



Understanding Contextual Differences in Residential LTC Provision for Cross-National Research: Identifying Internationally Relevant CDEs

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Abstract

Long-term care (LTC) reflects a growing emphasis on person-centered care (PCC), with services oriented around individuals' needs and preferences. Addressing contextual and cultural differences across countries offers important insight into factors that facilitate or hinder application of PCC practices within and across countries. This article takes an international lens to consider country-specific contexts of LTC, describing preliminary steps to develop common data elements that capture contextual differences across LTC settings globally. Through an iterative series of online, telephone, and in-person sessions, we engaged in in-depth discussions with 11 colleague experts in residential LTC and coauthors from six countries (China and Hong Kong, England, Sweden, Thailand, Trinidad and Tobago, and the United States). Our discussions yielded rich narrative describing a vast range in types of LTC settings, leading to our development of a working definition of residential LTC. Scope of services, funding, ownership, and regulations varied greatly across countries and across different residential LTC settings within countries. Moving forward, we recommend expanding our activities to countries that reflect different stages of residential LTC development. Our goal is to contribute to a larger initiative underway by the WE-THRIVE consortium to establish a global research measurement infrastructure that advances PCC internationally.

Keywords

financing, regulation, nursing home, ownership, nursing

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Introduction

Recent trends have shown a growing shift in the configuration of services for older people, emphasizing services delivered to the person's home. There remains, however, a global demand for long-term care (LTC) (Organisation for Economic Co-operation and Development (OECD), 2017) with increasing emphasis on individualized, needs-oriented services. Developed countries, including the United States and Scandinavian countries, have implemented a number of innovative strategies for the delivery of services for older adults including assisted living, hospice care, community-based alternative programs, and public/private partnerships (Sloane, Zimmerman, & D'Souza, 2014). The demands for services as well as the nature of LTC services will continue to change, consistent with a number of economic, technological, and biological factors (International Federation on Ageing, 2012; Sloane

et al., 2014) and the level of functioning and type of service needed (Cesar, 2017).

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Person-Centered Care (PCC) as a Global Strategy and Vision

The institutional nature of LTC has given way to a culture change movement, with focused attention to person-centered structures and processes (Edvardsson, Winblad, & Sandman, 2008; Sloane et al., 2014). The concept of PCC—based on a humanistic philosophy and ethical values—is considered the gold standard by nursing for LTC delivery (Brooker, 2004; Edvardsson et al., 2008; McCormack, 2004; McCormack & McCance, 2006). Although there is no internationally agreed-upon definition of PCC, central PCC features reflected in existing conceptualizations include maintaining personhood despite illness, using personal experiences to individualize care and the environment, creating a supportive social environment, prioritizing relationships and seeing behavior from the person's perspective, involving relatives in care and offering shared decision making (Brooker, 2004; Edvardsson et al., 2008; McCormack, 2004; McCormack & McCance, 2006). Evidence suggests that PCC can be delivered effectively (Rokstad, Vatne, Engedal, & Selbaek, 2015; Rosemond, Hanson, Ennett, Schenck, & Weiner, 2012), and residents in LTC can benefit from this approach (Bone, Cheung, & Wade, 2010; Chenoweth et al., 2009; Rokstad et al., 2015). The concept of PCC has been embedded in international policy documents and guidelines worldwide (Department of Health & Social Care, 2009; Swedish National Board of Health and Welfare, 2017; U.S. Department of Health & Human Services, 2010), and the World Health Organization (WHO) has declared person-centered services a global strategy to address the diverse range of care needs emerging as the population ages (WHO, 2015b).

LTC and PCC Contextual Differences and Challenges for Cross-National Research

International research and practice communities highlight the need for conceptual clarity and a shared understanding of the structures and formalization of LTC systems across contexts globally (Harding, Wait, & Scrutton, 2015; McCance, McCormack, & Dewing, 2011; WHO, 2015a). Although recent trends show a growing emphasis on individualized, needs-oriented services, dramatic variations exist in the availability and affordability of LTC services between low-, middle-, and high-income countries across the globe (OECD, 2017; WHO, 2015b). Cultural, socioeconomic, political, and geographical factors and LTC systems inform the way PCC services are adopted (WHO, 2015b). With challenges in translation of PCC in practice (Edvardsson, Sandman, & Borell, 2014; Moore et al., 2017; WHO, 2015b), PCC needs to be considered in wider contexts (McCormack, Karlsson, Dewing, & Lerdal, 2010). Attention to contextual and cultural differences offers important insights into factors that facilitate and hinder application of PCC practices within and across countries and serves as a basis for interpreting study findings and

identifying ways to organize, measure, implement, and sustain PCC in everyday practice.

This article takes an international lens to consider the context of LTC in different countries. We describe preliminary steps to develop common data elements (CDEs) that capture contextual differences across LTC settings globally. CDEs are specific types of data (i.e., data elements) that can be collected across research studies and used for cross-study comparisons, data aggregation, and data sharing (U.S. National Library of Medicine, 2013). Our goal is to contribute to a larger initiative—underway by the Corazzini et al., 2019 consortium—to establish a global research measurement infrastructure that advances PCC internationally (Corazzini et al., 2019). This article describes efforts of the (WE-THRIVE) workgroup focused specifically on developing international CDEs for the *context domain* of residential LTC settings. Our workgroup includes representation from mainland China and Hong Kong, England, Japan, Sweden, Thailand, Trinidad and Tobago, and the United States.

Approach

During the year leading up to the IAGG 2017 World Congress of Gerontology and Geriatrics, various members of our workgroup met via online conferencing to explore candidate CDE concepts to capture the contexts of residential LTC internationally, and we continued our work in person at the (WE-THRIVE) preconference at IAGG 2017 (Corazzini et al., 2019). Using a nominal group process, we identified and prioritized three key concepts specific to the external context of residential LTC: *social resources and support, funding, and regulation*. Our initial goal was to develop conceptual and operational definitions for each concept and identify existing assessment/measurement tools, with input from the literature and LTC experts and mindfulness to applicability across countries, including low- and middle-income countries. Through an iterative series of activities following the IAGG preconference, we conducted online, telephone, and in-person sessions to collect information about the country-specific relevance of each of the three core concepts from 11 colleague experts in residential LTC and coauthors from six countries in total, representing mainland China and Hong Kong, England, Sweden, Thailand, Trinidad and Tobago, and the United States. Refer to Figure 1 for a map of the countries represented and the percentage of their population aged 65+ years.

The initial set of questions posed to our colleague experts focused on clarity and completeness of the three concepts identified at the IAGG 2017 preconference (*social resources and support, funding, and regulation*), including country-specific relevance of each concept to care outcomes, country-relevant definitions of each concept, and suggested tools/measures of the concepts. Our discussions yielded rich narrative describing a vast range in types of LTC settings and underlying

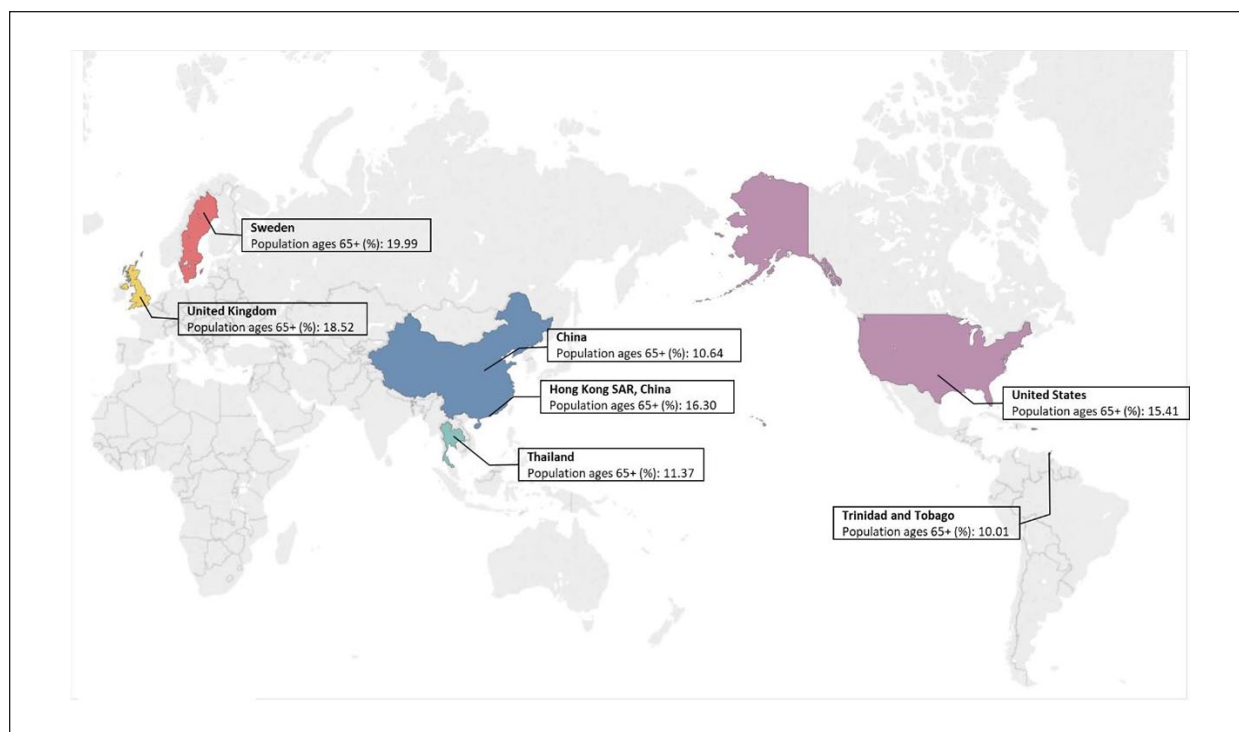


Figure 1. Countries and regions included in this article and their proportion of older adults.

Source. 2017 World Bank open data: <https://data.worldbank.org/>

sociocultural and political contexts, prompting us to broaden our inquiry to include key distinctions that differentiate (a) *residential LTC* from the broader umbrella term used for LTC within a country and (b) residential LTC settings within and across countries.

We explored the feasibility of an electronic survey to expand the number of countries represented by our initial inquiry. Our pilot testing suggested high response burden due to, first, multiple survey response fields for each of the different types of residential LTC settings within a country; and second, the lack of universal understanding of various terms (e.g., social support/services, short term/long term stay, etc.). Therefore, we continued our information-gathering sessions using in-person and online discussions to clarify and summarize points as needed. For the next phase of this work, our goal is to use the insights gained from these initial sessions as a basis for developing a low response burden survey to capture the varying contexts of residential LTC across a larger sample of high-, middle-, and low-income countries.

Insights Gained From Our Initial Information-Gathering Sessions

A key finding from the sessions was the heterogeneity of residential LTC provision within any one country. For example, in Hong Kong, two types of settings offer residential LTC (*care and attention home, nursing home*) and three in England (*care home with on-site nursing, care home/beds without nursing, and housing that offers access to daily care*).

Key Distinctions That Differentiate Residential LTC From the Broader Umbrella Term Used for LTC

We noted different factors driving the types and extent of services, with implications for defining residential LTC settings as a distinct subset of the broader LTC services available in a given country. For example, a colleague spoke about the Chinese government funding LTC that offers room and board for rural older adults without children and no pension, and in return, they help with chores at the facilities, such as cooking, raising chickens, and so on. Others described LTC settings offering a consumer-driven “pay as you need” service, such as models supporting independent living (e.g., built villages in England, continuing care communities in the United States), with individuals moving to communities where they own/rent their own individual home/apartment with guaranteed access to personal care if needed.

Country-specific terminologies, variations in the formalization and structure of LTC services, and potentially vague distinctions between types of LTC provision added to the complexities of establishing a common understanding and standardized language for residential LTC in a given country. Our informal search of literature for a definition of *residential LTC* was inconclusive. Sanford and colleagues’ (2015) proposed international definition for the term *nursing home*, reflects a continuum of short-term and LTC services, with potential for some settings to focus primarily on short-term services. In the United States, while definitions of *residential care communities* are

Table 1. Types of and Expected Time Frames for Residential LTC Services.

Type of services	<ul style="list-style-type: none"> • Medical providers and/or nursing as a component of standard care services <ul style="list-style-type: none"> On-staff On-call, as needed and/or routine visits • Medical providers and/or nursing available by request, with fee for service
Expected time frame for services	<ul style="list-style-type: none"> • Short term <ul style="list-style-type: none"> Postacute services following hospital discharge Hospice care Respite care Rehabilitation services • Long term <ul style="list-style-type: none"> Personal care, ongoing support for chronic conditions Range of acute care services based on setting-specific criteria

Note. LTC = long-term care.

based on state-specific licensing or certification categories (Carder, O’Keeffe, & O’Keeffe, 2015), nursing homes/skilled nursing facilities are classified as a separate category (National Center for Health Statistics, 2018). Based on the country-specific information provided by our colleague experts, including the range of setting-specific terminology and contexts/criteria for LTC settings within and across countries, we drafted our own working definition for *residential LTC*.

Any type of setting other than the older adult’s own home, home of family/friends, or a hospital-based facility, where:

(1) older adults reside and receive some type of long term care services from paid staff (not just as requested), and

(2) there is the expectation of a long-stay, rather than short-stay rehabilitation and/or acute medical care followed by return to the community [i.e., intent to return to home/community].

Key Distinctions of Residential LTC Settings Within and Across Countries

Scope of services. Within the general scope of our working definition of *residential LTC*, our colleagues described a wide range of services and admission criteria for different settings, including various models for the provision of medical and nursing services, including: one or both types of providers on staff; routine provider visits or on-call services as part of standard care; and one or both types of providers available only if requested and paid for by encounter (i.e., a consumer-driven model). In addition, we noted the need for careful enquiry and discussion to clarify meanings of different terms. For example, medical services provided in a given type of setting may refer to services provided solely by nurses. Equally, in some countries, the term “*nurse*” is a title protected by statute, whereas in other countries, the term can include paid unlicensed assistive personnel or carers.

Some residential LTC settings in certain countries offer care intended for short term, including postacute services following hospital discharge, rehabilitation, respite services, intermediate care, and palliative and/or hospice care (e.g., the United States and Swedish *nursing homes* and English *care homes*). Our colleagues from Hong Kong highlighted a delineation between residential LTC services and long-term medical care services for older adults and disabled persons requiring 24/7 medical/nursing oversight for the remainder of their lives due to some type of trauma/accident or medical condition (e.g., seizures); depending on their level of dependency, these individuals will reside in one of the two types of residential LTC settings (*care and attention home* or *nursing home*) or in an *infirmarium ward* if care needs exceed those offered in the residential LTC settings. In China, some settings lack clear differentiation between medical/acute care settings and residential LTC settings. For example, some major hospitals have geriatric wards, with many of these in-patient wards providing LTC services (i.e., patients may stay for long periods of time). In addition, some community-level hospitals referred to as geriatric hospitals/nursing homes actually serve as LTC residential facilities. Table 1 provides a summary of our findings related to various types of services and expected time frames for services.

Specific services for dementia care also varied across countries, including dementia-specific facilities (Sweden) and specialist provision or units within more generalist settings (England, the United States, Sweden). In China, older adults with dementia are excluded from admission to many LTC facilities. In Hong Kong, while there are no government-sponsored LTC facilities providing specific space for dementia care service, facilities attend to the care needs of residents with cognitive impairment; some high-end private settings offer dementia-specific units. Figure 2 highlights the range of dementia-specific services identified across countries.

Within-country differences in scope of services across some care settings are flexible. For example, in Sweden, there are no limits concerning levels of care for

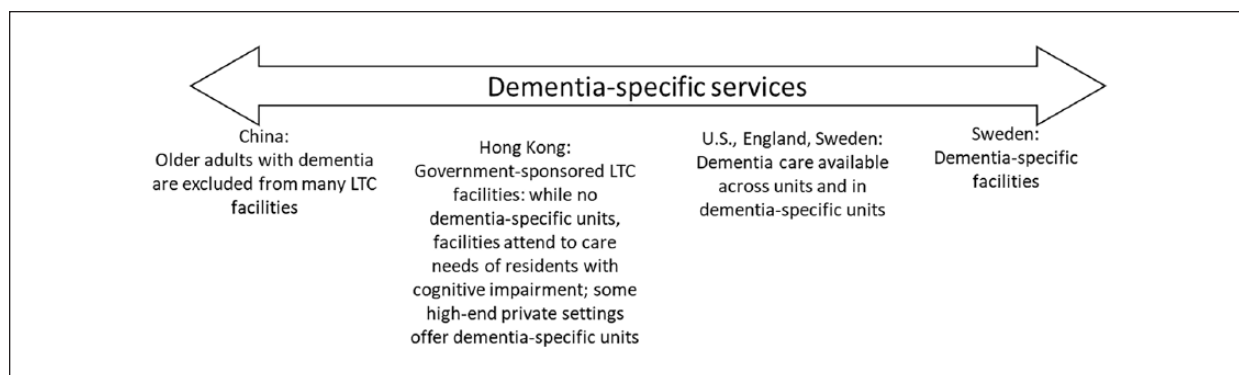


Figure 2. Examples of range in dementia-specific services in residential LTC settings across countries.
Note. LTC = long-term care.

a given unit (general or dementia). If an individual resides in a general unit and develops dementia, they can still stay in that particular unit. If they have dementia before moving to a residential LTC setting, attempts will be made to offer a dementia-specific unit; but if none are available, they will be offered a place in a general setting, and that general setting is obligated to provide care as needed. In England, sometimes a resident in a setting without on-site nursing will be reassessed as needing nursing care, requiring a move to another institution. In settings where there is dual provision of nursing and nonnursing services, situations involving a change in nursing care needs are easier to manage, as relocations to other settings are not needed.

Funding and ownership. We identified multiple funding streams for LTC, with implications for how and why people chose a facility. At a high level, government- and private-funding categories are applicable across countries. However, some settings receive funding from a mixture of payers; a country might have government-owned facilities and private facilities, and when the state provision is limited, the government might pay for a bed in a private facility that meets certain accreditation standards (e.g., Hong Kong). In England, the dominant method of provision is by independent providers (for profit and not for profit). Some of these providers will only accept residents who are able to self-fund and do not hold contracts with local authorities. Others accept a mixture of state-funded residents and self-funders. In some situations, relatives will provide “top up” funding (i.e., in addition to state funding) to secure the care home of their choice. Residents who are assessed as needing care equivalent to care that would otherwise be provided in a hospital will have their care paid by the National Health Service. In Trinidad and Tobago, LTC ownership is primarily private and residents pay for care using a government pension available to all individuals; however, individuals may need to access and pay for outside supplementary care if care needs are not covered by their pension. In other countries (e.g., the United States), non-government-owned facilities commonly receive more

than half of their funding from public sources. In Thailand, welfare homes are available based on financial need and to those who have no caregiver or cannot live with their caregiver at home. Nursing homes in Thailand are owned by the private sector; lower and middle-income individuals often cannot afford the services of private settings.

Regulation. Although residential LTC regulations and enforcement in England, Sweden, and the United States are well-established, other countries reflect various stages of regulatory development and enforcement. For example, in Thailand, standards and regulations for LTC facilities are currently waiting enactment in law. In Trinidad and Tobago, we understand that the legislation has been approved by the Parliament for Homes for older persons, but this has not been proclaimed by the President; furthermore, regulations exist under a different legislation in relation to care for older persons, but these are not necessarily enforced or monitored. In China, standardized requirements are established, but there is inconsistency in their enforcement or monitoring. Our colleagues in Hong Kong indicate the enforcement of regulations is emerging as the government considers the region’s increasing demand in services for the elderly. Refer to Figure 3 for an illustration of the range in development and enforcement of residential LTC regulations.

In countries with any level of established regulations, the scope or focus of regulations varies. For example, some countries have regulations spanning environment, safety, and quality (e.g., the United States, England, Sweden), whereas in other countries, the focus of regulations may be more specific and vary across setting types. For example, in Hong Kong, regulations in *care and attention homes* focus on environment and safety (e.g., fire alarms) and in *nursing homes*, regulations focus on requirements for the nursing workforce.

Other country/setting-specific characteristics: Age, personal space. Although age was not highlighted by most of our colleague experts as a key distinction between criteria for entry to different settings, we learned from discussions

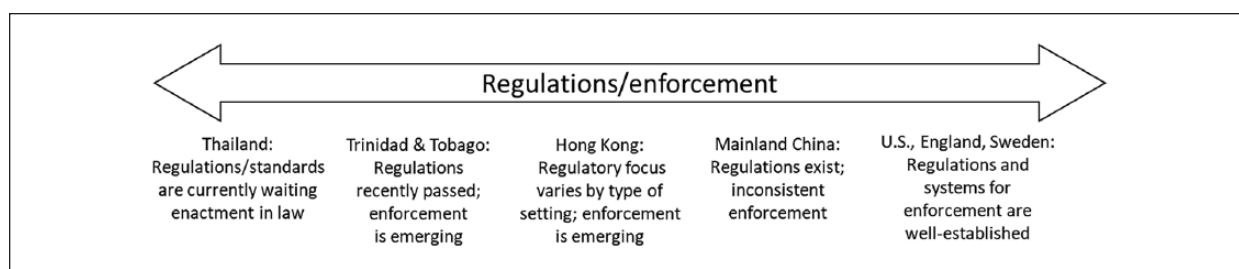


Figure 3. Examples of range in scope and enforcement of residential LTC regulations.
Note. LTC = long-term care.

with our colleagues from Sweden and England that there are different residential LTC settings for individuals above or below 65 years of age; even if the same services are needed, individuals younger than 65 years with congenital or acquired disabilities are served in a different setting. In Hong Kong, an age-eligibility criteria to receive elderly welfare for LTC is currently under discussion.

In addition to age, some colleagues spoke about allocation of personal space to individuals in residential LTC. For example, our colleagues from Hong Kong referred to floor space requirements of at least 65 ft² per resident, with an emphasis on “efficiency” of personal space due to population density and limited availability of land. In contrast, our colleague from Sweden described most residential LTC settings as offering mini-apartment-type spaces, with small kitchens and bedrooms that can accommodate spouses to coreside even if they do not require LTC services. Further inquiry is needed to determine the extent of these and other types of characteristics, which are contextual key factors to differentiating between residential LTC settings within and across countries.

Discussion and Next Steps

This article represents work in progress toward developing internationally relevant CDEs that can capture contextual differences across residential LTC settings globally. Our work aligns with WHO/IAGG findings that there is a major need for more in-depth investigations of nursing home care worldwide (Tolson et al., 2013) and complements the health care organizational-specific context work of Estabrooks and colleagues (2009) and others (Goodman, Unpublished).

Unlike hospital settings that are arguably more comparable, discussions with our colleague experts reflected heterogeneity of the residential LTC sector, both within and across countries. Similar to prior research that identified heterogeneity in nursing home populations and the ambiguity of the term “nursing home” used in international literature (Sanford et al., 2015), we discovered a wide range of services offered by residential LTC settings across and within countries, ranging from the sole provision of social services to a range of nursing/medical services and specialty care services, such as dementia care. In addition, we identified a few key contextual

characteristics (age criteria and inclusion/exclusion of people with non-age-related medical conditions or high acuity care needs) that should be considered in terms of a working definition of residential LTC. Moving forward, we recommend expanding the scope of inquiry to a larger sample of residential LTC settings across and within countries, including high-, middle-, and low-income countries that reflect different stages of residential LTC development.

Further work is needed to develop conceptual/operational definitions of key concepts that distinguish settings within and across countries, including funding sources, government/private ownership, mixture of public/private funding, and regulation and enforcement. In addition, expanding our inquiry will offer opportunities to further explore the influence of a new concept that emerged from our work—allocations of personal space—as a potentially important contextual factor, along with others that may emerge from future inquiry. This research direction will provide a mechanism for pinpointing commonalities and differences across countries, ultimately informing debates about international standards, the scope and range of residential LTC for different populations, regulatory practices across countries, and the development of tools to evaluate the quality of care across countries.

Our findings of variations in scope, implementation, and enforcement of regulations for LTC across countries further highlights the absence of a cross-national understanding of quality care and a minimum standard of provision. This is in contrast to what we would argue is a shared understanding of the value of person-centered approaches and settings that support PCC (WHO, 2015a, 2015b). High-quality PCC is focal for residents. One study conducted in residential LTC in China suggests that resident-centered care should be an important principal to improve older residents’ quality of life (Wang, Wang, Cao, Jia, & Wu, 2018), with empowering care an important attribute of resident-centered care (Morgan & Yoder, 2012).

Residential LTC is highly context-specific and determined by how hospital and community services are organized to support older people in need of LTC. More research on improving PCC in residential LTC facilities worldwide is in great need (Corazzini et al., 2019). Our

overarching goal is to develop CDEs for key characteristics of residential LTC contexts that can inform the development of culturally appropriate and effective person-centered interventions for some of the most vulnerable members of society. Globally, the use of CDEs—in combination with local values and cultural preferences—can inform policy makers and health care professionals in their design and implementation of PCC policies, programs, and services.

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