s nature of being very organized and her need to be in control. In general, it appears that the local siblings have positive relationships with each other. They all express that they wish their

brothers could be more involved and communicative, however, they also acknowledge that they are not fully informed on what's going on with their lives and that one brother and his wife are caring for her parents who have extensive health problems.

PROCESS: All nine children were invited to participate in the project and four of them agreed to participate (David, Joanne, Marilyn, and Lisa). For the last six years, the family has operated on a schedule that ensures that at least one of the children visits with John and Laurel for several hours each day—typically in the afternoon and evening during the week and at other times on the weekend. Four of the nine children (David, Joanne, Marilyn, and Lisa) live locally and share the majority of the responsibility for these daily visits. David (age 57) is married and works full-time. His children are grown and out of the house. Joanne is also married and works full-time. Her children are also grown. Marilyn is divorced and also works full-time, however, she still has a 12 year old daughter at home. Lisa is also divorced and lives about five hours away and comes to visit for long weekends about every other month during the school year, and more often in the summer. When she visits, she spends the entire day with John and Laurel and sleeps at her sister's home. The local participating family members all report that Lisa's visits are very helpful in that it gives them a break and she is able to bring a different perspective of how their parents are doing because she spends such intensive time with them.

OUTCOME: The “Star” family reported that it was a switch for them to think of their father as the PWCN because so much energy has been focused on their mother's condition and care needs. However, they acknowledge that now that their mother's physical needs are taken care of by facility staff and she is no longer communicative, really their focus IS on their father and helping him deal with their mother's decline. The most important outcome of the Our Family, Our Way process for the “Star” family was the satisfied affirmation of their existing care and support plan. Some members reported that it was very helpful to include their father in the family meeting, although there was some discussion within the group as to whether this was a good idea. Although communication was a reported strength of this family, three of the five members said that their communication somewhat improved through this process. (The remaining two said that it had no effect. All of the “Star” family participants said that they would be very or somewhat likely to recommend the Guide to others.)

Care Intensity Level: MIDDLE

Strain: MIDDLE

Congruence: MIDDLE

Going-in Efficacy: MID-to-HIGH

Fidelity: MIDDLE

Impact: LOW

APPENDIX B EVALUATION TOOLS

TIME 1 Caregiver

Evaluation CAREGIVER Individual Interviews

Ahead of interview, pre-fill what demographic info you know.

Name _____

Relationship to PWCN: (Check one)

<input type="checkbox"/>	Spouse/partner	<input type="checkbox"/>	Son
<input type="checkbox"/>	Daughter	<input type="checkbox"/>	Step-son
<input type="checkbox"/>	Step-daughter	<input type="checkbox"/>	Son-in-law
<input type="checkbox"/>	Daughter-in-law	<input type="checkbox"/>	Other:

TURN ON RECORDER and get consent.

Okay the recorder is on. This is _____ [participant name] on _____ [date], with the Our Family, Our Way project. Do you agree to go ahead with the interview according to the consent form you received?

To begin, let me get some basic information. First, it's important that you know that anything you share with me during our telephone interviews is confidential and will not be shared with your family members.

1. What is your age? _____
2. What is your gender? _____
3. How do you identify your race or ethnicity? _____
4. What is your marital status? (Check one)

<input type="checkbox"/>	Married	<input type="checkbox"/>	Divorced
<input type="checkbox"/>	Partnered	<input type="checkbox"/>	Separated
<input type="checkbox"/>	Widowed	<input type="checkbox"/>	Never married

5. Do you have children? (Circle one)

Yes No

How many do you have? _____

What are their ages? _____

(If struggling with actual ages, ask for year(s) the child(ren) were born.)

6. How far do you live from _____ [PWCN] in miles? _____

How long does it take you to get there? _____

7. What is the highest level of education you've completed? (Check one)

<input type="checkbox"/>	Less than high school	<input type="checkbox"/>	College graduate
<input type="checkbox"/>	High school graduate or GED	<input type="checkbox"/>	Post graduate
<input type="checkbox"/>	Some college	<input type="checkbox"/>	Other:

8. Are you currently employed? (Circle one)

Yes No

(If yes) Are you employed?

<input type="checkbox"/>	Full-time hrs. per week: _____	<input type="checkbox"/>	Part-time hrs. per week: _____
--------------------------	-----------------------------------	--------------------------	-----------------------------------

What is your (current / or former) occupation?

9. Only if you feel comfortable answering, can you tell me if your approximate annual household income is? (Check one)

<input type="checkbox"/>	Less than \$25,000
<input type="checkbox"/>	Between \$25,000 and \$50,000
<input type="checkbox"/>	Between \$50,000 and \$100,000
<input type="checkbox"/>	Over \$100,000

10. Would you rate your own physical health as? (Circle one)

Excellent Good Fair Poor

Identify all blanks that apply and fill in **before** interview.

Family Processes

Now I am going to ask you some questions about your family and the care and support arrangement. By care and support arrangement, I mean who does what, where, when, and how, to care for or support your _____ [PWCN].

In these questions, when I ask you to think about “we” or “us”, I mean you, your _____ [PWCN], your _____ [caregiver], your _____ [caregiver], your _____ [caregiver], etc.

So again, please consider all of those people.... as a whole.... as you answer these questions.

Since we’re doing this over the phone and you don’t have the questions in front of you to look at, I’ll be reading the questions. There may be times when I repeat things just to make sure they’re clear. And, I can repeat anything you need me to. Just say “Repeat the question.”

Now, I am going to read a few statements and then I’ll ask you to tell me whether you think the statement is mostly true, somewhat true, mostly false, or you’re not sure.

Okay, here we go, first statement....and don’t forget to include your _____ [PWCN] when you’re thinking about these statements.

1. We see eye to eye when it comes to what care and support is needed.

Do you think that’s: (Circle one)

Mostly true Somewhat true Mostly false Or, are you Not sure

- a. [If mostly true/ somewhat true]: Can you give me a brief example of a care or support need that you see eye to eye on?
- b. [If mostly false]: Can you give me an example of where you don’t see eye to eye about what care and support is needed?
- c. [If not sure]: Can you tell me what makes you unsure?

Okay, second statement....

2. Generally, we don’t have explicit conversations about who will do what, where, when and how in the care arrangement. Instead, the care arrangement just happens.

Do you think that’s: (Circle one)

Mostly true Somewhat true Mostly false Or, are you Not sure

- a. [If mostly true/ somewhat true]: **Can you give an example of how the care arrangement “just happens”?**
- b. [If mostly false]: **Can you give an example of explicit decisions you have made with the others about the care arrangement?**
- c. [If not sure]: **Can you tell me what makes you unsure?
Now the last statement....**

3. All of us are included in important conversations about who does what, when, where, and how in the care and support arrangement.

Do you think that's: (Circle one)

Mostly true Somewhat true Mostly false Or, are you Not sure

- a. **Which of you are less likely to be included in those conversations?**
- b. **Can you give an example of the kinds of conversations that don't include all of you?**
- c. [If unsure]: **Can you tell me what makes you unsure?**

Identify all blanks that apply and fill in **before** interview.

Equity Appraisal Tool (including fairness rating)

Now we are going to talk about the amount you and the others are doing when it comes to the care and support arrangement. Again, by care and support arrangement, we mean who does what, where, when, and how, to care for and support your _____ [PWCN].

Just a few questions about the amount you and others are doing.

First: Given the care and support your _____ [PWCN] needs, if you could change the amount you do, would you do less, more, or do you do about the right amount? (Circle one)

Less More Right amount

Could you say a bit more about that?

Now: If you could change the amount the others do, would you like some of them to do more? (Circle one)

Yes No Not sure

Could you say a bit more about that?

Would you like some of them to do less? (Circle one)

Yes No Not sure

Could you say a bit more about that?

Do you think some of them do the right amount? (Circle one)

Yes No Not sure

Could you say a bit more about that?

Okay, finally: When it comes to everybody's involvement in the care and support arrangement, how fair do you think it is? (Circle one)

Not very fair Somewhat fair Very fair

Identify all blanks that apply and fill in **before** interview.

Distress Rating

I've been asking you about the amount of care and support provided by all of you, including your _____ [PWCN]. When you think about how care and support is divided in your family, I'd like to know how that makes you feel.

For example, I would ask, When you think about how care is divided in your family, how depressed do you feel? We'll use a scale from 1 to 10—that is, 1 being not at all depressed and 10 being extremely depressed. You would rate how depressed you feel or not on that scale from 1 to 10.

SO, here we go:

On a scale from 1 to 10, when you think about how care is divided in your family, how depressed do you feel? Again, 1 being not at all to 10 being extremely. (Circle #)

1. Depressed 1 2 3 4 5 6 7 8 9 10

When you think about how the amount of care is divided in your family, how _____ do you feel.....

As needed, repeat "On a scale from 1 to 10 when you think about how care is divided in your family, how _____ do you feel...." before each item, or just "How _____ do you feel..."

- | | | | | | | | | | | |
|-----------------|---|---|---|---|---|---|---|---|---|----|
| 2. Happy | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 3. Guilty | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 4. Angry | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 5. Stressed | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 6. Frustrated | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 7. Resentful | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 8. Disappointed | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 9. Anxious | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 10. Thankful | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 11. Sad | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 12. Contented | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

(Not at all)

(Extremely)

Is there another emotion you would choose to describe how you feel about how the amount of care and support is divided in your family? (Circle)

Yes No

(Emotion) _____

And how would you rate that emotion on a scale from 1 to 10? (Circle)

1 2 3 4 5 6 7 8 9 10

(Not at all)

(Extremely)

Identify all blanks that apply and fill in **before** interview.

Perceived Family Efficacy Scale

Okay, one *last set* of questions. This last set is about how well you think your family works together as a whole when it comes to the care and support arrangement. Again, for our purposes, by family, we mean you, your _____ [PWCN], your _____ [caregiver], your _____ [caregiver], your _____ [caregiver], etc.

To answer, this time we'll use a grading scale of A through F. A is Excellent, B is Good, C is Satisfactory, D is Poor, and F is Failing. So, grade how well you think your family works together as a whole.

Working together.... as a whole..... how well can your family...

(Circle grade)

As needed, repeat answer categories after each question.

1. Resolve differences in opinion about the care and support arrangement

A B C D F

2. Agree to decisions that are in the best interests of the family

A B C D F

3. Make the fairest possible decisions for everyone in the family

A B C D F

4. Get each other to share in care and support responsibilities

A B C D F

5. Support each other in times of stress

A B C D F

6. Count on each other

A B C D F

7. Build a sense that you are in this together

A B C D F

8. Find community resources

A B C D F

9. Make good use of community resources

A B C D F

10. Honor each other's limits

A B C D F

11. Honor each other's preferences about how they want to spend their daily lives

A B C D F

WRAP-UP: Okay, those are all of my questions. Is there anything you'd like to add or any questions about anything we've talked about?

Okay, as soon as all the participants in your family have completed this interview, we'll be sending each of you a packet that includes the Guide and tools you'll need to prepare for your family meeting. All of the guidelines for the process will be right there in the packet.

Thank them for their time and for the interview.

Evaluation PWCN Individual Interviews

Ahead of interview, pre-fill what demographic info you know.

Name _____

TURN ON RECORDER and get consent.

Okay the recorder is on. This is _____ [participant name] on _____ [date], with the Our Family, Our Way project. Do you agree to go ahead with the interview according to the consent form you received?

To begin, let me get some basic information. First, it's important that you know that anything you share with me during our telephone interviews is confidential and will not be shared with your family members.

1. What is your age? _____
2. What is your gender? _____
3. How do you identify your race or ethnicity? _____
4. What is your marital status? (Check one)

<input type="checkbox"/>	Married	<input type="checkbox"/>	Divorced
<input type="checkbox"/>	Partnered	<input type="checkbox"/>	Separated
<input type="checkbox"/>	Widowed	<input type="checkbox"/>	Never married

5. How many children do you have? _____ Sons or daughters? _____

What are their ages? _____

(If struggling with actual ages, ask for year(s) the child(ren) were born.)

6. What type of home do you live in? (Check one)

<input type="checkbox"/>	House	<input type="checkbox"/>	Assisted Living
<input type="checkbox"/>	Apartment	<input type="checkbox"/>	Independent Living
<input type="checkbox"/>	Condo	<input type="checkbox"/>	Other:

7. Who lives in your household? (Fill in response)

8. What is the highest level of education you've completed? (Check one)

<input type="checkbox"/>	Less than high school	<input type="checkbox"/>	College graduate
<input type="checkbox"/>	High school graduate or GED	<input type="checkbox"/>	Post graduate
<input type="checkbox"/>	Some college	<input type="checkbox"/>	Other:

9. Are you currently employed? (Circle one) Yes No

(If yes) Are you employed?

<input type="checkbox"/>	Full-time hrs. per week: _____	<input type="checkbox"/>	Part-time hrs. per week: _____
--------------------------	-----------------------------------	--------------------------	-----------------------------------

What is your (current / former) occupation? _____

10. Only if you feel comfortable answering, can you tell me if your approximate annual household income is: (Check one)

<input type="checkbox"/>	Less than \$25,000
<input type="checkbox"/>	Between \$25,000 and \$50,000
<input type="checkbox"/>	Between \$50,000 and \$100,000
<input type="checkbox"/>	Over \$100,000

11. Would you rate your own physical health as: (Circle one)

Excellent Good Fair Poor

Identify all blanks that apply and fill in **before** interview.

Family Processes

Now I am going to ask you some questions about your family and the care and support arrangement. By care and support arrangement, I mean who does what, where, when, and how, to care for or support you.

In these questions, when I ask you to think about “we” or “us”, I mean you, your _____ [caregiver], your _____ [caregiver], your _____ [caregiver], etc.

So again, please consider all of those people.... as a whole.... as you answer these questions.

Since we’re doing this over the phone and you don’t have the questions in front of you to look at, I’ll be reading the questions. There may be times when I repeat things just to make sure they’re clear. And, I can repeat anything you need me to. Just say “Repeat the question.”

Now, I am going to read a few statements and then I’ll ask you to tell me whether you think the statement is mostly true, somewhat true, mostly false, or you’re not sure.

Okay, here we go, first statement....

2. We see eye to eye when it comes to what care and support I need.

Do you think that’s: (Circle one)

Mostly true Somewhat true Mostly false Or, are you Not sure

- a. [If mostly true/ somewhat true]: Can you give me a brief example of a care or support need that you see eye to eye on?
- b. [If mostly false]: Can you give me an example of where you don’t see eye to eye about what care and support you need?
- c. [If not sure]: Can you tell me what makes you unsure?

Okay, second statement....

3. Generally, we don’t have explicit conversations about who will do what, where, when and how in the care arrangement. Instead, the care arrangement just happens.

Do you think that’s: (Circle one)

Mostly true Somewhat true Mostly false Or, are you Not sure

- a. [If mostly true/ somewhat true]: Can you give an example of how the care arrangement “just happens”?

- b. [If mostly false]: **Can you give an example of explicit decisions you have made with the others about the care arrangement?**
- c. [If not sure]: **Can you tell me what makes you unsure?**

Now the last statement....

- 4. **All of us are included in important conversations about who does what, when, where, and how in the care and support arrangement.**

Do you think that's: (Circle one)

Mostly true Somewhat true Mostly false Or, are you Not sure

- a. **Which of you are less likely to be included in those conversations?**
- b. **Can you give an example of the kinds of conversations that don't include all of you?**
- c. [If unsure]: **Can you tell me what makes you unsure?**

Identify all blanks that apply and fill in **before** interview.

Equity Appraisal Tool (including fairness rating)

Now we are going to talk about the amount you and the others are doing when it comes to the care and support arrangement. Again, by care and support arrangement, we mean who does what, where, when, and how, to care for and support you, as well as the care you take care of yourself.

Just a few questions about the amount you and others are doing.

First: Given the care and support you need, if you could change the amount you do, would you do less, more, or do you do about the right amount? (Circle one)

Less More Right amount

Could you say a bit more about that?

Now: If you could change the amount the others do, would you like some of them to do more? (Circle one)

Yes No Not sure

Could you say a bit more about that?

Would you like some of them to do less? (Circle one)

Yes No Not sure

Could you say a bit more about that?

Do you think some of them do the right amount? (Circle one)

Yes No Not sure

Could you say a bit more about that?

Okay, finally: When it comes to everybody's involvement in the care and support arrangement, how fair do you think it is? (Circle one)

Not very fair Somewhat fair Very fair

Distress Rating

I've been asking you about the amount of care and support provided by all of you, including the care you do for yourself. When you think about how care and support is divided in your family, I'd like to know how that makes you feel.

For example, I would ask, When you think about how care is divided in your family, how depressed do you feel? We'll use a scale from 1 to 10—that is, 1 being not at all depressed and 10 being extremely depressed. You would rate how depressed you feel or not on that scale from 1 to 10.

SO, here we go:

On a scale from 1 to 10, when you think about how care is divided in your family, how depressed do you feel? Again, 1 being not at all to 10 being extremely. (Circle #)

13. Depressed 1 2 3 4 5 6 7 8 9 10

When you think about how the amount of care is divided in your family, how _____ do you feel.....

As needed, repeat "On a scale from 1 to 10 when you think about how care is divided in your family, how _____ do you feel...." before each item, or just "How _____ do you feel..."

- | | | | | | | | | | | |
|------------------|---|---|---|---|---|---|---|---|---|----|
| 14. Happy | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 15. Guilty | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 16. Angry | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 17. Stressed | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 18. Frustrated | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 19. Resentful | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 20. Disappointed | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 21. Anxious | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 22. Thankful | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 23. Sad | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 24. Contented | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

(Not at all)

(Extremely)

Is there another emotion you would choose to describe how you feel about how the amount of care and support is divided in your family? (Circle) Yes No

(Emotion) _____

And how would you rate that emotion on a scale from 1 to 10? (Circle)

1 2 3 4 5 6 7 8 9 10

(Not at all)

(Extremely)

Identify all blanks that apply and fill in **before** interview.

Perceived Family Efficacy Scale

Okay, one *last set* of questions. This last set is about how well you think your family works together as a whole when it comes to the care and support arrangement. Again, for our purposes, by family, we mean you, your _____ [caregiver], your _____ [caregiver], your _____ [caregiver], etc.

To answer, this time we'll use a grading scale of A through F. A is Excellent, B is Good, C is Satisfactory, D is Poor, and F is Failing. So, grade how well you think your family works together as a whole.

Working together.... as a whole..... how well can your family...

(Circle grade)

1. Resolve differences in opinion about the care and support arrangement

A B C D F

2. Agree to decisions that are in the best interests of the family

A B C D F

3. Make the fairest possible decisions for everyone in the family

A B C D F

4. Get each other to share in care and support responsibilities

A B C D F

5. Support each other in times of stress

A B C D F

6. Count on each other

A B C D F

7. Build a sense that you are in this together

A B C D F

8. Find community resources

A B C D F

9. Make good use of community resources

A B C D F

10. Honor each other's limits

A B C D F

11. Honor each other's preferences about how they want to spend their daily lives

A B C D F

WRAP-UP: Okay, those are all of my questions. Is there anything you'd like to add or any questions about anything we've talked about?

Okay, as soon as all the participants in your family have completed this interview, we'll be sending each of you a packet that includes the Guide and tools you'll need to prepare for your family meeting. All of the guidelines for the process will be right there in the packet.

Thank them for their time and for the interview.

Evaluation CAREGIVER Individual Interviews

Ahead of interview, pre-fill what demographic info you know.

Name _____

Relationship to PWCN: (Check one)

<input type="checkbox"/>	Spouse/partner	<input type="checkbox"/>	Son
<input type="checkbox"/>	Daughter	<input type="checkbox"/>	Step-son
<input type="checkbox"/>	Step-daughter	<input type="checkbox"/>	Son-in-law
<input type="checkbox"/>	Daughter-in-law	<input type="checkbox"/>	Other:

TURN ON RECORDER and get consent.

Okay the recorder is on. This is _____ [participant name] on _____ [date], with the Our Family, Our Way project. Do you agree to go ahead with the interview according to the consent form you received?

To begin, let me get some basic information. First, it's important that you know that anything you share with me during our telephone interviews is confidential and will not be shared with your family members.

In this interview, you'll recognize questions from our first interview and we have added several questions at the end, so I will do my best to be respectful of your time.

Before we begin, has anything changed since our last phone interview, such as marital status, housing or living arrangement, employment status, income, or health status?

No changes _____ Change(s) _____ [Note change(s) below.]

1. What is your age? _____
2. What is your gender? _____
3. How do you identify your race or ethnicity? _____

4. What is your marital status? (Check one)

<input type="checkbox"/>	Married	<input type="checkbox"/>	Divorced
<input type="checkbox"/>	Partnered	<input type="checkbox"/>	Separated
<input type="checkbox"/>	Widowed	<input type="checkbox"/>	Never married

5. Do you have children? (Circle one)

Yes No

How many do you have? _____

What are their ages? _____

(If struggling with actual ages, ask for year(s) the child(ren) were born.)

6. How far do you live from _____ [PWCN] in miles? _____

How long does it take you to get there? _____

7. What is the highest level of education you've completed? (Check one)

<input type="checkbox"/>	Less than high school	<input type="checkbox"/>	College graduate
<input type="checkbox"/>	High school graduate or GED	<input type="checkbox"/>	Post graduate
<input type="checkbox"/>	Some college	<input type="checkbox"/>	Other:

8. Are you currently employed? (Circle one) Yes No

(If yes) Are you employed?

<input type="checkbox"/>	Full-time hrs. per week: _____	<input type="checkbox"/>	Part-time hrs. per week: _____
--------------------------	-----------------------------------	--------------------------	-----------------------------------

What is your (current / or former) occupation? _____

9. Only if you feel comfortable answering, can you tell me if your approximate annual household income is? (Check one)

<input type="checkbox"/>	Less than \$25,000
<input type="checkbox"/>	Between \$25,000 and \$50,000
<input type="checkbox"/>	Between \$50,000 and \$100,000
<input type="checkbox"/>	Over \$100,000

10. Would you rate your own physical health as: (Circle one)

Excellent Good Fair Poor

Identify all blanks that apply and fill in **before** interview.

Family Processes

Now I am going to ask you the same questions I asked in the first interview. We'll go through these relatively quickly to save time for our added questions.

As you will recall, these first questions are about your family and the care and support arrangement. By care and support arrangement, I mean who does what, where, when, and how, to care for or support your _____ [PWCN].

In these questions, when I ask you to think about "we" or "us", I mean you, your _____ [PWCN], your _____ [caregiver], your _____ [caregiver], your _____ [caregiver], etc.

So again, please consider all of those people.... as a whole.... as you answer these questions.

Since we're doing this over the phone and you don't have the questions in front of you to look at, I'll be reading the questions. There may be times when I repeat things just to make sure they're clear. And, I can repeat anything you need me to. Just say "Repeat the question."

Now, I am going to read a few statements and then I'll ask you to tell me whether you think the statement is mostly true, somewhat true, mostly false, or you're not sure.

Okay, here we go, first statement....and don't forget to include your _____ [PWCN] when you're thinking about these statements.

5. We see eye to eye when it comes to what care and support is needed.

Do you think that's: (Circle one)

Mostly true Somewhat true Mostly false Or, are you Not sure

- a. [If mostly true/ somewhat true]: Can you give me a brief example of a care or support need that you see eye to eye on?
- b. [If mostly false]: Can you give me an example of where you don't see eye to eye about what care and support is needed?
- c. [If not sure]: Can you tell me what makes you unsure?

Okay, second statement....

6. Generally, we don't have explicit conversations about who will do what, where, when and how in the care arrangement. Instead, the care arrangement just happens.

Do you think that's: (Circle one)

Mostly true Somewhat true Mostly false Or, are you Not sure

- a. [If mostly true/ somewhat true]: **Can you give an example of how the care arrangement “just happens”?**
- b. [If mostly false]: **Can you give an example of explicit decisions you have made with the others about the care arrangement?**
- c. [If not sure]: **Can you tell me what makes you unsure?**

Now the last statement....

- 7. **All of us are included in important conversations about who does what, when, where, and how in the care and support arrangement.**

Do you think that's: (Circle one)

Mostly true Somewhat true Mostly false Or, are you Not sure

- a. **Which of you are less likely to be included in those conversations?**
- b. **Can you give an example of the kinds of conversations that don't include all of you?**
- c. [If unsure]: **Can you tell me what makes you unsure?**

Identify all blanks that apply and fill in **before** interview.

Equity Appraisal Tool (including fairness rating)

Now we are going to talk about the amount you and the others are doing when it comes to the care and support arrangement. Again, by care and support arrangement, we mean who does what, where, when, and how, to care for and support your _____
[PWCN].

Just a few questions about the amount you and others are doing.

First: Given the care and support your _____ [PWCN] needs, if you could change the amount you do, would you do less, more, or do you do about the right amount? (Circle one)

Less More Right amount

Could you say a bit more about that?

Now: If you could change the amount the others do, would you like some of them to do more? (Circle one)

Yes No Not sure

Could you say a bit more about that?

Would you like some of them to do less? (Circle one)

Yes No Not sure

Could you say a bit more about that?

Do you think some of them do the right amount? (Circle one)

Yes No Not sure

Could you say a bit more about that?

Okay, finally: When it comes to everybody's involvement in the care and support arrangement, how fair do you think it is? (Circle one)

Not very fair Somewhat fair Very fair

Identify all blanks that apply and fill in **before** interview.

Distress Rating

I've been asking you about the amount of care and support provided by all of you, including your _____ [PWCN]. When you think about how care and support is divided in your family, I'd like to know how that makes you feel.

For example, I would ask, When you think about how care is divided in your family, how depressed do you feel? We'll use a scale from 1 to 10—that is, 1 being not at all depressed and 10 being extremely depressed. You would rate how depressed you feel or not on that scale from 1 to 10.

SO, here we go:

On a scale from 1 to 10, when you think about how care is divided in your family, how depressed do you feel? Again, 1 being not at all to 10 being extremely. (Circle #)

25. Depressed 1 2 3 4 5 6 7 8 9 10

When you think about how the amount of care is divided in your family, how _____ do you feel.....

As needed, repeat "On a scale from 1 to 10 when you think about how care is divided in your family, how _____ do you feel...." before each item, or just "How _____ do you feel..."

26. Happy 1 2 3 4 5 6 7 8 9 10

27. Guilty 1 2 3 4 5 6 7 8 9 10

28. Angry 1 2 3 4 5 6 7 8 9 10

29. Stressed 1 2 3 4 5 6 7 8 9 10

30. Frustrated 1 2 3 4 5 6 7 8 9 10

31. Resentful 1 2 3 4 5 6 7 8 9 10

32. Disappointed 1 2 3 4 5 6 7 8 9 10

33. Anxious 1 2 3 4 5 6 7 8 9 10

34. Thankful 1 2 3 4 5 6 7 8 9 10

35. Sad 1 2 3 4 5 6 7 8 9 10

36. Contented 1 2 3 4 5 6 7 8 9 10

(Not at all)

(Extremely)

Is there another emotion you would choose to describe how you feel about how the amount of care and support is divided in your family? (Circle) Yes No

(Emotion) _____

And how would you rate that emotion on a scale from 1 to 10? (Circle)

1 2 3 4 5 6 7 8 9 10

(Not at all)

(Extremely)

Identify all blanks that apply and fill in **before** interview.

Perceived Family Efficacy Scale

Okay, one *last set* of questions. This last set is about how well you think your family works together as a whole when it comes to the care and support arrangement. Again, for our purposes, by family, we mean you, your _____ [PWCN], your _____ [caregiver], your _____ [caregiver], your _____ [caregiver], etc.

To answer, this time we'll use a grading scale of A through F. A is Excellent, B is Good, C is Satisfactory, D is Poor, and F is Failing. So, grade how well you think your family works together as a whole.

Working together.... as a whole..... how well can your family...

(Circle grade)

As needed, repeat answer categories after each question.

1. Resolve differences in opinion about the care and support arrangement

A B C D F

2. Agree to decisions that are in the best interests of the family

A B C D F

3. Make the fairest possible decisions for everyone in the family

A B C D F

4. Get each other to share in care and support responsibilities

A B C D F

5. Support each other in times of stress

A B C D F

6. Count on each other

A B C D F

7. Build a sense that you are in this together

A B C D F

8. Find community resources

A B C D F

9. Make good use of community resources

A B C D F

10. Honor each other's limits

A B C D F

11. Honor each other's preferences about how they want to spend their daily lives

A B C D F

Tools and Family Meeting Evaluation

Now to the NEW questions. These are questions about your experience with the individual tools and the family meeting. The thing we care about most is having tools and a process that really works for families, so we need your very frank feedback. Give us the good, the bad, and the ugly. We want to hear it all!

Our Family, Our Way is designed for persons with care needs and their partners and adult children.

- 1. Including those who participated in the project and those who did not, how many adult children, children-in-law, and step-children are in your family?**

Adult children: _____

Children-in-law: _____

Step-children: _____

- 2. Were all of these family members invited to participate in the project? (Circle one)**

Yes

No

- 3. How did your family decide who would be invited to participate in the project?**

- 4. If you could do it over, who would you invite to participate in the Our Family, Our Way process and why?**

Individual Tools:

First, I'm going to ask you about the individual tools. This was the separate wire-bound piece located a few pages into your binder that asked your personal opinions about what's needed, wanted, and possible in the care arrangement.

1. Did you complete your individual tools before the family meeting? (Circle one)
Yes No

[If no] Can you tell me about why not?

- [If yes] Did you complete the tools in one sitting? (Circle one) Yes No

2. About how long did it take you to complete the individual tools? Minutes _____

3. Overall, when it came to completing the individual tools, did you find them very easy, somewhat easy, neither easy nor difficult, somewhat difficult, or very difficult to complete? (Circle one)

Very easy Somewhat easy Neither easy nor difficult Somewhat difficult Very difficult

- a. Could you say a bit more about that?

Family Meeting:

Now we are going to talk about the family meeting.

1. Did you attend your family meeting, either in person or remotely (that is, by phone or some other way)?

Yes, in person_____

Yes, remotely (Describe means of communication) _____

No_____

[If No] Can you tell me about why not?

2. Did any others attend the meeting remotely?

Yes (Describe means of communication) _____

No_____

3. About how long was your family meeting? Minutes_____

4. Did your family get all the way through the Family Meeting Guide in one meeting?
(Circle one)

Yes No

[If No]

- a. Can you tell me about why not?

- b. Can you tell me at what point the meeting ended and why?

- c. Does your family have plans to continue with the meeting at another time? (Circle one)

Yes No Not sure

[If Yes] Briefly describe those plans:

[If No] Can you tell me why not?

[If Not Sure] What makes you unsure?

5. **The Guide recommended that your family assign family members to act as reader, timer, and recorder during your family meeting. Did your family assign these roles? (Circle one)**

Yes No

[If No] Would you tell me a little about why you did not assign the roles?

[If Yes]

a. **During the family meeting, did you act as the reader, timer, or recorder? (Check all that apply)**

Reader _____

Timer _____

Recorder _____

b. **Did you find that having those roles in the meeting was helpful? (Circle one):**

Yes No Not sure

[If Yes] How was it helpful?

[If No] Why wasn't it helpful?

[If Not sure] What makes you unsure?

c. **Did anyone take on more than one role? (Circle one)**

Yes No Not sure

[If Not sure] What makes you unsure?

[If Yes] How well did that work?

Individual Tools Exchange:

Let's talk briefly about exchanging the individual tools at the family meeting. The Guide recommended that you pass your individual tools to the person on your right and take 10 minutes to review them, then repeat that process until everyone had reviewed each other's individual tools.

1. Is that how your family handled the individual tools exchange, or did you do it differently?

Yes, we followed the guidelines _____

No, we did it differently _____

Not Sure _____

[If No or Not sure] How did you handle the individual tools exchange?

[If some family members attended remotely]: How did you share your individual tools with the family members who attended remotely?

2. Can you briefly tell me what the individual tools exchange was like for you?

Shared Assessment:

After the individual tools exchange, the Guide asked you to complete a shared assessment of what's needed and wanted in your care arrangement. This involved looking at underlying health considerations, environmental considerations, and the care and support needed by your _____ [PWCN] and identifying the places where you agreed and disagreed on what's wanted and what's needed.

1. Overall, when it came to completing the shared assessment, did you find it very easy, somewhat easy, neither easy nor difficult, somewhat difficult, or very difficult to complete? (Circle one)

Very easy Somewhat easy Neither easy nor difficult Somewhat difficult Very difficult

a. Can you say a bit more about that?

Family Goal/Goals:

After the shared assessment, the Guide asked you to think about what you wanted for yourselves and for each other and to create a shared goal or goals statement for your family. It started with “As a result of our family’s care and support arrangement, we want the following to happen:...”

1. Overall, when it came to completing a shared goal or goals statement, did you find it very easy, somewhat easy, neither easy nor difficult, somewhat difficult, or very difficult to complete? (Circle one)

Very easy Somewhat easy Neither easy nor difficult Somewhat difficult Very difficult

- a. Can you say a bit more about that?

Family Care and Support Plan:

The last thing the Guide asked you to do in your family meeting was to review your shared assessment and goals statement and create a Family Care and Support Plan that indicates who will do what and when.

1. Overall, when it came to completing the Family Care and Support Plan, did you find it very easy, somewhat easy, neither easy nor difficult, somewhat difficult, or very difficult to complete? (Circle one)

Very easy Somewhat easy Neither easy nor difficult Somewhat difficult Very difficult

- a. Can you say a bit more about that?

Content Summary:

1. What part or parts of the Family Meeting Guide did you feel were most useful to your family?
2. What parts of the Family Meeting Guide were not useful to your family?
3. Were there things that your family needed to talk about that weren’t included in the Family Meeting Guide?

Yes No Not sure

[If Yes] What were those things?

[If Not sure] What makes you unsure?

4. **During the meeting, or since the meeting, did your family make use of the Family Resources Booklet that was in the back of your binders?**

Yes No Not sure

[If Yes] Can you describe how you used it?

[If Not sure] What makes you unsure?

Process Summary:

1. Which of the following best describes the impact of using the Our Family, Our Way Guide on your family's communication about the care and support arrangement?

- Our communication greatly improved.
- Our communication somewhat improved.
- It had no effect on our communication.
- Our communication somewhat worsened.
- Our communication greatly worsened.

a. Could you give examples?

2. As a result of your family meeting, did your family's care and support arrangement change in any way? (Circle one)

- Yes No Not Sure

[If No] How do you feel about the arrangement staying the same?

[If Not Sure] What makes you unsure?

[If Yes] Would you say that your arrangement is significantly better, somewhat better, somewhat worse, or significantly worse?

- Our arrangement is significantly better.
- Our arrangement is somewhat better.
- Our arrangement is somewhat worse.
- Our arrangement is significantly worse.

[If better/somewhat better] Better for whom and in what way?

[If worse/somewhat worse] Worse for whom and in what way?

3. We assume, like every family, there were differences of opinion and perspective. Could you give examples of some of the differences of opinion or perspectives that came up in your meeting?

4. How did your family deal with those differences?

5. At the very end of the Guide was a page that offered some suggestions of what to do if you had major differences about what's needed. Did your family use this page? (Circle one)

Yes No Not sure

[If Not sure] What makes you unsure?

[If Yes] Did you find it helpful? (Circle one)

Yes No

[If Yes] How was it helpful?

[If No] Why wasn't it helpful?

Because this project is evaluating the Our Family, Our Way tools and process to see how well they work, we are compensating your family and have asked you and your family to do some extra activities, like completing these telephone interviews. Families that would use the Guide in the future would not be interviewed and would not be compensated. Keeping that in mind...

6. How likely would you be to use the Our Family, Our Way Guide or some parts of the Guide again?

____ Very likely

____ Somewhat likely

____ Not sure

____ Somewhat unlikely

____ Very unlikely

- a. Could you say a bit more about that?

7. **How likely would you be to recommend this Guide to other families in situations like yours?**

____ Very likely

____ Somewhat likely

____ Not sure

____ Somewhat unlikely

____ Very unlikely

a. **Could you say a bit more about that?**

Now, I'm going to ask you about the least and most helpful things about your experience with Our Family, Our Way.

8. **Overall, what was the *least* helpful thing about the Our Family, Our Way experience?**

9. **Overall, what was the *most* helpful thing about the Our Family, Our Way experience?**

10. **At any point in the process, did you have any "A-ha" moments? That is, a time when you learned something that surprised you? (Circle one)**

Yes No Not sure

[If Yes] What were your "A-ha" moments?

11. **Do you have any suggestions for how we can improve the Our Family, Our Way tools or process for families?**

WRAP-UP: Okay, those are all of my questions. Is there anything you'd like to add or any questions about anything we've talked about?

Thank them for their time and for the interview; tell them you'd like to do a quick check-in phone call to see how things are going, in about ____ weeks. (Up to September 30.)

Evaluation PWCN Individual Interviews

Ahead of interview, pre-fill what demographic info you know.

Name _____

TURN ON RECORDER and get consent.

Okay the recorder is on. This is _____ [participant name] on _____ [date], with the Our Family, Our Way project. Do you agree to go ahead with the interview according to the consent form you received?

To begin, let me get some basic information. First, I want to remind you that anything you share with me during our telephone interviews is confidential and will not be shared with your family members.

In this interview, you'll recognize questions from our first interview and we have added several questions at the end, so I will do my best to be respectful of your time.

Before we begin, has anything changed since our last phone interview, such as marital status, housing or living arrangement, employment status, income, or health status?

No changes _____ Change(s) _____ [Note change(s) below.]

1. What is your age? _____
2. What is your gender? _____
3. How do you identify your race or ethnicity? _____
4. What is your marital status? (Check one)

<input type="checkbox"/>	Married	<input type="checkbox"/>	Divorced
<input type="checkbox"/>	Partnered	<input type="checkbox"/>	Separated
<input type="checkbox"/>	Widowed	<input type="checkbox"/>	Never married

5. How many children do you have? _____ Sons or daughters? _____
What are their ages? _____

(If struggling with actual ages, ask for year(s) the child(ren) were born.)

6. What type of home do you live in? (Check one)

<input type="checkbox"/>	House	<input type="checkbox"/>	Assisted Living
<input type="checkbox"/>	Apartment	<input type="checkbox"/>	Independent Living
<input type="checkbox"/>	Condo	<input type="checkbox"/>	Other:

7. Who lives in your household? (Fill in response)

8. What is the highest level of education you've completed? (Check one)

<input type="checkbox"/>	Less than high school	<input type="checkbox"/>	College graduate
<input type="checkbox"/>	High school graduate or GED	<input type="checkbox"/>	Post graduate
<input type="checkbox"/>	Some college	<input type="checkbox"/>	Other:

9. Are you currently employed? (Circle one)

Yes No

(If yes) Are you employed?

<input type="checkbox"/>	Full-time hrs. per week: _____	<input type="checkbox"/>	Part-time hrs. per week: _____
--------------------------	-----------------------------------	--------------------------	-----------------------------------

What is your (current / former) occupation? _____

10. Only if you feel comfortable answering, can you tell me if your approximate annual household income is? (Check one)

<input type="checkbox"/>	Less than \$25,000
<input type="checkbox"/>	Between \$25,000 and \$50,000
<input type="checkbox"/>	Between \$50,000 and \$100,000
<input type="checkbox"/>	Over \$100,000

11. Would you rate your own physical health as? (Circle one)

Excellent Good Fair Poor

Identify all blanks that apply and fill in **before** interview.

Family Processes

Now I am going to ask you the same questions I asked in the first interview. We'll go through these relatively quickly to save time for our added questions.

As you will recall, these first questions are about your family and the care and support arrangement. By care and support arrangement, I mean who does what, where, when, and how, to care for or support you.

In these questions, when I ask you to think about "we" or "us", I mean you, your _____ [caregiver], your _____ [caregiver], your _____ [caregiver], etc.

So again, please consider all of those people.... as a whole.... as you answer these questions.

Since we're doing this over the phone and you don't have the questions in front of you to look at, I'll be reading the questions. There may be times when I repeat things just to make sure they're clear. And, I can repeat anything you need me to. Just say "Repeat the question."

Now, I am going to read a few statements and then I'll ask you to tell me whether you think the statement is mostly true, somewhat true, mostly false, or you're not sure.

Okay, here we go, first statement....

8. We see eye to eye when it comes to what care and support I need.

Do you think that's: (Circle one)

Mostly true Somewhat true Mostly false Or, are you Not sure

- a. [If mostly true/ somewhat true]: Can you give me a brief example of a care or support need that you see eye to eye on?

- b. [If mostly false]: Can you give me an example of where you don't see eye to eye about what care and support you need?

- c. [If not sure]: Can you tell me what makes you unsure?

Okay, second statement....

9. **Generally, we don't have explicit conversations about who will do what, where, when and how in the care arrangement. Instead, the care arrangement just happens.**

Do you think that's: (Circle one)

Mostly true Somewhat true Mostly false Or, are you Not sure

- a. [If mostly true/ somewhat true]: **Can you give an example of how the care arrangement "just happens"?**

- b. [If mostly false]: **Can you give an example of explicit decisions you have made with the others about the care arrangement?**

- c. [If not sure]: **Can you tell me what makes you unsure?**

Now the last statement....

10. **All of us are included in important conversations about who does what, when, where, and how in the care and support arrangement.**

Do you think that's: (Circle one)

Mostly true Somewhat true Mostly false Or, are you Not sure

- a. **Which of you are less likely to be included in those conversations?**

- b. **Can you give an example of the kinds of conversations that don't include all of you?**

- c. [If unsure]: **Can you tell me what makes you unsure?**

Identify all blanks that apply and fill in **before** interview.

Equity Appraisal Tool (including fairness rating)

Now we are going to talk about the amount you and the others are doing when it comes to the care and support arrangement. Again, by care and support arrangement, we mean who does what, where, when, and how, to care for and support you, as well as the care you take care of yourself.

Just a few questions about the amount you and others are doing.

First: Given the care and support you need, if you could change the amount you do, would you do less, more, or do you do about the right amount? (Circle one)

Less More Right amount

Could you say a bit more about that?

Now: If you could change the amount the others do, would you like some of them to do more? (Circle one)

Yes No Not sure

Could you say a bit more about that?

Would you like some of them to do less? (Circle one)

Yes No Not sure

Could you say a bit more about that?

Do you think some of them do the right amount? (Circle one)

Yes No Not sure

Could you say a bit more about that?

Okay, finally: When it comes to everybody's involvement in the care and support arrangement, how fair do you think it is? (Circle one)

Not very fair Somewhat fair Very fair

Distress Rating

I've been asking you about the amount of care and support provided by all of you, including the care you take care of yourself. When you think about how care and support is divided in your family, I'd like to know how that makes you feel.

For example, I would ask, When you think about how care is divided in your family, how depressed do you feel? We'll use a scale from 1 to 10—that is, 1 being not at all depressed and 10 being extremely depressed. You would rate how depressed you feel or not on that scale from 1 to 10.

SO, here we go:

On a scale from 1 to 10, when you think about how care is divided in your family, how depressed do you feel? Again, 1 being not at all to 10 being extremely. (Circle #)

37. Depressed 1 2 3 4 5 6 7 8 9 10

When you think about how the amount of care is divided in your family, how _____ do you feel.....

As needed, repeat “On a scale from 1 to 10 when you think about how care is divided in your family, how _____ do you feel....” before each item, or just “How _____ do you feel...”

- | | | | | | | | | | | |
|------------------|---|---|---|---|---|---|---|---|---|----|
| 38. Happy | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 39. Guilty | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 40. Angry | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 41. Stressed | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 42. Frustrated | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 43. Resentful | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 44. Disappointed | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 45. Anxious | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 46. Thankful | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 47. Sad | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| 48. Contented | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

(Not at all)

(Extremely)

Is there another emotion you would choose to describe how you feel about how the amount of care and support is divided in your family? (Circle) Yes No

(Emotion) _____

And how would you rate that emotion on a scale from 1 to 10? (Circle)

1 2 3 4 5 6 7 8 9 10

(Not at all)

(Extremely)

Identify all blanks that apply and fill in **before** interview.

Perceived Family Efficacy Scale

Okay, one *last set* of questions. This last set is about how well you think your family works together as a whole when it comes to the care and support arrangement. Again, for our purposes, by family, we mean you, your _____ [caregiver], your _____ [caregiver], your _____ [caregiver], etc.

To answer, this time we'll use a grading scale of A through F. A is Excellent, B is Good, C is Satisfactory, D is Poor, and F is Failing. So, grade how well you think your family works together as a whole.

Working together.... as a whole..... how well can your family...

(Circle grade)

1. Resolve differences in opinion about the care and support arrangement

A B C D F

2. Agree to decisions that are in the best interests of the family

A B C D F

3. Make the fairest possible decisions for everyone in the family

A B C D F

4. Get each other to share in care and support responsibilities

A B C D F

5. Support each other in times of stress

A B C D F

6. Count on each other

A B C D F

7. Build a sense that you are in this together

A B C D F

8. Find community resources

A B C D F

9. Make good use of community resources

A B C D F

10. Honor each other's limits

A B C D F

11. Honor each other's preferences about how they want to spend their daily lives

A B C D F

Tools and Family Meeting Evaluation

Now to the NEW questions. These are questions about your experience with the individual tools and the family meeting. The thing we care about most is having tools and a process that really works for families, so we need your very frank feedback. Give us the good, the bad, and the ugly. We want to hear it all!

Our Family, Our Way is designed for persons with care needs and their partners and adult children.

- 5. Including those who participated in the project and those who did not, how many adult children, children-in-law, and step-children are in your family?**

Adult children: _____

Children-in-law: _____

Step-children: _____

- 6. Were all of these family members invited to participate in the project? (Circle one)**

Yes

No

- 7. How did your family decide who would be invited to participate in the project?**

- 8. If you could do it over, who would you invite to participate in the Our Family, Our Way process and why?**

Individual Tools:

First, I'm going to ask you about the individual tools. This was the separate wire-bound piece located a few pages into your binder that asked your personal opinions about what's needed, wanted, and possible in the care arrangement.

4. **Did you complete your individual tools before the family meeting? (Circle one)**
Yes No

[If no] **Can you tell me about why not?**

- [If yes] **Did you complete the tools in one sitting? (Circle one)**
Yes No

5. **About how long did it take you to complete the individual tools? Minutes_____**

6. **Overall, when it came to completing the individual tools, did you find them very easy, somewhat easy, neither easy nor difficult, somewhat difficult, or very difficult to complete? (Circle one)**

Very easy Somewhat easy Neither easy nor difficult Somewhat difficult Very difficult

- b. **Could you say a bit more about that?**

Family Meeting:

Now we are going to talk about the family meeting.

6. Did you attend your family meeting, either in person or remotely (that is, by phone or some other way)?

Yes, in person_____

Yes, remotely (Describe means of communication) _____

No_____

[If No] Can you tell me about why not?

7. Did any others attend the meeting remotely?

Yes (Describe means of communication) _____

No_____

8. About how long was your family meeting? Minutes_____

9. Did your family get all the way through the Family Meeting Guide in one meeting?

(Circle one)

Yes No

[If No]

a. Can you tell me about why not?

b. Can you tell me at what point the meeting ended and why?

c. Does your family have plans to continue with the meeting at another time? (Circle one)

Yes No Not sure

[If Yes] Briefly describe those plans:

[If No] Can you tell me why not?

[If Not Sure] What makes you unsure?

10. The Guide recommended that your family assign family members to act as reader, timer, and recorder during your family meeting. Did your family assign these roles?

(Circle one)

Yes No

[If No] Would you tell me a little about why you did not assign the roles?

[If Yes]

- a. **During the family meeting, did you act as the reader, timer, or recorder? (Check all that apply)**

Reader_____

Timer _____

Recorder_____

- b. **Did you find that having those roles in the meeting was helpful? (Circle one):**

Yes No Not sure

[If Yes] **How was it helpful?**

[If No] **Why wasn't it helpful?**

[If Not sure] **What makes you unsure?**

- c. **Did anyone take on more than one role? (Circle one)**

Yes No Not sure

[If Not sure] **What makes you unsure?**

[If Yes] **How well did that work?**

Individual Tools Exchange:

Let's talk briefly about exchanging the individual tools at the family meeting. The Guide recommended that you pass your individual tools to the person on your right and take 10 minutes to review them, then repeat that process until everyone had reviewed each other's individual tools.

3. **Is that how your family handled the individual tools exchange, or did you do it differently?**

Yes, we followed the guidelines _____

No, we did it differently _____

Not Sure _____

[If No or Not sure] **How did you handle the individual tools exchange?**

[If some family members attended remotely]: **How did you share your individual tools with the family members who attended remotely?**

4. **Can you briefly tell me what the individual tools exchange was like for you?**

Shared Assessment:

After the individual tools exchange, the Guide asked you to complete a shared assessment of what’s needed and wanted in your care arrangement. This involved looking at underlying health considerations, environmental considerations, and the care and support needed by your _____ [PWCN] and identifying the places where you agreed and disagreed on what’s wanted and what’s needed.

2. Overall, when it came to completing the shared assessment, did you find it very easy, somewhat easy, neither easy nor difficult, somewhat difficult, or very difficult to complete? (Circle one)

Very easy Somewhat easy Neither easy nor difficult Somewhat difficult Very difficult

b. Can you say a bit more about that?

Family Goal/Goals:

After the shared assessment, the Guide asked you to think about what you wanted for yourselves and for each other and to create a shared goal or goals statement for your family. It started with “As a result of our family’s care and support arrangement, we want the following to happen:...”

2. Overall, when it came to completing a shared goal or goals statement, did you find it very easy, somewhat easy, neither easy nor difficult, somewhat difficult, or very difficult to complete? (Circle one)

Very easy Somewhat easy Neither easy nor difficult Somewhat difficult Very difficult

b. Can you say a bit more about that?

Family Care and Support Plan:

The last thing the Guide asked you to do in your family meeting was to review your shared assessment and goals statement and create a Family Care and Support Plan that indicates who will do what and when.

2. Overall, when it came to completing the Family Care and Support Plan, did you find it very easy, somewhat easy, neither easy nor difficult, somewhat difficult, or very difficult to complete? (Circle one)

Very easy Somewhat easy Neither easy nor difficult Somewhat difficult Very difficult

b. Can you say a bit more about that?

Content Summary:

5. **What part or parts of the Family Meeting Guide did you feel were most useful to your family?**
6. **What parts of the Family Meeting Guide were not useful to your family?**
7. **Were there things that your family needed to talk about that weren't included in the Family Meeting Guide?**

Yes No Not sure

[If Yes] What were those things?

[If Not sure] What makes you unsure?

8. **During the meeting, or since the meeting, did your family make use of the Family Resources Booklet that was in the back of your binders?**

Yes No Not sure

[If Yes] Can you describe how you used it?

[If Not sure] What makes you unsure?

Process Summary:

12. Which of the following best describes the impact of using the Our Family, Our Way Guide on your family's communication about the care and support arrangement?

- Our communication greatly improved.
- Our communication somewhat improved.
- It had no effect on our communication.
- Our communication somewhat worsened.
- Our communication greatly worsened.

b. Could you give examples?

13. As a result of your family meeting, did your family's care and support arrangement change in any way? (Circle one)

- Yes No Not Sure

[If No] How do you feel about the arrangement staying the same?

[If Not Sure] What makes you unsure?

[If Yes] Would you say that your arrangement is significantly better, somewhat better, somewhat worse, or significantly worse?

- Our arrangement is significantly better.
- Our arrangement is somewhat better.
- Our arrangement is somewhat worse.
- Our arrangement is significantly worse.

[If better/somewhat better] Better for whom and in what way?

[If worse/somewhat worse] Worse for whom and in what way?

14. We assume, like every family, there were differences of opinion and perspective. Could you give examples of some of the differences of opinion or perspectives that came up in your meeting?

15. How did your family deal with those differences?

16. At the very end of the Guide was a page that offered some suggestions of what to do if you had major differences about what's needed. Did your family use this page? (Circle one)

Yes No Not sure

[If Not sure] What makes you unsure?

[If Yes] Did you find it helpful? (Circle one) Yes No

[If Yes] How was it helpful?

[If No] Why wasn't it helpful?

Because this project is evaluating the Our Family, Our Way tools and process to see how well they work, we are compensating your family and have asked you and your family to do some extra activities, like completing these telephone interviews. Families that would use the Guide in the future would not be interviewed and would not be compensated. Keeping that in mind...

17. How likely would you be to use the Our Family, Our Way Guide or some parts of the Guide again?

___ Very likely

___ Somewhat likely

___ Not sure

___ Somewhat unlikely

___ Very unlikely

b. Could you say a bit more about that?

18. How likely would you be to recommend this Guide to other families in situations like yours?

___ Very likely

___ Somewhat likely

___ Not sure

___ Somewhat unlikely

___ Very unlikely

b. Could you say a bit more about that?

Now, I'm going to ask you about the least and most helpful things about your experience with Our Family, Our Way.

19. Overall, what was the *least* helpful thing about the Our Family, Our Way experience?

20. Overall, what was the *most* helpful thing about the Our Family, Our Way experience?

21. At any point in the process, did you have any "A-ha" moments? That is, a time when you learned something that surprised you? (Circle one)

Yes No Not sure

[If Yes] What were your "A-ha" moments?

22. Do you have any suggestions for how we can improve the Our Family, Our Way tools or process for families?

WRAP-UP: Okay, those are all of my questions. Is there anything you'd like to add or any questions about anything we've talked about?

Thank them for their time and for the interview; tell them you'd like to do a quick check-in phone call to see how things are going, in about ____ weeks. (Up to September 30.)

Time 3 Evaluation

Participant Name _____ Date: _____

Prior to call:

- 1) Note whether participant reported any changes to care and support arrangement in T2 interview. [This question is included here just for review/reference. You won't ask it of the participant.]

As a result of your family meeting, did your family's care and support arrangement change in any way? (Circle one)

Yes No Not Sure

[If Yes] Would you say that your arrangement is significantly better, somewhat better, somewhat worse, or significantly worse?

_____ Our arrangement is significantly better.

_____ Our arrangement is somewhat better.

_____ Our arrangement is somewhat worse.

_____ Our arrangement is significantly worse.

[If better/somewhat better] Better for whom and in what way?

- 2) Review family data to identify examples of changes to the care and support arrangement – either expressed in shared assessment, family care and support plan, T2 interview, or your own review of data.

[When participant is reached, greet them, ask how they're doing, etc.]

As I mentioned in our last interview, we're calling our participants to check in and follow-up on their experience with the Our Family, Our Way process now that it's been a while since you went through the process. Do you have a few minutes for some quick questions?

[If participant agrees to interview.]

Great! Thanks! And, if you don't mind, I'll be recording our call, just like I did in our previous telephone interviews.

Okay, the recorder is on. This is _____ [participant name] on _____ [date] with the Our Family, Our Way project. Do you agree to continue with the call according to the consent form you received? Thank you!

1. Since I last spoke with you, have you had any new insights about your participation or your experience with the Our Family, Our Way process?

[If YES] Can you tell me what those insights are [that insight is]?

[If NO, move on to next question.]

2. Have you or your family had any conversations or made any decisions or changes as a result of your family meeting or because of your participation in Our Family, Our Way?

[If YES] Can you briefly describe those [that] to me?

[If NO – and the participant reported that there were NO changes at T2]

In our last interview, you reported that there were no changes in your family's care and support arrangement as a result of your family meeting, however, as I was reviewing your family's documents, I noted...

- provide specific examples from family's/participants shared assessment, family care and support plan, or T2 interview
- affirm that you believe these items are indeed changes
- ask the participant about those items and if there was follow-through, etc.

[If NO – and the participant reported that there WERE changes at T2:]

1. In our last interview, you reported that there were some changes to your family's care and support arrangement...

- provide specific examples from family's/participants shared assessment, family care and support plan, or T2 interview
- ask the participant about those items and if there was follow-through, etc.

[If you found other examples of changes in your document review.]

2. In my review of your family's documents, I also noted these items...

- provide specific examples from family's/participants shared assessment, family care and support plan, or T2 interview
- affirm that you believe these items are indeed changes

[If NO to both Q1 and Q2]

Okay, thank you. And since this will be our last time to talk, is there any final thing you think we should know about the impact that this experience has had on you or your family?