

An Exploratory Study of Stakeholder Perspectives on Quality Priorities for Long-Term  
Services and Supports for Older Adults

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## **Dedication**

This thesis is dedicated to my grandparents.

## **Abstract**

Major state and federal initiatives are underway to assess and improve the quality of long-term services and supports (LTSS) received by older adults in nursing homes, assisted living facilities, and other community-based settings. Although people who use LTSS (consumers) and their families are key stakeholders in LTSS quality, they are rarely included in the policy and organizational discussions in which priorities for LTSS quality are set. Prior studies have typically used qualitative methods and examined consumer and family views on LTSS quality in relation to only one setting. Most of these studies were completed 15-20 years ago and results may not reflect the values of consumers and families today. Further, prior studies have rarely included multiple stakeholder perspectives, limiting the ability to compare priorities across different groups.

The present study explored which aspects of LTSS quality consumers, families, and LTSS professionals value most highly and whether stakeholder views on quality priorities differ. The study addressed nine domains of quality from a person-centered perspective. Several methods were used, including: 1) development of an integrated valuing framework for LTSS quality; 2) use of Q methodology, which uses a forced ranking distribution, factor analysis, and qualitative interpretation of patterns observed; and 3) a survey containing rating, ranking, and open-ended questions. A convenience sample of 70 individuals in Minnesota representing the targeted stakeholder groups participated the Q methodology component of the study and 417 participated in the survey.

Across two data collection methods, participants overall identified safety/security, dignity/respect, and staffing/staff competence as the highest priorities for LTSS quality. Although there was considerable agreement among stakeholders on top priorities, consumers rated most aspects of LTSS quality as less important than professionals, which may indicate diminished or adjusted expectations. However, consumers placed more emphasis on aspects of the physical environment than professionals. Study participants, particularly consumers and families, rated autonomy/choice as less important than most other aspects of LTSS quality, a finding that necessitates further exploration. By-person factor analysis and participant comments provide insights into survey findings. Study results highlight the need for more dialogue to clarify stakeholders' values related to LTSS and ensure policies and practices align with these goals.

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## Chapter 1. Introduction

*Quality of care means to me that I'm respected.*

- A nursing home resident<sup>1</sup>

*The best part of my day is waking up knowing I'm not in a nursing home.*

- A consumer who receives LTSS at home<sup>2</sup>

*...We can get very easily sucked into having a good [compliance] survey... And that might not have a thing to do with how the people who are receiving services feel about it.”*— A community-based LTSS provider<sup>3</sup>

Views of quality in long-term services and supports (LTSS) have been heavily shaped by state and federal agencies that finance and regulate LTSS. The government's role in defining and overseeing LTSS quality is a result of several factors, including rising costs of LTSS borne largely by states and the federal government, consumer and legal advocacy agency reports on abuse in LTSS facilities, and a growing movement nationally emphasizing the importance of service delivery quality. However, when it comes to defining and assessing the quality of LTSS for older adults, the experiences and perspectives of those whose lives are the most directly affected—people who use LTSS and their families—are heard on the margins, if at all. This is true particularly in nursing homes, which are more heavily regulated than other LTSS settings such as assisted living facilities, adult day programs, and home-based care.

In their assessments, state and federal agencies have emphasized accountability measures of clinical care and consumer safety over other aspects of service quality. The government's responsibility to safeguard people from needless harm and to assure

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<sup>1</sup> Entry to the Residents' Voice competition, an initiative of The National Consumer Voice for Quality in Long-Term Care. Accessed 8/20/18: <http://theconsumervoice.org/home>

<sup>2</sup> Entry to the Residents' Voice competition (same source as above).

<sup>3</sup> Comment from a focus group participant in January 2016 (Mueller, Davila, & Kirk, 2016).

standards of care is undoubtedly important. Individuals who use LTSS and their families also expect care that minimizes negative experiences and outcomes. However, the government's regulatory focus on service and facilities management and consumer safety has dominated other aspects of LTSS quality, such as consumer and family satisfaction and consumer quality of life. In the data the federal government publicly reports on nursing home quality, for example, rates of pressure sores, urinary tract infections, falls, and other indicators of clinical safety overshadow people's overall experience with care.

LTSS represents an important public policy issue, with nearly two-thirds of LTSS expenses paid by Medicaid, a program administered by individual states and funded jointly by states and the federal Centers for Medicare and Medicaid Services (CMS). More than 11 million older adults use LTSS (Freedman & Spillman, 2014; Kaye, Harrington, & LaPlante, 2010) and over \$300 billion<sup>4</sup> is spent on LTSS annually (Colello, 2017). People of all ages use LTSS, although those over age 65 are the most likely to need these services (Kaye, et al., 2010). Many people underestimate their future LTSS needs (Henning-Smith & Shippee, 2015); however, seventy percent of people aged 65 and older will need LTSS at some point (Reaves & Musumeci, 2015). By 2050, LTSS needs in the U.S. are expected to double, largely because of the aging population (Kaye, et al., 2010).

LTSS involves a variety of programs and services, which may be related to medical, functional, social, housing, or other needs a person has due to illness, disability, including related to the aging process (CMS, 2016a). LTSS is delivered over time—often for many months or years—and in various institutional and community-based settings.

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<sup>4</sup>Amount spent on LTSS across all age groups.

Unlike healthcare, which aims to prevent, improve, or cure the clinical conditions a person may have, older people who use LTSS are typically on a course marked by gradual physical and/or cognitive decline. Although health services often are part of a person's care needs, a substantial portion of LTSS involves assistance with routine daily activities such as getting dressed, bathing, or eating ("activities of daily living," or ADLs) or assistance with other regular tasks such as paying bills, getting groceries, getting out to socialize, or making meals ("instrumental activities of daily living," or IADLs) (CMS, 2016a). In LTSS, maximizing a person's independence, social connections, and overall quality of life remain fundamental goals, although current practices do not always fully support these aims.

### **Context of LTSS Quality**

Although improvements to the organization and delivery of LTSS have taken place over time (Kaye & Williams, 2014), the quality of LTSS remains a substantial concern. Historically, LTSS has experienced numerous problems, some of the most persistent of which include:

- System fragmentation and a lack of coordination among healthcare and LTSS providers (Kaye & Williams, 2014; Reinhard, 2013);
- A policy bias toward institutional over community-based services in LTSS for older adults (Kaye & Williamson, 2014; Thomas & Applebaum, 2015);
- Considerable variation in the quality of services delivered (Grabowski, Feng, Hirth, Rahman, & Mor, 2013; Mukamel, et al., 2012);
- A poorly compensated, largely unskilled workforce (Stone & Harahan, 2010);

- High rates of staff turnover and personnel shortages (Castle & Engberg, 2015; Ejaz, Bukach, Dawson, Gitter, & Judge, 2015; Thomas & Applebaum, 2015);
- Concerns about nursing home resident quality of life (Shippee, Henning-Smith, Kane, & Lewis, 2013; Thomas & Applebaum, 2015); and
- Evidence of abuse, neglect, and unmet consumer needs (Caspi, 2014; Malmedal, Iversen, & Kilvik, 2015; Serres, 2017).

State and federal government agencies have implemented a range of policy and regulatory strategies to promote higher quality in LTSS. In addition to regulatory oversight, including compliance inspections, other policy approaches have involved shifting Medicaid spending from institutional to community-based LTSS (Miller & Kirk, 2016), providing financial incentives to LTSS providers to achieve certain quality outcomes (Arling, Job, & Cooke, 2009; Grabowski et al., 2017), and reporting information publicly about the quality of services individual LTSS agencies provide (Perrailon, Brauner, & Konetzka, 2017). Another approach has focused on shifting the underlying philosophical orientation of LTSS from a top-down paradigm, in which consumers have little voice and control (White-Chu, Graves, Godfrey, Bonner, & Sloane, 2009) to a model that is more “person-centered,” driven by the preferences, needs, and experiences of individuals receiving LTSS (Koren, 2010).

### **Movement toward person-centered care.**

The movement toward person-centered care in LTSS has taken place over several decades and involved efforts by consumer advocates, LTSS providers, professional associations, and state and federal government agencies. During the 1980s, consumer advocates drew attention to the need for dramatic nursing home reform (Braithwaite,

Makkai, & Braithwaite, 2007; Hawes, 1987). In 1987, the federal government passed the Nursing Home Reform Act, which required facilities to provide individualized (i.e., person-centered) care to the residents in their care (Koren, 2010). In the late 1990s, continued work by consumer advocates led to the birth of the nursing home “culture change” movement, which focused on improving nursing homes by promoting individualized care, creating more “homelike” environments, and ensuring that the voices of residents were heard in decisions directly affecting them (Koren, 2010; White-Chu et al., 2009). Around the same time, disability advocates adopted the slogan, “*Nothing about Us without Us!*” to express the idea that the people who are the most directly affected by a policy should be fully and directly involved in related policy decisions (Barry & Edgman-Levitan, 2012; Charlton, 1998).

The 2001 Institute of Medicine (IOM) report, *Crossing the Quality Chasm*, marked another pivotal moment in the development of person-centered thinking and practices. The report came in response to persistent problems across the U.S. healthcare system that negatively affected clinical outcomes, overall costs, and people’s experiences with care (Berwick, Nolan, & Whittington, 2008; IOM, 2001). As part of the report, the IOM recommended several “aims for improvement,” including that care be “person-centered... respectful of and responsive to individual patient [consumer] preferences, needs, and values, and ensuring that patient [consumer] values guide all clinical decisions” (IOM, 2001). Later, the American Geriatrics Society (AGS) convened an expert panel, which further defined person-centered care for older adults as care that: 1) is goal directed, 2) is coordinated among providers, 3) involves the person receiving services in decisions related to their care, and 4) relies on feedback from individuals

receiving services and their families to assess program and service quality and guide quality improvement activities (AGS, 2016).

Several recent federal policies have set the stage for deepening person-centered practices in LTSS. In 2010, the CMS implemented a revised resident screening and assessment tool (the Minimum Data Set [MDS] 3.0) for nursing homes that shifted assessments from administrative records and observations to hearing directly from residents about their needs and preferences (Saliba & Buchanan, 2008). Beginning in 2016, the Quality Assurance and Performance Improvement (QAPI) program, an initiative of the Affordable Care Act, has required nursing homes to implement ongoing quality improvement (QI) activities focused on clinical care, resident choice, and resident quality of life (CMS, 2016b). Through QAPI, CMS encourages nursing home personnel to engage residents and families in ongoing performance improvement activities (CMS, 2016b), such as by soliciting their input on priority areas for improvement and eliciting their feedback on the impact of specific improvement initiatives.

Also, under the Affordable Care Act, the federal government requires all states that receive federal funds for home- and community-based services (HCBS) (i.e., through Medicaid “waiver” programs) to allow consumers the opportunity to live in community settings and make other meaningful choices about their services. States must also ensure that individuals who use Medicaid-covered HCBS are treated with dignity and respect and demonstrate that services are based on individuals’ values, needs, and preferences.

In collaboration with the Consortium for Citizens with Disabilities (CCD), the Leadership Council of Aging Organizations (LCAO), a coalition of 70 leading non-profit associations focused on ensuring the wellbeing of older adults, issued a position

statement for LTSS in 2006 that affirmed the shared values of their member organizations related to several key principles of person-centered care, including dignity, choice, integration, and inclusion (LCAO/CCD, 2006). Since that time, most aging- and disability-focused organizations and professional associations have also published position statements, guidelines, or other documents demonstrating their support for the principles of person-centered care.<sup>5</sup>

### **Problem Statement**

In recent decades, the quality of LTSS and other programs and services afforded to older adults and individuals with disabilities has taken on increasing importance (IOM, 2001; Berwick, et al., 2008; Grabowski, et al., 2014). Simultaneously, there has been a growing effort to place consumers and their families at the center of services with an intent to more fully consider their interests, preferences, and needs regarding the provision of LTSS services (Barry & Edgman-Levitan, 2012; Epstein, Fiscella, Lesser, & Stange, 2010; Koren, 2010). The person-centered care movement (Epstein et al., 2010), Affordable Care Act (Davis, Abrams, & Stremikis, 2011), and other initiatives such as nursing home culture change (Koren, 2010; Grabowski, et al., 2014), have aimed to engage consumers and families in improving the type, quality, and ultimately, the outcomes of services they receive. Within LTSS, greater attention is being paid to person-centered measures of quality such as quality of life (Burack, Weiner, Reinhardt, & Annunziato, 2012; Kane et al., 2003; Shippee, et al., 2013) and satisfaction (Lowe, Lucas, Castle, Robinson, & Crystal, 2003; Shippee, Henning-Smith, Gaugler, Held, & Kane, 2017; Straker, McGrew, Dibert, Burch, & Raymore, 2016). Research has begun to

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<sup>5</sup>Some groups prefer the term “family-centered care” over “person-centered care.” However, the basic principles remain essentially the same.

examine the effects of person-centered care models and practices in LTSS on quality of life (Kane, Lum, Cutler, Degenholtz, & Yu, 2007; Petriwsky, Parker, Brown Wilson, & Gibson, 2015; Zimmerman et al., 2005) and quality of care measures (Grabowski, et al., 2014; Petriwsky et al., 2015; Thomas et al., 2017). Despite these trends, the voices of individuals who use LTSS and those closest to them—families and other direct caregivers—remain largely absent from the broader discussions in which the overarching goals and priorities for LTSS are set.

Currently, LTSS lacks coherence and a clear sense of direction, which contributes to the many ongoing problems affecting LTSS today. Historically, individuals using LTSS have accessed needed services and supports through a broad array of programs, many of which are governed by differing rules and regulations. As states have moved to “managed” LTSS arrangements in Medicaid, however, the need for consistent, validated indicators of quality across LTSS programs has become more evident (Disability Rights Education and Defense Fund [DREDF] and National Senior Citizens Law Center [NSCLC], 2013; Thomas & Applebaum, 2015). Specifically, there is a need for measures that assess program outcomes across programs and settings, including the experiences of individuals using LTSS (DREDF & NSCLC, 2013; Gawande, 2014; Thomas & Applebaum, 2015).

The regulatory approach historically used to monitor LTSS quality has failed to result in widespread improvements, particularly in nursing homes. Further, limited provider-level data on HCBS quality limits the ability of the government, consumers, and providers to compare and improve quality across programs and settings. New, more inclusive and integrated approaches to evaluating and improving LTSS quality are

needed. Concretely, there is a need to involve individuals who use services and their families in determining priorities for LTSS and assessing the extent to which these priorities are achieved. However, the current lack of information on consumer and family priorities for LTSS limits the ability of policymakers and organizational leaders to design and implement policies and practices that align with these values and goals. Further, examining whether and how the priorities of stakeholders differ could highlight areas around which more dialogue is needed to determine what “matters most” in LTSS today (Gawande, 2014; House & Howe, 1999; Kane, 2015; Thomas & Applebaum, 2015).

### **Importance of Shared Beliefs, Values, and Guiding Principles**

An important first step in advancing improved quality in LTSS involves developing an overarching policy framework that promotes greater consistency in the values, principles, goals, and standards across LTSS populations, programs, and settings. Cross-cutting principles could provide clarity on the “most essential” goals or attributes of high quality LTSS across programs, services, and settings of care (Patton, 2011). The framework could be used at state and organizational levels to guide program planning and evaluation activities, including quality assessment. Ultimately, such a framework could set the stage for organizational and system-level improvements across the continuum of LTSS.

The field of evaluation has adopted professional standards that emphasize the importance of clarifying and addressing the values and interests of key stakeholders, particularly those whom a program or service is intended to benefit (Yarbrough, Shulha, Hopson, & Caruthers, 2011). In many publicly-funded programs, however, including in LTSS, evaluation remains primarily a technical, top-down exercise focused more on

accountability than on ensuring that the values and interests of program participants are addressed (Conway, Mostashari, & Clancy, 2013; Greene, 1997; Scriven, 1986; Stake, 2004).

Important advances have been made in developing the principles of person-centered care within organizations that provide LTSS, as well as in the state and federal agencies that provide funding and ongoing regulatory oversight for LTSS. Ultimately, although the principles of person-centered care have been widely affirmed by various stakeholders involved with LTSS, there remains a need to advance the underlying principles of person-centered care to influence public policies to support these needed changes in service delivery practices, including quality assessment. As House & Howe (1999) argue, there is a need to move from “individual self-determination” to “social determination” (p. 133).

### **Purpose and Significance of the Study**

The present study examines the priorities of key stakeholders in relation to LTSS quality and whether differences exist in the priorities identified by older adults who use LTSS (consumers), families, and LTSS professionals. This study draws on existing frameworks and concepts used to assess LTSS quality across populations and settings, including nursing homes, assisted living facilities, and HCBS. It also builds on previous qualitative studies related to consumer and family experiences and values related to LTSS quality. Prior studies examining perspectives on LTSS quality have tended to focus on a single stakeholder group within a specific LTSS setting, such as nursing homes (Bowers, Fibich, & Jacobson, 2001) or assisted living facilities (Ball, et al., 2000; Greene, Hawes, Wood, & Woodson, 1997; Levin & Kane, 2006), preventing the comparison of priorities

across stakeholder groups and settings. Most of these studies were completed 15-20 years ago and may not reflect the priorities of consumers and families today.<sup>6</sup> Although these studies provide valuable insights into aspects of LTSS quality that consumers, families, and professionals value, little remains known about which quality attributes stakeholders view as the *most* important or whether differences in priorities exist by stakeholder group or LTSS setting. Greater understanding and consensus are needed to improve and transform LTSS (House & Howe, 1999).

The results of this study are significant in several ways. First, this study contributes new insights into the perspectives of consumers, families, and selected LTSS professionals on priorities for LTSS quality. Similarly, insights are gained into reasons consumers and families value certain aspects of LTSS quality more highly than others. Second, because the perspectives of consumers, families, and LTSS professionals sometimes differ, the study highlights the importance of including consumers and families in discussions related to the evaluation of LTSS quality, including at the policy level. For example, results of this study demonstrate that, although there is considerable consensus among stakeholders on the highest priorities for LTSS quality, there are important differences that should be considered as well. In a related way, study results suggest several areas around which more reflection and dialogue among stakeholders is needed. Third, it provides an approach that LTSS providers and state government agency personnel could use to engage their stakeholders in dialogue related to priorities for LTSS quality at the local level. Finally, this study contributes to the field of evaluation by exploring the use of a values-engaged (Greene, DeStefano, Burgon, & Hall, 2006; Hall,

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<sup>6</sup>More recent qualitative studies on consumers' values and experiences with LTSS have been conducted in countries other than the U.S. See Appendix A for a more comprehensive list of these studies.

Ahn, & Greene, 2012), principles-driven (Patton, 2011) evaluation approach to explore gaps in existing policy frameworks for LTSS quality, as well as assess and improve the quality of LTSS.

### **Definition of Key Terms**

**Alzheimer’s disease and related dementias (ADRD):** The National Institute on Aging (NIA) defines ADRD as, “progressive and, currently, irreversible brain disorders that slowly destroy memory, thinking skills, and the ability to live independently” (NIA, n.d.). Alzheimer’s disease is the most common form of ADRD, currently affecting as many as 5.2 million Americans (NIA, n.d.). Currently, no interventions have been found that effectively slow the progression or delay the onset of ADRD (Alzheimer’s Association, 2018; Kane et al., 2017). More than 60% of nursing home and over 40% of assisted living residents have some form of cognitive impairment, including ADRD (Alzheimer’s Association, 2017).

**Assisted living/assisted living facility:** According to the National Center for Assisted Living (NCAL) (2018), assisted living facilities “provide a combination of housing, personal care services, and health care designed to respond to individuals who need assistance with normal daily activities in a way that promotes maximum independence.” Assisted living facilities can be part of multi-level LTSS campuses (e.g., an assisted living facility that is attached to a nursing home and/or an independent senior living building) or stand-alone facilities. Historically, assisted living facilities have been less heavily regulated by state and federal agencies than nursing homes. Currently, the rules and regulations related to assisted living and similar types of residential housing vary dramatically from state to state (Hawes & Phillips, 2007). Even within states, there

is often considerable variation in the size, cost, appearance, and types of services offered (Hawes & Phillips, 2007). The assisted living market is rapidly growing in response to consumer demand and changes taking place in public policy (Silver, Grabowski, Gozalo, Dosa, & Thomas, 2018).

**Consumer:** Evaluators typically refer to individuals who use a program or service as “participants.” In public policy and in aging research, however, individuals who use LTSS are commonly referred to as “consumers.” Although family members are often also considered consumers, the term consumer is used specifically in this study to distinguish individuals who personally use LTSS from family stakeholders. At times, the term “participant” is also used in this paper to refer to individuals who use LTSS, particularly through Medicaid waiver programs.

**Disability:** The Americans with Disability Act (ADA) defines a disability as a “physical or mental impairment that substantially limits one or more major life activities” (ADA National Network, 2018).

**Home care:** Although there are various types and definitions of home care, in this study, home care (also referred to as home-based care or in-home care) is used to describe supportive personal, therapeutic, and/or health services that are delivered within an individual’s private home over a period of three months or longer.

**Home- and community-based services (HCBS):** Medicaid uses “HCBS” to refer to LTSS provided to individuals outside of nursing homes. However, in this study, HCBS refers to services delivered outside of nursing homes and assisted living facilities. Currently, there is some debate about whether assisted living facilities should be considered HCBS or institutional settings (personal conversations with consumer

advocates, policymakers, and LTSS researchers). Although there is variation in the level of institutionalization across assisted livings, many assisted living facilities provide an “enclosed, formally administered round of life” and, thus, would qualify as institutions (Goffman, 1968).

**Multi-level LTSS campus or provider:** An organization that provides more than one type or “level” of LTSS on a single campus, such as nursing home, assisted living, and/or independent senior housing services.

**Long-term services and supports (LTSS):** Also called “long-term care,” LTSS includes a variety of services that can be provided in individual homes, community settings, assisted living facilities, or nursing homes because of physical, cognitive, developmental, chronic health conditions, or other functional limitations that people experience (CMS, 2016a). In this study, LTSS refers to services delivered over a period of months or years (i.e., not short-term rehabilitative or post-acute services, such as after a hospital stay). The stated goal of LTSS is to help people to live as independently as possible (CMS 2016a).

**Nursing home:** Also referred to as “nursing facilities,” or “care centers,” nursing homes are institutional settings that provide “24-hour care” (NIA, 2017) through short-term rehabilitation services and LTSS, primarily to older adults. Most nursing homes are licensed and certified to provide services covered by Medicaid (i.e., LTSS) and Medicare (i.e., short-term rehabilitation or post-acute services), although a small number of nursing homes only accept individuals who are paying privately for their care. In 2016, there were 15,452 nursing homes in the U.S., including 380 facilities in Minnesota, providing

services to 1.3 million and 25,203 thousand individuals respectively (Kaiser Family Foundation, n.d.).

**Older adult:** For the purposes of this study, an older adult is defined as someone age 65 or over, primarily because this is the age used in public policy to distinguish individuals for program eligibility. For example, most Americans begin qualifying for Medicare at age 65. In Minnesota, individuals age 65 and over who participate in Medicaid are eligible for the “Elderly Waiver” program, whereas younger people with disabilities are eligible for one of four other Medicaid waiver programs.

**Regulations:** In the context of this paper, regulations are defined broadly to encompass the licensing standards, federal compliance and payment standards, and other state and federal rules governing the administration of LTSS programs and services.

**Stakeholders:** The *Program Evaluation Standards* (Yarbrough et al., 2011) define stakeholders as “those who have a legitimate interest in or are served in some meaningful way by the program and are thus implicated in the program’s evaluation” (p. 23). For the purposes of this study, key stakeholders are defined as consumers, family members, LTSS administrators/executives, LTSS nursing leaders, and state policy, regulatory, and advocacy personnel.

**Values:** In this study, values are considered “things stakeholders believe to be important” (House & Howe, 1999).

## **Chapter 2. Background**

The organization and delivery of LTSS has been shaped by various social, economic, and political forces over several decades. Approaches to LTSS quality have been similarly shaped by these forces. The purpose of this chapter is to review relevant background related to quality in LTSS, including the role of values in defining, assessing, and attempting to improve LTSS quality. This chapter discusses the following major areas:

- 1) Federal policies that have influenced the development of LTSS, including a gradual shift from institutional to community-based services;
- 2) Valuing frames for understanding the goals and priorities for LTSS, including the medical and social models of disability and related “quality of care” and “quality of life” paradigms;
- 3) Approaches to defining, assessing, and improving LTSS quality across institutional and community-based settings;
- 4) Discussion of how a values-engaged approach to evaluating LTSS quality could advance the principles of person-centered care and contribute to organizational and system-level improvements.

### **Historical Background of LTSS**

The collection of programs and services known today as LTSS evolved in response to rapidly changing social and economic conditions taking place during the middle of the 20th century. As industrialization changed family structures, caregiving responsibilities normally fulfilled by family members increasingly went unmet. Consequently, there was a need for social programs to address the growing numbers of

older adults and people with disabilities who had inadequate financial resources and access to supportive care when they needed it. Much of the evolution of LTSS has been driven by federal legislation and expansive appropriations by Congress for programs and services.

### **Social Security Act.**

At the height of the Great Depression, the enactment of the Social Security Act (SSA) in 1935 provided older adults with money to pay for modest housing costs and supportive care. However, the SSA prohibited funds from going to residents of “public institutions,” which at the time included almshouses and “poor farms” (Haber, 2015; Watson, 2009). Small, independently run nursing homes emerged in response (Watson, 2009). In 1950, amendments to the SSA expanded Social Security eligibility, increasing the number of people who received program benefits. The amendments stipulated that states establish standards for nursing homes, although they did not dictate what the standards should entail. The amendments also reversed the previous SSA policy by allowing social security payments to residents of public institutions as well as payments directly to LTSS providers (Social Security Administration, n.d.). These policy changes led to a dramatic rise in the number of nursing homes throughout the U.S. in the 1960s and 1970s. As the federal government played an increasingly central role in LTSS, the regulations governing the industry became more stringent. Eventually, the small informal nursing homes that had sprung up after the passage of the SSA were driven out of business and larger firms took over (Watson, 2009).

### **Medicare and Medicaid.**

The enactment of Medicare and Medicaid in 1965 represented another major turning point in the development of LTSS. The legislation began requiring public programs to provide health insurance coverage to certain groups of Americans, principally older adults and individuals with disabilities. Institutional LTSS, including room and board in nursing homes, became eligible for coverage through *Medicaid* for qualifying individuals. Today, Medicaid remains the country's largest payer of LTSS. Under *Medicare*, short-term post-hospital recovery (rehabilitation or "post-acute care") became reimbursable services in "extended care facilities," including nursing homes. Although Medicare does not cover the costs of LTSS, many nursing homes provide short-term post-acute or rehabilitation services, which Medicare covers.

Reforms to Medicare in recent years have led to shorter hospital stays and a dramatic increase in the amount of post-acute care provided by nursing homes (Werner & Konetzka, 2018). Many nursing homes must therefore meet both Medicare and Medicaid regulatory requirements, which tends to blur the lines between short- and long-term care delivery goals in these facilities. Because Medicare payment rates are typically higher than those provided by Medicaid, there is an added incentive for providers to focus on their post-acute business. The growing dominance of post-acute services in nursing homes could have unintended consequences for LTSS consumers, whose goals and priorities differ from those of individuals receiving short-term rehabilitative services (Abrahamson, Shippee, Henning-Smith, & Cooke, 2017; Kaskie, 2018). For example, factors that influence quality of life, such as meaningful activities, relationships in the facility, control over one's daily routines, and food enjoyment, may be more important

for long-term residents than for individuals only staying in a facility for several weeks for rehabilitation services (Abrahamson, et al., 2017). Especially for long-term residents whose services are covered by Medicaid, there are few incentives currently in place to make their values and preferences providers' top priority.

### **Institutional LTSS.**

Sociologist Ervin Goffman argued that “total institutions,” such as prisons and nursing homes, are environments that control people’s daily lives, alienate them from society, and strip them of dignity and autonomy (Goffman, 1968). Early nursing home facilities, many of which still exist, were modeled after rural, state-run hospitals. Environmental features such as long hallways and conspicuous nurses’ stations reinforce the institutional feel of these facilities. Organizational processes that were designed to maintain hierarchical relationships and maximize efficiency, such as rigid staff roles and set dining and bathing times, disrupt the normal interactions and processes of people’s everyday lives (Goffman, 1968; Gubriam, 2012; White-Chu et al., 2009).

The institutionalization of LTSS has led to a range of serious problems, many of which continue today. State-run mental hospitals, state institutional settings for individuals with intellectual and developmental disabilities, and nursing homes have been especially problematic. The 1970s, for example, were marked by frequent exposés of egregious safety violations, as well as by abuse and neglect of institutionalized people (Gorbien & Eisenstein, 2005; Stannard, 1973). Beginning in 1969, the Special Committee on Aging, chaired by Senator Frank Moss of Utah, held a series of hearings on nursing homes. The sessions resulted in roughly 1,300 pages of testimony and a 12-volume report entitled, “Nursing Home Care in the United States: Failure in Public Policy” (U.S.

Senate, 1974). In 1975, Mary Mendelson exposed pervasive financial fraud associated with the “tender loving care” nursing homes purported to deliver (Mendelson, 1975). A primary concern was that public resources were going to private organizations to provide care to vulnerable members of society, a concern that persists (Ronald, McGregor, Harrington, Pollock, & Lexchin, 2016; Serres, 2017). In response to the evidence of gross mistreatment of nursing home residents and misuse of public funds, the government clamped down on the industry with steeper regulations.

### **Nursing home reform.**

As part of a broader agenda aimed at loosening market restrictions across sectors, President Ronald Reagan attempted to deregulate nursing homes in the early 1980s. The National Citizen’s Coalition for Nursing Home Reform and other consumer advocates led a public outcry against Reagan’s proposed deregulation (Braithwaite, et al., 2007; Hawes, 1987). To broker a compromise between groups who wanted more and less regulation of the nursing home industry, Representative Henry Waxman from California proposed that all changes to existing regulations be tabled until a comprehensive study of nursing home quality could be completed. Waxman’s proposal led to the establishment, in 1983, of the IOM Committee on Nursing Home Regulations, comprised of national experts on nursing home quality (U.S. House of Representatives, 2014).

The recommendations included in the resulting IOM report, *Improving the Quality of Care in Nursing Homes* (IOM, 1986), led to the passage of the Omnibus Budget Reconciliation Act of 1987 (OBRA 87), including the Nursing Home Reform Act. The legislation marked an important step in defining quality standards for nursing homes (Koren, 2010; White-Chu, et al., 2009) and it affirmed the rights of nursing home

residents to the same rights as other members of society (IOM, 1986). However, the legislation also led to the creation of a set of assessment and care guidelines that reinforced an emphasis on functional and health-related processes and outcomes while inadvertently neglecting other important aspects of residents' experience, including their overall quality of life (Koren, 2010; White-Chu et al., 2009).

### **Movement toward home- and community-based services.**

Over time, Medicaid spending on LTSS has shifted from nursing homes to community-based settings. This shift has been a result of ongoing work by consumer advocates, government efforts to contain costs, and changing public opinion (AARP, 2017; Musumeci, 2015). Until the mid-1980s, however, most LTSS was provided in nursing homes, state hospitals, and other institutions. Although Medicaid required states to cover institutional LTSS, it did not require similar coverage for LTSS provided in the community. As early as 1981, the federal government acknowledged that the “institutional bias” in Medicaid policy was one of the biggest problems facing LTSS (Doty, 2010). That year, under Section 1915(c) of the SSA, Medicaid began allowing states to apply for “1915c waivers” or “home and community-based service waivers” (HCBS waivers) to expand Medicaid coverage to community-based LTSS for people who would otherwise be institutionalized (CMS, n.d.a.). Implementation of the HCBS waivers was slow initially because of obstacles such as a “cold bed” rule, which required states to show that there was an empty institutional bed for every waiver participant (Shirk, 2006). States also were required to prove that overall program costs did not exceed those associated with institutionalization for similar populations (CMS, n.d.a.).

Since the establishment of the HCBS waivers, considerable progress has been made in “rebalancing,” or shifting, public spending from institutional to community-based LTSS. The 1999 U.S. Supreme Court Olmstead Decision pushed states to deepen their rebalancing efforts by upholding the “integration mandate” of the Americans with Disability Act (ADA) (Olmstead vs. L.C., 1999). Through Olmstead, the court ruled that states must allow individuals with disabilities to live in the community whenever possible. In 2001, President George W. Bush issued an executive order urging federal agencies to support states’ efforts to implement the Olmstead decision.

Between 1995 and 2013, Medicaid spending on community-based services more than doubled, increasing from one-fifth to over one-half of total Medicaid LTSS spending (Eiken, Sredl, Burwell, & Saucier, 2015). Because of how Medicaid is structured, however, states vary considerably in their Medicaid coverage of HCBS, with current percentages ranging from 27% to 81% of total Medicaid LTSS spending (Eiken, Sredl, Burwell, & Amos, 2018). Minnesota is one of the country’s leading states in LTSS rebalancing, with 76% of Medicaid-covered LTSS expenditures for services in the community (Eiken et al., 2018).

Although growing numbers of older adults are gaining access to Medicaid-covered HCBS, more progress has been made in shifting LTSS spending on services for younger people, particularly those with intellectual and developmental disabilities (IDD) (Hilltop Institute, 2011). In fiscal year 2016, Medicaid LTSS spending on HCBS

accounted for 78% of spending in programs for individuals with IDD and 45% in programs for older adults and people with physical disabilities (Eiken, et al., 2018).<sup>7</sup>

The difference in LTSS spending is primarily a result of the history of the waiver programs, which were established for younger populations first. However, ongoing advocacy efforts also play a role (Hilltop Institute, 2011). Disability advocates have strived to change negative views about people with disabilities as part of a broader movement for equal rights and community integration. Despite a growing movement to change how older people are viewed in society (AARP, n.d.; Pioneer Network, 2018), negative stereotypes about older adults persist, such as that they are frail and dependent (Palmore, 2015; Warmoth, Tarrant, Abraham, & Lang, 2018). These views can lead to emphasizing certain values in LTSS for older adults, such as protection and safety, without fully recognizing possible unintended consequences, such as institutionalizing individuals who could remain in the community with added supports (Kane & Cutler, 2015) or focusing on more on the medical needs of older adults than on their overall ability to continue living meaningfully lives (Gawande, 2014).

### **Social and Medical Models of Disability**

Two models, or valuing frameworks, have been used to frame the goals and priorities for LTSS, the medical and social models of disability. Today, views on LTSS for older adults remain more closely aligned with the medical model of disability, and care for younger people is more consistent with the social model.

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<sup>7</sup>An important consideration is that individuals with developmental disabilities may be more likely to need 24-hour supportive services than other populations served through Medicaid, which may increase their HCBS costs (Eiken, et al., 2018).

In its early years, LTSS evolved under a medical model of care, with clinical and safety outcomes prioritized (White-Chu, et al., 2009). Since the movement at the end of the 20th century to deinstitutionalize state-operated facilities for people with mental illnesses, developmental, and physical disabilities, LTSS has increasingly oriented toward a community-based social model of disability (Shakespeare & Watson, 1997). Within the social model, issues are framed around access to life's opportunities, such as inclusive and integrated education, employment, housing, and meaningful connections with others (Lakin & Turnbull, 2005). The ADA, which was built around supporting equal access to civic life for people with disabilities, arose from the momentum of the civil rights movement, which advanced equal rights for people regardless of race, and later, gender, sexual orientation, and age. Values such as self-determination, social freedom, and equal opportunity (Lakin & Turnbull, 2005) influenced gradual shifts in the service orientation of LTSS, such as the movement to HCBS away from institutional care.

The distinction between the medical and social models of disability is evident even in nomenclature. Within the social model, the term "long-term services and supports" (ideally delivered in inclusive community contexts) is preferred, whereas in the medical model, "long-term care" (most commonly associated with care delivered in nursing homes) is more common. Particularly in nursing homes, LTSS is often framed as "healthcare," even though LTSS is much broader: substantial ADL assistance, social services, and housing are often also provided. Nursing home residents are often referred to as "patients," terminology that reinforces a provider-recipient hierarchy and communicates that these individuals are defined primarily by their health needs.

The social policies and programs through which people obtain access to LTSS have been traditionally organized primarily by age and type of disability. This fragmentation contributes to ongoing differences in how LTSS programs are designed, as well as how quality is defined and measured. Recently, the government has taken steps to better integrate LTSS programs, such as through standard assessment processes for the HCBS waiver programs (e.g., *MNChoices*) (Minnesota Department of Human Services, 2016a). However, the goals and overall service orientation for two individuals with similar service needs can still vary depending on the person's age, type of disability, payer source, and setting in which the person receives LTSS. For example, Minnesota has five distinct HCBS waiver programs, one of which, Elderly Waiver, is specifically for people age 65 or over and managed by a different state division than the other four HCBS waiver programs (Minnesota Department of Human Services, 2016b).

**Evaluating LTSS quality: quality of care and quality of life.**

The historical development of LTSS has informed how LTSS quality is viewed and assessed today. In the medical model of disability, “quality of care” tends to be emphasized, whereas “quality of life” is typically viewed as more important in the social model (De Waele, Van Loon, Van Hove, & Schalock, 2005). Quality of care is generally understood to refer to processes of care delivery, such as timely and appropriate administration of medications, as well as clinically-and safety-oriented outcomes, such as rates of infections, hospitalizations, and falls. Most research on LTSS quality, particularly in nursing homes, has examined quality of care, with a robust body of research examining the influence of various external (e.g., policy, regulatory, geographic, economic) and

internal (e.g., leadership styles, staffing levels, profit/non-profit status) factors on clinical, functional, or cost outcomes.

Unlike quality of care, which places the emphasis on providers, quality of life is a person-centered outcome, focused on the experience of individuals receiving services. It is more closely aligned with the social model of disability. Key attributes of quality of life in LTSS include dignity and respect, emotional wellbeing, physical comfort, relationships, food and meal enjoyment, social integration, independence, mood, and autonomy or self-determination (Kane et al., 2003; Lakin & Turnbull, 2005). Challenges associated with defining and assessing quality of life among older adults who use LTSS, many of whom have cognitive impairment (Alzheimer's Association, 2017), may contribute to the ongoing emphasis on quality of care in assessments of LTSS quality (Gawande, 2014). Other reasons for the prevailing focus on quality of care include:

- Entrenched views of LTSS for older adults as primarily medical in nature;
- Existing policies and ready availability of datasets focused on clinical and functional data (e.g., data generated through MDS assessments in nursing homes);
- High costs and other challenges associated with collecting satisfaction and/or quality of life information directly from consumers and/or families; and
- The fact that much of the research and development work related to LTSS quality has been funded by the federal government, which has tended to emphasize accountability measures related to costs and clinical/functional outcomes.

Although quality of care and quality of life remain distinct constructs, the two are interrelated. For example, a person's level of pain affects their quality of life but can also reflect the quality of care they receive. Similarly, an individual's perception of being treated with respect can influence their quality of life. However, staff demeanor and interactions with the people they serve could also be considered an indicator of the quality of care they are providing. The primary difference between quality of care and quality of life is evaluative perspective: accountability (provider-focused) versus experience (participant-focused) (De Waele, et al., 2005).

### **Mechanisms to Assess Quality in LTSS**

#### **Nursing home quality.**

Avedis Donabedian's "structure, process, outcomes" framework for assessing the quality of medical care (Donabedian, 1968; 1988) has been widely used to examine nursing home quality (Castle & Ferguson, 2010). Nursing home quality has been heavily defined by the federal government, which strictly regulates the nursing home industry. Initially, the government primarily used structural indicators (such as staffing levels) to assess nursing home quality. Over time, the government has used more process (e.g., percentage of residents receiving flu shots or taking psychotropic medications) and outcome (e.g., rates of pressure sores or hospitalizations) indicators in their assessments (Castle & Ferguson, 2010). Although outcome measures are increasingly viewed as the preferred method for assessing LTSS quality (DREDF & NSCLC, 2013), structure and process measures remain common.

The most basic indicator of nursing home quality involves results of the annual certification ("survey") process used to assess facilities' compliance with existing state

and federal regulations. Deficiencies received by facilities for violations ranging from minor environmental issues to cases of actual harm to residents are posted online (via CMS's Nursing Home Compare database and websites maintained by state departments of health). Occasionally, facilities must pay fines ("civil monetary penalties") for deficiencies. In extreme cases, a facility can be placed on "special status," which requires heightened regulatory oversight, or forced to close. According to many providers, the survey process is subjective and, at times, focused on issues providers view as secondary to resident care, such as environmental intricacies or detailed staff documentation (Shippee, Davila, Werner, Brauner, & Konetzka, 2018). Even though many providers perceive the survey process to be flawed, most acknowledge the need for some external regulatory oversight (Shippee et al., 2018). Because the regulatory compliance surveys are such high stakes, they are a primary driver of provider behavior (personal conversations with LTSS providers and researchers, 2015-2018; Shippee et al., 2018).

Along with regular compliance surveys, the government monitors and publicly reports nurse staffing levels and numerous clinical and functional indicators of nursing home quality (CMS, n.d.b). Together, these metrics—results of compliance inspections, nurse staffing levels, and clinical/functional quality measures—comprise the Nursing Home Compare/5-star rating system, with compliance inspections receiving the most weight. The 5-star quality measures currently include seven short-stay and nine long-stay process and outcome measures, which are primarily derived from MDS assessments but also, in the case of three short-stay measures (hospitalizations, emergency department visits, and successful community discharges), Medicare claims data. Sample long-stay measures include the percentage of residents whose need for help with ADLs has

increased, the percentage of residents with a pressure sore, and the percentage of residents who experience a fall with major injury.

Since the 5-star ratings were first implemented a decade ago, they have become increasingly influential in the nursing home market (Perraillon, et al., 2017). Although consumers do not appear to use the 5-star ratings to select nursing homes to the extent that was originally envisioned (Grabowski & Town, 2011; Konetzka & Perrailon, 2016), the ratings can be essential to facilities' ability to maintain referrals and business contracts, such as with hospitals, accountable care organizations, and managed care organizations (Konetzka & Perrailon, 2016; Shippee et al., 2018).

Currently, the federal government does not systematically monitor or report consumers' experience with care in nursing homes. This is particularly notable because the government *has* implemented satisfaction surveys for several other consumer groups, including individuals who have used hospital, home care, and hospice services (Agency for Healthcare Research and Quality, n.d.). Although surveys were developed several years ago to assess the satisfaction of long-stay nursing home residents (Sangl et al., 2007) and family members (Frentzel et al., 2012), CMS has not yet required these surveys to be implemented. Currently, Minnesota and Ohio are the only states that systematically assess and report the experience of nursing home residents (quality of life in Minnesota; satisfaction in Ohio) (Kane et al., 2003; Straker, et al., 2016). The lack of a standardized, publicly-reported measure of consumer experience to supplement the metrics currently included in the 5-star ratings reinforces providers' the orientation to

priorities emphasized by the government rather than the priorities of consumers (personal conversations with LTSS providers, 2016-2018; Shippee et al., 2018).<sup>8</sup>

### **HCBS quality.**

The formal assessment of quality has progressed more slowly in HCBS settings than in nursing homes, an artifact of the historical evolution of LTSS. However, there is considerable momentum at the policy level for developing mechanisms to systematically assess and improve the quality of community-based LTSS (CMS, n.d.; National Quality Forum, 2016). The primary drivers for this shift have been the ongoing rebalancing of Medicaid LTSS spending away from nursing homes to HCBS, the movement to managed LTSS programs at the state level and related desire to compare quality across LTSS providers, consumer demands for more and better information, and continuing efforts to improve outcomes and reduce costs by better aligning incentives across the continuum of healthcare and LTSS.

### **Challenges associated with quality assessment in HCBS.**

The federal government requires states to routinely assess the quality of their publicly-funded HCBS (i.e., services funded through the Medicaid HCBS waivers). However, little is known about the extent to which states have systematically implemented quality measurement in their HCBS programs (DREDF & NSCLC, 2013). The decentralized nature of the waiver programs and heterogeneous nature of HCBS have made the assessment of HCBS quality difficult. Within HCBS, considerable variation exists in terms of services offered, number and types of individuals served, and

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<sup>8</sup>It is important to note that consumer satisfaction can be important to a nursing home's market share, particularly for post-acute rehabilitation services, even if not measured at the policy level.

characteristics of people who provide services and supports. For example, Medicaid-funded HCBS in Minnesota includes a wide range of services, including companion and homemaker services, personal support, respite care, behavioral support, residential-based services, and foster care, among others (Minnesota Department of Human Services, n.d.). Even within the assisted living sector alone, considerable differences exist among states in terms of how assisted living is defined, what services assisted living facilities are allowed and/or required to offer, and requirements related to staffing levels and qualifications (Hawes & Phillips, 2007).

A related issue is that standardized, validated instruments to assess quality in HCBS are currently limited (Bennett, Curtis, & Harod, 2018). Therefore, HCBS organizations and government agencies have little data available to assess, compare, and improve program quality. A 2015 evaluation of a Minnesota program that provided funding to 27 HCBS organizations to implement site-initiated quality improvement (QI) projects (The Minnesota HCBS Performance-based Incentive Payment Program [Minnesota HCBS PIPP]) found that a total of 90 unique process and outcome measures were used to assess project results across participating organizations. No single measure was used by more than one organization to assess quality improvement, which made assessing and comparing project results difficult. Further, many of the measures were “home-grown” assessments (e.g., a post-training staff satisfaction survey) and only four were based on validated instruments with established psychometric properties (Davila, Arling, & Mueller, 2015).

Finally, because HCBS aligns more closely with the social model of disability, measures related to the experiences of people who use LTSS often have been prioritized

over the types of clinical and functional indicators used in nursing homes (C. Lakin, personal communication, March 2017). For example, 77% of the QI projects funded through the Minnesota HCBS PIPP focused on promoting “consumer independence and increasing the person-centeredness of services,” foci that were actively promoted by the state (Davila et al., 2015). Although the focus on consumer experience is essential, older adults who use HCBS often have health needs in addition to other LTSS needs. Therefore, a more balanced measurement approach would include both experience-related information (participant satisfaction and/or quality of life) and clinical and functional outcomes.

#### **Current policy initiatives related to HCBS quality.**

Despite facing considerable challenges, government agencies are actively working to advance quality assessment in HCBS. In 2014, representatives of nine federal agencies gathered at CMS to develop a research agenda focused on quality measurement in HCBS. As part of their discussion, summit participants affirmed their commitments to community-based LTSS whenever possible and to supporting the choice and independence of LTSS consumers. Coming out of the meeting, the U.S. Department of Health and Human Services commissioned the National Quality Forum to complete an environment scan and evidence synthesis related to existing quality measures and measurement gaps in HCBS. As part of its review, the Forum assessed thousands of measures and “measure concepts,” to develop a conceptual framework for HCBS quality. The resulting framework included 11 domains and 40 subdomains related to individual, provider, and system quality outcomes (National Quality Forum, 2016).

Investigators at the University of Minnesota's Institute on Community Integration (Abery & Ticha, 2017) conducted a follow-up study to determine which NQF domains stakeholders (including people with disabilities [some with age-related disabilities], family members, HCBS providers, and program administrators), viewed as the most important. Study participants rated person-centered service planning and coordination, service delivery and effectiveness, choice and control, and human and legal rights as the highest priorities of the NQF domains, although all 11 domains were rated highly (range 89.0–94.9; scale: 0–100 points). Other quality domains included workforce, equity, holistic health and functioning, community inclusion, system performance and accountability, consumer leadership in system development, and caregiver support.

Although quality assessment in HCBS continues to evolve, the National Core Indicators (NCI) stands out as a promising framework for assessing LTSS quality in a way that integrates the medical and social goals and outcomes related to LTSS. The NCI has existed for 20 years as a voluntary mechanism for states to assess the performance of publicly-funded HCBS for people with IDD and compare their performance to other states. The NCI includes indicators related to several quality domains, including individual outcomes (i.e., aspects of health, wellness, and quality of life), system performance (system coordination and access to care), staff stability, and family (family support, involvement, and wellbeing), with an emphasis on the experience of consumers and families. Data are collected through interviews with a sub-set of consumers, their families, and staff members within each NCI state, with administrative records used to supplement the interviews. Currently, all but three states (Iowa, Montana, and West Virginia) participate in the NCI project (NCI, 2018).

In 2014, the NCI was expanded beyond IDD to “Aging and Disability” (AD) services through NCI-AD (NCI-AD, 2018). Currently, 23 states participate in the NCI-AD initiative, including Minnesota. Many of the domains and individual items included in the NCI are relevant across LTSS settings, including nursing homes. For example, indicators such as, “chooses daily schedule” (individual outcomes domain) and “average length of service for direct caregiving staff” (staff stability domain), could be readily used across settings. Although the NCI framework provides a more balanced perspective on LTSS quality than the 5-star quality rating framework used for nursing homes, a limitation is that NCI data collection processes are not standardized across states (personal communications, J. Bershinsky, 2015 and B. Abery, 2016). A further limitation is that data are not currently collected in a way that enables quality assessment at the provider level. However, these concerns could certainly be addressed, particularly if the federal government invests in further developing and expanding the NCI, as it has considered doing (personal communication, J. Bershinsky, 2015).

In addition to federal initiatives, some states are developing mechanisms to assess HCBS quality, particularly for assisted living. Minnesota, for example, is in the early stages of developing a consumer-focused “report card” for assisted living facilities (personal communications, V. Cooke and T. Shippee, September 20, 2018). The state also recently convened a workgroup to focus on “improving quality in safety” across settings in LTSS (M. Dotseth, personal communication, October 8, 2018). In the group’s first meeting, held in September 2018, the group determined that the biggest need for quality assessment in the state involved assisted living. The state is also working to establish better standards and regulations for assisted living facilities in response to

public concerns about consumer safety and provider transparency (personal communication, Residential Services Subcommittee, Alzheimer’s Disease Workgroup, Summer, 2018).

### **Consumer Views on LTSS Quality**

Efforts to understand consumer views on quality and develop ways to assess their experiences with LTSS first emerged during the person-centered care and nursing home reform movements in the 1980s. In a foundational study, the National Citizen’s Coalition for Nursing Home Reform sponsored a series of discussions to elicit nursing home residents’ perspectives on how nursing home quality should be defined and measured (Spalding, 1985). The study was funded by several agencies, including the federal Health Care Finance Administration (currently CMS), the Robert Wood Johnson Foundation, the Retirement Research Foundation, and AARP. Discussion sessions were held in 15 cities and involved 457 residents of 150 nursing homes.

Several themes emerged through these discussion, including that residents viewed *staffing levels and staff competence* (i.e., staff attitudes, communication, and overall demeanor, including treating residents with respect) and *individual choice* (about routines, roommate assignments, staff, and other healthcare providers) as the most important markers of LTSS quality. Other important aspects of quality related to *food* (variety, taste, preparation), *problem solving* (having mechanisms to resolve issues and being involved in the problem-solving process), being and feeling *safe and secure* (emotionally and physically), having *pleasant and “homelike” surroundings*, and receiving *individualized* services and supports that promoted *maximal independence* (Spalding, 1985). Similar themes arose in other early qualitative studies conducted to

understand the values of older adults who used LTSS and their family members in relation to LTSS.<sup>9</sup>

### **Home care quality.**

After completing telephone surveys with 720 older adults who used home care to assess their satisfaction with services, Woodruff and Applebaum (1996) completed in-depth case studies with six older adults to gain a deeper understanding into how participants viewed quality of care. Although participants viewed themselves as dependent on others for some support, they said they still wanted to maintain their *autonomy and independence*. Study participants also detailed the importance of *relationships* with their professional caregivers, *low staff turnover*, the *professionalism* of staff, and receiving *individualized services*, to their experience with home care. In addition, participants noted the importance of support from *family and friends* to their overall experience with care.

In another study, Piercy and Dunkley (2004) conducted interviews with 35 family caregivers of older adults who used paid home care services to understand how respondents perceived home care quality. The interviews revealed that family members viewed high quality home care primarily in two ways. First, family members described quality in terms of how it *enhanced their own ability to support their loved one's quality of life*, including by keeping them at home and maximizing their relative's dignity and independence. Second, participants said that high quality home care *enhanced their ability to be effective family caregivers*. For example, they described home care personnel

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<sup>9</sup> As footnoted in Chapter 1, many of the recent qualitative studies on consumers' views on quality in LTSS have been conducted in Canada and Northern Europe. Although similar themes have arisen in those studies, only research conducted in the U.S. is referenced here because of the differing contexts of LTSS in the U.S. compared to other countries.

as assisting with tasks or responsibilities they could not accomplish on their own, providing social support to the family caregiver, teaching the caregiver new skills, or helping the family caregiver to navigate the healthcare system.

### **Assisted living quality.**

Greene et al. (1997) conducted focus groups with family members of assisted living residents who had dementia to explore how they defined assisted living quality. Through the discussions, participants identified four main aspects of quality, including *staffing* (staffing levels, knowledge/training, attitudes, communication, turnover, and continuity), *services* (individualized, activities that promote maximum functioning, help with basic needs, meals, and transportation), *environmental features* (safety, “homelike” personal space, space for diverse activities) and *facility operational policies and practices* (costs, facility rules, discharge processes). Focus group participants were asked to review the list of quality attributes they had identified and select those they considered most important. Staff attitudes and caregiving practices were viewed by over half of the participants as most important, followed by characteristics of the environment.

In another study, Mary Ball and colleagues (2000) interviewed 55 residents of 17 assisted living facilities in Georgia to explore how they defined quality of life. Through these interviews, residents identified *psychological wellbeing* (including freedom from anxiety, depression and loneliness), *independence, autonomy* (e.g., decisions about daily routines), *social relationships* (including with family and friends, other residents, and professional caregivers), *meaningful activities, good and nutritious food*, and a clean and safe *environment* as essential to their quality of life. Residents also described *staff*

*competence*, the *attitudes* of caregivers (i.e., that caregivers are caring and respectful), and receiving care that is *individualized* to their personal needs as vital.

### **Nursing home quality.**

Within the nursing home context, Marilyn Rantz and colleagues (1999) conducted focus groups with nursing home residents (n=16) and family members (n=80) to understand what they considered key aspects of care quality. The researchers organized the findings into two categories: “staff” and “care.” Specifically, focus group participants said that sufficient *staffing levels*, *low staff turnover*, positive and professional *staff demeanor*, and *competent staff* were important to high quality care. In addition, participants said that having their *basic needs* met (such as help getting out of bed), *being treated kindly and gently* (e.g., several participants described seeing bruises on their family members presumably because of rough handling by staff when delivering assistance), having *good food* and *choices about what to eat*, and having a variety of *activities* were central to nursing home care quality.

Another study involved in-depth interviews with 26 nursing home residents in three Wisconsin facilities (Bowers, et al., 2001) to understand how residents defined nursing home quality. The majority of study participants (n=16) conceptualized quality primarily in terms of their *relationships with staff*, including the extent to which the relationships were reciprocal. Another group of residents (n=6), defined quality primarily in terms of *physical comfort*, including freedom from pain or discomfort (such as from sitting in the same position for too long). These residents tended to be frailer and have more care needs. Finally, four residents defined quality primarily in terms of “*service*.”

These residents focused on the competence of their caregivers, the efficiency with which services were delivered, and their perceived value of services they were receiving.

### **Quantitative measures of consumer experience.**

Numerous instruments have been developed to assess the satisfaction and/or quality of life of LTSS consumers. Nicholas Castle (2007) reviewed a total of 50 tools that had been developed to assess the satisfaction of older adults who use LTSS in residential settings, including nursing homes and assisted living facilities. Castle concluded that the instruments varied considerably in terms of length, survey format and, in some cases, the aspects of quality addressed. Despite the attention that has gone into developing these and other measures of consumer experience (e.g., Geron's measure of home care consumer satisfaction, published in 2000, and Kane's quality of life assessment for nursing home residents, published in 2003) (Geron et al., 2000; Kane et al., 2003), until such measures are integrated into quality frameworks at the policy level, it will remain difficult to systematically assess, compare, and improve people's experiences with LTSS across providers and settings.

### **Approaches to LTSS Quality: Quality Assurance and Quality Improvement**

Modern views of quality emerged within the trade guilds in medieval Europe and later within the industrial sector (Maguad, 2006). Initially, quality was viewed as a way of controlling access to production: only people who met specified requirements could perform certain duties. Professional licensing boards and credentialing bodies continue to serve this gatekeeping function. In LTSS, provider organizations must meet specified requirements to participate in the Medicare and Medicaid programs. Similarly, health and social service professionals, such as nurses, social workers, and physicians, must obtain

specified training and meet other requirements to obtain and maintain licenses to practice. Although licensing and credentialing processes ensure that some standard requirements are met by individuals and organizations that provide LTSS, merely being licensed or credentialed does not necessarily mean that a provider is necessarily “high quality.”

### **Quality assurance.**

The quality assurance (QA) approach grew out of the spread of industrial manufacturing and desire for more production-oriented techniques to monitor quality (Maguad, 2006). During World War II, standards became important to maintain product consistency. Initially, each item was inspected individually. To create more efficient inspection processes, manufacturers began using protocols, random sampling, and other statistical techniques to monitor product quality (Shewart, 1931; Shewhart & Deming, 1986). Gradually, QA made its way into U.S. education, healthcare, and LTSS. In 1987, the Nursing Home Reform Act began requiring nursing homes to hold quarterly QA meetings focused on monitoring the quality of their services. According to a 2003 report by the Inspector General of the U.S. Department of Health and Human Services (DHHS), most nursing homes reported using CMS’s quality indicators as the primary data source for their QA work, although the measures had only been in existing for four years at the time (DHHS, 2003).

Although QA remains the dominant approach to quality in LTSS, its overall impact on quality has been limited (Castle, 2010). The primary weaknesses of QA include that it reinforces existing systems and perspectives through its top-down, compliance-focused approach. Quality assurance has also been criticized for reinforcing a “minimum standards” framework (Berwick, 1989; Berwick 2008). Little attention is

given to understanding system processes that contribute to a problem and there is rarely the opportunity for organizational learning or development. Nursing home administrators, for example, devote considerable resources to ensuring compliance with state and federal regulations to avoid legal and/or financial consequences (Shippee et al., 2018). Consequently, there is often little space for innovation or quality improvement unless there are immediate and direct regulatory or financial implications (Baier et al., 2004; Shippee et al., 2018).

### **Quality improvement.**

Frustration with QA's limited impact in the industrial sector led management theorists to develop more comprehensive approaches to addressing quality issues. These approaches, initially referred to as "Total Quality Management" (TQM) and later as "Continuous Quality Improvement" (CQI), or simply QI, focused on modifying organizational processes with the aim of continually innovating product and service delivery (Goetsch & Davis, 2014). Techniques such as the "plan-do-study-act" (PDSA) cycle and "root cause analysis" were developed with the goal of involving broad layers of the organization in continually examining and improving performance (Goetsch & Davis, 2014). Quality improvement is a systems-oriented approach to quality, focused and dependent on organizational change (Berwick, 2008). The movement to QI also represented a shift in values, as the top-down orientation of QA was replaced with a focus on engaging stakeholders in determining areas for improvement, implementing change, and evaluating overall impact (Berwick, 2008; Juran & Gryna, 1980; Hoyer, Hoyer, Crosby, & Deming, 2001).

Industrial manufacturers were the first to systematically implement QI. After observing success with QI in the manufacturing sector, healthcare organizations began adopting QI in the mid-1980s (Shortell, Bennett, & Byck, 1988). In 1987, the Malcolm Baldrige National Quality Improvement Act was passed (Public Law 100-107). Under this legislation, named after former Secretary of Commerce Malcolm Baldrige, the Baldrige Program and Malcolm Baldrige National Quality Award were established to promote the principles of quality management in American government and business sectors (National Institute of Standards and Technology, 2017). During the late 1980s and 1990s, the methods of QI spread quickly throughout the healthcare industry, particularly in hospitals. An early question was whether QI was appropriate for health, social service, and LTSS settings, given the complexity of care delivery compared to industrial manufacturing.

The National Demonstration Project in Quality Improvement in Health Care showed that healthcare organizations could effectively implement the principles and techniques of QI and that improvements in costs and clinical outcomes could be attained in a relatively short period of time (Berwick, Godfrey, Roessner, Plsek, & Garvin, 1990). However, the demonstration also showed that the implementation of QI could be extremely difficult in complex healthcare organizations. Even with external support and technical assistance, the implementation of QI was inconsistent across participating sites and overall results of the demonstration were mixed. Key takeaways from the evaluation included that: 1) leadership was necessary but active involvement of all layers of the organization in QI is essential; 2) ideas for QI projects should be solicited broadly, from staff, patients, and other stakeholders; and 3) QI goals and processes should be aligned

with the mission and values of an organization is essential (Berwick et al., 1990). These early lessons have direct implications for LTSS quality today.

### **Quality improvement in LTSS settings.**

In 2002, the federal government initiated the Nursing Home Quality Initiative (NHQI). The NHQI introduced the public reporting of nursing home quality indicators and started requiring CMS-led Quality Improvement Organizations (QIOs)<sup>10</sup> to work with nursing homes to implement “systemic changes” aimed at improvement (Grabowski & Town, 2011). Heightened policy attention on LTSS quality had already led some nursing homes to start integrating QI into their organizational processes. In a survey conducted in 1994-1995, over 75% of Pennsylvania nursing homes reported that they practiced “some form of QI beyond QA” (Zinn, Brannon, & Weech, 1997). However, another survey, conducted in Kansas several years later, found that few facilities appeared to have active QI programs (Lee & Wendling, 2004). Lee and Wendling (2004) described taking extra steps to reduce the likelihood that providers would over-report the extent of QI engagement when designing their survey (i.e., they attempted to reduce social desirability bias), so it is possible that their results more accurately reflect QI activities in nursing homes than the earlier study. Because of the Affordable Care Act, all nursing homes that participate in the Medicare and/or Medicaid programs are now required to implement ongoing QI activities, although this requirement has only been in place since 2016 (CMS, 2016b).

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<sup>10</sup>Today, 14 regional QIOs exist in the U.S. The QIOs are led by CMS provide tools and resources to healthcare and LTSS providers to improve the quality of their services. Recent QIO efforts in nursing homes have focused on reducing hospitalizations, pressure sores, infections, and use of physical restraints.

Early research on nursing home QI showed not only that facilities varied in the extent of QI implementation, but also that QI did not necessarily lead to improved outcomes (Berlowitz et al., 2003). More recent research has found that various internal (e.g., leadership, staff involvement and support for change, education, data feedback, interdisciplinary communication and collaboration, and values alignments) (Abrahamson, DeCrane, Mueller, Davila, & Arling, 2014; Colon-Emeric et al., 2013; Davila et al., 2016; Siegel, Bakerjian, & Zysberg, 2018) and external (technical and/or clinical support, collaboration with other organizations, and financial incentives) (Colon-Emeric et al., 2013; Gurwitz, Bonner, & Berwick, 2017; Ouslander et al., 2011)<sup>11</sup> factors influence QI implementation and outcomes. Despite evidence that QI can be successfully implemented in LTSS settings and that improvements in quality can be achieved, QI processes are often highly variable (Berlowitz et al., 2003; Horn et al., 2009; Ouslander et al., 2011) and, at times, fail to result in improved outcomes (Berlowitz et al., 2003; Kane et al., 2017).

There are several possible reasons why QI has not had a bigger impact on LTSS quality. These include that LTSS organizations often lack the resources (i.e., finances, staffing levels) and organizational capacity (i.e., knowledge and skills, such as with using data) to implement QI (Abrahamson, et al., 2015; Baier et al., 2004). Further, the implementation of QI in LTSS has often been treated as a top-down process, with input from consumers, families, and direct care staff minimized (Beer, 2003; Davila et al., 2016; Scott, Vojir, Jones, & Moore, 2005). However, a core tenant of QI involves

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<sup>11</sup>Although research on QI in assisted living and HCBS remains limited, recent studies have examined organizational capacity and readiness for change (Abrahamson et al., 2016), as well as provider perceptions of state-mandated QI implementation in HCBS (Noureldin, Abrahamson, & Arling, 2018).

“meeting or exceeding customer expectations” (Berwick, 2008; Juran & Gryna, 1980; Hoyer, et al., 2001). The participatory focus of QI could be better utilized to further person-centered care as the ideal of high quality LTSS. Further, there may be practical reasons for more meaningfully including input from direct caregiving staff, families, and consumers in QI (Cousins & Whitmore, 1998). For example, although LTSS administrators often focus on financial or other business interests given their role in the organization, direct caregiving staff may be more attune to consumer quality of life (Kane et al., 2006) and motivated by a desire to improve it (Bowers et al., 2002; Davila et al., 2016; Parker et al., 2009). Ultimately, if the issues of most salience to consumers, families and staff are not targeted in QI efforts, the natural incentives and motivations for change may be missing for QI to take hold.

### **Values Engagement in LTSS Quality**

Quality has been defined as the “goodness of something” (Stake, 2004), the difference between consumer experiences and their needs or expectations (Parasuraman, Ziethaml, & Berry, 1985; 1988), and the “degree to which services for individuals and populations increase the likelihood of desired outcomes” (IOM, 2001). Quality is inherently *values-dependent* because defining quality involves deciding what a program’s standards and goals should be (Dahler-Larsen, 2011; Stake, 2004). In a related way, quality is inherently *evaluative* (Dahler-Larsen, 2011; Stake, 2004) because assessing quality involves making value judgments about the performance, merit, or worth of programs or services (Scriven, 1967, 1991).

The history of LTSS shows that quality is *dynamic* in that views on what constitutes quality change over time (Stake, 2004). For example, state-level spending on

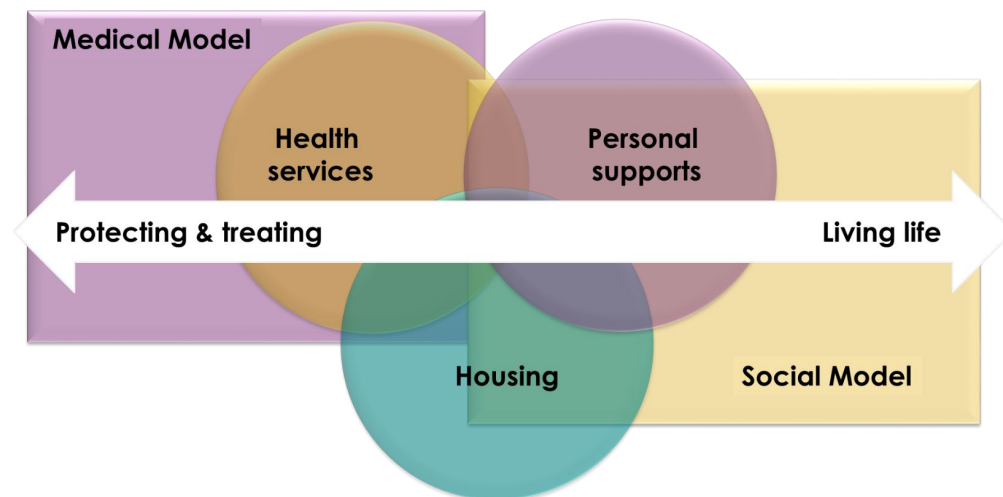
HCBS versus institutional LTSS is increasingly viewed as a marker of a high quality LTSS system (AARP, 2017). Similarly, LTSS that is person-centered is viewed as being of higher quality than care that is organized to maximize efficiency or convenience for staff. Quality can also be *political* because it legitimizes certain values over others and influences decisions about the allocation of public resources (Dahler-Larsen, 2011). Disability rights activities fought for their right to be included in policy discussions about LTSS. Their involvement, in turn, heavily influenced how the goals for LTSS were viewed and, subsequently, how LTSS has been organized and delivered. Thus, their engagement had political, economic, and social ramifications.

Finally, quality can be *subjective* because different stakeholders often define and assess quality differently based on their values and experiences (Moss & Pence, 2001; Stake, 2004). Whereas government regulators typically view quality through an accountability lens, LTSS consumers and families view quality through their own experiences. LTSS administrators and other personnel, on the other hand, must juggle the competing demands and priorities of government regulators and the consumers and families they serve. Because evaluations of quality in LTSS have typically been prescribed by the government and conducted from an accountability- or compliance-oriented perspective, the interests of consumers and families have often been under- or unaddressed in quality assessment. Consequently, many existing evaluations of LTSS quality, particularly in nursing homes, remain biased and incomplete (House & Howe, 1999; Poister, 2004).

Michael Scriven first argued that values were fundamental to the practice of evaluation (Scriven, 1966; Scriven, 1986; Shadish, Cook, & Leviton, 1991). Although

evaluations often do not explicitly identify the values they are endorsing or promoting, evaluations do seek to answer *certain* questions, not all questions (Greene, 1997). In LTSS, there is growing interest in answering questions that better serve the interests of consumers, their families, and personnel. To accomplish a more balanced perspective on LTSS quality, an explicitly values-engaged approach is needed. The proposed approach would not only attend to the priorities of different stakeholders but also elevate the values and interests of consumers and families (Greene, et al., 2006; Hall, et al., 2012). In a related way, a framework for evaluating LTSS quality is needed that better integrates the medical and social goals of LTSS, and that better balances the need for accountability with the importance of consumer quality of life. The following conceptual framework proposes to examine LTSS quality in a way that better incorporates the multiple goals and competing values associated with LTSS:

**Figure 1. Conceptual Framework for LTSS Quality**



Theorists within the values-engaged (Greene, et al., 2006; Hall et al., 2012; Scriven, 1966), democratic (House & Howe, 2008), and transformative (Mertens, 1999; Mertens & Johnson, 2012) evaluation trajectories focus on ensuring that the interests of

various stakeholders, particularly those whom a program or service is intended to benefit, are represented in programs and their evaluations. Evaluations conducted within these values-engaged perspectives often draw on higher level “prescriptive” values, such as democracy, social inclusion, equity, and justice (House & Howe, 1999; Greene, 1997; Mertens & Johnson, 2012; Stake, 2004) in addition to “descriptive” values, or evaluative criteria based on existing stakeholder perspectives (Julnes, 2012).

Within the field of evaluation, stakeholder-engaged and participatory evaluation processes are commonly viewed as strategies to increase the use of evaluation results (Patton, 2008), contribute to program improvement (Cousins, & Whitmore, 1998; King, Cousins, & Whitmore, 2007; Greene, 2000), develop organizational capacity for evaluation and quality improvement (King, 1998; Lawrenz et al., 2018), and facilitate democratic (House & Howe, 1999; Greene, 2000), empowerment-oriented aims (Cousins & Whitmore, 1998; Greene, 2000; Mertens, 2008; Mertens & Johnson, 2012). Therefore, there are both practical and emancipatory reasons for engaging stakeholders in evaluation processes (Cousins & Whitmore, 1998; Greene, 2000).

The limited effectiveness of regulatory, compliance-focused evaluation approaches at improving LTSS quality has opened space for new, more participatory and values-engaged methods, such as QI. The QAPI regulation for nursing homes is one example of this shift. Simultaneously, the person-centered care movement has raised awareness among policymakers, program administrators, and organizational leaders of the importance of including consumers and families in decisions about programs and services that affect them. Although prior research has contributed to knowledge about the attributes of LTSS that consumers and families value most highly, relatively little is

known about how best to include LTSS stakeholders, including consumers and families, in evaluation activities, or how to translate knowledge about their values and interests into public policy.

This study is part of the movement to more deeply engage older adults, families, and members of the LTSS workforce in evaluating and reshaping the organization and delivery of LTSS, including determining how LTSS quality should be defined and measured (Greene, 1997; House & Howe, 1999; Staniszewska, Haywood, Brett, & Tutton, 2012). The proposed study has practical implications for LTSS organizations, including internal efforts to align care delivery and QI activities with their own stakeholder values and build organizational capacity to more effectively implement and evaluate QI (King, 1998; Werner & Konetzka, 2010). However, the aims of this project are primarily emancipatory, focused on ensuring that the values and interests of LTSS consumers and their families are identified and represented in the public policies surrounding LTSS quality (Cousins & Whitmore, 1998; House & Howe, 1999).

### **Chapter Summary**

The history of LTSS over the past 50 years has shown that approaches to LTSS quality have been shaped within a broader political and social context. Problems with institutional LTSS and a desire to contain costs led to a shift to HCBS. This shift was accompanied by a growing movement toward a social, rather than a medical, model of disability. Over time, growing recognition of high costs, poor consumer experience, and relatively poor outcomes throughout the U.S. healthcare and LTSS systems has brought an increased focus on quality. Simultaneously, there has been a movement toward person-centered care, which today is widely recognized as the ideal of high quality LTSS.

A related focus on the experiences of individuals who use services, including measures of satisfaction and quality of life, has followed. Various approaches to quality have been implemented in LTSS, including QA and QI. Despite improvements to LTSS over time, there remains a need to further improve LTSS. A values-engaged approach is proposed as one way for advancing quality in LTSS, including by creating more consistent and equitable ways of defining and assessing quality across LTSS settings.

## **Chapter 3. Methodology**

### **Research Design Overview**

The primary objective of this study was to explore stakeholder perspectives on quality priorities for LTSS for older adults across the continuum of LTSS settings. The study took place in Minnesota and involved several stakeholder groups, including older adults who use LTSS (consumers); family members of older adults who use LTSS; LTSS administrators and executives; nursing leaders; and state policy, regulatory, and advocacy personnel. These stakeholders were selected because of their experience using LTSS (consumers and families), managing LTSS programs (administrators and nursing leaders), or overseeing LTSS quality across LTSS settings (policy, regulatory, and advocacy personnel).

Existing quality frameworks for LTSS tend to be setting-specific, focused on evaluating quality in nursing homes, assisted living facilities, or HCBS. Because the initial focus of the study was to examine views on quality across LTSS settings, the researcher first developed a valuing framework, which encompassed aspects of LTSS quality from multiple perspectives and settings. The resulting valuing framework was used to explore stakeholder perspectives through two data collection methods: Q methodology, and a survey involving rating, ranking, and open-ended questions (Table 1). The framework consisted of multiple domains related to LTSS quality, each with several items.

Stakeholder values have been assessed through various methods in other complex policy contexts, including techniques based on multi-attribute utility theory (Fishburn, 1967; Keeney & Raiffa, 1993; Levin & McEwan, 2000) and multi-attribute value theory

(Angelis & Kanavos, 2016; Stefanopoulos, Yang, Gemitzi, & Tsagarakis, 2014). Despite their theoretical appeal, the applicability of many of these methods to real-life decisions is often weak (Ubel, Loewenstein, Scanlon, & Kamlet, 1996; Brousselle & Lessard, 2011). In response to these limitations, more direct methods for involving stakeholders in valuing program attributes or policy alternatives are often used (Levin & McEwan, 2000). Direct methods, such as those used in this study, are based less on utility theory (Levin & McEwan, 2000). As a result, when stakeholder preferences are elicited through direct methods, results are generally understood to represent the underlying *value* of rated outcomes, rather than their utility (Levin & McEwan, 2000).

**Table 1. Overview of Research Design and Methods**

<b>Research Component</b>	<b>Sample</b>	<b>Methods</b>	<b>Timeline</b>
Phase 1. Development of LTSS quality framework	NA	<ul style="list-style-type: none"> <li>• Environment scan and literature review</li> <li>• Expert review and validation of LTSS quality framework</li> </ul>	Fall 2016
Phase 2. Q methodology to explore stakeholder perspectives	LTSS stakeholders n=70	<ul style="list-style-type: none"> <li>• Q sort (in person)</li> <li>• Exploratory t-tests</li> <li>• By-person factor analysis and qualitative interpretation</li> </ul>	Spring/ Summer 2017
Phase 3. Survey implementation to examine priorities and differences in views	LTSS stakeholders n=417	<ul style="list-style-type: none"> <li>• Mixed mode survey</li> <li>• Descriptive statistics (means, standard deviations, percentages)</li> <li>• Inferential statistics:               <ul style="list-style-type: none"> <li>○ Analysis of variance</li> <li>○ Pearson’s chi-square test for independence</li> </ul> </li> <li>• Analysis of responses to open-ended questions</li> </ul>	Fall 2017

Challenges associated with assessing stakeholder values (Levin & McEwan, 2000) led the researcher to use a multi-method approach. Multiple methods were also selected to gain a deeper and more nuanced understanding of stakeholder perspectives and values related to LTSS quality (Greene, 2007), as well as to facilitate the triangulation of findings across study components (Creswell & Creswell 2017). Analysis was completed separately and converged in the data interpretation stage. Although both data collection methods included aspects of qualitative and quantitative approaches, Q methodology fits more within a constructionist paradigm (Ramlo & Newman, 2011; Watts & Stenner, 2012) and survey methods within a post-positivist one (Creswell & Plano Clark, 2017). Through the methods described, the study addressed two main research questions:

- 1) Which aspects of LTSS quality do stakeholders view as the most important to the overall wellbeing of older adults who use LTSS?
- 2) Do views on quality priorities for LTSS differ based on stakeholder role?

### **Research Context**

The study took place in Minnesota, a state with a population of approximately 5.5 million people, 14 percent of whom are age 65 and over (U.S. Census Bureau, 2016). By 2030, the number of older adults is expected to represent over 20 percent of the state's population (Minnesota State Demographic Center, 2016). Rural parts of Minnesota are disproportionately affected by these demographic trends as the state's non-urban areas tend to be older (Minnesota State Demographic Center, 2017). As in other parts of the U.S., Minnesotans use LTSS in various settings, including nursing homes, assisted living and other residential settings, adult day programs, and their own homes. Over the past 30

years, use of nursing homes in Minnesota has declined while use of assisted living and community-based services have become more common (Minnesota Department of Health, 2018). Currently, Minnesota has approximately 370 licensed nursing homes, housing approximately 28,000 residents, compared to 1,500 assisted living facilities, with approximately 60,000 residents (Harrington, Carrillo, Garfield, Musameci, & Garfield, 2018; Minnesota Department of Health, 2017 and 2018). In fiscal year 2016, public spending on LTSS across age groups in Minnesota equaled about \$4.5 billion (Minnesota Department of Human Services, 2017).

### **Study Components**

#### **Phase 1: Development of a valuing framework for LTSS.**

The Phase 1 environmental scan and literature review involved a web-based search strategy to identify existing frameworks and measures that are used to assess LTSS quality across populations (i.e., people with disabilities, older adults) and settings in which LTSS is delivered. Through this search, several quality frameworks were identified, including the CMS Nursing Home Compare/5-Star Rating System; the National Core Indicators, a framework used primarily to assess the quality of HCBS; the National Quality Forum's Conceptual Framework for Measuring Quality in Home and Community-Based Services; and others. The literature review examined several conceptual frameworks related to LTSS quality, as well as qualitative studies that have been conducted with older adults and families about their values and perspectives related to LTSS quality. Several library databases, including Ovid MEDLINE, CINAHL, and Google Scholar were searched to identify relevant articles. See Appendix A for a list of source material resulting from these methods.

An initial list of concepts related to different aspects of LTSS quality of care and quality of life was developed through this process. The resulting concepts were grouped into tentative quality domains, converted into item statements, and revised to clarify meaning, reduce overlap, and achieve greater consistency in the level of specificity of the statements. Items related to LTSS costs and cost effectiveness were excluded because these are not generally considered person-centered outcomes (Patient Centered Outcomes Research Institute, n.d.). See Appendix B for the initial list and revised list of item statements.

A panel of five reviewers with expertise in different aspects of LTSS quality (Table 2) independently reviewed the draft statements and selected those that they viewed as the most important to consumer wellbeing and representative of LTSS quality, particularly related to the quality domains identified. They also reviewed the overall framework to ensure items were appropriately categorized by domain and that fundamental aspects of LTSS quality were not excluded. Experts reviewed items for clarity, completeness, and potential overlap. Based on reviewer feedback, those items (of 90 items) that achieved the highest overall ratings were included in the framework. A sixth reviewer provided feedback on the items selected by the other reviewers.

For Phase 2, the framework consisted of 9 domains (Table 3) and 52 item statements. Several minor changes were made between Phases 2 and 3, resulting in 50 final item statements used in the Phase 3 survey. Specifically, based on results of Phase 2, minor wording changes were made to several items, three items were deleted, two items combined into a single item, and two new items added, for a total of 50 items.

**Table 2. Reviewers for LTSS Quality Framework**

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<b>Reviewer</b>	<b>Title</b>	<b>Expertise</b>
Mary Absolom*	Manager, Facility Licensing and Certification, Minnesota Department of Health	LTSS quality across settings; state and federal regulations
Lois Cutler, PhD**	Faculty Emerita, School of Public Health, University of Minnesota	LTSS environments; quality of life
Robert Kane, MD	Professor and Chair in Long-term Care and Aging, School of Public Health, University of Minnesota	Quality assessment and improvement across LTSS settings; outcomes research
Charlie Lakin, PhD	Former Director of the National Institute for Disability and Rehabilitation Research; National Quality Forum Committee on Quality Measurement in HCBS	Disability policy & services; quality measurement in LTSS, particularly HCBS
Christine Mueller, PhD, RN	Long Term Care Professor and Associate Dean, School of Nursing, University of Minnesota	Person-centered care in LTSS; nursing home QI
Jane Straker, PhD	Director of Research and Senior Research Scholar, Scripps Gerontology Center, Miami University	Quality assessment in LTSS, particularly consumer/family satisfaction with LTSS

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\* Reviewed and provided feedback on the items but was not involved in the item selection process.

\*\* Focused review primarily on environmental items.

**Table 3. Quality Domains and Number of Items Included in Quality Framework**

<b>Domain</b>	<b>Brief Description</b>	<b>Items (n)*</b>
Activities and social inclusion	Having enjoyable and enough things to do; remaining involved in the community to the extent desired	7
Autonomy and choice	Making decisions about daily routines, personal risks, personal space, and health care	7
Dignity and respect	Being treated with kindness and respect; maintaining personal dignity; having concerns taken seriously	4
Emotional and spiritual wellbeing	Having one's emotional and spiritual needs met; not being anxious or depressed	6
Meals and food	Having good food and enjoyable mealtimes	3
Physical environment	Living in a supportive and comfortable environment; having adequate space; having private space	7
Relationships	Staying connected with family and friends; having good relationships with personnel; feeling cared about	6
Safety and security	Being safe from unnecessary harm; feeling emotionally and physically secure	4
Staffing and staff competence	Receiving care by skilled and competent personnel; getting enough help	6
<b>Total items</b>		<b>50</b>

\*Number included in final quality framework

Next, a brief overview of the designs of study Phases 2 and 3 are presented. Because the population, sample, and recruitment strategies were similar for these components of the study, they are discussed together for Phases 2 and 3, followed by more detailed descriptions of instrumentation, data collection, and data analysis procedures for each study component.

## **Phase 2. Q methodology to explore perspectives on LTSS quality.**

Q methodology is an exploratory and theory-generating method that integrates qualitative and quantitative approaches to explore people's attitudes, values, or beliefs on a given topic (Brown, 1980; McKeown & Thomas, 1988; Ramlo & Newman, 2011; Stenner, Dancey, & Watts, 2000). Q methodology was used in this study for two purposes: 1) to identify a range of distinct perspectives about LTSS quality across several stakeholder groups; and 2) because Q methodology uses a forced distribution, which enhances the ability to distinguish among many aspects of quality that participants may view as important.

Q methodology relies on purposive sampling and relatively small sample sizes to understand the range, rather than the prevalence, of perspectives that exist on a topic (Brown, 1980; McKeown & Thomas, 1988; Watts & Stenner, 2012). Because participants must engage deeply with the topic of inquiry by comparing each item statement with all other items in the item set, Q studies can create a more nuanced understanding of stakeholder values than traditional survey methods (Brown, 1980; McKeown & Thomas, 1998). There has been a resurgence in the use of Q methodology, with recent Q methodological studies examining stakeholder perspectives on a range of health and aging-related topics, including informed choice (Ahmed, Bryant, Tizro, & Shickle, 2012), vascular health (Honey, Bryant, Murray, Hill, & House, 2013), health-related quality of life (Stenner, Cooper, & Skevington, 2003), aging in place (Van Dijk, Cramm, Van Exel, & Nieboer, 2015), and chronic pain (McParland, Hezseltine, Serpell, Eccleston, & Stenner, 2011).

### **Phase 3. Rating and ranking survey to examine stakeholder values.**

Surveys are commonly used to gather information about the values, attitudes, and concerns of stakeholders on various issues (Dillman, Smyth, & Christian, 2014). The survey design used in this study was primarily quantitative, focused on understanding relationships between variables: stakeholder roles, setting of care, and priorities for LTSS quality (Creswell & Creswell, 2017). The survey also included several open-ended questions, which gave respondents the opportunity to explain the reason for their responses or share any additional information they wanted to about their experiences and/or background with LTSS. As in Phase 2, the survey was based on the study's valuing framework, developed in Phase 1. Unlike Q methodology, which usually involves smaller sample sizes (Watts & Stenner, 2012), a larger sample size was needed to allow comparisons across stakeholder roles and LTSS settings (Dillman, et al., 2014). Implementing a survey with a fairly large number of people can be relatively inexpensive and less time consuming than other data collection methods (Dillman et al., 2014). Further, a survey was needed to produce the empirical data needed to explore whether differences exist in opinions on LTSS quality between stakeholder groups and LTSS settings.

Effectively involving the targeted stakeholder groups was an important consideration. A tailored design method (Dillman et al., 2014) was used to gather information from LTSS stakeholders. The intent was to design a survey that would ease the cognitive burden on participants, particularly LTSS consumers and family members, and maximize the participation of multiple stakeholder groups, each with different types of experience with LTSS (Dillman et al., 2014). LTSS providers recommended

developing a survey that LTSS professionals could complete online in less than 15 minutes. Although professionals preferred an online survey, a web-based format was not feasible for many consumers or family members. Therefore, the survey was implemented in multiple modes, including in person (with some consumers), as a self-administered paper questionnaire (with consumers and families), and online (with families and LTSS professionals) (Dillman et al., 2014).

### **Population and Sample**

The target population for this study included stakeholders involved in using LTSS, managing LTSS programs, or overseeing LTSS for older adults in Minnesota (Table 4). A purposive, convenience sampling strategy was used, with the goal of achieving a diverse representation of selected stakeholders who had experience in different LTSS settings. Participants included older adults and family members, LTSS administrators, registered nurses, and state policy, regulatory, and advocacy personnel. Given available resources and the challenges associated with accessing these diverse stakeholder groups, random sampling was not feasible.

To be eligible to participate, consumers had to be age 55 or over with direct experience using LTSS. Because people age differently, age 55 rather than 65 was used as a lower age requirement to involve a more diverse group of older adults. Phase 2 included consumers who had at least 3 months of experience using LTSS. In Phase 3, the inclusion criteria were broadened to include some older adults who did not currently use LTSS, but who were thinking about their future LTSS needs. These participants, who represented approximately 15% of the Phase 3 consumer sample, had applicable family experience with LTSS, such as with a spouse or parent who had used LTSS.

**Table 4. Sampling Plan**

<b>Stakeholder Group</b>	<b>Inclusion Criteria</b>	<b>Recruitment Strategies</b>
Consumer	<ul style="list-style-type: none"> <li>• Age <math>\geq 55</math> years</li> <li>• Cognitively intact</li> <li>• Have used LTSS for <math>\geq 3</math> months (Phase 2) or have relevant personal experience with LTSS (Phase 3)</li> </ul>	<ul style="list-style-type: none"> <li>• Partnerships with several LTSS and HCBS providers</li> <li>• Word of mouth/ community outreach</li> </ul>
Family	<ul style="list-style-type: none"> <li>• Close family member of someone age <math>\geq 55</math> years who has used LTSS in any setting</li> </ul>	<ul style="list-style-type: none"> <li>• Posted flyers</li> <li>• Word of mouth/outreach</li> <li>• Partnerships with LTSS providers</li> </ul>
Administrator/ executive	<ul style="list-style-type: none"> <li>• Administrator or executive in an LTSS organization that serves older adults</li> </ul>	<ul style="list-style-type: none"> <li>• Partnership with a LTSS trade association</li> <li>• Word of mouth/outreach</li> </ul>
Nursing leader	<ul style="list-style-type: none"> <li>• Nursing leader in an LTSS organization that serves older adults</li> </ul>	<ul style="list-style-type: none"> <li>• Partnership with a professional nursing association</li> </ul>
State policy, regulatory, and advocacy	<ul style="list-style-type: none"> <li>• Leader in a state or federal agency involved in the oversight, regulation, financing, or consumer advocacy/protection in LTSS</li> </ul>	<ul style="list-style-type: none"> <li>• Word of mouth/ outreach</li> </ul>

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HCBS=home- and community-based services; LTSS=long-term services and supports

Further, many of these participants relied on family or friends for informal support, such as help with meals, chores, housing, or transportation. It was judged that these participants had enough background to have experience-based opinions about LTSS quality to be included in the study. Family members had to have experience with a close family member, such as a spouse, sibling, or parent, using LTSS in any care setting. Similarly, LTSS professionals and policy, regulatory, and advocacy leaders who had experience working directly in the field of LTSS were surveyed.

Several important stakeholder groups were not included in this study. Although unlicensed direct support professionals such as nursing assistants, personal care assistants, and home health aides provide most direct assistance to older adults who use LTSS (Stone & Harahan, 2010), considerable workforce challenges made it infeasible to include this group of stakeholders. Also excluded for feasibility reasons, and to keep the scope of the research manageable, were other members of the LTSS workforce, including social workers, recreation/activities personnel, physical and occupational therapists, and other healthcare providers such as physicians and nurse practitioners.

### **Recruitment Strategies**

#### **Consumers.**

To maximize participation, our recruitment strategies were tailored to each stakeholder group (Dillman et al., 2014). Given the purposive sampling strategy, the researcher collaborated with several residential and community-based LTSS agencies to reach a diverse group of consumers in terms of age, race, gender, socioeconomic status, geography (rural/suburban/urban location), and type of LTSS setting. Because the researcher had to work through LTSS providers to access consumers, rather than do outreach to this group directly, consumers were the most challenging group to engage.

For Phase 2, the researcher worked with two multi-level LTSS providers (one rural, one suburban), a Twin Cities metro high-end assisted living facility, a metro low-income senior housing community, and a metro area living at home/block nurse program to recruit participants. Providers distributed a recruitment flyer (Appendix C) to individuals whom they thought met eligibility criteria. Consumers who were willing to participate informed a point person within the organization, often the social worker or

volunteer coordinator, who helped facilitate a direct connection with the researcher. Participants were recruited in Phase 2 until the desired number of participants representing the targeted stakeholder groups and diverse characteristics were enrolled.

The original plan was to involve several additional multi-level LTSS sites in Phase 3. However, one multi-level site and a nursing home that had agreed to participate withdrew before survey implementation because of demands on staff related to new federal regulations for nursing homes that were implemented in October 2017 (National Consumer Voice for Quality Long-Term Care, n.d.). Several additional LTSS sites declined to participate, due to concerns related to staff workload and competing demands.

For Phase 3, a description of the study (Appendix D), copy of the survey (Appendix E), and consent form (Appendix F) were distributed to nursing home, assisted living, and low-income independent housing with services residents at our rural multi-level LTSS partner. Unfortunately, the site administrator decided not to invite family members of nursing home residents to participate in Phase 3 because of concerns that completing our survey and receiving an annual statewide resident family satisfaction survey would confuse or overwhelm family members. Similar materials were distributed to everyone who participates in our suburban partner's Meals on Wheels program. At the multi-level LTSS suburban campus partners, flyers about the survey were distributed to cognitively intact nursing home and assisted living residents. (The researcher provided packets containing a description of the study, copy of the survey, consent form, and return envelopes to the provider with the understanding that these would be distributed to all residents, like the procedure used on the other multi-level LTSS campus. However, leadership turnover within the organization led to these materials not being distributed as

planned. A compromise involved distributing copies of the study flyer and following up with potential participants individually instead.)

In addition, residents of two metropolitan low-income senior housing with services communities were invited to participate. At one of the sites, the researcher visited a monthly blood pressure check organized by a living at home/block nurse program and gave flyers to residents who attended the blood pressure check. Those who were willing to participate completed a self-administered paper survey. At the other site, the researcher participated in a monthly meeting of the resident council and invited interested residents to participate. Those who wanted to participate added their names and contact information to a sign-in sheet and a small group “survey session” was organized for the following week. All these surveys were completed independently by participants using a paper version of the survey. The partner metropolitan area living at home/block nurse program also reached out to a small number of home-dwelling seniors who are closely connected with their program to let them know about the study and ask if they were willing to have the researcher contact them about participating. The researcher then made direct contact with these individuals and all agreed to participate. Finally, several additional consumers were recruited through word of mouth/personal connections.

Only cognitively intact older adults were approached about participating, although no formal cognitive screening was performed. The decision not to conduct cognitive screening was made to protect the dignity of consumers who participated and because two of the LTSS partner organizations asked the researcher not to collect any health-related information that would be protected by the HIPAA federal regulation. Therefore, the point person at each organization determined which consumers should not be

recruited for the study and, during enrollment, the researcher asked participants several questions to ensure they understood the purpose of the study, that their participation was voluntary, and that their decision about whether or not to participate would not affect the services they received or their relationship with their LTSS provider or any other organization (Applebaum & Grisso, 2001). Based on this screening, the researcher decided not to include four nursing home and assisted living residents. In these cases, and per the IRB-approved protocol, the researcher seamlessly transitioned to an open-ended interview format, so individuals would not know they were “screened out,” and would still be able to contribute their opinions. These individuals were asked what was important to them in the services they received, what could be improved or added to make their experience with LTSS better, and if they had advice for other people who were thinking about using assisted living or nursing home services. Comments from these individuals were transcribed and included in the qualitative analysis.

Phase 2 participants were given a University of Minnesota coffee mug and \$10 Target gift card as a research incentive. When possible, Phase 3 participants were given a University of Minnesota coffee mug and small bag of candy, which was suggested by several LTSS providers. Research incentives were not given to people who responded to the survey via mail.

#### **Other stakeholder groups.**

Given the small sample size desired, family members were recruited for Phase 2 primarily through word of mouth and flyers at two partner LTSS campuses. For Phase 3, family members were recruited through flyers posted in Twin Cities metro area libraries, coffee shops, and senior centers; word of mouth; and partnerships with two rural and

suburban LTSS organizations, who sent information about the study to family members of assisted living (both campuses) and nursing home residents (one campus). Information sent to these families included a cover letter with information about the study, copy of the survey, consent form, and a self-addressed, stamped envelope so participants could return their completed survey directly to the researcher. Like consumers, family participants were given coffee mugs and \$10 gift cards as research incentives.

For Phase 2, recruitment of administrators, nurses, and policy leaders took place through word of mouth. For Phase 3, information about the study with a link to the survey was emailed to administrators and executives who are members of Care Providers of Minnesota, one of Minnesota's two LTSS trade associations. Similarly, a description of the study and survey link was emailed to members of the Minnesota Directors of Nursing Association, a professional association of nursing leaders who work in nursing homes and assisted living facilities. Follow-up reminder emails were sent to these groups one week and two weeks after the initial emails were distributed (Dillman et al., 2014). Direct recruitment strategies were used to recruit state policy, regulatory, and advocacy leaders with several agencies including the Minnesota Department of Health, the Minnesota Department of Human Services, Stratis Health (the region's CMS-funded Quality Improvement Organization), the Minnesota Area Agencies on Aging, and the Long-Term Care Ombudsman Program. (See Appendix G for copies of the invitation email used for LTSS professionals).

For Phase 2, a coffee mug and \$10 gift card were offered to administrators and nurses, although several participants declined the gift card. No Phase 2 incentives were given to policy, regulatory and advocacy leaders because state and federal employees are

not permitted to accept financial incentives. Online survey participants were given the option to enter their name into a drawing for one of several \$25 gift cards to Target or Amazon.com.

**Desired sample size.**

For Phase 2, approximately 60 participants were desired, an appropriate size for Q methodological studies (Watts & Stenner, 2012). Because we anticipated the views of consumers to be more varied, the plan was to enroll approximately 20 consumers and approximately 10 participants in each of the other stakeholder groups. For the consumer group, the plan included enrolling approximately equal numbers of nursing home residents, assisted living residents, and consumers who received services in their own homes. Similarly, for other stakeholder groups, the plan was to enroll participants who had experience in varied LTSS settings.

For Phase 3, a total of approximately 400 participants was desired, including approximately 120 consumers (30 nursing home residents, 30 assisted living or housing with services residents, 30 consumers who received services in their own homes, and 30 people who did not yet use LTSS); 90 family members; 90 administrators; 60 nursing leaders; and 40 policy, regulatory, and advocacy leaders. As in Phase 2, a larger consumer sample was planned because consumer views were expected to be more varied than the views of other stakeholder groups. In addition, a sufficient consumer sample size was desirable to facilitate a comparison of consumer views on quality priorities across LTSS settings. The number of nursing leaders was lower because the researcher anticipated that nurses would be more difficult to recruit given substantial LTSS nursing

workforce shortages. Finally, policy, regulatory, and advocacy leaders were also projected as lower because there are less state agency leaders to recruit.

### **Pilot Testing**

Pilot testing was conducted to identify and resolve any issues related to study instruments or data collection procedures before actual implementation (Dillman et al., 2014). Six individuals representing different stakeholder groups participated in the Q sort pilot (Phase 2) and 10 people participated in the survey pilot (Phase 3). Cognitive interviews were also conducted as part of the Q sort pilot to understand how participants understood each of the item statements (Tourangeau, Rips, & Rasinski, 2000). Minor changes were made to several item statements after the Q sort pilot and again between Q sort and survey implementation. In addition, several modifications were made to the survey format and instructions based on feedback from pilot participants.

### **IRB Procedure**

Prior to data collection, the University of Minnesota Institutional Review Board (IRB) approved the study for LTSS consumers and families (Appendix H). The IRB deemed data collection involving LTSS professionals (administrators, nurses, and policy/regulatory/advocacy leaders) to be exempt from IRB review. Participants were assured that their responses would be anonymous and informed consent was obtained from all participants.

### **Sociodemographic Information**

Sociodemographic information was collected from all participants, including the individual's current role in relation to LTSS (i.e., stakeholder role), gender, race/ethnicity, current LTSS setting, and geographic location (rural/smaller community,

suburban/mid-sized community, urban). In addition, consumers were asked their age, marital status, and how long they had used LTSS. Family members were asked their relationship with their family member (e.g., spouse, son/daughter, etc.), the age of their family member, their family member's marital status, how long their family member had used LTSS, and whether their family member had been diagnosed with Alzheimer's disease or a related form of dementia (ADRD). Professionals were asked how long they had worked in LTSS and whether they worked primarily with people who had ADRD.

## **Instrumentation, Data Collection, and Data Analysis (Phase 2, Q Sort)**

### **Instrumentation.**

The first step in Q methodology involves creating the item set, with items representing a sample of the range of values or perspectives on a given topic, in this case LTSS quality (Watts & Stenner, 2012). Participants use these item statements to express their perspectives through the Q sort process (McKeown & Thomas, 1988; Watts & Stenner, 2012). The domains and items representing the Phase 1 valuing framework formed the item set (Q set) for the Q sort process. Item statements were printed onto small notecards for use in the Q sort process. Two sizes were printed to accommodate people with differing levels of eyesight. Each item statement was assigned a number from 1-52 for tracking purposes. Participants were given a Q set and Q grid, which resembled a semi-normal distribution (Figure 1) (Brown, 1980; McKeown & Thomas, 1988; Watts & Stenner, 2012). Data resulting from participant Q sorts formed the basis for analysis.



important” to “least important.” The number of items for each category ranged from 5 to 10 items. To ease the sorting task, participants were guided to complete the extreme ends of the distribution first (most and least important columns) and then move inward on the Q grid (Watts & Stenner, 2012). After the participant completed their Q sort, participants were asked to enter the numbers associated with the item statements into the column cells corresponding with their ranking of the item. In many cases, the researcher assisted with this task, particularly for consumers. To better understand each participant’s rank ordering, the interviewer asked each person to explain their reason for ranking certain items most important (top 5 items) and least important (bottom 5 items). Participants were also invited to make any additional comments during or after the Q sort interview. These comments were recorded and transcribed for later analysis.

All consumer and family Q sorts were conducted in one-on-one sessions with the researcher. These meetings were typically held in a meeting room at the LTSS campus or in another public space, such as a library. However, in several cases, Q sort sessions were held in people’s homes to accommodate the wishes of the participant.<sup>12</sup> Several LTSS administrators/executives and state policy, regulatory, and advocacy leaders completed Q sorts in small group sessions, although each participant completed their Q sort independently. In instances where Q sorts were completed in small group sessions, participants were given a form to complete at the end of the session asking them to

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<sup>12</sup> The researcher had an updated background check completed by the University of Minnesota and underwent volunteer training and background screening through the collaborating living at home/block nurse program before data collection. Home-dwelling consumers were invited to complete the session at a nearby public library. However, most participants said they preferred to meet in their own homes. All one-on-one in-home meetings involved participants of the same gender as the researcher (all were women). In one case, the researcher met with a man in his home. In this case, a long-time living at home/block nurse program volunteer and neighbor (and informal caregiver) of the participant sat in on the session as well.

explain why they selected certain items as most and least important. Q sort sessions ranged in length from 30 to 90 minutes (mean time: 50 minutes).

### **Data analysis.**

The primary analysis in Q methodology involves “inverted” or by-person factor analysis to identify participants who complete their Q sorts in similar ways (Brown, 1980; McKeown & Thomas, 1988; Stephenson, 1935; Watts & Stenner, 2012). Participants whose views are statistically correlated are interpreted as sharing a distinct perspective or viewpoint on the topic (Brown, 1980; McKeown & Thomas, 1988; Watts & Stenner, 2012). The number of distinct perspectives that emerge from a Q methodological study can range from a single perspective to 10 or more perspectives, although three to six perspectives is common (Watts & Stenner, 2012).

Q sort data were analyzed using PQMethod (version 2.35, 2014). An initial inter-correlation matrix was produced that compared each Q sort with every other Q sort (70 x 70 matrix). Next, principal components analysis (PCA) with varimax rotation was used to create a factor pattern matrix, which enabled the researcher to examine the loading, or correlation, of each Q sort on each factor (Watts & Stenner, 2012). Although several techniques exist for extracting factors (or “components” when PCA is used), PCA with varimax rotation is the best mathematically: it maximizes the similarities within each perspective as well as the differences between perspectives (Watts & Stenner, 2012). To be interpretable, each factor must have an eigenvalue greater than one and at least one Q sort that loads significantly on only that one factor (Watts & Stenner, 2012). Q sorts that loaded on a factor with a correlation coefficient of 0.36 or greater were considered statistically significant at the 0.01 level of significance (Watts & Stenner, 2012). Q sorts

that loaded significantly on only one factor were retained as exemplars for that perspective.

The exemplar sorts for each factor were merged and an idealized Q sort was created based on a weighted average for the exemplar sorts representing that factor (Brown, 1980; Watts & Stenner, 2012). These composite sorts, referred to as factor arrays, were interpreted to understand the value orientation of participants who shared that perspective on LTSS quality (McKeown & Thomas, 1988; Watts & Stenner, 2012). The entire factor array (i.e., all the items in the Q sort) was considered in the interpretation of each factor. Particular attention was paid to items ranked highest (+3) and lowest (-3) within each factor array, as well as items that distinguished each perspective from other perspectives (Watts & Stenner, 2012). Distinguishing statements represented those that were ranked differently (higher or lower) by one factor versus all other factors, with the difference being statistically significant at the 0.05 level of significance (Watts & Stenner, 2012).

Comments made by participants during the Q sort process were transcribed and imported into NVivo qualitative software (Version 11, QSR International, 2015). A primarily deductive approach was used for analyzing the data: the valuing framework served as the organizing framework for participant comments in response to specific items. For example, comments made in response to Item 12 were coded *Dignity and Respect/Having the people who help me take my concerns about health or other issues seriously* (Item 12). Other comments made by participants, which did not directly correspond to specific item statements, were thematically analyzed with the quality domains again used as the overarching analytical framework (Braun & Clarke, 2006).

These comments, as well as sociodemographic details and other information participants shared about their background or experience with LTSS, were used in the process of interpreting the value orientation of each perspective.

In addition to factor analysis, basic descriptive analyses were conducted of data resulting from the Q sorts to facilitate more direct triangulation of results with the Phase 3 survey. Stata/IC (Version 15, StataCorp, 2017) was used for this analysis. Item scores were converted from the Q sort scale (-3 to +3) to a 1-7 rating scale. Mean scores and standard deviations for each item and domain were computed. Kruskal-Wallis test by ranks, a nonparametric version of one-way analysis of variance (ANOVA), was used to compare domain means for each stakeholder group.

### **Instrumentation, Data Collection, and Data Analysis (Phase 3, Survey)**

#### **Instrumentation.**

The survey consisted of two close-ended question formats and several open-ended questions (Appendix E, previously referenced). A variation of magnitude estimation (Stevens, 1956; Waltz, Strickland, & Lenz, 2010) was used to obtain importance ratings from participants. Participants were asked to rate items using an 11-point scale, where 0 represented not at all important and 10 represented critically important (T. Rockwood, personal communication, June 15, 2017). An 11-point scale, rather than a more typical 4- or 5-point scale, was used to allow for more variation in participant ratings. Five descriptive labels were included above the 0-11 rating scale to further orient participants as they selected their responses (T. Rockwood, personal communication, June 15, 2017). Because it was anticipated that most respondents would want to rate many if not all items highly, question instructions encouraged participants to “use the full rating scale,

reserving the highest points for items viewed as most important” (Masino & Lam, 2014). To ease the cognitive burden on participants (Dillman et al., 2014) and because grouping questions by domain improves construct reliability (Goodhue & Loiacono, 2002; T. Rockwood, personal communication, June 15, 2017) rating items were presented to participants in domains, with each quality domain containing 3 to 7 items.

For the rating question, participants were asked to respond to slightly different questions based their role. The questions were consistent with those asked of Q sort participants: consumers were asked to rate items in terms of each item’s importance to themselves and their overall wellbeing; family members were asked to rate each item based on their opinion of each item’s importance to their family member’s wellbeing; and professionals were asked to rate items in terms of their importance to the overall wellbeing of older adults who use LTSS. Items were randomly ordered within each domain to reduce order effects, measurement error related to the order in which survey items are presented (Dillman, et al., 2014). Three versions of the online survey were used, each presenting different item orderings within each domain.

The survey also included a ranking question, which presented participants with a brief description of each quality domain and asked them to select and rank order the three domains they viewed as the most important priorities for organizations that provide LTSS. Participants were not asked to rank all nine domains because of the difficulty of ranking items (Dillman, et al., 2014; T. Rockwood, personal communication, June 15, 2017). On the online survey, the list of quality domains was randomly ordered to reduce order effects. The three paper versions of the survey each contained a different domain ordering. Finally, several open-ended questions probed for any additional background or

experiences with LTSS that participants wanted to share, participants' reasons for selecting certain aspects of LTSS quality as most important, and for any other comments, including about priorities for LTSS quality, the participant wished to share.

### **Data collection.**

Three versions of the survey were tailored to each stakeholder group: consumer, family, LTSS professionals (Dillman et al., 2014). Qualtrics® (2018) online survey platform, available through the University of Minnesota's Office of Measurement Services, was used for web-based survey administration and data storage. Participants who completed the survey online were first presented with a question that asked them to select their primary role. Respondents were then triaged to the appropriate version of the survey. Paper versions of the surveys were developed for consumers and families that mirrored the online survey as closely as possible (Dillman et al., 2014).

Assisted living residents, low-income housing with services residents, and home-dwelling older adults who received paper versions of the survey were given two options for participating. They could return their completed survey in a self-addressed stamped envelope provided by the researcher or meet in person with the researcher to complete a survey. Most consumers (90%) who received a copy of the survey chose to return their survey through the mail. At the site where flyers about the study were distributed, the researcher visited the campus on two dates and followed up directly with potentially eligible nursing home and assisted living residents about their willingness to participate. Four residents declined to participate, two residents were unwell on the dates the researcher visited, one resident said she wanted to participate but seemed distressed and

the researcher decided not to interview her, and several assisted living residents were not in their apartments at the time of the researcher's visit.

When surveys were completed in individual sessions with the researcher, survey administration was computer-assisted. The researcher pulled up the online survey on an iPad and helped the consumer complete the questionnaire. In about half of the cases, consumers preferred to complete the survey independently after learning how to use the iPad. In the other cases, often because the participant had vision limitations, the researcher read the survey instructions and questions to the participant using structured survey interviewing techniques (Dillman et al., 2014). One consumer completed the online survey after hearing about the study through a friend.

Families who received a mailing about the study from the LTSS campuses (two campuses) returned their completed surveys in a self-addressed stamped envelope provided by the researcher (43% of family respondents). Other family participants, who learned about the study from a posted flyer, social media, or word of mouth completed the survey online. LTSS administrators and executives, nursing leaders, and policy, regulatory, and advocacy leaders completed the survey online. Data for all participants who completed at least one rating question were retained in the analysis.

#### **Data analysis.**

Raw data resulting from the surveys were used for analysis. Data were first screened for evidence of participants who had marked all rating items the same, particularly those who rated all items 10. Ten participants met this criterion, including four consumers, two administrators, and four nurses. These data were retained in the analysis. For missing data, pairwise deletion was used to retain as much data as possible

in the analysis. Descriptive analyses, including means, standard deviations, and percentages were computed and used to summarize the data, including demographic information about the sample.

Outcomes for the rating questions were analyzed using one- and two-way ANOVA models, with primary analysis conducted at the domain level. Kruskal-Wallis non-parametric test was also used to examine outcomes, primarily because of the sample size differences between stakeholder groups, although none of the results changed based on using the Kruskal-Wallis test compared to ANOVA.

First, one-way ANOVA was used to examine whether mean ratings differed by stakeholder group. Two-way ANOVA models then explored whether stakeholder views differed based on LTSS setting or for family and professional caregivers of people with ADRD versus other family and professional caregivers. These additional analyses were conducted because results of the Q sort analysis suggested that LTSS setting and experience with ADRD may influence stakeholder views on quality priorities. For domains in which statistically significant differences were observed between groups, post-hoc analysis with Bonferroni correction was conducted to identify where the differences occurred. Bonferroni correction was applied to avoid inflating the chance of committing a type I error since multiple comparisons were conducted (Sedgwick, 2014).

For the ranking question, Pearson's chi-square test for independence, a non-parametric statistical test, was used to compare the proportion of participants in each stakeholder group that selected each domain in the top 3 of importance. Stata/IC (Version 15, StataCorp, 2017) was used for statistical analyses. Responses to open-ended questions were analyzed thematically (Braun & Clarke, 2006).

The integration of the results of Phase 2 (Q sort) and Phase 3 (traditional survey) occurred during the interpretation of study results. Qualitative comments made in response to specific item statements (Phase 2), other comments made by respondents during their Q sort session (Phase 2), and responses to open-ended questions (Phase 3) aided in the interpretation of study findings. Themes identified in participants' open-ended comments (both phases) were compared to the quantitative findings to better understand stakeholder views on LTSS quality and how views differed (Creswell & Plano Clark, 2011).

## **Chapter 4. Q Sort Results**

This study used two data collection methods to examine which aspects of LTSS quality key stakeholders viewed as most important and identify whether and how stakeholder priorities differ. This chapter presents results of the Q sort (Phase 2) component of the study, which involved exploratory analyses of differences by stakeholder role and by-person factor analysis with qualitative interpretation involving demographic information and participant comments to determine profiles or patterns of individuals with shared perspectives on priorities related to LTSS quality.

### **Description of the Sample**

Seventy individuals representing the targeted stakeholder groups participated in the Q sort component of the study. These respondents are identified in Table 5. Participants included 22 older adults who use LTSS; 10 family members; 15 LTSS administrators; 11 nurses; and 12 state policy/ regulatory/advocacy leaders. The majority of participants were women (77% female; 23% male). Consumer participant ages ranged from 65 to 94 (mean 76; SD 7 years) and 74% were white/Caucasian. Half of the family participants were spouses of a person who uses LTSS (four wives; one husband) and half were adult children of LTSS users (three daughters; two sons). Sixty percent of family participants indicated their relative had been diagnosed with ADRD.

All participants had experience using, delivering, or overseeing in various LTSS settings, including private homes, low-income senior housing with services (such as meals, transportation, nursing services, and/or help with chores), assisted living facilities, and nursing homes. Several administrators, nurses, and policy leaders had in the past or currently worked with multiple LTSS settings. Approximately one-third of participants

were from rural areas of the state, one-third from suburban regions of the Twin Cities, and one-third from Minneapolis/St. Paul.

**Table 5. Q Sort Participants**

Stakeholder group	Mean consumer age (SD)	Female	ADRD	Participants by LTSS setting					Total
				Home	Housing	AL	NH	Multi-setting	
Consumer	76 (7)	68%	NA	4	6	6	6	NA	22
Family	82 (13)*	70%	70%	1	1	6	2	NA	10
Administrator	NA	60%	20%	1	2	4	4	4	15
Nurse	NA	100%	9%	1	2	4	4	0	11
Policy	NA	100%	NA	0	0	0	4	8	12
				7	11	20	20	12	70

\*Mean consumer age (not the age of the participating family member)

ADRD=Alzheimer's disease or related dementias; AL=assisted living; LTSS=long-term services and supports; NH=nursing home; SD=standard deviation

### Descriptive and Exploratory Analyses

The Q sort method required participants to sort items into seven categories of importance, with an equal number of items ranked high and low using a forced distribution. Basic descriptive and exploratory analyses of the resulting data were performed (see Table 6), to get an initial sense of stakeholder priorities, as well as to facilitate triangulation with the results of the Phase 3 survey.<sup>13</sup> To facilitate these analyses, each category of importance was assigned a numerical rating from 1 to 7. For stakeholder groups combined, mean domain ratings ranged from 5.04 to 3.36 (SD 0.90

<sup>13</sup> Although the Q sort method can be used to better distinguish the importance of items than traditional rating scales because of its forced ranking distribution, the primary analysis of Q sort data involves the by-person factor analysis described in the subsequent section.

across domains). Due to the forced distribution, mean ratings clustered around 4.0, which corresponded to the mid-point of the Q grid and the overall mean rating for the 52 items.

As shown in Table 6, stakeholders overall selected items related to Dignity/Respect (mean 5.04; SD 0.82), Safety/Security (4.57; SD 1.05), and Staffing/Staff Competence (4.36; SD 0.97) as most important. The Kruskal-Wallis tests (non-parametric one-way analysis of variance on ranks) revealed statistically significant differences in mean stakeholder ratings for four of the nine quality domains. Whereas Dignity/Respect (H: 16.94;  $p=0.002$ ) and Safety/Security (H: 9.74;  $p=0.045$ ) were ranked lower by consumers than other stakeholder groups, items related to Physical Environment (H: 19.00;  $p=0.0008$ ) and Activities/Social Inclusion (H: 14.15;  $p=0.007$ ) were ranked higher by consumers than others. Items related to Autonomy/Choice were ranked lowest of all domains by consumers and families. On the other hand, Autonomy/Choice was ranked the third most important domain by members of the policy/regulatory/ advocacy group, individuals who tend to have more “voice” and authority in determining how LTSS quality is defined at the policy level. Stakeholder rankings of items related to the Physical Environment also differed, with consumers ranking this domain second highest and professionals ranking it second lowest. Finally, priorities articulated by the consumer group were distributed more equitably across the domains, perhaps demonstrating that the views of consumers were more varied, as expected, or that consumers more carefully balanced tradeoffs when ranking items. Whereas the difference between the highest and lowest domains in the consumer group was only 0.67, the difference for other groups was substantially higher: 1.8 for families, 2.06 for policy leaders, 2.38 for nurses, and 2.4 for administrators.

**Table 6. Mean Domain Ratings by Stakeholder Group**

	Overall (n=70)	Consumer (n=22)	Family (n=10)	Admin (n=15)	Nurse (n=11)	Policy (n=12)	
Domain	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	p-value
Dignity/Respect	5.04 (0.82)	4.43 (0.83)	5.15 (1.03)	5.33 (0.41)	5.41 (0.60)	5.35 (0.60)	0.002**
Safety/Security	4.57 (1.05)	4.06 (1.06)	4.35 (1.21)	4.78 (0.79)	5.23 (0.98)	4.81 (0.87)	0.045*
Staffing/Staff Competence	4.36 (0.97)	3.99 (0.94)	4.73 (1.23)	4.62 (0.79)	4.74 (0.76)	4.03 (0.94)	0.097
Meals/Food Enjoyment	4.17 (1.44)	3.86 (1.64)	4.50 (1.03)	4.93 (1.24)	4.14 (1.38)	3.54 (1.37)	0.067
Emotional/Spiritual Wellbeing	4.11 (0.74)	3.98 (0.84)	4.03 (0.38)	4.47 (0.67)	4.11 (0.86)	3.97 (0.73)	0.319
Autonomy/Choice	3.85 (0.80)	3.76 (0.48)	3.35 (0.71)	3.88 (0.97)	3.88 (0.88)	4.39 (0.83)	0.073
Relationships	3.79 (0.60)	3.98 (0.74)	3.64 (0.54)	3.68 (0.50)	3.64 (0.62)	3.84 (0.39)	0.417
Physical Environment	3.68 (0.94)	4.26 (0.78)	4.03 (1.12)	3.16 (0.70)	3.26 (0.97)	3.35 (0.67)	0.0008***
Activities/Social Inclusion	3.36 (0.80)	3.82 (0.81)	3.47 (0.84)	2.93 (0.69)	3.03 (0.55)	3.29 (0.62)	0.0068**

\* p<0.05; \*\*p<0.01; \*\*\*p<0.001; Admin = Administrator/Executive; SD=standard deviation  
Scale: 1-7, using a force distribution

### **By-Person Factor Analysis: Viewpoints on LTSS Quality Priorities**

In addition to the exploratory analyses already described, the by-person factor analysis that characterizes Q methodology (Brown, 1980; McKeown & Thomas, 1988; Watts & Stenner, 2012) was used to identify several distinct perspectives on LTSS quality that were shared by individual Q sort participants. Unlike the analyses described above, in which the researcher predetermined comparisons by stakeholder role, factor analysis allows latent patterns and relationships existing in the data to be discovered abductively (Watts & Stenner, 2012). Patterns and relationships are first observed in the data. Then other information, such as demographic information about participants and comments made as participants completed their Q sorts, is used to interpret the patterns and relationships that are observed.

In this study, shared perspectives on LTSS quality were discovered by first examining how Q sorts were statistically correlated with each other, regardless of the stakeholder roles of the individuals involved. The prior experiences of individuals, including participants' roles and settings, were then used in interpreting the patterns that were observed. Comments made by participants about why they ranked certain items higher or lower than other items provided additional insights. Given the study's research questions, the researcher was particularly interested in the extent to which shared perspectives would be defined by stakeholder role or other factors, such as LTSS setting, although it was possible that no patterns by role or setting would be found.

Completed Q sorts for the 70 participants were analyzed using PQMethod software (Version 2.35, 2014). To facilitate the analysis, Q sort data were recoded from a 1 to 7 scale to -3 to +3 (-3, -2, -1, 0, 1, 2, 3) corresponding to the seven categories of

importance.<sup>14</sup> Factor analysis was conducted using principal components analysis and varimax rotation. The best solution consisted of six factors, each with an eigenvalue greater than one and defined by at least two non-confounded Q sorts (Table 7) (Watts & Stenner, 2012). A significance level of 0.01 was used to determine factor loadings. The resulting six factors (also referred to as viewpoints or perspectives) accounted for 52% of the total variance in the data. The six-factor solution included all but four of the 70 Q sorts, which did not significantly load on any of the factors. (These four individuals had viewpoints on LTSS quality that were unique to themselves.) Several Q sorts loaded significantly on more than one factor and were therefore not used further in the analysis (Watts & Stenner, 2012).

Q sorts that loaded significantly on only one factor were used to create idealized Q sorts for each factor (Table 8). In creating these idealized sorts, Q sorts that were more strongly correlated with a factor received more weight (Watts & Stenner, 2012). A structured approach to factor interpretation was used, which involved interpreting information from the idealized Q sorts, demographic information about the participants whose Q sorts loaded on each factor, and comments made by participants as they completed their Q sorts. Particular attention was paid to distinguishing statements, items that were significantly different for one perspective compared to other perspectives (distinguishing statements are indicated in Table 8). Descriptive titles for each factor or viewpoint were developed based on participant comments and the researcher's interpretation of the primary orientation of each perspective. There were no consensus statements between viewpoints.

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<sup>14</sup> This data format is required by the software used to conduct factor analysis with Q sort data.

**Table 7. Summary of Stakeholder Viewpoints (Results of By-Person Factor Analysis)**

	<b>Viewpoint 1</b>	<b>Viewpoint 2</b>	<b>Viewpoint 3</b>	<b>Viewpoint 4</b>	<b>Viewpoint 5</b>	<b>Viewpoint 6</b>
Primary orientation of viewpoint	Clinical care and safety (medical model)	Alzheimer’s caregivers (basic things)	Demanding respect (assisted living)	Protective advocacy (vulnerable)	Connected and involved (engaged)	Individualized care (family supports)
Exemplars associated with viewpoint	15 exemplars	10 exemplars	11 exemplars	6 exemplars	8 exemplars	3 exemplars
Eigenvalue (explained variance)	9.8 (14%)	7.7 (11%)	6.3 (9%)	4.9 (7%)	4.2 (6%)	3.5 (5%)
Characteristics of individuals whose Q sorts define this viewpoint	Professionals (various roles and settings) except one housing with services consumer who has had recent health scares	Family and professional caregivers of people with ADRD, plus 1 NH resident who negatively loads on factor	Primarily consumers: 9 people who use LTSS, one daughter of AL resident, 1 NH administrator	Professionals, varied roles and settings	6 consumers (4 low-income senior housing, 1 private home, 1 NH resident) 1 family member, 1 policy/program leader new to field aging	2 consumers (1 of whom negatively loaded on factor), plus a family member of person with ADRD

ADRD=Alzheimer’s Disease and Related Dementias; AL=assisted living; HCBS=home and community-based services; NH=nursing home

**Table 8. Idealized Q Sorts for Each Perspective**

Domain and statement <sup>‡</sup>	Viewpoint					
	1	2	3	4	5	6
<i>Autonomy/choice</i>						
1. Controlling my daily routines, such as what time I get up in the morning, eat meals, etc.	1	1	0	3	-1**	3
2. Choosing where I live and receive services	1	-2**	1	1	0	-1**
3. Deciding who may enter my house, apartment, or room	1*	-2	-2	0	-2	0
4. Choosing the people who help me with my daily needs	-2	-1	-3	-1	-3	3**
5. Doing things for myself, even if it takes more time	1	-1	-2	2*	0	0
6. Making choices others may disagree with	2*	-2	-3*	2*	-2	0*
7. Choosing my doctor and other healthcare providers	0	-3	0	-3	2**	-3
8. Making decisions about my healthcare	3	-1**	2	2	3	1
<i>Dignity/respect</i>						
9. Receiving assistance that is tailored to my individual needs and preferences	2	0	1	2	-1**	1
10. Being treated with kindness and respect by the people who help me	2	3	2	3	1	-2**
11. Receiving assistance in a way that allows me to maintain my dignity and personal privacy	3	2	2	3	0	1
12. Having the people who help me take my concerns about health or other issues seriously	2	1	1	0**	0	1
<i>Activities and social inclusion</i>						
13. Being able to do the things I enjoy	-1**	1	1	1	3**	1
14. Having enough to do; not being bored	-3**	-1	0	1	-2	-2
15. Having access to entertainment I enjoy	-2*	0	1	-2*	1	0
16. Choosing whether to spend my time alone or with others	-2	-2	-1	0	-1	1
17. Not being forced to participate in activities in which I am not interested	-1	0	-3	0	-3	0
18. Going out to run errands, eat out, or participate in other activities in the community	-2	-3	0**	-2	2**	-2
19. Staying connected and involved in the community	-3	-3	-1**	-3**	2**	-3
<i>Meals and food</i>						
20. Having pleasant and enjoyable mealtimes	-2	1	0	1	-2	-3*
21. Eating the foods I like	0	1	0	2	-2	-3

\* Distinguishing statement (p<0.05); \*\* distinguishing statement (p<0.01)

<sup>‡</sup> Items reworded for family members and professionals

**Table 8. Idealized Q Sorts for Each Perspective**

Domain and statement <sup>‡</sup>	Viewpoint					
	1	2	3	4	5	6
<i>Relationships</i>						
22. Seeing my family and friends when I want to	0**	-1**	3	2	3	1
23. Staying in touch with people via phone/email	0	-3	1	-1**	2	-3
24. Having good relationships with staff	-1	2**	0	-2	0	-1
25. Not being lonely	-1	0	-1	0	-3**	-2
26. Helping others or giving gifts when I want and am able to	-3	-2	-3	-3	0**	-2
27. Feeling that others care about me	1	3*	1	2	0	2
28. Feeling connected to the people around me	-1	0	-2**	0	1	0
29. Having a sense of community where I live	-2**	1	-2**	1	3**	0
<i>Safety and security</i>						
30. Being confident I will receive the assistance I need, including in an emergency	2	1	2	0**	2	2
31. Knowing that I will not be hurt, yelled at, or intimidated by others	3	3	-1	3	0	0
32. Receiving assistance in a way that I am not hurt or injured	2	2	-1	-2	-1	1
33. Having my belongings safe from being lost, stolen, or damaged	2**	-1	0	0	-3*	-1*
<i>Staffing and staff competence</i>						
34. Receiving enough time and attention from the people who help me	0	2	-2**	1	-1	3
35. Being free of substantial pain or other physical discomfort	3	2	3	1	0	-1
36. Receiving help from skilled and competent personnel	3	2	3	-2**	0	0
37. Having my health closely monitored to avoid getting sick or having unnecessary complications	1**	0	0	-3	-2	-2
38. Receiving care or help from the same people over time	-2	3*	-1	-1	-2*	3**
39. Having staff care for me communicate effectively with each other to avoid mistakes or confusion	2	2	2	0	2	2
<i>Emotional and spiritual wellbeing</i>						
40. Not feeling anxious or depressed	1	3**	-1*	1	-3	-2
41. Feeling calm and peaceful	0	2*	1	-2	1	-1
42. Feeling happy	-1	1	2	-1	1	-1
43. Feeling a sense of purpose in my life	0	0	-2	3	3	-2
44. Having my religious and spiritual needs met	1*	-1	-2**	-1	2	2
45. Having someone to talk to when I have concerns, feel down, or am having a bad day	0	0	-2**	0	-1	2*

\* Distinguishing statement (p<0.05); \*\* distinguishing statement (p<0.01)

‡ Items reworded for family members and professionals

**Table 8. Idealized Q Sorts for Each Perspective**

<b>Domain and statement<sup>‡</sup></b>	<b>Viewpoint</b>					
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<i>Physical environment</i>						
46. Living in a homelike environment	-1	0	2**	-1	1	0
47. Having my own room or home	-2	-2*	3**	2	-2	2
48. Living in a place that is easy for me to get around	-1	0	2	-2*	2	2
49. Living in a place that is designed to help me do things on my own, such as shelves being at a height I can reach, good lighting, etc.	0	-2*	-1	-1	1	3**
50. Being able to personalize my space with my belongings	0	-2	0	-3	1**	-1
51. Having access to outdoor space	-3	-1	-3	-2	-1	-1
52. Having a private bathroom	-3	-3	3*	-1*	-1*	2*

\* Distinguishing statement (p<0.05); \*\* distinguishing statement (p<0.01)

<sup>‡</sup> Items reworded for family members and professionals

### **Factor Interpretation**

#### **Viewpoint 1. “Medical stability is the most important,” (medical model).**

The first viewpoint, shared by 15 participants whose Q sorts significantly loaded on this factor, accounted for 14% of the total variance and had an eigenvalue of 9.8. All the respondents associated with this factor were professionals except a 76-year-old woman who receives services in a low-income housing community and who told the researcher about several recent health scares, which have led her to feel anxious about her health. Professionals associated with this factor included six administrative/executive leaders (one of whom is also a registered nurse), four state policy/ advocacy/regulatory leaders, and four nursing leaders (all registered nurses). The LTSS settings with which participants currently worked included the full continuum of LTSS: nursing homes, assisted living, memory care, home care, and low-income senior housing with services.

Most of the professionals associated with this perspective had considerable experience in LTSS, ranging from seven to over 40 years, and many had worked in various settings.

The primary orientation of this viewpoint was toward meeting the needs of older adults who have substantial physical (health or functional) needs, which may require them to depend heavily on others. This perspective might be best thought of as representing the traditional “medical model” of LTSS, with a focus on health and safety over meaningful activities, food enjoyment, relationships, or features of the environment. A sense of physical vulnerability comes through in this perspective and there is a related focus on ensuring the safety of people who use LTSS. Although a sense of protectionism seems evident in the idealized sort and participant comments for this perspective, respondents with this viewpoint may prioritize health and safety because they see these as necessary attributes to maintaining a good quality of life for LTSS consumers. A nurse manager with 20 years of experience in LTSS who currently works in a nursing home commented,

Overall, medical stability is the most important because without that you can’t achieve the rest... we need to help them [consumers] make safe choices—that’s our role. When they’re in a place like this, that’s where we nurses step in. We document unsafe activities, such as not following a recommended diet. There is a balance, I know, because quantity and quality of life, but we need to do what we can to help them be safe.

Similarly, a policy/regulatory leader with nine years of experience in home and community-based LTSS settings said, “If your healthcare providers aren’t really

assessing what’s going on—your history—things can creep up. If you lose your health, you can lose so much. You can lose your independence.”

Because a person’s medical needs are dominant in this perspective, it is important that LTSS personnel are skilled and competent (item 36, rated 3) and that professionals communicate effectively with each other to avoid mistakes or confusion (item 39, rated 2), suggesting that more than just “simple” help is needed. The single LTSS consumer who loaded on this factor said,

Most of my choices [item rankings] are because my health has gotten worse over the past years.... Pertaining to my doctors, I want them to know what they're doing. My health has gotten worse and I've had to go to the hospital a few times.

The distribution of other items in the idealized Q sort suggested that people who shared this perspective view care provided by LTSS professionals as central to consumers’ overall wellbeing and their experience of quality. They valued assistance that is provided in a way that allows consumers to maintain their dignity and personal privacy (item 11, score: 3), that consumers are free of substantial pain and other physical discomfort (item 35, 3) and that the concerns of consumers are taken seriously (item 12, 2). In addition, having consumers’ health closely monitored (item 37, 1) was more important to people who share this viewpoint than to individuals with other perspectives, again highlighting the focus on clinical care and safety.

**Viewpoint 2. “Basic things, like kindness,” (ADRD caregivers).**

Viewpoint 2, defined by ten exemplars, represents the perspective of family and professional caregivers for people who have ADRD. Factor 2 had an eigenvalue of 7.7 and explained 11% of the total variance. Four of the participants holding this perspective

were LTSS professionals who work primarily with adults living with ADRD: a continuum of care campus administrator with a substantial proportion of residents with ADRD, a nursing home administrator, a memory care (assisted living) administrator who is also a nurse), and a registered nurse who works in an adult day program for people living with ADRD. Each of these professionals had considerable experience in LTSS, ranging from 20 to 40 years in the aging services field. Five family caregivers of people living with ADRD also shared this viewpoint, including the daughter of an 87-year-old woman living in the memory care unit of a large suburban assisted living facility, the wife of an 82-year-old man who participates in an adult day program for people with ADRD, the son of a 65-year-old woman with early-onset ADRD, the wife of a 66-year-old assisted living/residential care home resident also with early-onset ADRD, and the daughter of a 66-year-old woman who has cognitive impairment after experiencing a stroke. In addition, a 65-year-old woman who has lived in a rural nursing home for several years negatively loaded on this factor, meaning that her perspective was opposite from those who positively loaded on this factor. Interestingly, this woman has been very vocal about her need to be meaningfully involved in decisions and activities affecting the campus on which she lives.

Viewpoint 2 focuses on the needs of LTSS consumers who require services and supports primarily for cognitive reasons, rather than physical ones. Although physical needs may also be present, they are overshadowed by a person's cognitive limitations. To people who share this perspective, the emotional security of people who use LTSS is particularly important, perhaps because anxiety and depression are common in people with ADRD (Korczyn & Halperin, 2009; Seignourel, Kunik, Snow, Wilson, & Stanley,

2008; Winter, Korchounov, Zhukova & Bertschi, 2011). People sharing viewpoint 2 wanted to ensure that LTSS consumers are not anxious or depressed (item 40, 3), that they are calm and peaceful (item 41, 2), that they feel as though others care about them (item 27, 3) and that they are treated with kindness and respect (item 10, 3). People with ADRD may be more vulnerable to abuse and mistreatment because they are less able to protect themselves or tell others if they are being harmed. Therefore, ensuring that people using LTSS will not be hurt, yelled at, or intimidated by others (item 31, 3) and that they will receive assistance in a way so that they are not hurt or injured (item 32, 2) were also important.

The daughter of an 87-year-old woman with advanced ADRD explained her reason for prioritizing certain items related to her mother's care: "Everything is distilled to basic things now, like kindness," she told the researcher. Similarly, a woman whose husband living with early-onset ADRD recently moved to a residential care home commented: "Even though he can't talk anymore, he can feel. He knows how people are treating him." The administrator of a small assisted living that specializes in caring for people with ADRD echoed these statements. "Our residents can tell if they are being treated with kindness and respect. We can do everything better if they know we care about them," she said.

Other priority items in this perspective included receiving sufficient time and attention from staff (item 34, 2) and having good relationships with staff (item 24, 2). Interestingly, although most other factors viewed consistent staffing as relatively unimportant compared to other aspects of LTSS quality, consistent staffing was a high priority to individuals with this perspective (item 38, 3). The wife of the man with early-

onset dementia explained, “It’s important that they [staff] know him and know how he responds to things. I don’t know if he necessarily knows them, but they can just relate to him better if they’re consistent.” The assisted living administrator agreed:

Continuity of care for people with dementia is a basic [principal of dementia care]. Everything goes so much more smoothly when we know them and they know us. They might not remember exactly who we are, but we are familiar to them and we know their likes/dislikes and preferences. We know how to work with them.

For the nursing home resident who negatively loaded on this perspective, her reasons for being in the facility were primarily physical, rather than cognitive. In her interview with the researcher, she talked at length about feeling “at home” in the nursing home. She also discussed her need to be meaningfully connected with residents and staff, as well as her desire to be included in making decisions about her own care as well as activities taking place in the building. The primary differences between her rankings and those who positively loaded on this factor related to her focus on items related to Autonomy/Choice, as well as her emphasis on items related to Meaningful Activities and Social Inclusion.

Overall, items related to Autonomy/Choice, Activities/Inclusion, Relationships (particularly those external to the care setting), and Physical Environment tended to be ranked low by people with this perspective. Many participants explained that the priorities for people with ADRD, particularly items related to Autonomy/Choice and Activities/Inclusion, were lower than they were for other people who use LTSS. Several participants commented that that being asked to make too many choices caused anxiety

or stress for people with ADRD, or that they were incapable of making decisions or participating in activities—particularly group activities—as they had in the past. A nurse who serves adults with ADRD through an adult day program noted: “Some of these [items], because they have dementia, just aren’t important anymore. It’s such a changing journey with this disease.”

**Viewpoint 3. “I may need some help, but I demand respect.”**

Viewpoint 3, defined by 11 exemplars, represented the perspectives of individuals who are relatively independent and who use or identify with LTSS provided in assisted living facilities. This viewpoint had an eigenvalue of 6.3 and explained 9% of the variance. Nine of the people associated with this factor were LTSS consumers (eight of whom lived in assisted living facilities and a nursing home resident with a large private room who told the researcher she was living in assisted living). The other two exemplars, who had the lowest loadings on the factor (but still statistically significant at the 0.01 level), included the daughter of a 96-year-old woman who moved to a high-end assisted living facility six months ago and the administrator of a well-respected continuum of care campus in a rural community, which included nursing home, assisted living, memory care (also assisted living), and low-income independent senior housing with services.

In Viewpoint 3, priority is placed on the quality of care provided by staff. Receiving help from skilled and competent personnel (item 36, 3), being free of pain or other physical discomfort (item 35, 3) and effective communication among staff (item 39, 2) are all important. However, other staff-related items, including receiving enough time and attention from staff (item 34, -2), consistent staffing (item 38, -1), and choosing one’s staff (Autonomy/Choice domain, item 4, -3) were not important. As a 71-year-old woman

who lives in a spacious assisted living apartment explained, “I don’t much care about what nurse comes in and helps me as long as they’re competent.” Despite wanting to be sure assistance is available when needed (item 30, 2), people who shared this viewpoint did not view themselves (or LTSS consumers in the case of the daughter and administrator) as vulnerable. They expressed confidence in demanding high-quality services and respect from staff. A 90-year-old male assisted living resident explained:

I don’t need to have a say in staff initially, but I want to have a say in whether I keep them. I demand respect. If you don’t treat me right, I’ll kick you out of here! [Pausing for a moment] Is it important for other people to do this for me, or is it my responsibility? This is my responsibility.

This group also seemed to reject the idea that congregate senior housing was a way of building social connections or accessing social support (Roy, Dube, Depres, Freitas, & Legare, 2018). They were not concerned about being lonely (item 25, -1), feeling connected to the people around them (item 28, -2), or having a sense of community where they live (item 29, -2). Similarly, they placed more emphasis on seeing their family and friends (item 21, 3) than on having their religious and spiritual needs met (item 44, -2) or someone to talk to when they had concerns or a bad day (item 45, -2). Several participants commented that, although religion or having someone to talk were important to them, they could handle these things themselves and did not need their LTSS provider involved in their religious/spiritual or relationship matters.

Perhaps because most assisted living facility residents must pay privately for their care (Polivka & Rill, 2015), which tends to be expensive, emphasis was also placed on items related to the Physical Environment and, specifically, how the environment

supported the person's independence and continued sense of dignity. A 94-year-old nursing home resident (who thought she was living in assisted living) told the researcher: "I swore years ago I wouldn't move in with my children... I said to them, you can help find a place for me to go, but I'm not moving in with you." She explained that she loathed the idea of being dependent on anyone, but particularly on her children. She also said that she wanted her own space, even if it was small.

People who shared this perspective placed high value on having a private room or apartment (item 47, 3), having a private bathroom (item 52, 3), living in a homelike environment (item 47, 2), and living in a place that is easy to get around (item 48, 2). The importance of the physical environment may have stood out in this perspective because most of the participants had sufficient resources to pay for services themselves. People whose LTSS is covered by Medicaid may not feel as justified in expecting nice physical space, particularly since Medicaid is known primarily a health insurance program, not a form of subsidized housing.

**Viewpoint 4. "Relatively independent, but still vulnerable," (protective).**

The fourth viewpoint, defined by six exemplars, had an eigenvalue of 4.9 and explained 7% of the variance. All the participants who loaded onto this factor were professionals, including two LTSS administrators/executives, two registered nurses (one of whom works primarily with older adults with severe mental illness), and two policy/regulatory/advocacy leaders. The LTSS administrators/executives both had experience working in multiple settings, including urban low-income senior housing with services. One of the administrators also had prior experience in a policy/advocacy-focused role. Both state personnel had positions that required overseeing and/or

advocating for the rights of LTSS consumers. Professional experience in the field of aging for people with this perspective ranged from several years to over 30 years.

Although this viewpoint shared some similarities with Viewpoints 1 and 2 (Viewpoint 1: medical model – LTSS professionals; Viewpoint 2: ADRD caregivers) there were some notable differences. In terms of similarities, being treated with kindness and respect (item 10, 3), receiving assistance in a way that allows the person to maintain their dignity and personal privacy (item 11, 3) and knowing that older adults who use LTSS will not be hurt, yelled at, or intimidated by others (item 31, 3) were all viewed as high priorities. However, in Viewpoint 4 there was greater emphasis on the personal autonomy and choice of older adults, and less on items related to the complex physical (Viewpoint 1) and cognitive (Viewpoint 2) needs of people who use LTSS.

In this perspective, LTSS consumers are viewed as relatively independent, while still requiring a certain level of support. A registered nurse who serves older adults in an adult day program commented: “They [program participants] are all pretty independent, so they want to do things themselves... People don’t think of themselves as vulnerable, but yet they are in some sense.”

Items viewed as more important in this perspective than in any other perspective included [consumers] being able to do things for themselves (item 5, 2), having enough to do/not being bored (item 14, 1) and eating the foods they like (item 21, 2). Interestingly, items related to staffing levels and staff competence were generally rated lower by professionals who shared this perspective than by other LTSS professionals. Consumers’ being able to control their own daily routines (item 1, 3) and feeling a sense of purpose in their lives (item 43, 3) were viewed as very important. Being independence and

maintaining a sense of personhood were seen as interconnected in this viewpoint. When asked why she prioritized people's ability to control their daily routines, a state policy/regulatory/ advocacy leader responded:

Control over routines and daily life choices shows the person they have control over their life, which validates a person.

**Viewpoint 5. “Staying connected, involved, and enjoying life.”**

Viewpoint 5, characterized by 8 exemplars, had an eigenvalue of 4.2 and explained 6% of the variance. Six of the eight participants who shared this perspective used LTSS themselves: four participants lived in the same urban low-income senior housing with services community; a 79-year-old woman who lived in her own home and received Medicaid HCBS waiver services through the state; and an 80-year-old female nursing home resident who has lived in the facility for five years and who lived in an assisted living facility previously. In addition, the wife of an 88-year-old man living with ADRD who participates in an adult day program, and a state program leader with a background in social work, shared this perspective. Three of the six LTSS consumers were African American and all the consumers who shared with this perspective participated in Medicaid.

The overarching emphasis of this viewpoint was on relationships, broader social engagement, and meaningful activities. More than the other factors, Viewpoint 5 faced externally and focused on staying engaged with life. Most of the consumers who shared this perspective were relatively independent, although the nursing home resident and LTSS consumer who received services in her own home both had mobility issues (one used a motorized wheelchair and the other used a walker). In this perspective, people

prioritized being able to do things they enjoy (Item 13, 3), seeing their family and friends when they wanted (Item 22, 3), having a sense of community where they live (Item 29, 3), staying connected and involved in the community (Item 19, 2), and feeling a sense of purpose in their lives (Item 43, 3). The woman who receives services in her own home explained that the sense of community she feels in her neighborhood is what keeps her from moving to a senior housing environment.

I love my neighborhood! My neighbors are wonderful. One drops by when I need it. He's a handyman, but much more than that. I do not want to leave this neighborhood, even more than I don't want to leave this house. [Pause] I did look into senior living places—I talked to my son and daughter about it—but I just couldn't imagine ever replacing the diversity and support here.

When describing why relationships and social engagement were important to her, the 80-year-old nursing home resident described how painful it was to be cut off from others, particularly they were involved in social activities and outings in the community. Being left out, particularly because of her physical limitations or because she lived in a nursing home, seemed to be a particularly hard part of her experiences with LTSS. She said,

When I moved here, I was told I could participate in any of the activities. I just [early today] tried to go to an activity in the assisted living [attached to the nursing home] and they told me I couldn't come in because the event was just for assisted living. Another time, I was trying to get on the bus to go on an outing and

someone yelled at me, “You can’t go. You belong in the nursing home!” That hurt a lot.

Although most of the items related to Autonomy/Choice were ranked low in Viewpoint 5 (6 items with 0 to -3 rankings), items related to healthcare decision-making were viewed as important (two items within the Autonomy/Choice domain). Participants said they wanted to make decisions about their healthcare (Item 8, 3) and choose their own doctor and other healthcare providers (Item 7, 2). Unlike Viewpoint 3, which represented the views of assisted living residents, having a private room (Item 47, -2) and having a private bathroom (Item 52, -1) were not nearly as important in this perspective. This may be, however, because most of the people who loaded on this factor had their own apartments or homes, so ensuring private space was not an issue.

**Viewpoint 6. “Avoiding an institution” (individualized care).**

The final viewpoint, defined by three exemplars (one of whom negatively loaded on the factor), had an eigenvalue of 3.5 and explained 5% of the variance. The two participants who positively loaded on the factor included the wife of a 90-year-old man with ADRD who, until recently, only used personal care assistant (PCA) services and family supports in his own home. He and his wife recently moved to an independent housing building on a suburban continuum of care campus, where they continue to purchase PCA services and can move to the campus’s assisted living building in the future if they need additional supports. The other participant who positively associated with this factor was a 78-year-old woman who lives in her own home with her adult son, who provides most of the caregiving support she needs. She also receives some volunteer and low-cost services organized through a local block nurse program. This participant

also spent a few months in a nursing home for rehabilitation after suffering a stroke a couple of years ago. The participant who negatively loaded on the factor was an 80-year-old man who lives in an urban low-income senior community. He described himself as extremely independent, only receiving occasional meals (perhaps for convenience and/or social connection than because of actual need) through the housing provider.

Items prioritized in this viewpoint suggest an individualized or person-centered view of LTSS. Comments made by the two women (a family member and a consumer) whose Q sorts positively loaded on this factor suggest that avoiding institutional care was a high priority to both families. The items that were prioritized similarly emphasized aspects of daily life that are often sacrificed when someone moves into a group residential care setting. Statements ranked highest in this perspective included being able to control their daily routines (item 1, 3), choosing the people who help them with their daily needs (item 4, 3 [which was ranked below 0 by all other perspectives]), receiving sufficient time and attention from the people who help them (item 34, 3), receiving care or support from the same people over time (item 38, 3), and living in a place designed to allow the person to be as independent as possible (item 49, 3). Having someone to talk to about concerns or problems (item 45, 2) and having one's religious or spiritual needs met (item 44, 2) were viewed as more important to this group than to others (Viewpoint 5 similarly ranked the religious/spiritual needs item as 2).

Items related to engagement with the outside world, meals and food, and choosing their healthcare providers were viewed as less important in this perspective than other aspects of quality, perhaps because of substantial family involvement. In addition, because daily family support was present for those with this perspective, being treated

with kindness and respect by the people who help them (item 10, -2) may be less important than it was for individuals who shared other perspectives.

### **Chapter Summary**

This chapter described the use of Q sort methodology to explore stakeholder priorities for LTSS quality. Non-parametric Kruskal-Wallis tests showed statistically significant differences in the priorities identified by stakeholder groups for four of nine quality domains. For stakeholders combined, items related to Dignity/Respect, Safety/Security, and Staffing/Staff Competence were assessed as being the most important. Items related to Dignity/Respect and Safety/Security were ranked lower by consumers than other stakeholder groups, whereas items related to the Physical Environment and Activities/Social Inclusion were ranked higher by consumers than others. Notably, consumers ranked the Physical Environment as the second most important domain and professionals ranked the Environment as the second lowest.

Although there were some items that were viewed as higher or lower priorities by most participants, by-person factor analysis revealed six distinct viewpoints or perspectives on LTSS quality. Two of the viewpoints represented the perspectives of LTSS professionals; one viewpoint represented the viewpoint of ADRD family and professional caregivers; and three viewpoints primarily represented the perspectives of LTSS consumers. Although there were similarities in the values expressed by several perspectives (see Appendix I for correlations between perspectives), there were no consensus statements between the six viewpoints.

## **Chapter 5. Survey Results**

This chapter presents results of Phase 3 of the study, which involved a multi-mode survey implemented with the five targeted stakeholder groups: consumers, family members, LTSS administrators/executives, LTSS nursing leaders, and state policy/regulatory/advocacy personnel. The survey was designed to examine aspects of LTSS key stakeholders viewed as the most important and determine whether differences existed in the priorities articulated by different stakeholder groups. The survey included two main questions (see Chapter 3 for more details on the survey design, and Appendix E for a copy of the survey instrument), which asked respondents to:

- 1) Rate 50 items related to various aspects of LTSS quality of care and quality of life in terms of their importance; and
- 2) Select the three most important domains out of nine domains of quality LTSS provider organizations should prioritize.

Participants were also asked to provide basic demographic information and given the opportunity to comment on the reasons for their responses or to add any other information that they wanted to share about their experiences with LTSS, their views on priorities for LTSS quality, or anything else they wanted to share.

### **Survey Response and Missing Data**

The individuals who participated in Phase 2 (Q sort) and Phase 3 (survey) were independent, with the exception of two family members and six members of the policy, regulatory, and advocacy group who participated in both study phases. Response rates were not always possible to ascertain but ranged from 22% to 95% depending on the stakeholder group and recruitment strategy (see Appendix K for more detail on response

rates). For the online survey, 326 people completed the initial triage question and 257 completed at least one rating question. Twenty-two individuals did not fit into one of the targeted stakeholder groups and were screened out of the online survey. In addition to online responses, paper versions of the survey were returned by 164 individuals. One of the returned surveys was blank and three included unusable responses, leaving a total of 417 usable surveys for the analysis.

For the rating question, survey attrition followed normal patterns: 417 respondents completed the first rating section (Autonomy/Choice) and 402 (96.4% of respondents) completed the last rating section (Physical Environment). Other than participant dropout, missing data for the rating question (such as a single unanswered question within a section, or a skipped section) appeared to be randomly distributed. The ranking question was more problematic, however, particularly in the self-administered paper-pencil version of the survey. Whereas 94.5% of policy/regulatory/ advocacy group participants (34 of 36 respondents), 94.3% of family participants (83 of 88 respondents), and 90% of administrators/executives (85 of 93 respondents) completed the ranking question, only 83.3% of nurses (50 of 60 respondents), and 76.4% of consumers (107 of 140 respondents) completed the question or provided responses that could be used for analysis. A number of participants, particularly in the consumer group, selected more than three domains as most important, so their responses were unusable for analysis. The question format only posed problems on the paper version of the survey since the online survey platform had functionality that prevented respondents from selecting more than three domains. There were no differences between consumers who completed the ranking question and those who did not (or who provided responses that were unusable) in terms

of mean age (80.3 years versus 77.4 years;  $p=0.19$ ), proportion male (0.32 versus 0.27;  $p=0.62$ ), or proportion receiving LTSS in a residential versus non-residential setting (0.50 versus 0.52;  $p=0.84$ ).

### **Description of the Sample**

Table 9 presents demographic information for the 417 survey participants. The sample included 140 consumers; 88 family members; 93 LTSS administrators/executives; 60 registered nurses; and 36 state policy, regulatory and advocacy leaders. Overall, the majority of participants were women ( $n=287$ , 68.8% female;  $n=115$ , 27.6% male;  $n=15$ , 3.6% left item blank). Of the 408 respondents who reported their race, the majority (90.9%) were white. For the consumer group, the mean age was 77.6 years ( $SD=11.0$ ; range=55-98 years). Two-thirds (66.2%) of consumer participants lived in urban or suburban/mid-sized regions of the state and most (72.1%) reported that they used LTSS in a residential care setting, such as a housing with services building (47.1%), an assisted living facility (14.3%), or a nursing home (10.7%). The majority of consumers (67.1%) reporting using LTSS for at least one year and 14.3% indicated they had not yet used formal LTSS. All of these respondents had other experience with LTSS, such as with a family member, and many relied on informal supports provided by family and/or friends.

For family participants, there were more adult children (62.2%) than spouses (22.2%) or other family respondents such as siblings or grandchildren (15.6%). The average age of family participants' relative who used LTSS was 84.6 years ( $SD=9.1$ ; range=60-100 years). Most family respondents indicated that their relative used LTSS in an assisted living (57.8%) or a nursing home (27.8%). The majority of family participants

**Table 9. Survey Participants (n=417)**

Descriptive variable	Stakeholder group				
	Consumer (n=140)	Family (n=88)	Admin (n=93)	Nurse (n=60)	Policy (n=36)
<i>Background characteristics</i>					
Consumer age	M: 77.6 SD: 11.0	M: 84.6* SD: 9.1	NA	NA	NA
Female	69.3%	60.2%	62.8%	96.7%	75.0%
White race (respondent)	90.3%	97.6%	97.6%	95.1%	97.2%
Widowed (consumer)	51.5%	56.5%	NA	NA	NA
ADRD**	NA	64.7%	16.0%	19.7%	11.1%
<i>Geography</i>					
Rural	33.8%	17.6%	36.0%	57.1%	31.4%
Suburban/mid-sized	28.1%	56.5%	25.6%	25.0%	14.3%
Urban	38.1%	25.9%	38.4%	17.9%	54.3%
<i>LTSS setting</i>					
Home/apartment	27.9%	11.1%	11.7%	11.5%	NA
Housing w/ services	47.1%	3.3%	3.2%	0%	NA
Assisted living	14.3%	57.8%	24.5%	13.1%	NA
Nursing home	10.7%	27.8%	26.6%	57.4%	13.9%
Multi-setting/other	NA	NA	34.0%	18.0%	86.1%
<i>Length of consumer experience with LTSS</i>					
No formal LTSS	14.3%	NA	NA	NA	NA
Less than 1 year	18.6%	37.6%	NA	NA	NA
1-3 years	32.1%	35.4%	NA	NA	NA
More 3 years	35.0%	27.2%	NA	NA	NA
<i>Length of professional experience in LTSS</i>					
Less than 3 years	NA	NA	7.4%	3.3%	2.8%
3-10 years	NA	NA	23.4%	16.4%	16.6%
11-20 years	NA	NA	21.3%	31.1%	30.6%
More than 20 years	NA	NA	47.9%	49.2%	50.0%

\* Mean consumer age (not the age of the participating family member)

\*\* Family members whose relative had been diagnosed with ADRD; professionals who work primarily with people living with ADRD

ADRD=Alzheimer's disease or related disorders; AL=assisted living; LTSS=long-term services and supports; M=mean; SD=standard deviation

(82.4%) lived in an urban or suburban/mid-sized community and approximately two-thirds (64.7%) said their relative had been diagnosed with ADRD.

LTSS professionals had experience in a variety of settings, including individual homes (e.g., home care), low-income housing with services communities, assisted living facilities, and nursing homes. Many professionals indicated that they had experience working in various LTSS settings. Most administrators and nurses currently worked in assisted living facilities (24.5% of administrators; 13.1% of nurses), nursing homes (26.6% of administrators; 57.4% of nurses), or across multiple care settings (34% of administrators; 18% of nurses). The majority of state policy, regulatory, and advocacy leaders (86.1%) worked with programs or policies across the continuum of LTSS settings, although several worked primarily with nursing homes. Professionals had considerable experience with LTSS, with nearly half (48.7%) having more than 20 years of experience. Overall, 16.2% of professionals indicated they worked primarily with adults living with ADRD, or primarily with programs that served people with ADRD.

### **Mean Importance Ratings**

Respondents were asked to rate 50 items related to aspects of LTSS quality in terms of their importance. The items were presented to respondents in domains, with each domain consisting of 3-7 items. Construct validity of the domains and items was established through the literature review, environmental scan, and expert review previously described (Phase 1, described in Chapter 3). Internal consistency, estimated using Cronbach's alpha coefficient, was high, ranging from 0.87 to 0.92 per domain.

Respondents were asked to use an 11-point (0-10) scale to rate the importance of each item, with 0 representing "Not at all important" and 10 equaling "Critically

important.” There were concerns that ratings would be positively skewed (i.e., that there would be ceiling effects) leading to a lack of response variability (Masino & Lam, 2014). Therefore, language was added to the survey instructions encouraging respondents to “use the full rating scale, reserving the highest points for items viewed as most important.” As with the Q sort component of the study, the instructions for the rating question differed slightly by stakeholder role. Consumers were asked to rate items based on their opinion of each item’s importance to themselves and their overall wellbeing. Family members were asked to rate items based on their opinion of each item’s importance to their relative’s overall wellbeing. Professionals were asked their opinion about each item’s importance to the overall wellbeing of older adults who use LTSS.

Mean ratings and standard deviations for the combined items associated with each domain are presented in Table 10. (For a full list of items with mean ratings and standard deviations by stakeholder group, see Appendix L.) As expected, mean ratings for the groups combined were high, ranging from 7.72 to 9.10 per domain. Items related to Safety/Security were rated highest (9.10; SD: 1.22), followed by Dignity/Respect (8.87; SD: 1.49) and Staffing/Staff Competence (8.55; SD: 1.36). Items related to Autonomy/Choice (7.80; SD: 1.73) and Activities/Inclusion (7.72; SD: 1.60) were rated lowest.

One-way analysis of variance (ANOVA) tests were conducted to examine whether mean domain ratings differed between stakeholder groups. Differences of means were also tested using Kruskal-Wallis non-parametric tests. However, these results were consistent with the ANOVA findings; therefore, the ANOVA results are presented.

Statistically significant differences between group ratings were observed for eight of nine quality domains. To determine where differences in ratings existed, post-hoc

analyses were conducted with Bonferroni correction to account for multiple comparisons. Most of the differences observed were between consumers and professionals, with statistically significant differences between these groups for all domains except two: Physical Environment and Activities/Social Inclusion. Most of the differences observed between consumers and professionals involved the administrator and nursing groups. However, the policy group included fewer individuals, resulting in less power to detect possible differences.

Where significant differences existed, consumer ratings were *lower* than those of professionals. Consumer views also tended to be more varied, with larger standard deviations for ratings than those observed in other groups. Although no statistically significant differences were observed between consumer and professional ratings for Physical Environment, consumers rated this domain as the second most important and professionals rated it as second least important. Therefore, relative to their ratings of other domains, consumer and professional views on the importance of the Physical Environment differed. Consumer and family ratings were more similar than the views of consumers and professionals, with statistically significant differences in ratings observed for only three domains, all of which consumers rated lower than families. These domains included Safety/Security (consumer mean: 8.57 [SD: 1.54]; family mean: 9.14 [SD: 1.07];  $p \leq 0.01$ ), Dignity/Respect (consumer mean: 8.10 [SD: 2.07]; family mean: 9.17

**Table 10. Mean Stakeholder Ratings by Domain**

Quality domain	Stakeholder Group						F	p
	Overall (n=417)	Consumer (n=140)	Family (n=88)	Admin (n=93)	Nurse (n=60)	Policy (n=36)		
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
Safety/security	9.10 (1.22)	8.57 (1.54)	9.14** (1.07)	9.49*** (0.87)	9.48*** (0.68)	9.51*** (0.67)	12.63	<0.0001
Dignity/respect	8.87 (1.49)	8.10 (2.07)	9.19*** (0.99)	9.28*** (0.83)	9.31*** (0.80)	9.24*** (0.83)	15.60	<0.0001
Staffing & staff competence	8.55 (1.36)	8.06 (1.58)	8.68** (1.29)	8.82*** (1.13)	8.97*** (1.02)	8.67 (1.09)	7.29	<0.0001
Relationships	8.42 (1.41)	8.00 (1.59)	8.43 (1.51)	8.73 (1.11)	8.82 (1.09)	8.69 (1.06)	6.02	<0.0001
Physical environment	8.29 (1.37)	8.38 (1.46)	8.18 (1.45)	8.26 (1.27)	8.30 (1.20)	8.27 (1.29)	0.29	0.99
Emotional/spiritual Wellbeing	8.22 (1.53)	7.89 (1.79)	8.11 (1.53)	8.50* (1.25)	8.69** (1.20)	8.29 (1.34)	3.83	0.007
Meals & food	8.08 (1.67)	7.54 (2.00)	8.07 (1.50)	8.46*** (1.30)	8.63*** (1.35)	8.40* (1.35)	7.13	<0.0001
Autonomy/choice	7.80 (1.73)	7.51 (2.06)	7.02 (1.73)	8.28***§ (1.29)	8.32*§ (1.16)	8.69***§ (1.02)	12.07	<0.0001
Activities/inclusion	7.72 (1.60)	7.62 (1.69)	7.03 (1.81)	8.00§ (1.30)	8.26§ (1.30)	8.23§ (1.27)	7.92	<0.0001

Group mean significantly different than consumer mean (Bonferroni corrected): \*=p≤0.05, \*\*=p≤0.01, \*\*\*=p≤0.001

Group mean significantly different than family mean: §=p<0.001

[SD: 0.99];  $p \leq 0.001$ ), and Staffing/Staff Competence (consumer mean: 8.06 [SD: 1.58]; family mean: 8.68 [SD: 1.29];  $p \leq 0.01$ ). There were two domains, Autonomy/Choice and Activities/Social Inclusion, for which family ratings differed from those of all three professional groups ( $p \leq 0.001$ ). There were no statistically significant differences between the three professional groups' ratings for any domain.

### **Domains Identified by Stakeholders as the Highest Priorities**

Survey respondents were also presented with a question that asked them to review the list of nine quality domains and select the three domains they viewed as the most important areas for LTSS providers to focus on. A brief description of each domain was provided (see Table 11). Importantly, the question respondents were asked differed from the question asked through the rating question. Rather than focusing on the importance of various aspects of LTSS quality to their own wellbeing, the wellbeing of their family member, or the wellbeing of LTSS consumers in general, respondents were asked to identify quality priorities for LTSS provider organizations. To reduce ordering effects, domains were presented to respondents in random order.

Overall, the same three domains were identified by respondents as the highest priorities as in the previous rating question, although the order of these domains differed from the previous question. Top domains included Dignity/Respect, which 262 of 359 (73%) of respondents ranked in the top three (confidence interval [CI]: 0.69, 0.78); Staffing/Staff Competence, which 183 of 359 (51%) of respondents selected (CI: 0.46, 0.56); and Safety/Security, which 158 of 359 (44%) of respondents selected as most important (CI: 0.39, 0.49). For groups combined, Emotional/Spiritual Wellbeing, which 14% of respondents selected as a top priority (50 of 359), and Activities/Inclusion, which

11% of respondents chose (40 of 359), were viewed as the least important. (See Table 12 for a list of full results.)

**Table 11. Domain Descriptions Presented in Ranking Question**

Quality domain	Description
Autonomy/choice	Making decisions about daily routines, personal risks, personal space, and health care
Dignity/respect	Being treated with kindness and respect, maintaining personal dignity, having concerns taken seriously
Activities/inclusion	Having enjoyable and enough to do, remaining involved in the community to the extent desired
Meals & food	Having good food and enjoyable mealtimes
Relationships	Staying connected with family and friends, having good relationships with personnel, feeling cared about
Safety/security	Being safe from unnecessary harm, feeling secure
Staffing & staff competence	Receiving care by competent personnel, getting enough help
Emotional/spiritual wellbeing	Having one's emotional and spiritual needs met
Physical environment	Living in a supportive and comfortable environment, having adequate and private space

Pearson's chi-square test was used to examine whether the proportion of respondents in each stakeholder group who selected each domain as being in the top three in terms of importance differed. The ranking question revealed larger discrepancies in the quality priorities articulated by stakeholder groups than the rating question did, which was unsurprising given the question format. Statistically significant differences between

groups were observed for all domains except two: Safety/Security, which 44% of respondents overall selected as in the top three of importance ( $X^2=7.07$ ,  $p=0.13$ ); and Emotional/Spiritual Wellbeing, which 14% of respondents overall viewed as most important ( $X^2=7.21$ ;  $p=0.13$ ).

Although Dignity/Respect was most consistently selected by all stakeholders as a top priority, the proportion of respondents selecting this domain differed significantly by group (45 of 50 nurses [90%]; 72 of 83 family members [87%]; 68 of 85 administrators/executives [80%]; 23 of 34 members of the policy/regulatory/ advocacy group [68%]; and 57 of 107 consumers [53%];  $X^2=39.68$ ;  $p<0.0001$ ). Stakeholder views differed on the second most important aspect of quality. Whereas consumers selected Relationships (54 of 107 respondents [50%]) as the second most important domain, Families identified Staffing/Staff Competence (63 of 83 respondents [76%]), Nurses selected Safety/Security (29 of 50 [58%]), and members of the Administrator and Policy/Regulatory/Advocacy groups selected Autonomy/Choice (45 of 85 respondents, [53%]; and 21 of 34 respondents [62%] respectively).

As observed in the previous rating question, there was more variation in consumer views than those observed in other stakeholder groups. Only one domain, Activities/Inclusion, was selected by fewer than 20% of consumers as being a top priority (18%, 19 of 107 consumers). For other domains, between 21% and 53% of consumers identified that aspect of quality as being a top priority. Priorities articulated by families and professionals were more concentrated in four domains. For families, in addition to Dignity/ Respect (87%), top quality domains included Staffing/Staff Competence (76%), Safety/Security (43%), and Relationships (31%). For professionals, in addition to

**Table 12. Proportion of Respondents Ranking Domain in Top 3**

Quality domain	Stakeholder Group						$\chi^2$ (4Df)	p-value
	Overall (n=359)	Consumer (n=107)	Family (n=83)	Admin (n=85)	Nurse (n=50)	Policy (n=34)		
	Proportion (CI)	Proportion (CI)	Proportion (CI)	Proportion (CI)	Proportion (CI)	Proportion (CI)		
Dignity/respect	0.74 (0.69, 0.78)	0.53 (0.44, 0.63)	0.87 (0.77, 0.93)	0.80 (0.70, 0.87)	0.90 (0.78, 0.96)	0.68 (0.50, 0.82)	39.68	<0.0001***
Staffing/staff competence	0.51 (0.46, 0.56)	0.37 (0.29, 0.47)	0.76 (0.65, 0.84)	0.49 (0.39, 0.60)	0.44 (0.31, 0.58)	0.50 (0.33, 0.67)	29.61	<0.0001***
Safety/security	0.44 (0.39, 0.49)	0.37 (0.29, 0.47)	0.43 (0.33, 0.54)	0.42 (0.32, 0.53)	0.58 (0.44, 0.71)	0.53 (0.36, 0.70)	7.07	0.13
Autonomy/choice	0.36 (0.31, 0.41)	0.26 (0.19, 0.35)	0.13 (0.07, 0.23)	0.53 (0.42, 0.63)	0.50 (0.36, 0.64)	0.62 (0.44, 0.77)	47.64	<0.0001***
Relationships	0.36 (0.31, 0.41)	0.50 (0.40, 0.59)	0.31 (0.22, 0.42)	0.32 (0.23, 0.43)	0.20 (0.11, 0.34)	0.35 (0.21, 0.53)	15.56	0.004**
Meals & food	0.18 (0.14, 0.22)	0.28 (0.20, 0.37)	0.12 (0.07, 0.21)	0.15 (0.09, 0.25)	0.14 (0.07, 0.27)	0.09 (0.03, 0.25)	12.39	0.015*
Physical environment	0.16 (0.13, 0.20)	0.29 (0.21, 0.38)	0.12 (0.07, 0.21)	0.13 (0.07, 0.22)	0.06 (0.02, 0.18)	0.09 (0.03, 0.25)	19.81	0.001***
Emotional/spiritual wellbeing	0.14 (0.11, 0.18)	0.21 (0.15, 0.30)	0.11 (0.06, 0.20)	0.09 (0.05, 0.18)	0.14 (0.07, 0.27)	0.12 (0.04, 0.29)	7.21	0.13
Activities/inclusion	0.11 (0.08, 0.15)	0.18 (0.12, 0.26)	0.14 (0.08, 0.24)	0.06 (0.02, 0.14)	0.04 (0.01, 0.15)	0.03 (0.00, 0.20)	13.17	0.01**

\*p≤0.05; \*\* p≤0.01; \*\*\*p≤0.001

Admin=administrator/executive; CI=confidence interval; Df=degrees of freedom

Dignity/Respect (80.5%), all three professional groups prioritized Staffing/Staff Competence (44% to 50%), Safety/Security (42% to 58%), and Autonomy/Choice (50% to 62%) over other aspects of quality.

The Physical Environment, which was rated the second most important domain by consumers in the previous rating question, was selected by less than one-third of consumers (29%, 31 of 107 respondents) as being a top priority in the ranking question. Still, the proportion of consumers selecting the environmental domain remained significantly higher than the proportion of other stakeholders selecting this domain, which ranged from 6% to 13% per group ( $X^2=19.81$ ;  $p=0.001$ ). Importantly, consumers and families viewed items related to Autonomy/Choice as substantially less important than professionals did (26% of consumers and 13% of families selected this domain as most important compared to 50% of nurses, 53% of administrators, and 62% of policy/regulatory/advocacy leaders) ( $X^2=47.64$ ;  $p<0.0001$ ).

### **Secondary Analyses Based on Domain Ratings**

Several additional analyses were conducted to determine whether differences existed in stakeholder ratings of quality domains based on several factors. First, two-way analysis of variance (two-way ANOVA) was used to examine whether differences existed in stakeholder ratings based on LTSS setting. The analysis explored the effects of two independent variables (stakeholder role, LTSS setting) on ratings and whether an interaction of role and setting existed. LTSS settings included nursing homes, assisted living facilities, housing with services communities, home/independent settings, and continuum of care/multiple settings. No significant effects for LTSS setting or for the

interaction of stakeholder role and setting were observed. In a second model, the number of settings was reduced to two: residential versus non-residential. Again, no significant differences were observed.

Because family and professional caregivers of adults living with ADRD demonstrated a unique perspective on LTSS quality priorities in Phase 2 (Q sort Viewpoint 2), another two-way ANOVA model explored whether domain ratings for family and professional caregivers of adults with ADRD differed from other family members and professionals. No significant differences in ratings at the domain level were found. However, it is important to note that several of the items were slightly reworded between Phases 2 and 3 to include language indicating that choices or decisions could be made either “by myself or with someone I designate or include,” which could explain why the views of survey participants who were ADRD caregivers did not differ from other family and professional caregivers.

Two final analyses examined whether consumer ratings differed based on their gender or length of time using LTSS. For these comparisons, two-sample t-tests were used. First, domain-level ratings were compared for women (n=97) versus men (n=43). Statistically significant differences were found for two domains, both of which women rated higher than men: Relationships (women’s mean rating: 8.20 [CI: 7.91, 8.49]; men’s mean rating: 7.56 [CI: 6.99, 8.12]; p=0.02) and Emotional/Spiritual Wellbeing (women’s mean rating: 8.17 [CI: 7.85, 8.48]; men’s mean rating: 7.32 [CI: 6.66, 8.00]; p=0.01). Second, domain ratings were compared for consumers based on whether they had one year or less of experience with LTSS (including no experience yet with formal LTSS)

(n=46) versus more than one year of experience (n=94). No statistically significant differences were observed.

### **Responses to Open-Ended Questions**

Following the ranking question, respondents were asked if they had any comments about the aspects of LTSS quality they selected as most important or if they had any additional feedback or comments about LTSS that they wanted to share. Several respondents, including several family members and older adults who had not yet used formal LTSS, indicated that every aspect of LTSS quality was equally important and that priorities should not need to be made. Other participants commented that the priorities they selected represented aspects of quality they viewed as more fundamental or all-encompassing than other aspects. These comments tended to focus on the importance of two domains: Dignity/Respect and Staffing/Staff Competence.

Family respondents seemed especially clear about these two priorities. Respondents who had relative living with ADRD were particularly articulate about the importance of people being treated with dignity and respect regardless of a person's physical or cognitive abilities. An 85-year-old woman who lives with her son and daughter-in-law and who had experienced LTSS previously with her husband who died with ADRD wrote, "Everything starts with dignity and respect, which is so important, particularly when someone has a condition like dementia where they're not fully themselves anymore." Similarly, the daughter of a 65-year-old female assisted living resident said, "I think that dignity and respect are critical. People with cognitive and/or physical limitations deserve just as much dignity and respect as anyone else. It creates an

environment of trust.” The wife of an 80-year-old male assisted living facility resident likewise commented, “If dignity and respect are given, the other items will most likely fall into place.”

Many respondents described Safety/Security and Dignity/Respect as corollaries of or Staffing/Staff Competence. A 76-year-old male nursing home resident wrote, “If staff are competent, then safety and security shouldn’t be a concern, nor should dignity and respect.” The daughter of a 95-year-old female nursing home resident explained:

With competent, respectful caregivers who listen and validate feelings—provide appropriate, adequate, purposeful activities to maintain quality of life at whatever level the senior—the color of paint or shared bathroom or soggy broccoli is less important.

Challenges related to workforce issues—low staffing levels and high rates of staff turnover in LTSS—were also commonly discussed themes, particularly for family members. The daughter of an 87-year-old male assisted living facility resident wrote, “Longevity and happiness of staff in a facility are important. Frequent staff turnover is disruptive when residents need to feel safe and bonded with employees in a facility.” A number of respondents—consumers and families—described needing to wait too long for assistance (e.g., getting to the bathroom, help returning to one’s room after an activity, etc.). The daughter of a 65-year-old female memory care resident wrote, “It would be helpful to have better staffing for all units, especially memory care units. It feels like there is never enough staff to meet everyone’s needs.”

LTSS administrators and executives often described facing considerable financial constraints in their ability to offer consumers and families the level of high-quality care they wanted to provide. Several also noted that consumer and family expectations are at times unrealistic given the resources available. Some also alluded to new federal regulations that require LTSS organizations to provide individualized (person-centered) services to the people they serve. An experienced nursing home administrator wrote,

Wanting high quality is everyone's desire. It does increase the cost of services, however... There is a difference between what people need, want, or desire. What will only be paid for and by whom should be discussed. If every resident in my facility wanted a bath/shower every day, 7 days a week, we would not be able to deliver due to the labor shortage and costs associated with it. Do we get cited [by the state/federal regulators] for not delivering person-centered care?

The administrator of a continuum of care campus similarly wrote, "All of the items previously listed are very/critically important in a perfect world. In a world of one. It is financially unaffordable to provide these "individualized services" for most Americans." Another campus administrator said, "Unrealistic expectations given the financial reality is something that I deal with each week."

Numerous older adult respondents described a need for more and better transportation options. A couple of family respondents and two professionals described the importance of addressing the social isolation faced by many older adults. (Two older adults who commented on being lonely said loneliness was what they expected at this

stage in their lives. Both were widowed.) Several family members talked about a tension between respecting their loved one's preference to "isolate themselves" (i.e., because of depression or cognitive decline, etc.) and the family's desire to ensure that their relative remained socially engaged such as by participating in social outings and group activities.

Finally, several respondents across stakeholder groups discussed other problems or issues they had experienced with the LTSS "system." Issues raised included a lack of awareness and/or good communication from medical providers to consumers and families about LTSS options, a need for more transparency and government oversight of assisted living facilities, the negative perception held by many people of assisted living and nursing homes, and (according to several LTSS providers and nursing leaders) the need for fewer "rules and regulations," which they described as detracting from time and resources that could be spent on resident care, especially in nursing homes.

### **Chapter Summary**

This chapter presented results of survey implemented with consumers, families, and LTSS professionals to determine which aspects of LTSS quality participants viewed as most important. A total of 417 individuals representing the targeted stakeholder groups participated. The survey included rating, ranking, and open-ended questions. Across rating and ranking question formats, stakeholders identified Dignity/Respect, Safety/Security, and Staffing/Staff Competence as the most important. The lowest priorities identified by stakeholders included Autonomy/Choice and Inclusion/Activities for the rating question, whereas Emotional and Spiritual Wellbeing and Inclusion/Activities were identified as lowest priorities in the ranking question.

Although there was considerable agreement on the highest and lowest priorities for LTSS quality, some differences in stakeholder perspectives were observed. Consumers rated most aspects of LTSS quality as less important than families and professionals. Compared to other aspects of quality, consumers viewed the Physical Environment as a high priority, whereas professionals viewed this domain as considerably less important. In response to open-ended questions, participants focused on why they viewed certain aspects of quality as being the highest priorities, particularly Staffing/Staff Competence and Dignity/Respect. Comments also focused on challenges associated with workforce shortages and financial challenges facing LTSS providers.

## **Chapter 6. Discussion**

This study examined stakeholders' perspectives on the importance of nine domains of quality in LTSS, including aspects of quality traditionally considered quality of care and quality of life. Two research methods were used to elicit stakeholder values related to quality in LTSS: 1) Q methodology, which integrates qualitative and quantitative approaches, and 2) a traditional survey method that involved rating, ranking, and open-ended questions. Overall stakeholder priorities and differences in the priorities articulated by different stakeholders were examined using a convenience sample of 481 individuals in Minnesota representing consumer, family, and professional groups. Participants had experience using, delivering, and/or overseeing LTSS in various settings, including nursing homes, assisted living facilities, and various community-based settings.

This chapter begins with a discussion and interpretation of study findings. Then, the implications of the study for policy and practice are discussed. Finally, limitations of the study conclude this section.

### **Highest LTSS Quality Priorities: Dignity, Safety, and Staff**

Across two study components, stakeholders identified three domains of quality as the most important: Dignity/Respect, Safety/Security, and Staffing/Staff Competence. Although some differences in the relative importance of these domains were found across groups and methods based on the data obtained and analyzed, study participants consistently prioritized these quality attributes, adding to the robustness of this finding. Comments made by participants as they completed their Q sorts (Phase 2) and written comments made by survey participants (Phase 3) provide insights into why participants

prioritized these three domains over other aspects of LTSS quality. Family members and professionals often described Dignity/Respect as a basic human right that should be guaranteed to everyone, including people who use LTSS. The highest ranked item in both the Q sort and survey related to LTSS consumers being treated with kindness and respect by personnel (Dignity/Respect domain). Although consumer participants also viewed Dignity/Respect as important, many said they were confident in their ability to “stand up for themselves,” or demand that others treat them with respect. Family and professional participants, on the other hand, focused on the vulnerability of older adults who use LTSS, particularly those who are living with ADRD.

An important consideration in interpreting these findings is that over half of family participants indicated that their family member had been diagnosed with ADRD, whereas none of the consumers who participated in this study were identified as having cognitive impairment. Therefore, those consumers who participated in this study may feel—and be—better able to advocate for themselves than other older adults who use LTSS. This sampling issue may have influenced participant responses. Although relatively little is known about how quality of life differs for LTSS consumers who are living with ADRD versus other LTSS consumers (Abrahamson, Clark, Perkins & Arling, 2012; Shippee, et al., 2013), being treated with kindness and respect may have heightened importance for individuals who experience cognitive impairment (Williams, Hyer, Kelly, Leger-Krall, & Tappen, 2005). Additionally, compared to consumers themselves, family members may be more focused on the way their loved ones are

treated because of a sense of responsibility for their family member's wellbeing (Koplow, Gallo, Knafl, Vincent, Paun, & Gruss, 2015).

**Valuing the interrelationship of quality attributes.**

Numerous respondents reflected on the interrelationship of the top three quality domains. Several survey respondents commented, for example, that safety and security related to older adults being treated with dignity and respect, as well as having competent staff and appropriate staffing levels. Family members and professionals often described dignity and respect as an aspect of staff competence. Several family participants even said that staff members' interpersonal skills, such as communicating effectively or treating their family member with kindness, were more important than the technical or clinical skills staff had. Several participants commented that the realization of other attributes of LTSS quality depended on first achieving goals related to the top three domains. Food and Meal Enjoyment, Meaningful Activities, and Social Inclusion were often described as corollaries of Dignity/Respect and Staffing/Staff Competence. Autonomy/Choice, a domain that stakeholders viewed as being a lower priority than many other aspects of LTSS quality, was described by some participants as an outcome of Dignity/Respect. For example, in a follow-up discussion of study results with LTSS providers, a nursing home administrator commented that if older adults are respected, their family and professional caregivers will solicit their opinions and do their best to ensure that the person's wishes are respected.

### **The LTSS workforce: fundamental to service quality.**

Many consumer and family participants said that staffing-related issues are especially critical to the effectively delivery of LTSS. Many participants noted that staff turnover negatively impacted consumers' and families' experience with care. High rates of staff turnover in LTSS have been well documented (Donoghue, 2010; Ejaz, et al., 2015) and shown to negatively affect consumer and organizational outcomes (Castle & Anderson, 2011; Lerner, Johantgen, Trinkoff, Storr, & Han, 2014; Thomas, Mor, Tyler, & Hyer, 2012; Tilden, Thompson, Gajewski, & Bott, 2012). Consumer participants who received services in nursing homes and assisted living facilities often said that having *consistent* staff was relatively unimportant if staff were competent. However, those consumers who received services in their own homes often placed higher value on consistent staffing, and numerous family and professional participants suggested that having consistent staff was especially critical to ensure high quality care for individuals living with ADRD. Although research on the effects of consistent staffing on consumer outcomes in LTSS has been inconclusive (Roberts, Nolet, & Bowers, 2013), consistent staff assignment has been promoted by leading quality and advocacy organizations (Gilster, Boltz, & Dalessandro, 2018) and associated with increased job satisfaction among home care workers (Stone et al., 2016).

Despite federal regulations related to appropriate staffing levels in LTSS, numerous consumer and family participants described the negative impact of low staffing levels on their experience with LTSS, a finding consistent with prior research on staffing and LTSS quality (Castle, 2008; Kane, Shamllyan, Mueller, Duval, & Wilt, 2007;

Schnelle, et al., 2004). In this study, several consumers and family members described needing to wait considerable amounts of time for assistance with basic daily activities, such as using the bathroom or getting out of bed. Several family members said that low staffing levels in assisted living memory care contributed to their loved one being alone for long periods of time without interacting with staff or other residents. Especially if an individual has incontinence, waiting for assistance can negatively affect a person's sense of dignity (Xu & Kane, 2013).

Many participants also described low staffing levels as a safety issue. The son of a memory care resident described finding his mother with her face nearly submerged in a bowl of soup at the dinner table in her assisted living facility. Several family members said they worried that a staff member or another resident would hurt or intimidate their loved one because there was insufficient staff or administrative oversight in the facility. In discussions with stakeholders about the study's findings, LTSS administrators often described financial constraints as an obstacle to increasing staffing levels. Recent changes related to the reporting of nursing home staffing data to the federal government have confirmed that many facilities across the U.S. have been staffing at considerably lower levels than what is needed to ensure high quality care (Rau, 2018). In addition, there are efforts taking place in Minnesota to develop standards and requirements related to staffing in the assisted living sector (personal communication, participation in Residential Services Subcommittee, Alzheimer's Disease Workgroup, spring/summer, 2018).

### **Consumer safety: A public concern.**

Safety and security were viewed by stakeholders as vital to the emotional and physical wellbeing of older adults who use LTSS. Safety/Security was often described as important to both the present wellbeing of LTSS consumers, as well as to prevent individuals' increased loss of wellbeing and independence (Nieboer, Koolman, & Stolk, 2010). This may explain the study's finding that Safety/Security was consistently viewed by stakeholders as more important than Autonomy/Choice. As discussed previously, there is a long history in the U.S. of mistreatment and neglect of vulnerable adults in institutional settings (Castle, Ferguson-Rome, & Teresi, 2015; Lachs & Pillemer, 2015; Malmedal, et al., 2015). This history and ongoing cases of abuse and neglect likely compound people's fears about LTSS.

Toward the end of data collection for the study, a five-part series exposing cases of elder abuse, neglect, and mistreatment in Minnesota "senior care homes" (assisted living facilities and nursing homes) and the state's inadequate response was published in the *Minneapolis Star Tribune* in November of 2017 (Serres, 2017). Less than a year earlier, CNN had similarly profiled several dramatic cases of sexual assault against Minnesota assisted living and nursing home residents (Ellis & Hicken, 2017). In addition to setting off a statewide response, these media exposés heighten already existing anxieties surrounding LTSS, particularly in residential settings. It is likely that concerns surrounding safety and security will take even more precedence in the future, particularly in assisted living facilities, which have historically been much less regulated than nursing homes. Recently, a state-appointed work group examined steps needed to improve

services and supports for individuals with ADRD in Minnesota, including LTSS in residential care settings. Safety concerns have been central in many of these discussions (personal communication, participation in Residential Services Subcommittee, spring/summer, 2018).

### **Lower Quality Priorities: Autonomy/Choice and Activities/Inclusion**

In general, stakeholders rated items related to Autonomy/Choice and Meaningful Activities/Social Inclusion as lower priorities than other aspects of LTSS quality. The Q sort (Phase 2) and survey (Phase 3) included seven items related to Autonomy/Choice, including items related to a person's control over their daily routines, being able to make decisions about one's life even if other people disagree with those choices, choice over where one receives LTSS, and health care decision-making. Similarly, seven items related to activities and social inclusion were included. These items involved being able to do things one finds enjoyable, having enough to do, going out to eat or out shopping, and participating in public forums or other community events.

In Phase 2 (Q sort), stakeholders overall ranked items related to autonomy/choice sixth out of nine quality domains. In the Phase 3 survey rating question, autonomy/choice-related items were rated eighth of nine domains. For the final survey ranking question, in which respondents were asked to select the three domains of quality they thought were the most important priorities for LTSS organizations (versus important to the wellbeing of consumers), stakeholders placed slightly more emphasis on Autonomy/Choice, as it was the fourth most consistently selected quality priority by stakeholders. Items related to Meaningful Activities/Social Inclusion were consistently

rated last by stakeholders across all three question formats (Q sort, survey rating, and survey ranking questions). The low performance of these domains was somewhat surprising given current policy initiatives and emphasis that consumer advocates have placed on these aspects of consumer quality of life (Kaye & Williamson, 2014; Lin & Lewis, 2015; Scharlach & Lehning, 2013; Sciegai, et al., 2016).

**Consumers and families valued autonomy/choice less than professionals.**

Consumers and family members viewed Autonomy/Choice as less important than professionals did across all three question formats. Consumer and family participants ranked items related to Autonomy/Choice *lowest* in both the Q sort and survey rating question, and only slightly higher in the ranking question. Compared to consumers and families, members of the policy/regulatory/advocacy group in particular viewed Autonomy/Choice as a considerably more important priority for LTSS providers, selecting this domain as the third most important domain in the ranking question. The heightened focus on consumer choice by policy/regulatory/advocacy leaders could reflect the influence of current policy initiatives focused on increasing the self-determination of LTSS consumers, such as self-directed LTSS programs (Kaye & Williamson, 2014) and new regulations designed to promote person-centered practices in the delivery of LTSS (Stevenson, 2018). These types of policy discussions regarding consumer choice are relatively recent and it may take some time before consumers, families, and LTSS professionals place more value on choice in LTSS. In addition, the concept of autonomy is extremely complex and may be considerably more difficult to measure than other aspects of LTSS quality. Unlike other attributes of LTSS quality, which may be easier to

measure at the service level, autonomy operates more broadly in a person's life. For example, the majority of older adults have been fairly autonomous throughout their adult lives and may accept some diminished choice in their later years, particularly when needing LTSS.

**Specific concerns related to autonomy/choice.**

During the Q sort component of the study and in follow-up discussions with stakeholder groups about survey results, family members and professionals frequently expressed the opinion that giving LTSS consumers “too much” choice can put undue pressure on vulnerable older adults, particularly those who are already under cognitive and/or emotional stress. Stakeholders made similar comments about several items related to activities/social inclusion, especially items related to doing things in the community or participating in public events. These comments were strongest for family and professional caregivers of people living with ADRD.

Related to both choice and activities, several family members and professionals expressed concern about older adults making decisions that are “unsafe,” such as driving with cognitive impairment or eating unhealthy foods with certain health conditions. Nurses seemed particularly attuned to issues of consumer safety. The differing opinions between consumers/families and professionals on the relative importance of consumer choice suggest the need for more dialogue among stakeholders, particularly related to the tension between autonomy/choice and safety/security (House & Howe, 1999; Kane & Kane, 2015; Moye & Braun, 2010). Greater dialogue between stakeholders could also clarify whether consumers and families place lower importance on choice because they

truly view it as less important than other aspects of LTSS quality, or if there are other reasons for their lower ratings of this domain, such as perceptions of limited options, or safety fears that could be mitigated with sufficient supports.

### **Differences in Stakeholder Perspectives**

In addition to the lower priority placed on Autonomy/Choice by consumers and families compared to professionals, several additional differences in stakeholder perspectives on LTSS quality were observed. The first was that priorities articulated by the consumer group were distributed more equitably across the nine quality domains than the views of other stakeholders. In the Q sort component of the study, which used a forced distribution, the difference between highest and lowest domains in the consumer group was only 0.67 points, whereas the difference between the highest and lowest domains for other groups ranged from 1.8 to 2.4 points. Similarly, for the survey rating question, mean domain ratings for consumers ranged from 8.57 to 7.62, a difference of only 0.95 points, whereas differences between the highest and lowest mean ratings for other groups ranged from 1.22 points to 2.11 points. Finally, for the survey ranking question, the percentage of consumers who selected each domain as being a “top three” priority ranged from 18% to 53% compared to a range of 14% to 87% per domain for families, and 4% to 90% per domain for nurses. Similarly, larger standard deviations were observed for consumer ratings than for the ratings of other groups.

These findings likely demonstrate that the views of consumers are more unique to the individual, as would be expected. They may also suggest that consumers more carefully balance tradeoffs than other stakeholders when making decisions about quality

priorities or goals for LTSS. This seems consistent with the reality that LTSS often affects nearly every aspect of a person's daily life (Kane, Kane & Ladd, 1998; Gawande, 2014). People using LTSS likely have a broader or more holistic view of quality, seeing how each of the elements of LTSS inter-relate in their daily lives. Families and professionals, on the other hand, appear to be more focused on the importance of a few key domains (i.e., dignity/respect, safety/security, staffing/staff competence) likely, as already discussed, because they view these attributes as necessary to the realization of other quality goals. Families and professionals may also underestimate the importance of other aspects of quality to older adults who use LTSS.

Another finding was that consumer views on the *level* of importance of many aspects of LTSS quality differed from those of other stakeholders. Results of the survey rating question (the only format that enabled differences in the magnitude of respondents' preferences to be observed) showed statistically significant differences between the views of consumers and professionals in seven of nine quality domains. Interestingly, these differences were primarily because consumers rated these aspects of quality as *less* important than professionals did.<sup>15</sup> These findings, which are consistent with research on differences between experienced and decision utility (Dolan & Kahneman, 2008; Kahneman, 2000; Oswald & Powdthavee, 2008) suggest that consumers may have adjusted (or lowered) their expectations based on their lived experiences with LTSS.

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<sup>15</sup> Consumers also rated items related to three domains of quality (items related to the top three domains: dignity/respect, safety/ security, staffing/staff competence) as less important than family participants. In other cases, however, the views of consumers and families were more similar than the views of consumers and professionals, with no other statistically significant differences observed.

Therefore, it is more useful to compare the relative ratings of quality domains across stakeholder groups than to merely compare stakeholder groups' mean ratings.

Finally, across all three question formats (Q sort, survey rating question, and survey ranking question) consumers placed considerably more emphasis on the physical environment than professionals did. For both the Q sort and survey rating question, consumers rated the physical environment (seven items) as the second most important quality domain, whereas professionals rated it as the second least important. Even for items within the environmental domain, considerable differences were apparent.

Most notable was the difference of opinions on the importance of having a private bathroom, which participants described as an issue of privacy. Consumers rated this item as the most important of all 50 items included in the survey and professionals rating it relatively low compared to the majority of other survey items (consumer mean rating: 8.79; SD: 1.70; professional mean rating: 7.88; SD: 1.91;  $p < 0.001$ ). Consumers' higher rating of private bathrooms is particularly noteworthy given that consumers rated most survey items lower than professionals did. Although consumers placed less emphasis on physical environment for the final ranking question than they did in the Q sort and rating question, they still valued the environment more highly than other stakeholders, with 29% of consumers selecting the physical environment as a top priority versus 6% to 13% for other stakeholder groups ( $p < 0.001$ ). In follow-up discussions with stakeholders on study results, professionals often reflected on the importance of the physical environment to themselves but said that costs prohibited being able to develop optimal physical environments for LTSS consumers, particularly for those whose LTSS is covered by

Medicaid. Private rooms and private bathrooms (e.g., for nursing home residents) were viewed as particularly cost prohibitive, although these were the environmental attributes consumers said they cared about the most. The differences observed in stakeholder perspectives demonstrates the importance of including consumers, families, and LTSS professionals (particularly those who work most closely with consumers and families) in discussions related to priorities for LTSS.

### **Distinct Perspectives on LTSS Quality**

One of this study's unique contributions involves results of the by-person factor analysis conducted as part of the study's Phase 2 (Q sort). Through this analysis, six distinct viewpoints on LTSS quality were observed. These perspectives revealed more nuance on differences in stakeholder perspectives than the Phase 3 survey. These perspectives were largely defined by stakeholder role and, perhaps to some degree, by socioeconomic status and LTSS setting.

Two of the viewpoints (viewpoints 1 and 4) represented the views of LTSS professionals. The first viewpoint, defined by 15 participants, aligned with the traditional medical model of LTSS with a focus on clinical aspects of care and consumer safety (White-Chu, et al., 2009). The second viewpoint, defined by 10 participants, focused more on affirming the independence of LTSS consumers and less than on their health needs, while also recognizing their vulnerability. The majority of individuals who shared this perspective held current or past roles that involved advocating for the rights of older LTSS consumers. Of note, among all six viewpoints, viewpoints 1 and 4 were the most highly correlated (Appendix I). Although the two perspectives were distinct,

professionals' views on LTSS quality were more similar than the views of other stakeholders. This finding is consistent with the survey results, which showed no statistically significant differences between professional groups' ratings of any quality domains.

One of the perspectives (viewpoint 2, defined by 10 participants) represented the priorities articulated by family and professional caregivers of people with ADRD. More than other viewpoints, this perspective focused on staff-related items (i.e., staffing levels, consistent staffing, staff competence, staff demeanor), as well as the emotional wellbeing of LTSS consumers. More dialogue is needed to determine how and why the aspects of LTSS quality that are most relevant to the wellbeing of people with ADRD differ from the priorities of other LTSS consumers (National Quality Forum, 2014). For example, items related to autonomy/choice tended to be ranked low by this perspective. However, discussions with stakeholders also suggest that, although different aspects of autonomy/choice may be important for individuals with ADRD than other consumers, choice is still important. Autonomy/choice can also be conceptualized differently, such as honoring choices a person has previously made, such as related to daily routines, meaningful activities, or healthcare decisions.

Finally, there were three viewpoints that primarily represented the views of LTSS consumers. One of these perspectives (viewpoint 3, defined by 11 participants) was held by people who live in or identify with care in assisted living facilities. This viewpoint prioritized specific aspects of dignity/respect and the physical environment, particularly a person's private space. Assisted living tends to be expensive and available primarily to

individuals who are paying privately for their care (Stevenson & Grabowski, 2010).

Therefore, it is difficult to determine whether the views of the individuals who shared this perspective differed from other consumers' views because of differences in LTSS needs, values that lead some people to choose assisted living over other forms of LTSS, or other factors such as socioeconomic status. Although the physical environment was valued more highly by consumers than professionals overall, the emphasis on certain environmental attributes in this viewpoint could point to differing expectations for LTSS held by individuals who are paying privately for LTSS versus those whose services are covered by Medicaid.

The second consumer perspective (viewpoint 5, defined by 8 participants) focused on staying connected and engaged in the world through meaningful activities and relationships, including relationships within the LTSS setting. Unlike viewpoint 3 (assisted living), which placed a high value on the physical environment, physical space was relatively unimportant in this perspective. Half of the individuals who shared this perspective lived in low-income senior housing communities and several described having experienced homelessness earlier in their lives. Several participants also noted being separated or alienated from their families, either due to physical distance or because of past challenges, such as domestic abuse or chemical dependency. Related to this, some of the participants who described overcoming significant life challenges said that these past experiences contributed to their current desire to maximize "living life," including by meaningfully connecting with others.

Participants exemplifying viewpoints 3 (assisted living) and 5 had differing views on relationships. In viewpoint 3, relationships within the assisted living facility were relatively unimportant. However, in viewpoint 5, feeling connected to others (including in the facility/building) was a central focus. Consistent with other research, most of the assisted living residents who participated in the Q sort component of the study said they were well-connected with family and friends, which may explain why relationships within the facility were not as important as they were to individuals sharing viewpoint 5 (Jang, Park, Domingue, & Molinari, 2014; Roy, et al., 2018). The difference in views on relationships between these two viewpoints could point to differing values related to socioeconomic status or to other factors, such as mental health or level of family involvement.

The third consumer perspective, focused on individualized care and family support, was unique to single female consumer and the wife of a man living with ADRD. Another individual, a low-income senior housing resident who was relatively independent, negatively loaded on this factor, i.e., his views were opposed to those who positively loaded on the factor. This perspective seemed to reject LTSS in residential settings and instead focused on the importance of maintaining control over aspects of daily life with the support of family and friends. Both the consumer, who lived in her own home with an adult son, and the family caregiver talked about making tradeoffs to avoid institutional care. For example, the family caregiver said that she and her husband prioritized staying together in the same home versus receiving more assistance from others, such as in a nursing home. The consumer described living in an orphanage as a

child and said she was willing to live with less help now than end life “in an institution... where she had started life.”

**Tradeoffs, changes over time, and limited choice.**

The Q sort process required participants to make difficult tradeoffs between aspects of LTSS quality that most participants agreed are at least to some extent important. While completing the Q sort activity, many participants commented that prioritizing some attributes of quality over others was difficult. Selecting the most and least important item statements appeared relatively easy for most participants; it was the items in the middle categories that seemed more difficult to sort. Completing the activity seemed the hardest for professionals, particularly state policy, regulatory, and advocacy personnel, individuals who often work with multiple LTSS programs and settings. Several professionals also said that it was difficult to distinguish between their own preferences—or what they thought a parent would prefer—from what they thought supported the overall wellbeing of other LTSS consumers. Many also commented that it was hard to prioritize items for LTSS consumers in general, given the importance of ensuring that services are person-centered.

Several participants speculated that the quality attributes they prioritized through their Q sort would have been different if they had completed the activity at another point in time, such as earlier in a disease process (e.g., family caregivers of people with ADRD, etc.) or before moving to a residential care setting. People who had experience with HCBS often pointed out that some items, such as deciding who may enter one’s room or home or having a private bathroom, were more relevant to people who lived in assisted

living or nursing home settings than to those who used HCBS. Several other participants said they ranked certain items as less important because they did not view those aspects of quality (typically quality of life) as possible. These items often related to autonomy/choice, which may help explain the low performance of this domain in the Phase 3 survey.

Consumers at times commented on feeling constrained by the options available to them. For example, many assisted living and nursing home residents said that they would have preferred to remain in their own homes but that this was no longer feasible due to family concerns or because they needed a higher level of assistance than they thought was possible at home. Similarly, participants who lived in low-income senior housing at times said they did not have much choice about where they lived or who provided their health care. Ultimately, these findings show that, when forced to make decisions, consumers and professionals may value aspects of LTSS quality differently. They also show that, although individual consumers may hold differing views on the most important aspects of quality, there may still be distinct patterns, or “personalities,” in what they prioritize.

### **Implications for Policy and Practice**

In addition to the findings already discussed, the results of this study suggest several additional implications for the policies and practices surrounding LTSS and the field of evaluation. Given this study’s focus, it is important to understand how better aligning the policies and practices surrounding LTSS with stakeholder values could

contribute to improving the organization and delivery of LTSS, and the role that evaluation could play in these efforts.

### **Need for overarching principles to guide transformation in LTSS.**

Prior studies on consumer views on LTSS quality have found fairly consistent priorities across residential and non-residential settings, as previously detailed, as well as in European and Canadian LTSS contexts (Guse & Masesar, 2015; Iwasiw, Goldenberg, Bol, & MacMaster, 2003; Milte et al., 2016). The consistency of their priorities across different contexts suggests that consumer views on LTSS quality likely relate more to shared underlying values (albeit Western values) related to service quality (Parasuraman, et al., 1985; Parasuraman, et al., 1988) than to the capacities of a specific provider or setting in which a person receives LTSS. The consistency of consumer values observed across studies also supports the development of an overarching policy framework for LTSS, with consistent goals, standards and priorities that could be adapted and applied across LTSS settings.

The results of this exploratory study suggest preliminary evidence that stakeholders view several aspects of LTSS quality as the highest priorities. Further research is needed to determine the consistency of these priorities across populations, geographies, and LTSS settings. Probability sampling strategies and larger sample sizes could create more generalizable results. At the same time, participatory processes aimed at shared reflection and understanding among LTSS stakeholders may ultimately be more effective at changing views about LTSS quality than generalizable study results (House & Howe, 1999). In sharing results of this study with local stakeholders, for example,

thoughtful discussions have taken place, such as about the role of Autonomy/Choice in LTSS and reasons study participants rated this as a lower priority than most other aspects of LTSS quality. In discussions about LTSS quality, evaluation professionals can play a role in bringing attention to the roles of values and how stakeholder views often differ (Alkin, Vo, & Christie, 2012). Evaluators can also ensure that the interests of consumers and families are represented in policy-level and organizational quality/evaluation-related discussions, either through facilitating their direct involvement or through other methods, such as collecting information about their values and interests and sharing it with other stakeholders (Alkin et al., 2012).

Despite the need for more discussion and deliberation among stakeholders about priorities for LTSS (House & Howe, 1999), the priorities stakeholders in this study agreed were top priorities (Dignity/Respect, Safety/Security, Staffing/Staff Competence) could be used as a starting point to develop overarching principles and standards for LTSS, which could be applied across LTSS settings (Patton, 2011). In follow-up discussions about study results with various stakeholder groups in Minnesota, stakeholders have affirmed the centrality of these three aspects of quality, including their relevance across LTSS settings.

The principles-based approach proposed by Patton (2011) could be especially suitable for development and evaluation work in LTSS because of the complexity of LTSS and need for principles and standards that can be applied and adapted across various populations and LTSS settings (Patton, 2011). An overarching policy framework for LTSS could be used to support the integration of the social and medical goals of

LTSS across all care settings. Consistent, cross-setting principles could elucidate gaps in existing frameworks and quality measurement systems. For example, the lack of any person-centered measures (i.e., quality of life or consumer satisfaction) in the federal nursing home 5-star rating system becomes more apparent when examining quality through an integrated framework that encompasses standards and values from both nursing home and HCBS contexts.

Consistent principles and standards could also facilitate greater equity in the delivery of LTSS in other ways. For example, not all older adults who use LTSS have access to services and supports in the same settings. Disparities in access to more desirable forms or settings of LTSS may be particularly acute for people of color, those of lower socioeconomic status, and individuals who live in rural areas (Feng, Fennell, Tyler, Clark, Mor, 2011; Hernandez, 2012; Stevenson & Grabowski, 2010). Disparities in access are important to address as an equity issue because some settings (such as many nursing homes) are more heavily institutionalized than others (such as most assisted living and community-based service settings), creating environments that impose greater restrictions on the daily lives of individuals who use services in these settings. At the same time, individuals who use services in the community may not always have access to the level of healthcare services they need.

Consistent principles could also enable consumers, payers, and policymakers to compare service capabilities and performance across individual sites and different LTSS settings. For example, cross-cutting principles such as that *consumers are treated with kindness and respect by personnel*, or that *services are individualized to each person*

*using LTSS*, could be used to assess quality within Medicaid managed LTSS programs, which typically involve various LTSS populations, sites, and settings. This information could be used to support informed decisions about where to receive (consumers) or pay for services (state payers), or where to invest public resources (policymakers). Cross-setting principles could also be used to guide decisions about program planning and financial investment at the policy level. For example, a principle such that consumers *be safe from being harmed or mistreated by others* could be used as a starting point for state-mandated personnel training on elder abuse, including resident-to-resident aggression and family/domestic abuse in addition to staff-related mistreatment of consumers. Such a principle could also be used to articulate the need for added public investments to ensure appropriate staffing levels within LTSA organizations, as well as support external consumer advocates, such as the long-term care ombudsmen.

Developmental evaluation approaches could also be used at the program or site level to better align programming with principles with values articulated by stakeholders (Patton, 2011). As part of local quality improvement efforts, LTSS organizations could use methods like those used in this study, or other qualitative methods, to elicit the priorities of their own stakeholders and work toward better aligning their services with these values. Organizations could also implement local quality improvement projects, including staff training, to better align local programming with core values and/or principles advanced at the policy level. Organizational leaders and evaluation professionals could involve staff in data collection efforts or other activities related to implementing and evaluating improvement initiatives (Alkin et al., 2012; Cousins &

Whitmore, 1998; King, 1998). For example, a principle such as that *individuals be involved in decisions about policies and practices affecting them* could lead a site to involve consumers and families in discussions and decisions about quality improvement priorities. It could also serve as the foundation for staff training on the philosophy and practices of person-centered care and implementation of modified care practices that align with the principles of person-centered care.

Despite the need for cross-setting principles and standards, there are certain aspects of quality that require more individualized approaches. Such measures would address the concern raised by some professionals, including several who participated in this study, that using standard, cross-cutting measures could work against care that is person-centered. Therefore, person-centered measures (Bangerter, Heid, Abbott, & Van Haitsma, 2016; Bangerter, Van Haitsma, Heid, & Abbott, 2015) could be used for aspects of quality about which stakeholders expressed more varied opinions, such as interpersonal relationships, emotional/spiritual wellbeing, meaningful activities, or food/meals enjoyment. These measures could assess the extent to which consumers' needs or preferences are met in these areas (Bangerter, et al., 2015; Bangerter et al., 2016). Similarly, certain aspects of quality, such as aspects of the physical environment, personal space, and privacy, are more relevant to residential care settings. Therefore, even if a comprehensive, overarching framework is developed to advance general principles of high quality LTSS, person-centered measures could be included, and certain measures could be tailored to the specific LTSS setting or type of services provided.

### **Areas for further discussion.**

Participants in this study identified staffing and staff competence as key priorities for LTSS. Although consumer advocates have argued the need to professionalize the LTSS direct support workforce (Larson, Lakin, & Hewitt, 2002; Stone & Harahan, 2010), these individuals remain largely undertrained and underpaid (Stone & Harahan, 2010). Future research and evaluation efforts could focus on better understanding the knowledge and skills needed to provide high quality services and supports to older adults, particularly those with ADRD or other complex conditions. Research and evaluation are also needed to examine strategies to develop innovative policies and organizational strategies to recruit and retain high quality personnel in LTSS. Similarly, because study participants had differing views on the importance of consistent staffing, future research could examine whether consistent staffing is more important in certain settings or for certain individuals, such as those with ADRD.

There are two aspects of LTSS quality in particular around which greater dialogue among stakeholders is needed. The first involves the physical environment. This study demonstrated that consumers and professionals held differing views on the importance of the physical environment compared to other aspects of quality. More research is needed to understand the relationship between the physical environment and wellbeing of older adults (Mackenzie, Curryer, & Byles, 2015; Wahl, Iwarsson, & Oswald, 2012), particularly those who use LTSS in residential care settings (Cutler, 2007; Kane & Cutler, 2015). Further discussion and agreement among stakeholders is also needed around the implications of Medicaid's coverage of the housing component of LTSS in

nursing homes but not in assisted living settings (Kane & Kane, 2015). Despite efforts to shift LTSS spending away from nursing homes to HCBS, this extant inequity in Medicaid policy continues to perpetuate the “institutional bias” in LTSS for older adults (Kane & Kane, 2015). Relatedly, greater consensus is needed around access to certain types of housing (e.g., assisted living) and types of environmental features for Medicaid participants.

Another area around which additional dialogue is needed involves autonomy/choice, which was viewed as a relatively low priority by study participants, particularly consumers and families. As previously discussed, comments made by study participants suggest that they may view autonomy/choice as less important because of concerns that choices may contribute to increased stress for vulnerable older adults, concerns about older adults making “unsafe choices,” and perceptions that LTSS consumers may not have many real or meaningful choices to make. Although consumer choice has become an increasingly important priority in public LTSS programs, the findings of this study suggest that a deeper understanding of how stakeholders view and value different aspects of autonomy/choice for older adults may be needed (Kane & Kane, 2001; Laundau, Auslander, Werner, Shoval, & Heinik, 2011; Sims-Gould, McKay, Feldman, Scott, & Robinovitch, 2014). Future research could examine the relationship between autonomy/choice and safety/security more deeply through qualitative methods of methods that enable stakeholders to more directly compare aspects of these two domains (Thurstone, 1927). Additionally, research could explore which aspects of

autonomy/choice and safety security are most relevant at different points in the care trajectories of older adults who use LTSS, including those with cognitive impairment.

Ultimately, there is a clear need for more focused, facilitated discussions (House & Howe, 1999) among consumers, families, policy leaders, and LTSS professionals to determine priorities for LTSS and how best to confront the many challenges stakeholders face related to LTSS. Over the course of the study, many family members expressed frustration with various aspects of LTSS, highlighting the need for LTSS programs and services that better serve older adults and their families. They described a lack of coordination between healthcare and LTSS providers, confusing insurance/payment systems, inadequate staffing levels, high rates of staff turnover, and what they perceived to be false advertising on behalf of LTSS providers, particularly assisted living facilities. Because LTSS is evolving, challenges will emerge that need to be addressed along the way. Therefore, ongoing evaluative processes are needed that accommodate and respond to changing conditions and people's experiences in LTSS.

### **Limitations**

In addition to the considerations discussed throughout this paper, several additional limitations should be considered. The study was initially conceptualized such that the Q sort *technique* (i.e., sorting item statements into several categories of importance) would be used to narrow the number of items included in the final survey from over 50 to approximately 25 items. The idea was that the items consistently ranked lowest by study participants would be eliminated from the item set before implementation of the survey to reduce the burden on participants, particularly older adults and family

members. Mid-way through implementation of the Q sort component of the study, however, advice from the researcher's dissertation committee and an external survey methodologist (T. Rockwood, personal communication) led to the decision to retain most of the items in the Phase 2 survey with some minor modifications. This decision was mainly because, although some items were consistently receiving higher (or lower) ratings than others, it was also clear that there were considerable variations in the priorities articulated by study participants. Therefore, other than in the cases of a few items, it was unclear which items should be eliminated. Therefore, the original purpose of the Q sort phase as an item reduction method was not realized. This design modification led the researcher to: 1) increase the sample size of the Q sort component of the study so the results could stand on their own and used to complement results of the Phase 3 survey, 2) complete additional analyses (i.e., the by-person factor analysis and qualitative interpretation that characterize Q methodology), and 3) triangulate findings across both the Q sort and survey methods to provide deeper insights and greater depth to the overall study findings.

An additional limitation relates to the generalizability of study findings. This research relied on a convenience sampling strategy and took place only in Minnesota. Recruitment was limited to a relatively small number of LTSS organizations, most of which were non-profits. The sample was also limited in its number of nursing home residents and people of color. Although more racial and ethnic diversity was observed in the consumer group, family and professional participants were almost entirely white (95.1 – 97.6%, depending on stakeholder group). Another consideration (although

unlikely to affect the racial/ethnic composition of the sample) is that LTSS providers helped in selecting consumers to participate in the Q sort phase of the study, which could have resulted in some selection bias. For example, it may have been easier to approach certain consumers about participating than others, such as those who were more outgoing or who had closer relationships with staff. The researcher discussed these concerns with providers before study implementation, however, and worked with collaborating organizations to reduce this type of selection bias to the extent possible. Inconsistent implementation strategies for the Phase 3 survey in different locations and settings may have also added some additional bias to study results.

People with cognitive impairment were unable to participate in the research due to the complexity of the tasks study participants were asked to complete. However, the opinions and values of these individuals are important too and could be solicited through other methods. For example, the Minnesota Nursing Home Resident Quality of Life Survey only contains two response options (generally yes, generally no) for most questions to simplify the survey process so that many residents with cognitive impairment can participate (Minnesota Department of Human Services, Resident Quality of Life Interview Form, 2017). Similarly, although several key stakeholders were included in this research, other important groups were left out, including direct support professionals (e.g., nursing home nursing assistants, home health aides), physical therapists, social workers, and physicians. Future research could explore the perspectives of stakeholders not included in this study.

Several measurement challenges should also be noted. Although multi-mode surveys are commonly used to improve response rates, reach different stakeholder groups, reduce nonresponse error, and reduce costs, surveys implemented via multiple modes may increase the amount of measurement error since people may respond to survey items differently based on the mode in which questions are delivered (Dillman, et al., 2014). Further, while surveys are relatively inexpensive to implement and allow researchers to obtain information from larger numbers of people than more intensive qualitative methods, they do not allow for in-depth exploration of why respondents hold certain opinions or values. Similarly, surveys do not allow for follow-up questioning to explore unclear or missing responses, or responses that appear to be errors.

Given the desire to include items related to multiple quality domains in the study, a limited number of items were included to represent each domain. Although the researcher attempted to ensure that the included items were the most representative items for each domain, such as by engaging external experts in validating the domains and individual items included, each domain was necessarily incomplete. Through this project, the researcher gained greater appreciation for the complexity of defining and assessing LTSS quality, as well as of determine how and why stakeholder views on quality priorities may differ. In retrospect, an entire study could have been conducted on stakeholder values related to a specific aspect or domain of LTSS quality, such as autonomy/choice, dignity/respect, or safety/security. Similarly, not every aspect or domain of LTSS quality was included in this study. For example, items related to consumer rights, caregiver supports, service accessibility, equity (i.e., system equity or

equity within organizations), costs and cost effectiveness were excluded, although these are important concerns for consumers, families, providers, and payers.

The survey ranking question had a high rate of non-response and unusable responses, particularly on the paper version of the survey, which did not include the online features that made the question easier for participants to answer. Because all participating professionals completed the survey online, data for the consumer and family groups were primarily affected by this design limitation. More complete pilot testing of the paper version of the survey instrument could have led to improvements in survey design and reduced this limitation.

#### **Lessons learned.**

In addition to the limitations described above, implementing this study gave me (the researcher) the opportunity to reflect on several things that will inform how I conduct future research. The study could have benefitted from being narrower in scope. For example, a study focusing solely on the views of one or two stakeholder groups, quality priorities for one setting type (such as assisted living), or stakeholder priorities on a single multi-level campus would have been more manageable in scope. A more focused topic could also have led to findings that were easier to interpret and potentially more useful to LTSS providers and policymakers. Despite these limitations, two state policy-focused workgroups (i.e., the Assisted Living Report Card Workgroup and the Quality and Safety in Long-Term Care Workgroup [focused on quality and safety across LTSS settings], both facilitated by state agencies) are using study results, in addition to other resources, as background information for new initiatives focused on LTSS quality.

Further, although prior research and evaluation studies I have worked on have included data collection with LTSS providers and consumers, most of these studies involved state-sponsored programs or partnerships, which meant that the state played a pivotal role in facilitating provider involvement. Engaging LTSS providers in this study proved a considerably larger challenge than I had anticipated. In future studies, I will involve key stakeholders earlier in the research/evaluation process. For example, asking LTSS providers for input about planned data collection activities earlier in the project planning phase could have helped establish rapport and facilitate stronger partnerships throughout the project. In addition, I could have more effectively used existing relationships I have with LTSS professional associations and state agencies earlier in this work. This could have helped considerably in engaging LTSS providers. These considerations, I have learned, are particularly important in research and evaluation work related to LTSS because of the considerable challenges faced by LTSS providers.

## **Conclusion**

The need to better define LTSS quality has become more urgent. Growing numbers of older adults need LTSS and this trend will continue. The programs and services known today as LTSS are delivered in various institutional and community-based settings, each governed by different rules and regulations. As states increasingly move to managed LTSS programs, the need for an overarching policy framework that can be used to guide program development and evaluation activities across LTSS settings has become more evident. However, defining what constitutes “good quality” in LTSS remains an ongoing challenge.

The historical evolution of LTSS has led to quality being defined differently across LTSS settings, even if the individuals served have similar needs and priorities. Although considerable effort has gone into developing clinical and safety measures to assess care quality in nursing homes, less attention has been devoted to person-centered measures of quality, or to measures that could be used to assess quality across LTSS settings. This paper discusses one approach to engaging stakeholders in valuing various aspects of LTSS quality. The resulting framework, based on shared values and principles articulated by stakeholders, could be used to advance improved quality and greater equity across LTSS populations and settings. The implications of this study suggest that LTSS quality could be addressed in a more integrated way that accounts for the multiple goals of LTSS. Moving forward, participatory processes are needed that engage stakeholders, particularly consumers and families, in discussions focused on how best to improve and transform LTSS.

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## Appendices

## **Appendix A. Source Materials Reviewed in Developing Valuing Framework**

### Existing Frameworks/Initiatives/Measurement Tools

1. Advancing Excellence in America's Nursing Homes Quality Goals
2. Advancing Excellence\_PCCTrackingTool\_v1.15\_7-02-15 [Person-Centered Care Tracking Tool]
3. Advancing Excellence\_MobilityTrackingTool\_v1.4\_6-24-15
4. American Health Care Association/National Center for Assisted Living Quality Initiative
5. Centers for Medicare and Medicaid Services (CMS) Nursing Home Quality Measures
6. CMS Nursing Home Survey Family Interview
7. CMS Nursing Home Survey Resident Interview & Resident Observation
8. CMS Home Health Outcome Measures
9. Consumer Voice for Quality in Long-Term Care\_2011 Resident Voice Entries
10. Consumer Voice for Quality in Long-Term Care\_2012 Resident Voice Entries
11. Consumer Voice for Quality in Long-Term Care\_2013 Resident Voice Entries
12. Consumer Voice for Quality in Long-Term Care\_2014 Resident Voice Entries
13. Consumer Voice for Quality in Long-Term Care\_Resident-Rights-an-Overview\_
14. LeadingAge Confident Choices for Senior Living
15. Minnesota Nursing Home Family Satisfaction Interview
16. Minnesota Nursing Home Report Card Measures
17. Minnesota Nursing Home Resident Quality of Life Satisfaction Survey/Interview
18. My InnerView Resident Interview
19. National Core Indicators\_Health
20. National Core Indicators\_Individual Outcomes\_Choice
21. National Core Indicators\_Individual Outcomes\_Community\_Inclusion
22. National Core Indicators\_Individual Outcomes\_Relationships
23. National Core Indicators\_Individual Outcomes\_Satisfaction
24. National Core Indicators\_Individual Outcomes\_Self-Determination
25. National Core Indicators\_Respect\_Rights
26. National Core Indicators\_Restraints
27. National Core Indicators\_Safety
28. National Core Indicators\_Wellness
29. National Quality Forum HCBS Quality Final Report
30. Ohio Resident Family Satisfaction Survey Development 2016
31. PELI-Home Care Preference Importance Inventory
32. PELI-Nursing Home Preference Inventory
33. Pioneer Network\_Artifacts of Culture Change

### Studies on Consumer/Family Perspectives and Experiences with LTSS Quality

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## Appendix B. Item Tracking

Domain	Final Items (some reworded slightly)	Excluded Items
Autonomy/ Choice  Final: 7 items	<ol style="list-style-type: none"> <li>1. Choosing and controlling my daily routines, such as what time I get up in the morning, bathe or shower, and eat snacks or meals.</li> <li>2. Choosing where I live and receive services and supports.</li> <li>3. Deciding who may enter my house, apartment, or room.</li> <li>4. Doing things for myself, even if it takes more time.</li> <li>5. Making choices in my daily life that others may disagree with or view as unhealthy or unsafe.</li> <li>6. Choosing my doctor and other healthcare providers.</li> <li>7. Making decisions (by myself or with people I designate or include) about my healthcare, including whether to have certain treatments, enter a hospital, etc.</li> </ol>	<ol style="list-style-type: none"> <li>1. Choosing which clothes I wear.</li> <li>2. Deciding how to use my own spending money.</li> <li>3. Having control over my personal belongings.</li> <li>4. Choosing what I eat and drink.</li> <li>5. Choosing the people who help me with my daily needs.</li> <li>6. Choosing where and with whom I eat meals. (Moved to Food/Meals.)</li> <li>7. Deciding who is involved in discussions about my care.</li> <li>8. Participating in care conferences and other important discussions about my care.</li> </ol>
Dignity & respect  Final items: 4	<ol style="list-style-type: none"> <li>1. Receiving assistance that is tailored to individual needs and preferences.</li> <li>2. Being treated with kindness and respect by the people who help me.</li> <li>3. Receiving assistance in a way that allows me to maintain my dignity and personal privacy.</li> <li>4. Having the people who help me take my concerns about health or other issues seriously.</li> </ol>	<ol style="list-style-type: none"> <li>1. Being recognized and known as an individual.</li> <li>2. Having my requests honored by the people who help.</li> <li>3. Having my modesty and bodily privacy respected by the people who help me.</li> <li>4. Having information about me kept private unless I decide it can be shared with someone.</li> <li>5. Being able to visit with others or use the phone in private.</li> <li>6. Receiving enough time and attention from the people who help me.</li> </ol>

<b>Domain</b>	<b>Final Items (some reworded slightly)</b>	<b>Excluded Items</b>
Activities Final items: 7	<ol style="list-style-type: none"> <li>1. Being able to do the things I enjoy.</li> <li>2. Having enough to do; not being bored.</li> <li>3. Choosing whether to spend my time with others or alone.</li> <li>4. Being able to decline participation in activities in which I am not interested.</li> <li>5. Going out to shop, run errands, eat out, or participate in other activities in the community</li> <li>6. Staying connected and involved with what's happening in the world.</li> <li>7. Having access to reliable transportation; being able to get where I want or need to go.</li> </ol>	<ol style="list-style-type: none"> <li>1. Participating in classes or activities that allow me to learn and try new things.</li> <li>2. Having a pet or regularly interacting with animals.</li> <li>3. Regularly interacting with children.</li> <li>4. Having access to entertainment I enjoy, such as reading materials, music, television, etc.</li> <li>5. Getting physical exercise.</li> </ol>
Meals Total items: 3	<ol style="list-style-type: none"> <li>1. Having pleasant and enjoyable mealtimes.</li> <li>2. Eating the foods I like.</li> <li>3. Choosing where and with whom I eat meals.</li> </ol>	<ol style="list-style-type: none"> <li>1. Eating nutritious meals.</li> <li>2. Having a variety of foods.</li> <li>3. Having access to snacks when I want them.</li> </ol>
Relationships Total items: 6	<ol style="list-style-type: none"> <li>1. Seeing or staying in touch with my family and friends.</li> <li>2. Having good relationships with the people who help me.</li> <li>3. Not being lonely.</li> <li>4. Helping others when I want and am able to.</li> <li>5. Feeling that others care about me.</li> <li>6. Feeling connected to the people around me.</li> </ol>	<ol style="list-style-type: none"> <li>1. Having friends and neighbors with whom to regularly talk and share experiences.</li> <li>2. Spending time one-on-one with people I like.</li> <li>3. Meeting new people.</li> <li>4. Touching a person or people I care about.</li> <li>5. Staying in touch with the people who are important to me by phone or email.</li> <li>6. Giving gifts when I want and am able to.</li> <li>7. Having a sense of community where I live.</li> </ol>

<b>Domain</b>	<b>Final Items (some reworded slightly)</b>	<b>Excluded Items</b>
<p>Safety &amp; Security</p> <p>Total items: 4</p>	<ol style="list-style-type: none"> <li>1. Knowing that I will receive the assistance and support I need, including in an emergency.</li> <li>2. Knowing that I will not be hurt, yelled at, or intimidated by others.</li> <li>3. Receiving assistance in a way that that I am not hurt or injured.</li> <li>4. Having my belongings safe from being lost, stolen, or damaged.</li> </ol>	<ol style="list-style-type: none"> <li>1. Knowing that someone will help me in an emergency.</li> <li>2. Being able to lock the door to my home, apartment, or room.</li> <li>3. Being able to keep items of value in my home, apartment, or room if I want to.</li> </ol>
<p>Staffing &amp; staff competence</p> <p>Total items: 6</p>	<ol style="list-style-type: none"> <li>1. Receiving enough time and attention from the staff who help me.</li> <li>2. Being free of substantial pain or other physical discomfort.</li> <li>3. Receiving help from skilled and competent personnel.</li> <li>4. Having my health monitored by my care providers to avoid getting sick or having unnecessary complications.</li> <li>5. Receiving care or help from the same people over time.</li> <li>6. Having the people who care for me communicate effectively with each other to avoid mistakes or confusion.</li> </ol>	<ol style="list-style-type: none"> <li>1. Being able to get help from a nurse or doctor quickly when I need it.</li> <li>2. Having opportunities to exercise or walk to gain or maintain my strength and mobility.</li> <li>3. Receiving care from people who are knowledgeable about my health condition and treatment.</li> <li>4. Receiving assistance when I need it (i.e., in a timely way).</li> </ol>
<p>Emotional &amp; spiritual wellbeing</p>	<ol style="list-style-type: none"> <li>1. Not feeling anxious or depressed.</li> <li>2. Feeling calm and peaceful.</li> <li>3. Being happy.</li> <li>4. Feeling a sense of purpose in my life.</li> <li>5. Having my religious and spiritual needs met.</li> <li>6. Having someone to talk to when I have concerns, feel down, or am having a bad day.</li> </ol>	<ol style="list-style-type: none"> <li>1. Having access to mental health services when needed.</li> <li>2. Participating in religious observances that have meaning to me.</li> </ol>

<b>Domain</b>	<b>Final Items (some reworded slightly)</b>	<b>Excluded Items</b>
Physical Environment  Total items: 7	<ol style="list-style-type: none"> <li>1. Living in a place that feels like home.</li> <li>2. Having my own room or home, shared only with a person of my choice, such as my spouse or partner.</li> <li>3. Living in a place that is easy for me to get around.</li> <li>4. Living in a place that is designed to help me do things on my own (such as shelves or counters being at a height I can reach, accessible handles, good lighting, etc.)</li> <li>5. Being able to personalize my space with my belongings to make it feel like home.</li> <li>6. Spending time outside or feeling connected to the outdoors.</li> <li>7. Having a private bathroom.</li> </ol>	<ol style="list-style-type: none"> <li>1. Living in a place that is free of unpleasant noises and smells.</li> <li>2. Being able to adjust the temperature and lighting in my personal space.</li> <li>3. Having outdoor space that is accessible to people with differing needs and abilities.</li> </ol>

## Appendix C. Recruitment Flyer – Q Sort (Phase 2)

# What is “quality” in senior services?



Do you or a close family member use healthcare and/or supportive services in a nursing home, assisted living, or at home? **If so, we want to know what’s important to you!**

We are interested in learning about how people who have experience with nursing home, assisted living, or home care view “quality,” or what is most important, in senior services. We want to understand what has been important to you in the services you or your family member have received.

### Eligibility to Participate

- Age at least 65 years (person receiving services) **OR** family member (such as spouse, son, or daughter) of person receiving services
- Able to participate in an activity that involves ranking items
- For person receiving services: current or recent experience in a nursing home, assisted living, or in-home supportive services (such as home health, delivered meals, or help with chores) for at least 6 months
- For family members: familiarity with preferences of family member and the care or services they have received

### Contact information

Heather Davila, MPA, PhD candidate  
University of Minnesota  
Email: [wood0132@umn.edu](mailto:wood0132@umn.edu)  
Phone: 651-785-3528



This study has been approved by the University of Minnesota Human Subjects/Institutional Review Board (IRB).

## Appendix D. Description of Study (Phase 3)

### What is Quality in “Aging Services?” We want to know what is important to you!

Hello! My name is Heather Davila and I am completing my PhD at the University of Minnesota. I am writing to invite you to participate in a survey I am doing for my dissertation research. My study looks at how different people view “quality” or what is most important, in aging services. The survey takes about 20 minutes to complete.

Traditionally, quality priorities for aging services have been decided mostly by policy makers, rather than people who use services and their family members. **Your opinion is really important and should also be a part of deciding how quality is defined!**

I am fortunate that [organization] is partnering with me on this study. I am also working with other organizations in Minnesota to obtain information from several hundred people throughout the state.

If you decide to participate in the survey, you will be asked to rate a number of items in terms of their importance to you and your overall well-being. **There are no right or wrong answers: your opinion is what matters!**

I will use your responses and those of other participants to create a summary of which aspects of “quality” people throughout Minnesota think are most important. My goal is that information will be used by organizations in Minnesota to improve programs and services for people in our state. All responses will be anonymous.

You can return your completed survey to me in the attached self-addressed stamped envelope. Feel free to have a friend or family member help you fill out the survey if you need help. **Please return your survey by [Date].**

Participation in this survey is completely voluntary. Your decision about whether or not to participate will not affect your relationship with the University of Minnesota or any other organization. Please see the attached consent form for more information.

Thank you for considering this request. I greatly value your time and opinions! Feel free to contact me if you have any questions.

*Signed*

Heather Davila, MPA  
PhD Candidate  
University of Minnesota  
wood0132@umn.edu (email)  
612-626-9446 (phone)

## Appendix E. Copy of Survey (Consumer Version)

[Format revised slightly to meet dissertation formatting requirements.]

### Stakeholder Views on Quality in Long-term Services & Supports

#### BACKGROUND

The purpose of this survey is to get input from people who are involved with "aging services," or long-term services and supports (LTSS), about the importance of various aspects of LTSS quality.

We are seeking opinions from people who have experience with LTSS in nursing facilities, assisted living centers, adult day programs, independent homes, or other home- and community-based settings (HCBS). LTSS can be used by people of all ages, but the focus of this survey is on LTSS used by people who are at least 55 years old.

LTSS includes services related to health or functional needs a person has over a period of time. Such services can include health services, supportive housing, or help with activities such as transportation, household chores, or getting dressed.

#### BACKGROUND INFORMATION

First, we would like to ask a few background questions, which will help us better understand who participates in the survey.

What is your age? \_\_\_\_\_

What is your gender? \_\_\_\_\_ Male          \_\_\_\_\_ Female

Where do you currently live? (Select one)

- \_\_\_\_\_ House, apartment, condo, or townhouse (not located in a senior living community)
- \_\_\_\_\_ Independent senior housing (e.g., apartment or condo located in a senior community)
- \_\_\_\_\_ Assisted living center or residential care home
- \_\_\_\_\_ Nursing facility (i.e., a nursing home or "care center")
- \_\_\_\_\_ Other (Please describe): \_\_\_\_\_

For how long have you used LTSS? (Consider all services and supports received in any setting, including at home, adult day program, assisted living center, or nursing home.)

- \_\_\_\_\_ Fewer than 6 months                      \_\_\_\_\_ Between 1 and 3 years
- \_\_\_\_\_ 6 months to 1 year                              \_\_\_\_\_ More than 3 years

Is there any other information you would like to share about your experience or background with "aging services" or LTSS? If so, please add it here. [Space provided.]

## INTRODUCTION TO THE SURVEY RATING QUESTION

Now we would like to get your input on the importance of various aspects of LTSS quality. There are 9 categories of items, each containing several items. Please rate each item from 0 to 10 (0=not at all important to 10=critically important) based on your opinion of each item's importance to you and your overall well-being. Our goal is to determine which aspects of LTSS are truly the most important. Therefore, **we encourage you to use the full rating scale (0 to 10)**, reserving the highest points for items you view as most important.

**Rate each of the following items by using an “X” to indicate the item’s importance to you and your overall well-being.**

	Not at all Important		Somewhat important		Moderately important		Very important		Critically important		
<b>AUTONOMY AND CHOICE</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
Controlling my own daily routines, such as what time I get up in the morning, bathe or shower, and eat snacks or meals											
Choosing where I receive services and supports (choosing by myself or with someone I designate or include)											
Deciding who may enter my house, apartment, or room											
Doing things for myself, even if it takes more time											
Making choices in my daily life, even if others disagree or view my choices as unhealthy or unsafe											
Choosing my doctor and other health care providers (choosing by myself or with someone I designate or include)											
Making decisions about my health care, either by myself or with someone I designate or include (e.g., whether or not to have certain treatments, enter a hospital, etc.)											

	<b>Not at all Important</b>		<b>Somewhat important</b>		<b>Moderately important</b>		<b>Very important</b>		<b>Critically important</b>		
<b>DIGNITY AND RESPECT</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
Receiving assistance that is tailored to my individual needs and preferences											
Being treated with kindness and respect by the personnel who help me											
Receiving assistance in a way that allows me to maintain my dignity and personal privacy											
Having the people who help me take my concerns about health or other issues seriously											

<b>ACTIVITIES AND INCLUSION</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
Being able to do the things I enjoy											
Having enough to do; not being bored											
Choosing whether to spend my time alone or with others											
Being able to decline participation in activities in which I am not interested											
Going out to shop, run errands, eat out, or participate in other activities in the community											
Staying connected and involved with what's happening in the world (such as through news, voting, or public events)											
Having access to reliable transportation; being able to get where I want or need to go											

<b>MEALS AND FOOD ENJOYMENT</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
Having pleasant and enjoyable mealtimes											
Eating the foods I like											
Choosing where and with whom I eat meals											

<b>RELATIONSHIPS</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
Seeing or staying in touch with family and friends											
Having good relationships with the people who help me											
Not being lonely											
Helping others when I want and am able to											
Feeling that others care about me											
Feeling connected to the people around me											

<b>SAFETY AND SECURITY</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
Knowing that I will receive the assistance and support I need, including in an emergency											
Knowing that I will not be hurt, yelled at, or intimidated by others											
Receiving assistance in a way that I am not hurt or injured											
Having my belongings safe from being lost, stolen, or damaged											

<b>EMOTIONAL AND SPIRITUAL WELLBEING</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
Not feeling anxious or depressed											
Feeling calm and peaceful											
Being happy											
Feeling a sense of purpose in my life											
Having my religious and spiritual needs met											
Having someone to talk to when I have concerns, feel down, or am having a bad day											

<b>STAFFING AND STAFF COMPETENCE</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
Receiving enough time and attention from the personnel who help me											
Being free of substantial pain or other physical discomfort											
Receiving help from skilled and competent personnel											
Having my health monitored by my care providers to avoid getting sick or having unnecessary complications											
Receiving care or help from the same people over time											
Having the people who care for me communicate effectively with each other to avoid mistakes or confusion											

<b>PHYSICAL ENVIRONMENT</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
Living in a place that feels like home											
Having my own room or home (if relevant, shared only with a person of my choice, such as my spouse or partner)											
Living or receiving services in a place that is easy for me to get around											
Living in a place that is designed to help me do things on my own (such as shelves being at a height I can reach, good lighting, etc.)											
Being able to personalize my space with my belongings to make it feel like home											
Spending time outside or feeling connected to the outdoors											
Having a private bathroom											

## INTRODUCTION TO RANKING QUESTION

Now we would like to take a step back and ask you to think about the "big picture" of LTSS quality. Knowing that it is generally not possible to do everything equally well, we would like your input on which aspects of LTSS quality you think are the most important. Another way of thinking about this might be, with limited resources and competing demands, which aspects of LTSS should be prioritized by organizations that provide LTSS?

**Please select 3 of the following aspects of LTSS quality that you think are the most important and rank those 3 items in order of importance (1=most important; 3=least important).** (Do not rank the other items.)

Top 3 choices (rank 1, 2, 3)	Aspect
	<b>Relationships</b> (staying connected with family & friends, having good relationships with personnel, feeling cared about)
	<b>Dignity &amp; respect</b> (being treated with kindness and respect, maintaining personal dignity, having concerns taken seriously)
	<b>Staffing &amp; staff competence</b> (receiving care by competent personnel, getting enough help)
	<b>Activities &amp; inclusion</b> (having enjoyable and enough things to do, remaining involved in the community to the extent desired)
	<b>Physical environment</b> (living in a supportive and comfortable environment, having adequate and private space)
	<b>Autonomy &amp; choice</b> (making decisions about daily routines, personal risks, personal space, and health care)
	<b>Meals &amp; food enjoyment</b> (having good food and enjoyable mealtimes)
	<b>Safety &amp; security</b> (being safe from unnecessary harm, feeling secure)
	<b>Emotional &amp; spiritual well-being</b> (having one's emotional and spiritual needs met)

**Do you have any comments about the aspects of LTSS you selected as most important?**

**Do you have any other comments about priorities for LTSS quality?**

**Is there anything else you would like to share with us?**

**There are just a few last questions we would like to ask.**

**Which of the following best describes the area in which you live? (Select one)**

- \_\_\_\_\_ Urban area (>50,000 people)
- \_\_\_\_\_ Mid-sized or suburban area (10,000 – 50,000 people)
- \_\_\_\_\_ Smaller community or rural area (<10,000 people)

**What is your marital status?**

- Married/in a long-term relationship
- Widowed
- Separated/divorced
- Single

**What is your race or ethnicity?**

- White/Caucasian
- Black/African/African American
- Latino/Hispanic
- Native American/American Indian
- Asian/Pacific Islander
- Other (please describe): \_\_\_\_\_

**Thank you for your time and willingness to share your input with us!**

## **Appendix F. Consent Form**

[Format revised slightly to meet dissertation formatting requirements.]

### **Stakeholder views on quality priorities for long-term services and supports (LTSS): Toward a more inclusive view**

**Investigator: Heather Davila, MPA, PhD Candidate**

#### **CONSENT STATEMENT**

You are invited to participate in a survey related to how different people view quality priorities for “senior services” or long-term services and supports (LTSS). You were selected as a possible participant because you have relevant personal or professional experience. Please read this form before agreeing to complete the survey.

This study is being conducted by Heather Davila, a doctoral candidate in the Evaluation Studies Program in the Department of Organizational Leadership, Policy and Development at the University of Minnesota.

#### **Background Information**

The purpose of this study is to learn more about how people who have personal and/or professional experience with LTSS, including services provided in nursing facilities, assisted living centers, adult day programs, and/or at home, view quality priorities for LTSS. LTSS can include health services, personal supports, and/or housing that people receive over a period of time because of health or other needs. This study has two primary aims:

- To understand the opinions of different people involved with LTSS on which aspects of quality they view as the most important.
- To examine similarities and differences in how different people view quality priorities for LTSS.

#### **Procedures**

If you agree to participate in this study, you will be asked to complete a survey that asks for your input on the importance of various aspects of LTSS quality. Completing the survey should take approximately 15 to 20 minutes.

#### **Risks and Benefits of Being in the Study**

There is a small chance that you may feel uncomfortable while answering questions. However, all of the questions are optional. You may choose not to answer any of the questions or stop the survey at any time.

The survey is completely anonymous. No results will be linked to you or any other individual participant.

There are no immediate or expected benefits for you for participating in the survey. Results of this study are intended to assist organizations and agencies in Minnesota with improving LTSS so they meet the values and preferences of people who use LTSS.

**Confidentiality**

The results of your survey will not include your name or any other information that can identify you. All data will be stored securely and only the researcher will have access to the records. Data will be maintained until the end of the study.

**Voluntary Nature of the Study**

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota or any other organization, including the organization(s) from which you receive services. If you decide to participate, you are free to withdraw at any time without affecting those relationships.

**Contacts and Questions**

The researcher conducting this study is Heather Davila. If you have questions, **you are encouraged** to contact Heather at 651-785-3528 or wood0132@umn.edu. You may also contact Heather's dissertation advisor, Dr. David Johnson, at 612-624-1062 or johns006@umn.edu.

If you have any questions or concerns regarding the study and would like to talk to someone other than the researchers, **you are encouraged** to contact the Research Subjects' Advocate line, D528 Mayo, 420 Delaware Street SE, Minneapolis, Minnesota 55455; phone (612) 625-1650.

You may print a copy of this consent form to keep for your records.

## **Appendix G. Recruitment Emails to Professionals**

### **Email to Policy, Regulatory, and Advocacy Personnel**

[Date]

Dear [Name],

I am writing to invite you to participate in a brief survey I am doing as part of my doctoral dissertation at the University of Minnesota.

My study looks at quality priorities for long-term care/long-term services & supports (LTC/LTSS). Specifically, I am asking key stakeholders, including: 1) policy/regulatory/advocacy leaders, 2) LTC administrators & nurse leaders, 3) older adults who use LTC/LTSS and family members, to rate different aspects of quality of care and quality of life in terms of their importance.

I am looking broadly at all settings in which older adults use LTC/LTSS: in their own homes, adult day programs, assisted living, and nursing facilities.

**Would you consider participating in this survey as part of the policy/regulatory/advocacy stakeholder group?** The policy/regulatory/advocacy group will include about 40 people, including representatives from the Minnesota Department of Health, Minnesota Department of Human Services, LTC Ombudsmen program, the Minnesota Area Agencies on Aging, and Stratis Health. (Results for all policy/regulatory/advocacy representatives will be included in one group, not broken out by agency.)

**All survey responses are completely anonymous and the survey takes about 15 minutes to complete.**

**Here is a link to the online survey: [Quality Survey](#)**

Thank you in advance for your time and consideration! I greatly appreciate your willingness to share your input.

Sincerely,

Heather Davila, MPA  
PhD Candidate  
Evaluation Studies, University of Minnesota

## **Email to LTSS Administrators and Executives**

[Email sent out to members of LTSS administrators and executives through CareProviders professional/trade association.]

August 9, 2017

Dear Members,

Major state and federal initiatives are underway to promote “quality” in long-term care/long-term services & supports (LTSS) through value-based purchasing and public reporting programs. *(Note, LTSS is the more “global term” to include the continuum of care: nursing facilities, assisted living settings, and home and community based services.)* As a part of this trend, **new measures are being developed to assess and improve quality in skilled nursing facilities, assisted living settings, and home and community-based settings, as well as to compare quality across care settings.**

Historically, quality in LTSS has been defined primarily by policy makers, rather than the people who use and deliver LTSS. When “care” can affect nearly every aspect of a person’s daily life, how should quality be defined? Which aspects of “quality” are the most important?

A study, which is part of a dissertation at the University of Minnesota conducted by Heather Davila, aims to examine the underlying values that guide how we define “quality” in LTSS. There are two primary research questions:

- 1) Which aspects of LTSS quality do key stakeholders view as the most important to the overall well-being of older adults who use LTSS?
- 2) Do stakeholder views on quality priorities for LTSS differ?

**Would you be willing to contribute to this research by completing a brief online survey?** The survey takes about 10 minutes to complete and is completely anonymous. [Here is the link to the survey: LTSS Quality Survey](#)

**Please respond by Thursday, August 31, 2017**

If you participate, you will be asked to rate various aspects of quality of care and quality of life based on your professional opinion of what you think is in overall wellbeing of people who use LTSS (in any care setting). Participants have the option at the end of the survey to enter their name (via a separate link, not connected to survey results) in a drawing for one of several \$25 gift cards to Amazon.com.

Study results will be shared with Care Providers of Minnesota and other organizations that collaborate on this study. All results will be presented in a way that no individual or organization can be identified.

Thank you.

## **Email to LTSS Nursing Leaders**

[Email sent out to members of the Minnesota Directors of Nursing Association, MNDONA, by association leadership.]

September 13, 2017

Dear MNDONA Members,

We are writing to ask for your input into an important research study on which we are collaborating with PhD candidate Heather Davila. The study is part of Heather's dissertation research in program evaluation and gerontology at the University of Minnesota.

As you know, major state and federal initiatives are underway to promote "quality" in long-term care/long-term services & supports (LTSS) through value-based purchasing and public reporting programs. As a part of this trend, **new measures are being developed to assess and improve quality in nursing facilities, assisted living settings, and home and community-based settings.** There are also efforts to compare quality across care settings.

Historically, quality in LTSS has been defined primarily by policy makers, rather than the people who use and deliver LTSS. When "care" can affect nearly every aspect of a person's daily life, how should quality be defined? Which aspects of "quality" are the most important?

This study aims to examine the underlying values that guide how we define "quality" in LTSS. There are two primary research questions:

- 1) Which aspects of LTSS quality do key stakeholders (people who use LTSS, families, LTSS professionals, state policy & regulatory agencies) view as the most important to the overall well-being of older adults who use LTSS?
- 2) Do stakeholder views on quality priorities for LTSS differ?

**Would you be willing to contribute to this research as well by completing a brief online survey?** The survey takes about 10 minutes to complete and is completely anonymous. **Here is the link to the survey: [LTSS Quality Survey](#). Please respond by Monday, October 2, 2017.**

You will have the option at the end of the survey to enter your name (via a separate link, not connected to survey results) in a drawing for one of several \$25 gift cards to Amazon.com or Target.

Study results will be shared with MNDONA. All results will be presented in a way that no individual or organization can be identified. (The study overall will involve several hundred participants representing different stakeholder roles throughout Minnesota.)

Please feel free to contact Heather if you have any questions. She can be reached at [wood0132@umn.edu](mailto:wood0132@umn.edu) or [612-626-9446](tel:612-626-9446).

Thank you in advance!

## Appendix H. IRB Approval

### UNIVERSITY OF MINNESOTA

Twin Cities Campus

*Human Research Protection Program  
Office of the Vice President for Research*

*D528 Mayo Memorial Building  
420 Delaware Street S.E.  
MMC 820  
Minneapolis, MN 55455  
Phone: 612-626-5634  
Fax: 612-626-6061  
Email: [irb@umn.edu](mailto:irb@umn.edu)  
<http://www.research.umn.edu/subjects/>*

#### APPROVAL OF MODIFICATION

July 26, 2017

David Johnson

612-624-1062  
[johns006@umn.edu](mailto:johns006@umn.edu)

Dear David Johnson:

On 7/26/2017, the IRB reviewed the following submission:

Type of Review:	Modification/Update
Title of Study:	Stakeholder views on quality priorities for long-term care: toward a more inclusive view
Investigator:	David Johnson
IRB ID:	MOD00000242
Sponsored Funding:	None
Grant ID/Con Number:	None
Internal UMN Funding:	None
Fund Management Outside University:	None
IND, IDE, or HDE:	None
Documents Reviewed with this Submission:	<ul style="list-style-type: none"><li>• Consumer survey, Category: Other;</li><li>• Davila_flyer_pulloffs_July 2017b.pdf, Category: Recruitment Materials;</li><li>• Families survey, Category: Other;</li><li>• Consent form survey, Category: Consent Form;</li><li>• Survey introduction and triage, Category: Other</li></ul>

The IRB determined that the criteria for approval continue to be met and that this study continues to involve no greater than minimal risk.

Modifications/updates included:

This study involves two phases. All data collection for the first phase (Q-sort survey) has been completed.

**Driven to Discover<sup>SM</sup>**

The second phase of the study involves an online/in-person survey, which will be administered to people who represent the study's stakeholder groups: 1) older adults who use long-term services and supports (LTSS), 2) family members, and 3) professionals. (In January, 2017, the IRB determined that LTSS professionals do not meet the regulatory definition of human subjects research. Therefore, we have not included a copy of the survey designed for this group, although it contains the same basic survey items.)

The purpose of this amendment is to provide the IRB with a copy of the phase 2 online survey, as well as the revised consent form and recruitment flyer. The survey contains the same items as those previously approved by the IRB for phase 1 (with some minor wording changes). (The difference between phase 1 and phase 2 is survey format - Q-sort versus a standard survey with rating/ranking scale items). The consent form has also been slightly revised to reflect the different survey format, as well as that less time is required to complete the online/in-person survey than was required to complete the Q-sort.

You will be sent a reminder from ETHOS to submit a Continuing Review submission for this study. You must submit your Continuing Review no later than 30 days prior to the last day of approval in order for your study to be reviewed and approved for another Continuing Review period. If Continuing Review approval is not granted before 2/7/2018, approval of this protocol expires immediately after that date.

You must also submit a Modification in ETHOS for review and approval prior to making any changes to this study.

If consent forms or recruitment materials were approved, those are located under the Final column in the Documents tab in the ETHOS study workspace.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the [HRPP Toolkit Library](#) on the IRB website.

For grant certification purposes, you will need the approval and last day of approval dates listed above and the Assurance of Compliance number which is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Children's Specialty Healthcare FWA00004003).

Sincerely,

Clinton Dietrich, MA, CIP  
IRB Analyst

We value feedback from the research community and would like to hear about your experience. The link below will take you to a brief survey that will take a minute or two

to complete. The questions are basic, but your responses will help us better understand what we are doing well and areas that may require improvement. Thank you in advance for completing the survey.

Even if you have provided feedback in the past, we want and welcome your evaluation.

[https://umn.qualtrics.com/SE/?SID=SV\\_5BiYrqPNMJRQSBn](https://umn.qualtrics.com/SE/?SID=SV_5BiYrqPNMJRQSBn)

**Appendix I. Correlation among Perspectives (Phase 2)**

	1 (Medical Model)	2 (ADRD Caregivers)	3 (AL)	4 (Vulnerable)	5 (Connected)	6 (Individualized)
1 (Medical Model)	1.00					
2 (ADRD)	0.25	1.00				
3 (AL)	0.40	0.08	1.00			
4 (Vulnerable)	0.42	0.17	0.31	1.00		
5 (Connected)	0.06	0.28	-0.09	-0.02	1.00	
6 (Individualized)	0.17	0.14	0.16	0.19	0.02	1.00

ADRD=Alzheimer's Disease and Related Dementias; AL=Assisted Living

## Appendix J. Survey Response Rates

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Stakeholder Group	Response Rate
Consumers	Varied by organization and recruitment strategy (range 40-78%)
Families	Unable to determine given recruitment strategies used
LTSS Administrators	22%
LTSS Nursing Leaders	22%
Policy, Regulatory, Advocacy Personnel	97%

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## Appendix K. Full Survey Rating Question Results

### Items Related to Autonomy and Choice

Item	Overall Mean (SD)	Consumer Mean (SD)	Stakeholder Group			Nurse Mean (SD)	Policy Mean (SD)	F	p
			Family Mean (SD)	Admin Mean (SD)					
1. Controlling daily routines	7.69 (2.23)	7.63 (2.33)	6.82 (2.19)	8.09§ (2.30)	7.95§ (1.99)	8.56§ (1.42)	5.97	≤0.0001	
2. Choosing where LTSS is received	7.76 (2.13)	7.67 (2.30)	6.90 (2.57)	8.16§ (1.68)	8.02§ (1.54)	8.64§ (1.46)	6.58	≤0.0001	
3. Deciding who may enter room or home	7.67 (2.45)	7.65 (2.57)	6.51* (2.90)	8.11§ (2.08)	8.05§ (1.81)	8.69§ (1.45)	8.15	≤0.0001	
4. Doing things for myself	7.98 (2.07)	7.57 (2.24)	7.39 (2.27)	8.57*§ (1.80)	8.33 (1.71)	8.75*§ (1.30)	7.04	≤0.0001	
5. Making choices even if others disagree	7.34 (2.57)	6.61 (1.38)	6.38 (2.74)	8.22*§ (2.03)	8.16*§ (1.75)	8.72*§ (1.32)	14.16	≤0.0001	
6. Choosing healthcare providers	7.88 (2.21)	7.95 (2.38)	7.25 (2.55)	8.06 (2.00)	8.05 (1.79)	8.33 (1.53)	2.44	0.05	
7. Making healthcare decisions	8.37 (2.01)	7.80 (2.56)	8.28 (1.99)	8.68* (1.44)	8.72* (1.53)	9.36* (0.83)	6.23	≤0.0001	

\*Group mean significantly different than consumer mean ( $p \leq 0.05$ );

§Professional group mean significantly different than family mean (Bonferroni corrected) ( $p \leq 0.05$ )

See Appendix E for a copy of the full survey items.

**Items related to Dignity and Respect**

Item	Stakeholder Group						F	p
	Overall	Consumer	Family	Admin	Nurse	Policy		
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
1. Receiving individualized care	8.57 (1.84)	7.77 (2.52)	8.81* (1.42)	9.01* (1.21)	9.04* (1.00)	9.11* (0.98)	10.66	≤0.0001
2. Treated with kindness and respect	9.20 (1.52)	8.29 (2.18)	9.53* (0.88)	9.72* (0.56)	9.61* (0.68)	9.81* (0.47)	22.55	≤0.0001
3. Maintain dignity and privacy	8.91 (1.68)	8.11 (2.28)	9.20* (1.31)	9.35* (1.02)	9.26* (0.96)	9.50* (0.81)	13.06	≤0.0001
4. Having concerns taken seriously	8.86 (1.58)	8.26 (2.15)	9.13* (1.18)	9.26* (0.99)	9.11* (1.28)	9.08* (1.13)	8.12	≤0.0001

\*Group mean significantly different than consumer mean ( $p \leq 0.05$ );

§Professional group mean significantly different than family mean (Bonferroni corrected) ( $p \leq 0.05$ )

See Appendix E for a copy of the full survey items.

**Items related to Activities and Social Inclusion**

Item	Stakeholder Group						F	p
	Overall	Consumer	Family	Admin	Nurse	Policy		
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
1. Doing enjoyable things	8.41 (1.69)	7.93 (1.90)	8.26 (1.71)	8.80* (1.41)	8.72* (1.39)	9.00* (1.37)	6.00	≤0.0001
2. Having enough to do so not bored	7.71 (2.09)	7.37 (2.14)	7.64 (2.35)	7.97 (2.03)	8.11 (1.63)	7.89 (1.83)	1.88	0.11
3. Choosing when to be alone or with others	7.89 (1.93)	7.84 (2.10)	7.19 (2.07)	8.10 (1.84)	8.41§ (1.35)	8.47§ (1.36)	5.15	≤0.001
4. Being able to decline activities	8.00 (2.02)	7.58 (2.44)	7.56 (1.90)	8.41*§ (1.83)	8.43 (1.37)	8.94*§ (0.98)	6.33	≤0.0001
5. Going out to do things in community	7.14 (2.41)	7.26 (2.37)	6.15* (2.89)	7.46§ (2.18)	7.52§ (1.98)	7.72§ (1.89)	5.22	≤0.001
6. Staying connected through events	7.09 (2.42)	7.14 (2.52)	6.11* (2.72)	7.52§ (2.17)	7.16 (2.07)	7.92§ (1.70)	5.61	≤0.001
7. Having reliable transportation	7.88 (2.24)	8.26 (1.81)	6.47* (3.06)	8.11§ (1.94)	8.35§ (1.57)	8.44§ (1.61)	12.22	≤0.0001

\*Group mean significantly different than consumer mean ( $p \leq 0.05$ );

§Professional group mean significantly different than family mean (Bonferroni corrected) ( $p \leq 0.05$ )

See Appendix E for a copy of the full survey items.

**Items related to Meals and Food Enjoyment**

Item	Stakeholder Group						F	p
	Overall	Consumer	Family	Admin	Nurse	Policy		
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
1. Pleasant, enjoyable mealtimes	8.25 (1.75)	7.54 (2.16)	8.52* (1.44)	8.69* (1.38)	8.74 (1.23)	8.36 (1.46)	9.36	≤0.0001
2. Eating foods liked	8.31 (1.70)	7.78 (2.03)	8.34 (1.64)	8.73* (1.31)	8.67* (1.27)	8.69* (1.41)	6.14	≤0.0001
3. Choosing where and with whom to eat	7.65 (2.15)	7.28 (2.35)	7.40 (2.25)	7.97 (2.06)	7.94 (1.74)	8.42* (1.54)	3.27	0.01

\*Group mean significantly different than consumer mean ( $p \leq 0.05$ );

§Professional group mean significantly different than family mean (Bonferroni corrected) ( $p \leq 0.05$ )

See Appendix E for a copy of the full survey items.

**Items related to Relationships**

Item	Stakeholder Group						F	p
	Overall	Consumer	Family	Admin	Nurse	Policy		
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
1. Seeing family and friends	8.83 (1.47)	8.49 (1.67)	8.99 (1.67)	8.94 (1.16)	9.04 (1.20)	9.22 (0.99)	3.23	≤0.01
2. Relationships with staff	8.62 (1.42)	8.28 (1.50)	8.71 (1.49)	8.97* (1.17)	8.81 (1.37)	8.56 (1.34)	3.81	≤0.01
3. Not being lonely	8.37 (1.85)	7.69 (2.18)	8.65* (1.73)	8.75* (1.61)	8.80* (1.34)	8.58 (1.36)	7.31	≤0.0001
4. Helping others when possible	7.80 (2.08)	7.93 (1.81)	7.02* (2.68)	8.06 <sup>§</sup> (2.03)	7.94 (1.75)	8.19 <sup>§</sup> (1.56)	4.02	≤0.01
5. Feeling cared about by others	8.77 (1.58)	7.95 (1.91)	9.14* (1.42)	9.29* (0.95)	9.13* (1.13)	9.11* (1.17)	16.19	≤0.0001
6. Feeling connected to people around	8.20 (1.92)	7.70 (2.11)	7.99 (2.35)	8.66* (1.45)	8.70* (1.37)	8.72* (1.16)	5.73	≤0.01

\*Group mean significantly different than consumer mean ( $p \leq 0.05$ );

<sup>§</sup>Professional group mean significantly different than family mean (Bonferroni corrected) ( $p \leq 0.05$ )

See Appendix E for a copy of the full survey items.

**Items related to Safety and Security**

Item	Stakeholder Group						F	P
	Overall	Consumer	Family	Admin	Nurse	Policy		
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
1. Be assured of needed assistance	9.21 (1.21)	8.76 (1.46)	9.19 (1.32)	9.58* (0.78)	9.57* (0.72)	9.47* (0.70)	9.21	≤0.0001
2. Being safe from abuse or intimidation	9.21 (1.35)	8.48 (1.76)	9.44* (1.07)	9.66* (0.65)	9.52* (1.06)	9.81* (0.52)	18.34	≤0.0001
3. Receiving assistance that avoids injury	9.19 (1.35)	8.55 (1.69)	9.35* (1.29)	9.63* (0.66)	9.44* (1.16)	9.72* (0.61)	13.77	≤0.0001
4. Belongings safe from being lost or stolen	8.83 (1.65)	8.55 (1.98)	8.44 (1.86)	9.25* (1.13)	9.26 <sup>§</sup> (1.10)	9.17 <sup>§</sup> (1.13)	5.16	≤0.001

\*Group mean significantly different than consumer mean (p≤0.05);

<sup>§</sup>Professional group mean significantly different than family mean (Bonferroni corrected) (p≤0.05)

See Appendix E for a copy of the full survey items.

**Items related to Staffing and Staff Competence**

Item	Stakeholder Group						F	p
	Overall	Consumer	Family	Admin	Nurse	Policy		
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
1. Receiving sufficient help	8.50 (1.61)	7.87 (1.91)	8.74* (1.51)	8.86* (1.39)	8.83* (1.20)	8.81* (1.06)	8.02	≤0.0001
2. Being free of pain or discomfort	8.80 (1.46)	8.41 (1.74)	8.90 (1.44)	9.00* (1.15)	9.08* (1.16)	9.00 (1.35)	3.57	≤0.01
3. Having skilled and competent staff	8.95 (1.34)	8.45 (1.64)	9.07* (1.26)	9.33* (0.94)	9.25* (0.98)	9.00 (1.20)	7.63	≤0.0001
4. Having health monitored	8.53 (1.63)	8.14 (1.89)	8.46 (1.72)	8.90* (1.20)	8.89* (1.37)	8.56 (1.42)	3.84	≤0.01
5. Receiving help from consistent staff	7.80 (1.92)	7.30 (2.05)	7.76 (2.16)	8.19* (1.61)	8.23* (1.53)	8.00 (1.71)	4.00	≤0.01
6. Communication among staff/providers	8.82 (1.46)	8.34 (1.76)	9.06* (1.43)	9.08* (1.15)	9.11* (1.01)	8.89 (1.21)	5.50	≤0.001

\*Group mean significantly different than consumer mean (p≤0.05);

§Professional group mean significantly different than family mean (Bonferroni corrected) (p≤0.05)

See Appendix E for a copy of the full survey items.

**Items related to Emotional and Spiritual Wellbeing**

Item	Stakeholder Group						F	p
	Overall	Consumer	Family	Admin	Nurse	Policy		
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
1. Not anxious or depressed	8.29 (1.70)	7.89 (2.09)	8.40 (1.53)	8.38 (1.49)	8.68* (1.16)	8.65 (1.47)	3.07	≤0.05
2. Feeling calm and peaceful	8.29 (1.66)	8.11 (1.92)	8.43 (1.51)	8.29 (1.55)	8.55 (1.37)	8.24 (1.65)	0.88	0.47
3. Being happy	8.25 (1.70)	7.99 (1.90)	8.44 (1.44)	8.30 (1.66)	8.45 (1.55)	8.37 (1.75)	1.28	0.28
4. Feeling a sense of purpose	8.26 (1.95)	8.02 (2.02)	7.89 (2.29)	8.53 (1.77)	8.68 (1.33)	8.74 (1.70)	2.95	≤0.05
5. Having religious and spiritual needs met	8.10 (2.10)	7.88 (2.29)	7.52 (2.60)	8.56 <sup>§</sup> (1.56)	8.62 <sup>§</sup> (1.36)	8.37 (1.61)	4.27	≤0.01
6. Having someone to talk to when needed	8.12 (2.03)	7.57 (2.40)	8.13 (2.17)	8.44* (1.67)	8.68* (1.22)	8.46 (1.48)	4.40	≤0.01

\*Group mean significantly different than consumer mean (p≤0.05);

<sup>§</sup>Professional group mean significantly different than family mean (Bonferroni corrected) (p≤0.05)

See Appendix E for a copy of the full survey items.

**Items related to the Physical Environment**

Item	Stakeholder Group						F	p
	Overall	Consumer	Family	Admin	Nurse	Policy		
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)		
1. Living in a place that feels like home	8.55 (1.52)	8.56 (1.56)	8.48 (1.67)	8.51 (1.50)	8.77 (1.18)	8.47 (1.54)	0.36	0.83
2. Having own room or home	8.44 (1.97)	8.51 (2.02)	8.69 (1.94)	8.01 (2.22)	8.44 (1.66)	8.71 (1.41)	1.67	0.16
3. Space easy to get around in	8.55 (1.45)	8.43 (1.55)	8.51 (1.65)	8.77 (1.32)	8.52 (1.16)	8.59 (1.26)	0.82	0.51
4. Space promotes independence	8.19 (1.85)	8.24 (1.74)	7.78 (2.33)	8.29 (1.94)	8.31 (1.23)	8.51 (1.25)	1.49	0.20
5. Being able to personalize space	8.48 (1.69)	8.29 (1.87)	8.29 (1.95)	8.76 (1.42)	8.60 (1.43)	8.71 (1.20)	1.56	0.18
6. Feeling connected to the outdoors	7.77 (2.18)	7.98 (2.27)	7.27 (2.60)	7.86 (1.80)	8.02 (1.67)	7.56 (2.20)	1.76	0.14
7. Having a private bathroom	8.28 (1.93)	8.77 (1.70)	8.37 (2.12)	7.65* (2.03)	8.10 (1.63)	8.17 (1.95)	5.05	≤0.001

\*Group mean significantly different than consumer mean ( $p \leq 0.05$ );

§Professional group mean significantly different than family mean (Bonferroni corrected) ( $p \leq 0.05$ )

See Appendix E for a copy of the full survey items.