

# Journal of AGING (i)fe CARE™

VOLUME 32  
ISSUE 1  
SUMMER 2022

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## EDITOR'S MESSAGE

**Kaaren Boothroyd, Editor**

We are fortunate to include in this issue three articles that address prevalent and continuing concerns of Aging Life Care Managers®\* and others who work in the field of aging.

*Long-Term Care Resident Perspectives on Person-Centered Care: Intersections of Practice and Theory* — by Mary Lou Ciolfi, JD, MS; Catherine Taylor, BS; Kayla Toppin, BA, MSW; Jennifer A. Crittenden, PhD, MSW; Lenard W. Kaye, DSW, PhD; Angela Hunt, MS, RPT; Paul Nebenzahl; David Wihry, MPA; Tracy Ericson, BA; and Melanie Marchman, BS, RN — takes our readers deep into their research and thoughts on the implications of how Aging Life Care Managers might use this information to assess the quality of care in their clients' long-term care (LTC) settings.

Aging Life Care Managers are frequently contacted by families dealing with conflict about the care or financial management of an elder. Janet L. Smith's article on *Elder Mediation: Honoring the Voice of the Elder* explains what Elder Mediation is, when a matter is appropriate for mediation, and how an Aging Life Care Manager can help a family prepare to resolve their dispute through mediation.

*Stop the Revolving Door of Hospitalizations by Keeping Seniors Safe at Home*, by Randy Bartosh, OTR; David Chandler, RN, BSN, MBA, CFE; and Debbie Miller, BSc addresses a familiar topic for Aging Life Care Managers. This article shows how a system of scoring and tracking the individual risk factors that lead to hospitalizations can have an immediate effect on the health and wellbeing of seniors and their families, as well as decrease the cost to the healthcare system.

We welcome your feedback on these articles and suggestions you may have for future *Journal* topics.

\*Only members of the Aging Life Care Association can call themselves Aging Life Care Managers®, Aging Life Care Professionals® or Aging Life Care Experts®.

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Published by the Aging Life Care Association®  
(Formerly National Association of Professional Geriatric Care Managers)  
3275 W. Ina Road, Suite 130, Tucson, Arizona, 85741  
aginglifecare.org

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# Long-Term Care Resident Perspectives on Person-Centered Care: Intersections of Practice and Theory

By Mary Lou Ciolfi, JD, MS; Catherine Taylor, BS; Kayla Toppin, BA, MSW; Jennifer A. Crittenden, PhD, MSW; Lenard W. Kaye, DSW, PhD; Angela Hunt, MS, RPT; Paul Nebenzahl; David Wihry, MPA; Tracy Ericson, BA; Melanie Marchman, BS, RN

## SUMMARY

Person-centered care is an approach to care and services in which the individual and their unique needs and preferences guide care delivery (American Geriatrics Society, 2016). While it has a long history in mental health and traditional healthcare, implementation of person-centered practices has been incrementally migrating into the long-term care sector for the past twenty years yet still lacks clarity and a comprehensive definition.

As one part of a national, multi-year project to develop a designation of excellence (DoE) in person-centered long-term care informed by long-term care resident, family, and staff voices, 247 residents in 23 long-term care communities around the country participated in a conversation activity answering questions about daily life. This article explores the intersection of person-centered care from the resident perspective by applying relevant theory to resident responses, with the goal of understanding how life in long-term care can align with and preserve identity, environment, social life, and agency. Resident responses to conversation activity revealed five primary themes: their views on social life, physical environment, knowledge about them, how they are treated, and strong emotional content.

Resident responses are then interpreted in the context of three social and behavioral theories: continuity theory, person-environment fit theory, and self-determination theory. Applying a theoretical lens to resident comments offers critical perspective on how long-term care providers can identify residents at greater risk of poor transition or adaptation to a long-term care setting and how emotional needs can be better met. The resident responses take on greater meaning when viewed through the lens of theory and lead to recommendations for practice.

## Background

The quality of long-term care (LTC) in nursing homes and assisted living centers around the country is increasingly in the spotlight due to the COVID-19 pandemic. The National Academies of Sciences, Engineering, and Medicine's (NASEM) recent report, *The National Imperative to Improve Nursing Home Quality: Honoring Our Commitment to Residents, Families, and Staff*, conveys the urgency of LTC reform to achieve high-quality, person-centered, equitable care and services for individuals living in LTC communities (NASEM, 2022). One area of importance highlighted in the NASEM report is the need for resident input to inform change. Residents' daily lived experience in LTC settings must be the primary driver of reform

to attain the goal of meaningful person-centered, individualized care and services for every resident. Person-centeredness in long-term care settings lacks a comprehensive agreed-upon definition, although it is generally understood to mean care and services guided by each unique individual benefitting from that care or service (AGS, 2016).

By collecting the opinions and experiences of LTC stakeholders, including current residents of LTC, the Mayer-Rothschild Foundation Designation of Excellence in Person-Centered Long-Term Care project offers an opportunity to define the meaning and priorities of high-quality person-centered care and better align service delivery with what matters to those stakeholders. The importance of listening to all LTC stakeholders

led the project team to design a study that combined participatory action research (PAR) methods (Chevalier & Buckles, 2013) with a broad review of the relevant literature. One resident-engagement activity, the Message Board Activity (MBA), elicited hundreds of responses from residents on several topics related to their day-to-day experiences. These responses were revealing and emotionally evocative. The MBA responses will be integrated with a myriad of other project data from family members, LTC staff and leaders, and from prospective users of LTC.

### *Message Board Activity Methods*

The Message Board Activity (MBA) consisted of informal group or one-on-one conversations, facilitated by staff at each long-term care community, about

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how LTC residents experience aspects of care, services, environment, and interpersonal relationships. While the conversation was prompted by two questions<sup>1</sup> in each of the four domains of *My Care Partners; My Personal and Shared Spaces; My Family, Friends, and Community; and My Wishes and Feelings*, all comments by residents were welcome. Anonymous resident responses were submitted to the Designation of Excellence Team and then coded using Quirkos qualitative analysis software. Initial open coding identified general codes and three additional rounds of coding and discussion resulted in a final codebook that was applied to all MBA responses.

### Message Board Activity Responses

A total of 247 residents in 23 long-term care communities participated in the MBA. Based on qualitative data analysis, 14 themes and 22 subthemes were identified across all resident responses. Four of these themes – social life, physical environment, knowledge about me, and how I am treated – accounted for the majority of responses. However, we also include a fifth theme of 32 responses that were so laden with emotion that the emotional content was more central than the substance of the response. Within each of these five themes, a variety of subthemes emerged (see Table 1). While the topics and substance of the responses were informative for the project team, the tone and emotion embedded within them conveyed deep and nuanced meaning that bears further attention and analysis.

### Social Life Key Theme

Five subthemes emerged from the comments about the social aspects of daily life in long-term care: relating and connecting, family, activities, visiting, and phone and e-visits. Comments within the *social life* theme were frequently couched in terms of love, feeling cared for, feeling “like part of a family,” connecting with others, feeling compatibility with others, sharing and celebrating, or having a “need” to socialize and connect. Many comments expressed sadness and longing for connection: “I wish my family members were all close by”; or I would like “more free time to go out with family, without being questioned”; or “I don’t like to be alone.”

Some residents expressed a wish to connect with staff or hoped that staff would connect with *them*: one commented that they “wished staff would stop walking when I have a question”; another wanted to “see the aides as friends”; and another likes “when staff visit on a social basis.” Interestingly, though not surprisingly, several comments noted the desire to help or support other residents who need assistance. One commented they enjoy “when I am able to do something for someone else. I am so needy for someone else’s help, it feels good to help someone else”; or when there is “something I can do to help somebody.” Many noted they enjoy the spontaneity of staff visits “when they stop by to see me.” While a few residents spoke of ways to pass the time and the types of social activities they enjoyed (e.g., “a variety of activities breaks up the day”), most remarks conveyed the

importance of connecting and relating with others in ways that felt satisfying and fulfilling for them. This suggests that connecting with others may hold greater value for residents than activities that pass the time.

### Physical Environment Key Theme

Four subthemes emerged from the resident comments about physical environment: personal space and belongings, outdoors and community, privacy, and cleanliness. A number of residents remarked about wanting more space for belongings or wanting their room set up “to my preference”; they often bemoaned the “clutter” of their personal spaces. Many others remarked about not wanting their personal belongings touched or moved by others: “respect my personal items”; “return items to correct places”; “[I’d like] to be able to have my personal possessions that people don’t go through.” Sharing a room is problematic for many residents: “This is supposed to be our golden years, and we have to share small rooms with strangers”; “[I want] a space that is my own, that others don’t have access to”; “you have to be aware of other people in shared spaces, so you don’t bump into them, or them bumping into me.”

While the comments about one’s social life evoked desire, suggestive of longing, many of the comments about physical environment represented entitlement, infringement, and encroachment bordering on violation. Residents expressed frustration at being unable to maintain their space in ways that were customary and familiar to them and appeared to resent the intrusions into their physical and psychological spaces. With resident concerns of differentiating between personal and shared spaces, “[I don’t like] wandering visitors in our rooms, sometimes getting stuck and needing staff to help get out, touching our personal items, and banging doors (they need freedom to move, but not in my personal space).” Residents noted their need for privacy and simultaneously decried their loss of it, “It’s important to know there is no true privacy in a nursing home”; “there is no privacy when you have a roommate.”

**Table 1 | Partial List of Key Themes and Subthemes**

Theme	Subthemes
Social life	visiting; relating and connecting; activities; family; phone and e-visits
Physical environment	personal space or belongings; privacy in my space; cleanliness; outdoors and community events
Knowledge about me	life history; food and dining; daily care; medical and health
How I am treated	respect; dignity
Emotional content	things I don’t like; trust

Other comments confirmed that residents see their personal space as a retreat (“alone time [in my room] when I want it”) and, thus, when private space is not respected, residents are understandably distressed (“If you are coming into my home, please knock and announce yourself like you would at a real home”).

### Knowledge About Me Key Theme

Resident comments highlighted the importance of being seen and known by staff. Several residents mentioned that staff should at least know their names: “remember [my] name and information”; “call me by my name, know who I am”; “my name makes me feel at home.” Residents want staff to know their history and life story, their health and medical needs, their personal care preferences, and their needs and preferences around food and dining. Resident remarks such as, “good care is where you work with each other, and we understand each person is different in their physical, emotional, and spiritual needs” and “caregivers need to know my diagnosis and how to deal with that, but treat me as a person rather than my diagnosis” reflect that learning about residents is an expectation – an essential ingredient of providing care.

Several residents remarked that they want staff to know how they lived before they came to the LTC setting; “[I want to be] recognized as a person who has a lot of stories and experiences”; “acknowledge the things I’ve experienced in life.” These comments tie in with residents’ need and desire to be visible as a whole person and not simply as someone who has health or cognitive deficits. Whether and how we are seen by others impacts how we are treated, which in turn drives how we internalize our very existence (Pirhonen & Pietilä, 2015). One resident stated plainly, “trea[t] me like a human being.”

### How I Am Treated Key Theme

A surprising number of comments were responses related to the experience of poor treatment by staff. For instance, “the care provider should not say ‘don’t tell me how to do my

job”; or “we are mature adults and should be treated as such, not like children. We should not be told how we feel and think.” Several remarks were directed at feeling rushed by staff (“don’t rush me”), or exemplified physical needs not acknowledged or noticed. For example, “[staff] should talk directly to any person who is hard of hearing”; or “if I am hard of hearing, I am usually ignored when I am in a group. Please be sure I am included in the conversation/activity.”

The comments reflect a sense of injustice and inequity in treatment, and they point to the long history of marginalization of older people in our society (World Health Organization, 2021) that has not yet been rectified. “I would like to be involved in my care. I don’t like being controlled”; “[I want] to ask for something without feeling that I am...inconveniencing someone.” These reactions demonstrate that residents are keenly aware of emotional and physical transgressions by staff and others that may be subconscious reminders of the historic – and current – low social status that older people have internalized (Levy, 2009).

### Comments with Emotional Content

Several resident comments exhibited such raw emotion that they reflected the underlying emotion more than the literal content of the comment. For example, “I feel like I am in prison, and I will never get to leave. I have to depend on those who are in control, so I say nothing”; or “don’t act like you’re doing me a favor”; “please don’t treat my things like they aren’t important, my things are all I have now.” These comments reflect a profound sense of loss and grief, and it is critical to better understand the root causes of these feelings at a population and an individual level if efforts to design and implement a fully person-centered long-term care system are to be successful. The depth and rawness of feeling speaks to the absence of something fundamental; this might reflect the organizational culture, but also our ageist society as a whole. “We need to feel like our lives matter; we are real people, not fake people.”

### Relevant Associated Theories

The project’s literature reviews for the primary domains of person-centered care (PCC)<sup>2</sup> revealed several social and behavioral theories relevant to the phenomenon of the lived experience in LTC. Three theories have particular applicability to the resident MBA comments about the life transition precipitated by a move into LTC (e.g., sharing a room with a stranger, having no or little privacy; “getting care from someone else is a big change for me”). If meaningful PCC<sup>2</sup> is to be achieved, understanding resident experiences in the context of studied theory is essential, as is finding ways to operationalize any insights.

### Continuity Theory

Throughout the life course, individuals develop strategies to help adapt to change. Continuity theory confirms that the availability and use of these strategies to navigate changed circumstances speaks to our capacity to adapt and “maintain morale in the face of discontinuity” (Atchley, 1999). Adaptive strategies are born out of our unique worldviews, values, beliefs, temperament, coping strategies, and personal philosophy of life, but individuals are all similarly motivated to maintain continuity as we maneuver through life transitions. A move into a residential care environment and the associated shift to even moderately dependent care involves such upending of life, home, belongings, and relationships that one researcher has referred to it as breaking up a home (Gubrium, 1997, Pirhonen & Pierela, 2015). Such a dramatic upheaval requires both external and internal adjustments; residents may be challenged to create continuity in their surroundings and in how they perceive themselves – or are perceived by others – in ways that are familiar and manageable even as they seek to create and sustain a “new self” (Atchley, 1989).

Residents’ comments that speak to expectations of being “known” by staff, and of being acknowledged as unique human beings with specific needs and preferences, can be interpreted as requests to support maintenance of

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their former lives and selves. These resident expressions indicate efforts to adjust to a changed landscape by creating continuity in how they perceive themselves and how they are perceived by others in this new environment. When organizational policy or staff attitudes or behavior impede adaptation or create discontinuity, quality of life and wellbeing often suffer (Atchley, 1971; Henning, Lindwall, & Johansson, 2016). To maintain continuity, individuals must be able to stay connected to those parts of their personal and/or professional history that are most important to them, otherwise "integrity is lost" (Atchley, 1989). Resident comments about wanting staff to know about their past reflect this need ("understan[d] our backgrounds"). Comments such as "I wish my family members were all close by" and "no matter what, we need family members to visit" speak to the desire to maintain key attachments. LTC providers are advised to identify as early in the transition as possible the most important social contacts, and to facilitate and support ongoing connection to achieve continuity. For those residents who experience transition into LTC as a negative event or who have had a sudden health decline precipitating a LTC admission, the longing for continuity of relationships may be acute and trigger feelings of loss, grief, and lack of purpose.

## Person-Environment Fit Theory

Person-environment fit theory (P-E fit) was first developed in the mid-20th century and refined in subsequent decades to better understand the interplay between the person and their environment as it relates to stress (Lawton, 1982; Edwards, Caplan, & Harrison, 1998). Lawton (1982) and others extended these concepts into gerontology as the field of environmental gerontology (EG) evolved, finding its theoretical roots and its place in social, behavioral, and environmental science.<sup>3</sup> P-E fit theory's defining premises are "the relation

between the behavior of aging persons and their sociophysical environments" (Wahl & Weisman, 2003), through three primary domains: the maintenance, stimulation, and support in the environment as they relate to the individual. When P-E fit is achieved, it produces positive outcomes (Yu, 2009).

Within the person-environment fit theory, people and places are not perceived as entirely independent; they are interwoven, such as when places meaningful to us involve the people who occupy them and when people in an environment impact the way we experience it. These concepts feature heavily in LTC, where staff, other residents, our own visitors, and sometimes the visitors of other residents inhabit and influence daily life, particularly when intimate physical spaces are shared. When we cannot maintain our physical spaces the way we need or want or when there is an encroachment by others, we experience incongruence in our physical or social environment (Granbom, et al., 2014) and may struggle to regain normalcy. This may exhibit as insisting on boundaries; "[I want] personal space, a space that is my own, that others don't have access to"; and "everyone needs some private space and other people should respect it." The P-E fit concept has evolved to include place integration (Rowles, 2013), whereby the environment is viewed as dynamic and changing based on the individuals operating or intersecting within the space. The *place integration* concept potentially shifts the responsibility of facilitating fit, in part, to the LTC provider, most notably if the resident is unable to exercise control or influence over the environment due to physical or cognitive limitations. This view is reflected in the resident comments expressing sentiments such as "there is no true privacy in a nursing home." However, awareness of the value that an individual resident places on privacy offers the provider an opportunity to support better fit.

## Self-Determination Theory

Self-determination theory involves the innate human need for autonomy, competency, and relatedness (Deci & Ryan, 2012; Dattilo, Mogle, Lorek,

Freed, & Frysinger, 2018). We need to feel we can make our own choices and have the agency, will, competency, and self-efficacy to carry out our choices. We want to be sufficiently connected to others (relatedness), so we feel understood and cared about (Dattilo et al., 2018). These psychosocial needs factor heavily into a sense of well-being and increased quality of life, particularly for older people living in LTC settings (Kasser & Ryan, 1999). As health-related needs increase in late life and older persons transition into residential care settings where they have less control over their persons and their environment, the threats to self-determination and its components increase. Resident comments suggest that, even for those residents who have settled into life in LTC, maintaining the ability to make autonomous choices is important: "Independence means everything to me - going where I want when I want"; or "[I want] to be able to express my choices and choose for myself." For individuals who have lost their right of decision-making agency regarding their environment, care needs, socialization, and other aspects of daily life, the sense of violation is palpable. The right to self-determination is deeply embedded in American legal and ethical principles (Lesser, 2012), and the loss of that right is often experienced as a fundamental injustice (Ekelund, Dahlin-Iyanoff, & Eklund, 2014).

## Operationalizing Theoretical Concepts - Implications for Practice

Resident comments about their social lives, their environments, and the extent to which the staff know and understand them, align with relevant theories, and provide useful context when applying theory to the lived experience in LTC. But how might LTC providers use this information in a practical way to create a true person-centered environment where residents feel normalcy, when designing or implementing meaningful change? And, how might Aging Life Care Managers use this information to assess the quality of care in LTC settings that their clients may receive? We offer a few preliminary thoughts.

## Risk Implications

It is helpful to examine each of the theories in the context of resident characteristics that may put them most at risk for decreased well-being. (See Table 2 *Continuum of Risk* below.) This framework could be used at admission to support continuity and autonomy and at periodic check-ins with residents or family members, with the primary goal of reducing or eliminating risk of discontinuity and feelings of displacement, poor fit, disconnection with others, or loss of autonomy. As much as possible, finding out each resident’s capacity to adapt to change and the historic ways in which they have coped with significant change can guide provider behavior and decisions for that resident. Identifying which residents are likely to be at highest risk for discontinuity supports taking targeted, personalized steps to increase continuity, such as knowing more about how residents interact with their personal space and belongings and how attached they are to aspects of their environment, including people and belongings,

but also functional (e.g., proximity of items) and intangible aspects (e.g., “a sense of security”). Those residents who have strong attachments to the people, belongings, or intangibles that are least able to be accommodated in the LTC environment may be at highest risk for poor fit.

Reviewing and updating admission questionnaires or life story questionnaires, or interviewing the resident or family members with these specific theoretical concepts in mind, can help identify those at high risk. Taking extra time and allocating adequate staff and other resources to those residents at greater risk for a difficult transition will shorten periods of discontinuity and unsettledness and promote normalcy and wellbeing for those residents and their family members, and support staff in providing optimal person-centered care. Staff, particularly managers and front-line senior staff, will benefit from training focused on the basics of the theoretical concepts and the importance of residents’ maintaining emotional and environmental continuity, participating meaningfully in choice, and feeling a sense of volition

and agency. Consistently integrating these concepts – which resonate with all humans – into formal and informal care planning conversations can impact daily practice and gradually shift organizational culture.

Physical environment constraints (e.g., lack of single rooms, small rooms, poor access to outdoor spaces, limited private gathering spaces) will pose greater challenges for long-term care providers in their effort to facilitate smooth and stable transitions. However, for those residents at greatest risk, staff awareness of salient resident characteristics can, at a minimum, generate open discussion and planning among the resident, family members, and leadership, and promote strategic thinking to address constraints in creative ways. This might include, for example, carefully considering all options for room choice, room décor, personal belongings, placement of furnishings, lighting, noise, greenery, and similar features, to optimize features most closely aligned with essential resident attributes.

## Affective Implications

Resident comments display a range of emotions suggesting adaptive challenges in part explained by relevant theory. These emotions surely can be clues about what residents find most difficult about aspects of daily life in LTC and may offer opportunities for providers to promote positive change. An interesting finding from the analysis was that comments about certain topics seemed more likely to evoke one type of emotion. For instance, the emotion often expressed in resident comments about socializing was longing and desire, but in comments about physical space and privacy, it was more akin to entitlement, control, and a sense of justice, as were comments about how one is treated. In resident comments about being known and visible by staff, the emotional content was largely annoyance and disappointment about the expectations and predictability of care. The comments coded as heavy with emotional content expressed deep loss and grief.

## Conclusion

The COVID-19 global pandemic has made the need for LTC reform  
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**Table 2 | Continuum of Risk**

PERSONS MOST AT RISK	PERSONS LEAST AT RISK
<b>CONTINUITY THEORY</b>	
Least adaptive to change	Most adaptive to change
Individuals who are strongly attached to their personal or professional identity may need to maintain that identity even in retirement or into old age. If a health decline was sudden and dramatic (e.g., debilitating stroke), individuals may require time to adapt. Individuals who are emotionally resilient are most able to adapt. Determine how and how well individuals previously coped with significant change in their lives.	
<b>PERSON-ENVIRONMENT FIT THEORY</b>	
Least physically and cognitively able	Most physically and cognitively able
Most emotionally attached to place, things	Least emotionally attached to place, things
In optimal circumstances, individuals are able to achieve equilibrium with their physical and social environment; it accommodates their physical, functional, and emotional needs and is not overly taxing or burdensome in light of those needs. People and belongings that are important to the person are available and those that are unwanted can be avoided.	
<b>SELF DETERMINATION THEORY</b>	
Least able to express or carry out wishes	Most able to express or carry out wishes
The environment and interactions with individuals facilitate expressing and carrying out one’s preferences and supporting meaningful connections with others. Understanding choice, desire, and volition, and promoting execution of choice is key to equitable action. Individuals remain motivated to make choices and accomplish them, with the support of others if necessary.	

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more acute. The Mayer-Rothschild Foundation Designation of Excellence in Person-Centered Long-Term Care project's MBA provided direct information about resident lived experiences in their LTC communities and offered important emotional clues about both the challenging and supportive aspects of LTC life. The resident responses align with three relevant social theories. Within the framework of these theories there is an opportunity to identify risk factors and affective implications of the lived experiences of residents and find practical ways to increase the likelihood that residents will experience greater continuity, environmental fit, and opportunities for self-determination.

## Footnotes

1. Sample questions included: What is important for my care provider to know and understand; what aspects of personal and shared spaces are most important; how can my social needs and connections be supported in a meaningful way; and what makes me feel valued and respected.
2. As of this writing, the PCC domains are personhood, resident care, dining, physical environment, socialization & enrichment, staff empowerment, family engagement, leadership.
3. For a comprehensive history of the field of environmental gerontology, see Wahl and Weisman's Environmental gerontology at the beginning of the new millennium: Reflections on its historical, empirical, and theoretical development (2003).

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# Elder Mediation: Honoring the Voice of the Elder

Janet L. Smith, JD

## ABSTRACT

Aging Life Care Managers® are frequently contacted by families dealing with conflict about the care or financial management of an elder. “Elder Mediation” is an alternate dispute resolution process for disputes involving an elder’s care, well-being, financial management, or estate.

The mediator must determine if the elder will participate. To do so, the elder must have decisional capacity -- the ability to process information, weigh the options, and communicate the reasoning for his or her decision. The mediator must also determine if the elder is subject to being influenced or swayed by the other parties.

When an elder lacks decisional capacity, it is critical to honor the voice of the elder to the greatest extent possible. The resolution should be based upon “substituted judgment,” i.e., what the parties believe the individual would want if she were able to fully understand the facts and the issues. When substituted judgment is not possible, the decision should be made that is in the individual’s best interests.

An Aging Life Care Manager (ALCM) can help a family determine if mediation is appropriate, and then prepare the family for mediation by clarifying the issues, thinking about interests rather than positions, and staying focused on the future.

Mediation is a powerful tool for resolving elder disputes. Mediation gives the control to the parties, creates a safe space for communication and joint problem solving, and uses resources efficiently. Through mediation, family relationships may be strengthened or preserved.

ALCMs are frequently contacted by families dealing with conflict about the care or financial management of an elder. Long-standing issues, sometimes going back to childhood, can cloud decision-making and increase stress. This article will explain what Elder Mediation is, when a matter is appropriate for mediation, and how an ALCM can help a family prepare to resolve their dispute through mediation.

## 1. What is Elder Mediation?

“Mediation” has been defined as “a conflict resolution process in which a mutually acceptable third party, who has no authority to make binding decisions for disputants, intervenes in a conflict or dispute to assist involved parties to improve their relationships, enhance communication, and use effective problem-solving and negotiation procedures to reach voluntary and mutually acceptable understandings or agreements on contested issues” (Moore, 2014).

“Elder Mediation” is a dispute resolution process for matters in which an elder’s care, well-being, financial management, or estate is the focus of the dispute. Common issues in Elder Mediation are:

- a petition for guardianship or conservatorship;
- where an elder will live;
- who will provide caregiving services;
- who will serve as the elder’s fiduciary for health-care decisions or financial management;
- allegations of financial abuse or neglect;
- end-of-life decisions;
- a Will contest;
- the settlement of a decedent’s estate or Trust;

The parties to an Elder Mediation may include the elder, adult children or grandchildren, spouses or significant others, care providers, the elder’s sib-

lings or friends, and advocates such as clergy, counselors, ALCMs, or financial advisors.

## 2. Effectiveness of using mediation for elder disputes.

A review of 449 cases submitted to mediation that involved financial disputes found a settlement rate of almost 80%. The participants reported that mediation was less costly, more efficient, and led to greater satisfaction with the outcome than resolving the dispute through litigation or arbitration (Brett & Barsness, 1996).

There are few studies directed at mediation of elder issues. (Martin & Roberts, 2021). The reason for this

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is that elder disputes do not always proceed to litigation or result in formal settlement agreements, and thus measuring outcomes is challenging. One study found that mediation was effective in preventing and stopping the financial abuse of older people (Bagshaw, Adams, Zannettino, & Wendt, 2015).

Practitioners report that there are many advantages to using mediation to resolve elder disputes, including confidentiality, highly emotional issues, and flexibility (Radford, 2001). An international study of elder mediation practitioners found that all types of mediation – including interest-based, therapeutic, and facilitative – can be helpful when elder abuse or neglect is present (McCann-Beranger, 2010).

To date, the positive claims regarding the value and effectiveness of elder mediation are based on a limited number of studies combined with anecdotal evidence gleaned from elder mediators who have a solid practice and are enthusiastic about their experience. The evidence and experience available is suggesting strongly that families who participate in the mediation process are reporting enhanced quality of life, improvement of fragile relationships, and reduction or prevention of incidents of elder abuse and neglect (McCann-Beranger, 2010, p. 23).

### 3. Challenges in elder disputes.

Elder disputes present some unique challenges. A matter may involve a party with diminished capacity or dementia, multiple parties or factions, significant power imbalances, or a long history of conflict and dysfunctional communication. The issues can be highly emotional. One or more of the parties may have mental health problems, substance abuse disorder, or a high conflict personality. A parent might have been neglectful, domineering, or emotionally unavailable, yet now be dependent on children for care or decision-making. Children might

struggle with the best way to protect a parent from harm while honoring the parent's independence. While these issues make finding resolution challenging, the disputing parties are often motivated by a shared concern for the elder's happiness and best interests.

### 4. Case study: the story of Sam, Bill, and Suzie<sup>1</sup>

Most elder mediations start with a family locked in a dispute that to them feels intractable. In the matter of Sam, Bill, and Suzie, I was retained to mediate a dispute in which Sam had filed a petition to appoint a conservator/guardian for his 94-year-old father, Bill. Bill had been married to Sam's mother for more than fifty years. Sam was an only child who lived in several time zones away. Less than a year after Sam's mother passed away, Bill married Suzie, who had been a caregiver for Bill's wife. Suzie was more than 30 years younger than Bill. Sam was aware that large amounts of Bill's funds had been spent to fix up Bill's house, pay off Suzie's debts, and make gifts to Suzie's children from a prior marriage. Bill had a modest home, a good

pension, and adequate savings from his career as an aerospace engineer, but the amount the couple was spending appeared to Sam to be unsustainable.

### 5. A common theme: the need for safety versus independence.

A common theme in many disputes involving elders is the balance between the need for an elder's safety and protection versus the elder's desire for autonomy and independence. Bill had some memory loss but had not been diagnosed with dementia. He had mobility issues, no longer drove, and needed help with meal preparation, housekeeping, bathing, and dressing. He had always managed his own finances, but now let Suzie handle the checkbook. Bill told me that, more than anything, he wanted to remain in his own home. He told me that he loved Suzie and enjoyed her company. He said that he was the one who first suggested they get married. He was terribly angry with his son, Sam, for trying to interfere in his new marriage. Sam had always called Bill on Sunday evenings, but Bill did not want to talk to Sam if Sam could not accept his relationship with Suzie. Bill was almost ready to write Sam out of his Will, and had already changed his Durable Power of Attorney to appoint Suzie as his financial and health-care agent instead of Sam.

### 6. Is it really about the money?

Sam told me that he did not trust Suzie, and felt she was an opportunist who was financially exploiting Bill. Sam felt that Suzie had used undue influence to get Bill to marry her, pay off her debts, and give money to her children. Suzie had little education and no assets of her own. Sam worried that Suzie did not understand money management and would squander Bill's nest egg, leaving Bill without resources for his own care. Sam told me that his dad's memory was not what it used to be, and he had trouble recalling how much money he had or what he spent it on. Sam also accused Suzie of isolating Bill and alienating him

Most elder mediations start with a family locked in a dispute that to them feels intractable.

from Sam. Lately, when Sam made his regular Sunday evening calls to Bill's mobile phone, Suzie would answer and say that Bill was unavailable. Sam said his primary concern was his dad's welfare.

Suzie did not like Sam. She said that conversations between father and son had always been awkward, and they did not seem close. Suzie accused Sam of trying to get her out of the picture in order to preserve his own inheritance. She thought that if she were not there to care for Bill, Sam would move Bill to a care home. She said she loved Bill and wanted to take care of him. She said that Bill was strong-willed and capable of making his own decisions. She did the driving, grocery shopping, meal preparation, and housekeeping. She said that Bill had plenty of money but was also frugal, and he made the decisions on how to spend it. Most of the money spent to fix up the home was to make it more accessible for Bill. Paying off her debts enabled Suzie to take care of Bill full time, without having to work another job. She said that Bill liked her children, and that if he had given them money, that was his choice to make, not Sam's.

## 7. Does the Elder have decisional capacity?

When beginning an Elder Mediation, the mediator must first decide if the elder has the decisional capacity to participate fully in the process. In the context of medical decision-making:

The main goal when determining capacity is to see whether the decision being made makes sense logically based on the values, beliefs, culture and religion of the patient. The patient not only needs to understand what is being said, but also must be able to process the information and explain why he is making the decision he makes. Just being able to repeat information is not enough; the information has to be understood (Kind, 2018 p. 13).

The following questions are helpful to determine whether the individual has the ability to make his or

her own decisions:

- Does the individual realize there is a decision to be made?
- Can the individual understand the problem and the options for resolution? Can the individual retain information long enough to consider different options?
- Can the individual understand the limitations of different options, such as limited financial resources or the effect of physical/cognitive impairments?
- Can the individual understand the consequences of each of the different options, including the option to do nothing?
- Can the individual incorporate his or her own values and beliefs into the decision making, including how the choices would affect his or her life, and the impact on the other parties?
- Can the individual communicate his or her decision and explain why the individual made this decision?

Another issue to consider is whether the individual has fluctuating capacity. He may have some good days with full capacity to make well-reasoned decisions, and other days when capacity is diminished or absent. Families sometimes overemphasize the "good days" when describing an elder's decision-making capability.

It can also be difficult to be sure that the elder is communicating his or her own decision, free of influence from others. It is not uncommon for elders to be conflict-averse and not want to "ruffle feathers." In such cases, the elder's wishes may vary depending upon who talks with him about a decision that is being made. Sometimes families are aware of this tendency, and report, "She's telling everyone what they want to hear." In extreme cases, this may rise to the level of undue influence, where a person in a close relationship with the elder is manipulating a vulnerable adult for his or her own purposes.

In our example, although Bill tired easily, he was capable of participating in the mediation and expressing his own wishes. He had sufficient working

memory to engage in problem-solving, and to weigh the pros and cons of different proposals. He was able to understand that his behavior and the behavior of the other parties had consequences. He was able to participate as a party in the mediation, provided his stamina and mobility issues were accommodated.

"Honoring the voice of the elder" does not mean that the elder always gets everything he or she wants. An elder with decisional capacity must be able to come to the mediation as the other parties do, with an open mind, willing to engage in joint problem solving to resolve the dispute.

## 8. How can the mediator honor the voice of an elder who does not have the capacity to participate?

In another case study, Millie, a pleasant and friendly 80-year-old widow, suffered from moderate dementia. Her family members – a daughter, a granddaughter, a niece, and a cousin – all had differing opinions about Millie's care needs and where she should live. They were moving Millie around to spend time at various family members' homes. They were all certain they knew best because Millie told *each* of them what that person wanted to hear.

Millie was not able to participate in the mediation. She had insufficient capacity to understand and analyze her options. When an elder does not have the ability to advocate for herself, it is critical to honor her wishes and values to the greatest extent possible. When a person has lost decisional capacity, the decision-maker should, whenever possible, use "substituted judgment," which means making the decision you believe the individual would make if she were able to understand all the facts and consequences. When we cannot determine what the individual would want, then the decision should be made that is in the individual's best interests. In an elder mediation, there is a lot of room for disagreement as to what the elder would want or what is in her best in-

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terests. What the disputants should not do is make the decision that is best for *them*, disregarding the known wishes and values of the elder.

The first challenge in Millie's case was to help the family learn what Millie's care needs were and how those needs could be met in a way that honored Millie's wishes and values. After holding initial meetings with the family members, the parties agreed with my suggestion to retain an ALCM to interview Millie in a neutral location, meet with the family members, and review medical records to do an assessment of Millie's care needs. The ALCM performed the assessment and interviews. She learned that Millie loved all of her relatives but preferred a quiet life with low stimulation. She did not want to be around children, pets, or loud activity. She did not want to go back and forth between family members' homes, and did not enjoy activities away from home, apart from her weekly hair appointment. The ALCM presented her findings to the family members in a joint mediation session, then stayed to answer questions. The ALCM thus filled the role of a neutral expert, not affiliated with any party, and was able to educate the family members on Millie's needs and wishes. Because Millie was so pleasant and accommodating, the family members had an incomplete view of the extent of her dementia and how much care she needed. They all tended to project their own values – assuming a need for activity and stimulation – onto Millie. They were also overlooking the signs of Millie's agitation and distress resulting from the frequent moves. The ALCM reviewed the options of Millie living with a family member but recommended that Millie's care needs would be better met at a high-quality adult family home where she could get the 24-hour care that she needed in a calm environment, and all family members could have equal access for visits. The mediation was successful, with the family members coming together on a short-term plan for visiting and caring for Millie, including a search for an appropriate adult family home. I learned that she moved to an adult

For some families with a history of dysfunctional communication, a joint session may be too stressful. When a dispute is highly emotional, the brain gets hijacked by the fight, flight or freeze mechanism.

family home about six months after the mediation concluded.

Other options for honoring the voice of an elder who cannot participate include having an advocate such as a Guardian ad Litem, or Special Representative, friend, or advisor, advocate for the elder's substituted judgment or best interests. If the elder can express some wishes, but not fully understand the options under consideration, the mediator might meet with the elder privately, or ask the parties for historical information about the elder's long-held values and beliefs.

## 9. What is the process for elder mediation?

The process for Elder Mediation is very flexible and can be modified to suit the needs and abilities of the parties. Virtual mediation works well, since many families are separated geographically and have differing work and family obligations. Whether the mediation is virtual or in-person, the mediator should take all steps necessary to accommodate the parties' needs related to age, impairment, or stamina.

The mediator will decide whether the sessions should be individual (shut-

tle style) or joint. In the case of Sam, Bill and Suzie, sessions were conducted both privately and jointly. Sam and Suzie had strong opinions about the other but had not spent much time face to face. The joint in-person sessions were helpful for them to begin to build trust with each other. Having a neutral moderator and ground rules can create a safe space, and help feuding families learn to listen to each other without interrupting.

For some families with a history of dysfunctional communication, a joint session may be too stressful. When a dispute is highly emotional, the brain gets hijacked by the fight, flight or freeze mechanism. One party might get defensive and shut down, no longer hearing what the other party is saying. Even if there are areas of agreement, if emotions have taken over, the parties cannot access the problem-solving part of their brain to work towards an agreement (Eddy & Lomax, 2021). In such cases, individual sessions might be more productive.

## 10. How can an Aging Life Care Manager or mediator prepare parties for mediation?

First, an ALCM can help a family determine if a dispute is appropriate for mediation. Families often initially avoid confronting an issue because conflict is uncomfortable. They may believe they lack the power to force a change or are not yet ready to take action (Moore, 2014). A disagreement becomes a dispute when one or more parties are unable or unwilling to accept the status quo or accede to the demands of the other (Moore, 2014). To be ready for mediation, the dispute must have reached a level where the parties are ready to confront the issue and try to resolve it.

The first step toward preparing for mediation is to get the parties thinking about interests, not positions (Fisher & Ury, 2011). The interests of the parties might include such basic human needs as safety, financial security, recognition, or autonomy. I give them a preparation worksheet to help them clarify and list all the potential issues for consideration, to think about their

own interests, and the interests of the other parties. In preparing for mediation, it is important to focus on the big picture first, not the details.

It is also important to get the parties focused on the future, not past grievances. The past supplies the context for the dispute, but what happened cannot be changed. Bill Eddy, a mediator experienced in high conflict disputes, writes, "You can't mediate the past" (Eddy & Lomax, 2021). I try to keep the parties focused on what changes they want going forward, and ways that trust can be rebuilt.

Many ALCMs have received professional mediation training. There are times when it may be the best option for the ALCM to also serve as the mediator for an elder dispute. The advantages include a familiarity with the parties and the dispute, thorough knowledge of the options available for care and services in the community, and experience with implementing solutions. However, when the ALCM has already recommended a particular resolution, maintaining a facilitative neutral demeanor might conflict with the ALCM's standard of care. An independent elder mediator would be able to let the parties explore and discuss all options, interact with all parties in a neutral manner, and allow the ALCM to serve as an expert, make recommendations, and maintain ongoing relationships with the parties.

### 11. Sam, Bill, and Suzie – resolution was reached.

After several individual and joint mediation sessions, Sam, Bill, and Suzie were able to reach a resolution. Sam accepted the fact that his father wanted Suzie in his life. His focus shifted to putting up guardrails to protect Bill from financial exploitation or reckless spending. Bill agreed to appoint a professional fiduciary as his agent for financial management under his Durable Power of Attorney, and to let the fiduciary manage his investment accounts. All parties agreed that Bill and Suzie could use Bill's pension and social security income any way they wished, with the exception that Bill's funds would not be used for the benefit of Suzie's children. The professional fiduciary would review

the spending, but would not intervene as long as the agreed guidelines were followed. Bill agreed to retain an ALCM to assess the safety of the home, train Suzie as needed in caregiving skills, and check in on Bill and Suzie on a regular basis. If, at any point in the future, the ALCM felt that supplemental care was needed to keep Bill in his home, Bill and Suzie agreed to follow the ALCM's recommendations. Bill and Suzie agreed to keep Sam informed and to consult with him on all major health care decisions.

There is no guarantee that Elder Mediation will improve the parties' relationships. In many cases, the dispute is resolved but the parties remain estranged. In the matter of Sam, Bill, and Suzie, however, the relationships were changed for the better. At the close of the final in-person mediation session, plans were being made to have dinner together, and the rift between father and son was on the way to being repaired.

### 12. Conclusion.

Mediation is a powerful tool for resolving disputes concerning an elder's care, living situation, or finances. The process gives the control to the parties to create their own solution. The mediator creates a safe space for the parties to work together on joint problem-solving. Creative options may be available that could not be achieved by going to court. Mediation generally saves the parties time and money compared to other forms of dispute resolution. Family relationships may be strengthened or preserved.

### Footnotes

- Names and identifying information used in this article have been changed for privacy.

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# Stop the Revolving Door of Hospitalizations by Keeping Seniors Safe at Home

Randy Bartosh, OTR; David Chandler, RN, BSN, MBA, CFE; Debbie Miller, BSc

## SUMMARY

*Fall. Hospital. Rehab. Repeat.*

Sound familiar? Unfortunately, it is an all too well-known cycle for seniors and their concerned family members. Unsafe occurrences that lead to hospitalizations and rehospitalizations among seniors are continuing to rise each year (Mattison, 2021). As the population continues to age, the rate of hospitalizations is worrisome for seniors and their families, as well as for healthcare systems, government payors, and insurance providers.

The opportunity to mitigate risk is much greater if clear methodology and tools are available to correctly identify and address these risks before seniors return home. There are several requirements necessary to fill this need: first, a framework that captures all relevant social, behavioral, functional, and environmental influencers of senior health; second, a methodology for identifying and measuring related risks; and third, a model of care that effectively reduces risks and regularly tracks progress.

This article will show how a system of scoring and tracking the individual risk factors that lead to hospitalizations can have an immediate effect on the health and wellbeing of seniors and their families, as well as decrease the cost to the healthcare system.

This article seeks to share with Aging Life Care Managers® (ALCMs) the philosophy and research behind one particular assessment tool and to encourage a review and possible refinement of their own assessment tools.

## Introduction

When it comes to helping individual seniors and their families, broad changes to policies, spending, and societal influences (macro social determinants of health, or MSDOH) happen far too slowly to make a difference to daily life. However, by paying close attention to individual risk factors, or micro social determinants of health (mSDOH), Aging Life Care Managers (ALCMs) can have an immediate impact on the safety and well-being of their patients and families.

The concept around using micro social determinants of health to improve the lives of our aging population has come to the forefront after 20 years of research by Performance Based Healthcare Solutions (PBHS), including applied research collaboratives with more than 300 care organizations involving more than 75,000 patients. The result is the identification of five

key outcome areas that most often lead to senior falls and hospitalizations: Medical Condition Management, Safety in the Home, Independence, Burden of Care, and Quality of Life. By using a matrix of criteria that analyzes and scores each of these areas, care managers have access to specific and individualized feedback that allows them to successfully quantify and reduce risks, educate the family, and improve overall quality of life.

## Scope of the Problem

Research has shown that approximately 20% of high-need, high-cost adults discharged from the hospital will be readmitted within 30 days of discharge and more than 50% will be readmitted within one year (Alper et al., 2021). Having insufficient support for daily functional needs after discharge contributes to more than 90% of hospital readmissions (Alper & Greenwall, 2021). It is common for seniors

to have multiple chronic conditions and functional limitations, which increases the influence of risk factors and makes it even more important to reduce the cause of unsafe occurrences (Abrams & Hughes, 2019, p. 2). The good news is that, by identifying and addressing risk factors, 76% of readmissions are preventable (Van Walraven, Bennett, Jennings, Austin, and Forster, 2011).

## Exploring Social Determinants of Health

Social determinants of health (SDOH) are described by the World Health Organization as the conditions in which people are born, grow, work, live, and age, as well as the wider set of forces and systems shaping the conditions of daily life. SDOH have been found to have a more significant influence on health outcomes than genetics or even clinical care (Artiga & Hinton, 2018). Most discussions about SDOH are held within the public

health and public policy arenas. This is understandable, as investments that mitigate risk associated with SDOH at a societal level have the potential to benefit large populations. However, the health issues that elderly Americans face and the demand to achieve improved health outcomes imposed by the Centers for Medicare & Medicaid Services (CMS) create an urgency to find tools and resources based on individual situations that have immedi-

ate effect.

While no one wants to abandon the considerable promise that potential large-scale solutions could hold, many factors cannot be addressed in a timely manner on a macro scale. Thus, it is helpful to think of SDOH from two perspectives (see Figure 1 for more detail):

- **Macro Social Determinants of Health (MSDOH):** Socio-economic, cultural, and environmental

factors that are discussed and addressed at the population or community level

- **Micro Social Determinants of Health (mSDOH):** Social, functional, economic, cultural, and behavioral factors that are specific to individuals and addressed at the individual level

Compared to MSDOH factors, mSDOH factors that relate to the health and safety of our aging population have not been studied nearly as extensively. By their nature, mSDOH are myriad, personal, and variable. The influence of mSDOH on health outcomes for senior patients is not well understood, defined, or measured, making effective identification and mitigation of associated risks a significant challenge. What works for one patient may not work for another. Or, what causes one patient to fail may not be the same for the next. New tools and methodology need to be put in place to measure and address the influence of mSDOH at the individual level.

### Economic Impact of Micro Social Determinants of Health

An issue brief published by the Commonwealth Fund in 2016 noted that patients with three or more chronic conditions accounted for 53% of annual healthcare spending while accounting for only 34% of the population (Table 1). These patients were also 35% more likely to go to the emergency department (ED) than the average U.S. patient. Many seniors also have at least one functional limitation, increasing their likelihood of visiting the emergency department by more than 230%. Nearly two-thirds of high-need patients do not have the assistance they need to complete their activities of daily living, and more than 50% do not have adequate help with care coordination, resulting in a massive opportunity for ALCMs to intervene by providing needed support and reducing preventable and unnecessary healthcare expenditures (Hayes et al., 2016).

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**Figure 1: Examples of Social Determinants of Health**

SOCIAL & COMMUNITY FACTORS	
Macro SDOH Examples	Micro SDOH Examples
<ul style="list-style-type: none"> <li>• Social services</li> <li>• Community resources</li> <li>• Cultural and linguistically appropriate and competent services</li> </ul>	<ul style="list-style-type: none"> <li>• Interpersonal, social, spiritual, and community connections</li> <li>• Presence/quality/cost of home health caregivers</li> <li>• Presence/quality of family caregivers</li> <li>• Family caregiver support systems</li> </ul>
ECONOMIC FACTORS	
Macro SDOH Examples	Micro SDOH Examples
<ul style="list-style-type: none"> <li>• Legislative and policy</li> <li>• Income assistance</li> <li>• Food insecurity</li> </ul>	<ul style="list-style-type: none"> <li>• Individual income and savings</li> <li>• Contributing incomes and resources</li> <li>• Eligibility for assistance programs</li> </ul>
NEIGHBORHOOD & ENVIRONMENTAL FACTORS	
Macro SDOH Examples	Micro SDOH Examples
<ul style="list-style-type: none"> <li>• Social services &amp; community resources</li> <li>• Transportation network</li> <li>• Neighborhood safety</li> <li>• Air quality</li> <li>• Water and sanitation</li> </ul>	<ul style="list-style-type: none"> <li>• Safety risks in the home</li> <li>• Home ambulation and use of assistive devices</li> <li>• Functional ability (ADL and IADL)</li> <li>• Transportation (appointments, food, medications)</li> <li>• Knowledge of community resources</li> </ul>
HEALTHCARE ACCESS & QUALITY FACTORS	
Macro SDOH Examples	Micro SDOH Examples
<ul style="list-style-type: none"> <li>• Access to healthcare</li> <li>• Provider availability and linguistic and cultural competency</li> </ul>	<ul style="list-style-type: none"> <li>• Mental health assistance</li> <li>• Medical condition diagnosis and management</li> <li>• Nutrition and exercise</li> </ul>
EDUCATION FACTORS	
Macro SDOH Examples	Micro SDOH Examples
<ul style="list-style-type: none"> <li>• Literacy</li> <li>• Language</li> <li>• Higher education</li> </ul>	<ul style="list-style-type: none"> <li>• Health literacy &amp; diagnosis comprehension</li> <li>• Medical condition knowledge and management</li> <li>• Knowledge of community resources</li> </ul>

(continued from page 15)

Health costs associated with the presence of functional limitation are estimated to have totaled more than \$175 billion per year in 2020 (Table 2). Using mSDOH indicators to identify risk factors for individual patients offers ALCMs the potential to dramatically reduce pain, suffering, and failure through a more detailed and measured care planning process (Hayes et al., 2016). This has significant potential to lower the billions of dollars that are spent each year on avoidable

admissions. Successful mitigation of these risks, if achieved using a model of care that recognizes a senior's need for autonomy, holds the potential to significantly improve their quality of life (Hayes et al., 2016).

### Redefining the Practice of Assessing Health Risks Using Micro Social Determinants of Health

The combination of a framework, methodology, and model for care that identifies and mitigates negative

health risks associated with micro-social determinants of health has the potential for significant benefit.

For instance, reducing safety risks can lower rates of hospitalization; such an approach must consider health status, examination of individual function, and related ability to perform day-to-day tasks and must be balanced with the pre-eminence of senior autonomy. Tools and protocols used to assess risk range from those used for specific risks, such as the Johns Hopkins Fall Risk Assessment Tool (JHFRAT), to those used for specific situations, such as the LACE Index Scoring Tool (used as part of hospital discharge planning), to more comprehensive solutions based on self-reported patient surveys, such as the Health Measures Patient-Reported Outcomes Measurement Information System (PROMIS). Most major electronic health record systems have screening tools for social determinants of health, but there are no broadly accepted standards for data collection or reporting.

A new assessment model centered around mSDOH could make possible the promise of improving outcomes, reducing costs, and allowing clinic and in-home services to be used more collaboratively and effectively. Scoring and outputs collected on such an assessment would lead to a care plan that is individualized and goal-driven, and that defines the individual and shared responsibilities for all participants involved in achieving positive care outcomes.

As an example, Performance Based Healthcare Solutions (PBHS) has used years of in-depth reporting and research to develop an mSDOH scoring and assessment model, called LIFE Profile, a proprietary tool. LIFE Profile scoring has shown efficacy in predicting the risk of future hospitalization. When examined within a cohort of 196 Medicare patients in Houston, Texas, a 2018 observational study of this method showed correlation between autonomy scores and the likelihood of a hospital admission within six months of the assessment. The result of the assessment produces a score that determines the likelihood of a three-

**Table 1: Selected Demographics of “High-Need” Patients**

STATISTIC	U.S. ADULT PATIENTS	PATIENTS WITH 3+ CHRONIC CONDITIONS	HIGH-NEED PATIENTS (3+ Chronic & Functional Limitations)
Population	232 million	79 million (34%)	12 million
Avg healthcare spend/patient/year	\$4,845	\$7,526	\$21,000
% Of annual healthcare spending	100%	53%	22%
% Medicare Eligible	17%	31%	50%
% Medicaid Eligible	8%	7%	13%
% Dual Eligible	3%	3%	20%
ED visits per 1,000	183	248	613
Hospital discharges per 1,000	107	147	535
Avg # of home health days per year	1.6	0.35	26
Avg # of medical office visits per year	3.6	6.2	9.6

Source: “High-Need, High-Cost Patients: Who Are They and How Do They Use Health Care?” The Commonwealth Fund, August 29, 2016.

**Table 2: Projected Growth of High Cost, High Need Patient Populations**

Patient with 3+ Chronic Conditions	2016	2020	2030
Size	79 million	88.9 million	112 million
Yearly Health Care Spend (@\$7,526/pp)	\$594.5 billion	\$669 billion	\$843 billion
“High-Need” Patients: 3+ Chronic Conditions and Functional Limitation	2016	2020	2030
Size	12 million	13.5 million	17 million
Yearly Healthcare Spend (@\$21,000/pp)	\$252 billion	\$283.5 billion	\$357 billion
Delta in Spending related to Functional Limitation (@\$13,474/pp)	\$161.7 billion	\$182 billion	\$229 billion

Source: “High-Need, High-Cost Patients: Who Are They and How Do They Use Health Care?” The Commonwealth Fund, August 29, 2016



plus-day hospitalization in the next six months. A score of less than 34 has a risk of hospitalization that is greater than 80%, while a score equal to or greater than a 45 has a hospitalization risk of less than 10% (Table 3).

**Table 3: LIFE Profile autonomy scoring and its relation to 3+ day hospitalizations within 6 months following an initial assessment**

Score	# Patients	% Hospitalized
>45	97	10.3%
34 – 44	34	55.9%
<33	65	89.2%

*Source: PBHS Study of 196 Patients in Houston TX, 1-1-2017 to 6-30-2018*

This model provides a comprehensive picture of risks associated with the mSDOH of an individual derived through scoring of the five key outcome areas proven to be necessary for successful aging and hospital avoidance.

### A Closer Look: Key Outcome Areas

When looking at the overall picture of the mSDOH that affect senior health and well-being, research shows that the risk factors distill into five key outcome areas that can be directly tied to the success or failure of individual health outcomes. Each component below represents an essential determinant for successful aging. The LIFE Profile system is based on a scoring matrix for each key outcome area, providing an opportunity to obtain quantifiable results to determine the likelihood of positive outcome for individual patients.

#### Medical Condition Management

When considering medical condition management, medication compliance typically comes to mind. However, the reality is that overall successful medical condition management is associated with the presence of

seven threshold factors that determine the likelihood that a patient’s chronic medical condition(s) will be controlled. A care manager can greatly impact patient outcomes by establishing a system to ensure that patients can meet the threshold of most of these factors. For example, a patient may be aware of symptoms specific to their medical condition(s), but without the related medical equipment, training, and tracking systems, may not be equipped to properly monitor the condition(s) and prevent the changes in health that would lead to rehospitalization. By scoring and analyzing all the factors associated with the patient’s condition(s), care managers can provide important resources beyond medication management.

#### Safety

Many unsafe occurrences in the home, such as falls, lead to hospitalizations. More than three million seniors are treated in the emergency room each year for fall-related injuries (Centers for Disease Control and Prevention, 2021). Typically, the senior returns home, post-discharge, without any consideration of the environment that

put the senior at risk in the first place.

By analyzing the home environment before the senior returns to their living space, care managers can identify the number of specific individual, task, and environmental safety risks that are present for the senior. PBHS research suggests that a set of 144 risks are commonly found to be significant in causing unsafe occurrences. Each risk factor needs to be examined to determine whether it is present in the home, and if so, action must be taken to remedy the issue.

#### Independence

While typical care plans review a senior’s ability to reliably perform activities of daily living (ADL) and instrumental activities of daily living (IADLs), a focus on mSDOH means that each typical task must be broken down into sub-components that are identified and scored to determine the specific tasks and actions where assistance is most needed.

Using the example of the LIFE Profile scoring system, identified ADL/IADL limitations are ranked according to the level of safety and consistency experienced by the patient in doing the activity on their own. After the detailed assessment, a care plan is designed to focus on what the patient can do for themselves, providing a sense of independence and self-esteem. A heavier focus of support is placed on the tasks the client cannot safely perform on their own.

#### Burden of Care

The burden of care on family members and other unpaid caregivers affects the ability of a senior to continue to age in place successfully. The average family caregiver provides 22 hours of care per week, and 25% of caregivers provide more than 44 hours of care each week (NYC Department for the Aging, 2017). Many adult caregivers stated that it is difficult to balance work and caregiving, with 75% of respondents saying they found caregiving to be stressful, and more than 50%

*(continued on page 18)*

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(continued from page 17)

found caregiving to be overwhelming (Bishop, 2021). Caregiver burnout is quickly becoming a healthcare issue, with depression affecting 20% to 40% of all caregivers (AgingInPlace.org., 2018).

Assessing the burden of care is an important place to start. PBHS research shows that there are 16 unique burden of care modalities for family caregivers that contribute to reduction of stress and burnout. Once identified, care plans can be designed to mitigate stressors and keep the burden of care within manageable ranges.

## Quality of Life

Quality of life is the overarching goal for our aging population. Regular engagement in activities meaningful to an individual is critical to long-term health maintenance as well as personal happiness. When setting specific personal goals, such as “I want to cook dinner again,” or “I want to be able to walk my dog every day,” seniors have more motivation to engage in the types of behaviors that support positive healthcare outcomes and achieve desired quality of life.

After scoring the patient’s quality of life through 12 key indicators of health (including absence of bodily pain, general viability and health, absence of emotion-based role limitations), the care manager can identify a list of favorite activities, hobbies, and connections that can be built into the care plan. Regular engagement with these activities correlates with improvement in quality of life.

## Role of the Aging Life Care Manager®

Seniors and their families look to ALCMs to be the experts in helping them maximize health, independence, functioning, and quality of life. ALCMs must be experts in the macro and especially the micro SDOH that impact seniors and be able to provide education and guidance to those

under their care to increase health literacy. By examining and addressing the mSDOH risk factors seniors are experiencing in their home environment, ALCMs can provide more individualized recommendations and care solutions, leading to improved health outcomes.

## Conclusion

By providing both a framework for understanding and a model for quantitative measurement, assessment protocols such as those described offer care managers new ways to identify and understand individual-level risks associated with micro social determinants of health and provide specific information for building more comprehensive and personalized care plans that mitigate those risks. Such personalization can be meaningful in promoting adherence with care plans, reducing hospitalizations, and achieving higher quality of life.

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Randy is the head of research for PBHS, which he founded in 1999. Over the course of the last 20 years, Randy has led applied research collaboratives with more than 300 care organizations and involving more than 75,000 patients. The research has been focused on categorizing and quantifying the outcomes patients want and need to achieve in order to be successful. He is also a board member of the RIGHTCARE foundation, which is using advanced methodology for community-based paramedicine programs with fire departments and senior ministry efforts around the country.

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David has served in various leadership roles, including executive director over several large senior living communities in Houston, TX. David also has an extensive background in skilled nursing facilities and served as director of clinical services for Brookdale Senior Living. David won the prestigious Hospital and Health System Association of Pennsylvania Patient Safety Achievement Award while working for the Cancer Treatment Centers of America in Philadelphia. His hobbies include camping, coaching his two kids' sports teams, and fishing.

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Debbie Miller is the owner of Senior Helpers of Middle Tennessee. She has been serving seniors since 2008 by providing quality home care and solutions that support aging in place. Her Senior Helpers organization is one of the largest in the country, providing over half a million care hours last year alone to Tennessee seniors. Using the LIFE profile, Debbie's care managers are now providing better outcomes and comprehensive solutions that help keep seniors safe at home. Debbie is a Dementia Care Specialist with over 12 years of experience as a dementia educator, helping family and professional caregivers better understand Alzheimer's disease and other types of dementia.

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