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Person-Centeredness in Home- and Community-Based Services and Supports: Domains, Attributes, and Assisted Living Indicators

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Abstract

As a result of the Centers for Medicare & Medicaid Services (CMS) interest in creating a unifying definition of “community living” for its Medicaid Home and Community Based Services and Support (HCBS) programs, it needed clarifying descriptors of person-centered (PC) practices in assisted living to distinguish them from institutional ones. Additionally, CMS’s proposed language defining “community living” had the unintended potential to exclude many assisted living communities and disadvantage residents who receive Medicaid. This manuscript describes the consensus process through which clarifying language for “community living” and a framework for HCBS PC domains, attributes, and indicators specific to assisted living were developed. It examines the validity of those domains based on literature review, surveys, and stakeholder focus groups, and identifies nine domains and 43 indicators that provide a foundation for defining and measuring PC practice in assisted living. Ongoing efforts using community-based participatory research methods are further refining and testing PC indicators for assisted living to advance knowledge, operational policies, practices, and quality outcomes.

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Keywords

person centered; person-centered care; HCBS; assisted living/residential care

Introduction

More than five million older and dependent adults rely on home and community-based services (home health care, homemaker services, adult day care, in-home skilled nursing care, assisted living) and supports (home-delivered meals, transportation, and case management) to remain in their homes and communities (AARP, 2011). More than three million of them are receiving Medicaid funding for these services and supports (Harrington, Ng, Kaye, & Sumer, 2009). Thus, it was of significance that in April, 2011 the Centers for Medicare & Medicaid Services (CMS), which administer Medicaid Home and Community Based Services and Supports (HCBS), announced proposed rule-making language related to person-centeredness (PC) that would potentially affect this funding. Specifically, CMS proposed new language defining "community living": "…home and community settings may not include a building that is also a publicly or privately operated facility which provides **inpatient institutional treatment or custodial care**; or in a building on the **grounds of, or immediately adjacent to, a public institution** or **disability-specific housing** complex, designed expressly around an individual's diagnosis that is geographically segregated from the larger community."

The Center for Excellence in Assisted Living (CEAL) and numerous other stakeholders were concerned that this proposed language, if applied to assisted living, could jeopardize Medicaid funding. Assisted living settings are a specific type of HCBS that provide room, at least one meal a day, support for activities of daily living, and unscheduled oversight 24 hours a day, to three quarters of a million older adults (Park-Lee, Caffrey, Sengupta, Moss, Rosenoff, and Harris-Kojetin, 2011; Zimmerman, Sloane, and Eckert, 2001). Because there currently are no national definitions or measures of PC by which to assess services or supports, an assisted living setting could be deemed "institutional" and so excluded from offering HCB Medicaid-supported services. Second, the proposed language excludes "disability-specific housing." Many assisted living settings are, or have, dementia or memory-specific residences, which is an important development considering that the majority of assisted living residents have cognitive impairment or dementia (Tilly and Reed, 2006; Zimmerman et al., 2007). Further, there are benefits for this "disability-specific" population to reside in these specialized environments, as their environmental features and physical structure are often designed to support and maximize independence and function (CARF, 2010). Finally, the proposed language could exclude HCBS Medicaid payments for service providers who operate assisted living as part of a campus that provides multiple levels of care, such as some continuing care retirement communities (CCRCs) or other assisted living-nursing home combinations; in each instance, assisted living could be considered as provided "… on the grounds of, or immediately adjacent to, a public institution" if the nursing home were considered a "public institution" in this context.

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Assisted living is primarily private-pay and not a federal or state entitlement program as is nursing home care for eligible, low-income individuals. However, many states have Medicaid waivers in place that provide *some* support for what is generally known as "assisted living"; at present 39 states have waiver programs in place, and several others are currently considering implementing a waiver program. These waivers vary from state-to-state, with some states imposing strict limits on the number of people served, while others reimburse only a small number of within-network providers or a limited number of services, and still others require that residents be eligible for, or transitioning from, nursing home care (National Center for Assisted Living, 2012). Recent reports show that approximately 19% of residents in assisted living receive support from Medicaid (Caffrey, Sengupta, Park-Lee, Moss, Rosenoff, and Harris-Kojetin, 2012). The opportunity to reside in assisted living is consistent with the *Olmstead v. L.C.* U.S. Supreme Court decision that mandates states to serve individuals in the least restrictive setting possible, as assisted living often meets the test of being a less restrictive environment for individuals with disabilities cited under *Olmstead*.

While assisted living is often perceived as inherently providing PC services and supports, this is not always the case. Assisted living communities are at various stages in their awareness, understanding, and implementation of the comprehensive structures, processes, and outcomes delineated in PC resource materials (Love, 2010; Frampton, 2010). For example, while assisted living pioneered the introduction of PC features of home (e.g., encouragement for residents to bring their own furnishings; laundry areas for resident use; meals served on table linen instead of on bare table tops or trays; front porches with rocking chairs and gliders; private dining rooms; carpeting; handrails crafted out of woodwork; no overhead announcement systems), many institutional practices are still exhibited in some settings including waking residents for staff convenience; hierarchical, non-staff empowered management practices; lack of consistent staff assignment; group approach to activities; and lack of understanding of the purpose and value of supporting meaningful life for each resident. While some of these practices and policies may be attributed to the increasing acuity of assisted living residents, there is no reason that attention to health care needs must preclude PC practice; in fact, the intersection of these two philosophies is the basis of the "culture change" movement that has been striving to reform nursing home care (Koren, 2010). As a case in point, Green House nursing homes illustrate the extent to which PC can be incorporated into nursing home care, as these small homes have private rooms for only 6–12 elders, and care is provided by a consistent, self-directed team of staff who are responsible for all care ranging from preparing meals in a centrally located open kitchen, to engaging in social activities (Zimmerman & Cohen, 2010).

Recognizing that the CEAL, a collaborative of 11 diverse national organizations[1] dedicated to fostering high quality assisted living, had undertaken broad discussion and examination of PC in assisted living to advance operational knowledge and practices (Love, 2010), CMS

[1]Organization members of CEAL include AARP, the Alzheimer's Association, the American Assisted Living Nurses Association (ALNA), the American Seniors Housing Association (ASHA), the Assisted Living Federation of America (ALFA), the Consumer Consortium for Advancing Person-Centered Living (CCAL), the National Center for Assisted Living (NCAL), NCB Capital Impact, LeadingAge, Paralyzed Veterans of America, and the Pioneer Network.

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was interested in having CEAL inform their current HCBS efforts by developing consensus recommendations on the definition of and PC practices from the perspective of the national assisted living community. The CEAL Board of Directors, in collaboration with the University of North Carolina at Chapel Hill (UNC), developed a framework of consensus domains and attributes of PC in HCBS in general, as well as more specific measurable indicators of PC in assisted living. This paper describes the domains, attributes, and indicators derived by consensus, and examines the validity of the domains based on literature review and expert stakeholder rating.

Methods

In May 2011, with support from The Commonwealth Fund, CEAL leaders began drafting material related to PC attributes for HCBS and, more specifically, measurable indicators for PC in assisted living. In June 2011 they convened a one-day invitational meeting of long-term care and other related experts to help inform their deliberations and recommendations. In addition to CEAL's organizational representatives, participants included advocacy, provider, and policy experts from Concepts for Community Living, Evergreen Estates Senior Living, The Green House Project, the Long-Term Care Quality Alliance, the Picker-Commonwealth Fund Long-Term Quality Improvement Program, and Planetree. A report entitled *Person-Centered Care in Assisted Living: An Informational Guide* (Love, 2010) served as the foundation to inform and advance this work.

Developing consensus recommendations during and after the meeting was the first step of this effort. The next step was to conduct a comprehensive literature review to determine the extent to which the consensus domains, attributes, and indicators were reflected in the related peer-reviewed and grey literature. As part of a concurrent community-based participatory research (CBPR) project conducted with UNC and funded by the National Institute on Aging (NIA), members from the CEAL and UNC identified search terms and sources to identify peer-reviewed literature in indexed databases (e.g., PubMed, PsycInfo) and "grey" literature (i.e., non-catalogued and/or non-peer-reviewed) to develop a non-duplicative, operationalized list of indicators and compare it to the domains, attributes, and indicators derived through consensus.

Finally, the indicators were programmed into an online survey, and a panel of ten PC experts representing diverse stakeholders including those involved in consumer advocacy and as consumer intermediaries individually rated the importance of each indicator to PC on a scale of 1-10, where 1=least important and 10=most important. In addition to the experts, two focus groups were held, one with assisted living families (n=5) and one with assisted living residents (n=3). Because focus group participants discussed the indicators in a group forum, and provided one overall response, each group completed one survey (i.e., the family focus group together answered one survey and the resident focus group together answered one survey). All respondents were primarily female, white, and non-Hispanic. Mean scores for each indicator and the overall domain were calculated for the twelve surveys. To promote item reduction, scores with an importance rating less than 8.0 were omitted, and an adjusted mean score was calculated. The cut-off of 8.0 was identified by the CBPR team because it

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corresponded to a natural break in the scores; more specifically, it constituted the cut-point of items scoring in the bottom 50% of the assigned scores.

Results

The CEAL recommendations delivered to CMS focused on PC domains and attributes that should be found in all HCBS settings, as well as specific indicators of those attributes for assisted living residences. Building on the framework presented in their 2010 informational guide, the Board endorsed nine domains and centered their recommendations around them accordingly: (1) Core Values and Philosophy, composed of (a) Personhood, (b) Respect and Dignity, (c) Autonomy, (d) Independence and Choice, and (e) Privacy; (2) Relationships and Community (Belonging); (3) Governance/Ownership; (4) Leadership; (5) Workforce Practices; (6) Meaningful Life and Engagement; (7) Services; (8) Environment; and (9) Accountability. The first column of Table 1 (General HCBS Domains and Attributes) is focused on HCBS and provides the rationale for or guidance related to each of these domains. For example, it indicates that the *personhood* of an individual should not get lost in a person's disability/disease; that intentional *relationships* should be nurtured; that the organization's mission, vision, values, policies, and practices should incorporate and operationalize PC principles and practices (*governance*); that *leadership* should demonstrate understanding of PC practices applicable to their role; that *workforce* assignment should be consistent; that *meaningful* choices that reflect personal preferences and interest should exist; that *services* should be designed to empower recipients; that the *environment* should look and feel like home; and that processes to determine whether PC outcomes are actually being achieved should be in place (*accountability*).

Measurable indicators for each attribute are provided specifically for assisted living, and are listed in the second column of Table 1. Among others, they include that residents respond affirmatively that staff know and honor their preferences (*personhood*), that management ensures services maximize their independence (*governance*), and that the *environment* feel like home; that residents can describe how they maintain positive *relationships* with others of their choosing; that staff report opportunities for meaningful input (*leadership*) and can articulate the strengths and capabilities of specific residents (*services*) and what specific residents find interesting and engaging (*meaningful*); that consistent *workforce* assignment is demonstrated; and that there is a process in place to ensure that PC outcomes are actually being achieved (*accountability*).

The next step in this effort was to determine the extent to which the literature supported these domains, attributes, and indicators. The search terms and sources of grey literature used for the search are listed in Table 2.

Based on these terms and sources, 121 discrete searches were conducted of literature published through November 2011 which yielded 521 peer-reviewed resources and 282 grey resources. Four CBPR team members representing both community and research partners reviewed each identified article/resource, and retained the English-language literature relevant to a structure, process, or outcome of PC. From this effort, 260 peer-reviewed and 165 grey resources were retained, reviewed in full, and abstracted to create a non-

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duplicative, operationalized list of PC indicators. In total, 250 indicators were identified and reviewed in terms of the extent to which they fit within the identified domains and attributes. Results indicated that two subdomains of Core Values and Philosophy were best combined (1c, autonomy, and 1d, independence and choice) due to the similarity in their related indicators, and that a new subdomain should be developed under Relationships and Community, specific to family.

Finally, scores related to the importance of each domain (or sub-domain) obtained from the expert panel are provided in Table 3. The “core values and philosophy” domain had the most items scored 8 or higher (42 items, on a scale of 1–10), and the “accountability” domain had the least items (12 items), although all of the items in that domain were considered important and were scored 8 or higher on the 10 point scale. After omitting items scored less than 8.0, the adjusted mean ratings indicated that the items related to “ownership/ governance” were most important (9.3) followed by those in the “core values and philosophy domain” (autonomy, independence, and choice; and privacy, both of which received a score of 9.1). Items related to “belonging” were scored lowest, receiving an adjusted mean score of 8.6 (on a 10 point scale, thereby still attesting to their importance).

Discussion

Person-centeredness has become the gold standard for health care and supportive services (Institute of Medicine, 2001). Although the 2010 Affordable Care Act calls for health care delivery to be based on a perspective of PC, it has long been a critical underpinning of HCBS, as its core values are to maximize privacy, autonomy and choice, meaningful access to the surrounding community, life engagement, and quality of life (CEAL, 2011). As a case in point, consumer direction and self-determination are the cornerstone of initiatives such as the Money Follows the Person Program, which provides personal and financial support so that individuals can reside in the community.

While many PC domains, attributes, and indicators may be relevant across all settings and services, others must be targeted to reflect the unique nature of the setting, service, or population. In assisted living, such setting-sensitive indicators might include a focus on social engagement outside of the building, and bringing guests to meals. Regardless of the extent of similarity or difference, however, the applicability of each must be made clear so as to provide guidance and a benchmark against which the quality of services and supports can be measured. This matter is especially true in the case of HCBS and assisted living, where their very availability may depend on such specificity. There is a real risk that if assisted living is not considered to embody PC, it will not be supported through public funds; consequently, those who meet eligibility criteria for nursing homes but choose to reside in assisted living would have no choice other than to move into a nursing home (i.e., some state regulations, such as those in Arkansas, Kansas, New Hampshire, and elsewhere, allow a resident who meets nursing home eligibility to be served in assisted living if required services can be provided; Polzer, 2013). This restriction runs counter to the *Olmstead vs. L.C.* U.S. Supreme Court decision noted earlier. Thus, it is that much more important to provide a metric by which to determine and promote PC in assisted living. It is important to

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stress, however, that while PC is important across settings, it is additionally important that individuals reside in the setting that best meet their needs.

This project is the first step towards creating such a metric, by identifying and validating through expert judgment and literature review the important domains, attributes, and indicators for assisted living. Through this effort, nine domains and six subdomains were identified as important. It is noteworthy that “family” was identified as an additional subdomain of importance, given that the majority of assisted living residents have some cognitive impairment (Zimmerman et al., 2007) and so family involvement is key to PC care and outcomes. The variability in ratings of importance was less than one-tenth of the entire range of scores (i.e., 8.6 to 9.3 on a scale of 1-10), indicating overall consensus as to their importance. Of note, it is premature to conclude that governance/ownership (rated 9.3) is more important than belonging (rated 8.6), as data represent scores from only 12 respondents.

It also is premature to conclude that the 43 indicators presented in Table 1 are those by which to actually measure PC, but they provide an important starting point. The literature search resulted in markedly more indicators – 250 all told – but these too are not definitive, for three key reasons: some were considered not important by the experts (e.g., families having access to a cooking area in the assisted living residence); some were not written with the level of specificity needed for a standardized metric (e.g., “residents and families are supported as they experience the end-of-life process”); and 250 indicators is too large a number to be a useful metric for PC in assisted living.

Now that PC domains, attributes, and indicators have been delineated, the next step is to create research-quality, PC measures that providers, regulators, and others can use to reliably and validly measure PC across settings and as a benchmark to improve care – and that is precisely what is being done. Our ongoing NIA-funded work is aimed at creating and validating such measures, based on the results of the work presented in this paper. The CBPR project partners are narrowing and refining the indicators, after which time the indicators will be cognitively tested with assisted living staff and residents (e.g., to assess clarity of items and determine whether important items were missed), revised, and then field tested to assess their psychometric properties in a large sample of assisted living residents and staff. At the completion of this testing, two questionnaires will result, one for administration to residents, and one for administration to staff. CEAL will advocate for use of the domains to guide changes in PC structures and processes in assisted living, and use of the questionnaires to benchmark and then measure the success of those change efforts. In total, 49 items will be included in the resident questionnaire, and 62 items in the resident questionnaire; they are available at http://www.shepscenter.unc.edu/wp-content/uploads/2014/01/Person-CenteredToolkitforAssistedLiving.pdf.

Moreso, the sample used in field test will be diverse, allowing for exploration of differences by racial group and other characteristics. Clearly one shortcoming of the effort presented in this manuscript was the small and relatively non-diverse sample of residents and families who contributed to the focus group rankings. This under-representation will be remedied in field testing, and respondents will be invited to comment on whether important items were

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missed. For example, residents might note that culturally relevant items (such as having access to traditional foods) were not included in the questionnaire. In fact, as the population of older adults living in assisted living becomes more racially and ethnically diverse, it will be necessary to expand this effort to assure that more culturally-sensitive items are included.

Additional future work will determine the extent to which these indicators of PC are feasible and in practice; the related facilitators and barriers that are encountered; the extent to which items are interrelated; and the extent to which PC structures and processes of care result in PC outcomes. In order to ensure that its services and supports are PC, some assisted living communities may need only to enhance aspects of their current processes and practices, while others may require systemic culture change beginning with the organization's governance and leadership. In the end, the intent is to provide guidance to promote quality PC assisted living and tangibly distinguish desired PC practices from undesirable institutional ones.

As the beginning steps of this effort, it was necessary that national experts be at the forefront of defining PC domains and attributes that generalize across all HCBS settings, as well as specific indicators for assisted living, so as to provide a blueprint for action that is relevant and realistic. These leaders are sensitive to the necessary variability among HCBS and assisted living residences themselves – including related to size, ownership, payment options, resident mix, specialized care options, staffing, services, amenities, and other areas (Zimmerman et al., 2003; Zimmerman et al., 2001) – and so their recommendations as related to PC attributes and indicators recognize and allow for such variability. Most notably, these experts recognize that smaller settings provide care for more dependent older adults, and are essentially the only settings that provide care for minorities (Zimmerman et al., 2003); thus, the extent to which practices are PC across all settings is tremendously important. Through their efforts and our ongoing next steps, evidence-based PC supports and services that enhance the quality of care and quality of life of older adults and other dependent persons will be markedly more informed and assured.

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Table 1

Person-Centered (PC) Domains and Attributes for Home and Community Based Services (HCBS) and Indicators for Assisted Living (AL) Derived from the Consensus Conference

General HCBS Domains and Attributes [1]	Initial AL Indicators [2]
1a. Core Values and Philosophy: Personhood • Learn and find ways to support the "personhood" of every individual; the personhood of the individual should not get lost in his/her disability or disease.	• AL residents respond affirmatively that staff know and honor their preferences. • Staff can provide personalized information about AL residents and their goals, history, and preferences; this information, including the resident's own words, is captured in the PC plan. • Residents and individuals of the resident's choosing are involved in the PC planning process. • A resident lifestyle preferences tool is used in the PC planning process. • The PC planning process addresses situations when the resident's decisions or preferences pose ethical, safety or other concerns. The process addresses reasonable alternatives developed jointly between the resident and provider. • Staff is provided education on and demonstrates competency in balancing safety concerns with being supportive of resident respect, dignity, autonomy, independence, and choice.
1b. Core Values and Philosophy: Respect and Dignity • Each individual is a unique person with inherent value and is worthy of being treated with respect, honor and dignity.	• The organization, including leadership, staff and volunteers, can articulate the core values of personal worth, respect, and dignity, and can describe where these values are evident in daily practice.
1c. Core Values and Philosophy: Autonomy • Aging-in-place is valued, and reasonable accommodations are made by both the provider and the state to accommodate aging-in- place.	• A reasonable accommodation process by both the provider and the state is in place to facilitate aging-in-place.
1d. Core Values and Philosophy: Independence and Choice • Each individual freely chooses and decides matters affecting him/her (e.g., health care decisions, schedules, what and when to eat, interesting and meaningful activities tailored to interests and preferences).	• Residents can, to the best of their abilities, describe their daily life in terms of control over decisions with personal preferences honored. • Observable variations are demonstrated in daily routines.
1e. Core Values and Philosophy: Privacy • Every individual has the opportunity for meaningful privacy in their lives at the times they choose.	• Residents have choice of a private room. (Of note, most states restrict room and board payments to levels that are insufficient to support private rooms). • It is preferable, but not required, that residents have choice of private bathing and cooking areas.
2. Relationships and Community (Belonging) • Experiences and intentional relationships should be built and nurtured between individuals receiving services and others of their choosing, including service providers. • Each individual should be known in a holistic manner (e.g., interests, history, preferences, values, culture). • Individuals should be supported to participate in activities and communities that they choose,	• Residents and staff can describe how they are building and maintaining positive relationships with individuals of their choosing. • The organization can demonstrate, in writing, group practices used to foster community, such as resident and family councils. • The organization can demonstrate how it supports and facilitates individual access to the greater community in other locations beyond the setting and through electronic means.

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General HCBS Domains and Attributes [1]	Initial AL Indicators [2]
whether within the setting, accessed through transportation, or through electronic means.	
3. Governance/Ownership • The organization's mission, vision, values, policies, and practices incorporate and operationalize PC principles and practices as outlined in this document. • Services and the environment are designed to empower the individual to maximize independence, choice and control. • Processes exist and are followed for including meaningful input from individuals in organizational decisions affecting their lives in a positive and receptive environment.	• The organization can demonstrate how its mission, vision, values, and practices operationalize the PC principles and practices outlined in this document. • The organization demonstrates proactive efforts to involve staff at all levels in decision making. • Residents respond affirmatively that the management ensures that services and the environment are designed to maximize their independence, choice and control. • Residents and family members can describe how they can provide meaningful input into organizational decisions affecting them.
4. Leadership • The system supports staff empowerment; an interdisciplinary workforce is nurtured and supported. • Leadership has a demonstrated understanding to the PC principles and practices applicable to their roles.	• Leadership ensures that staff has the training, skills and tools necessary to provide PC care. • Staff report opportunities for meaningful input in decision making. • Staff report administrative support for their involvement in developing work schedules based on resident needs and preferences. • The workforce is stable as measured by items such as turnover, retention, absenteeism, and staff satisfaction. • Supervisors have received training in staff management techniques. • Leadership (e.g., administrator/executive director and department heads) can articulate PC principles and practices applicable to their roles and can demonstrate their implementation.
5. Workforce Practices • The organization supports consistent staffing assignment. • All staff and volunteers have a demonstrated understanding of the PC principles and practices applicable to their role(s). • Staff annual performance evaluations include PC outcomes. • Staff-direction of services is encouraged, and individuals are given choice regarding who provides services.	• The organization can demonstrate that direct care staff are consistently assigned to the same resident(s). • All staff and volunteers can articulate PC principles and practices applicable to their role(s) and demonstrate their implementation. • The organization can demonstrate in writing on each staff's annual performance evaluation how PC practices are being operationalized in his/her role. • Resident's preferences regarding who provides services are reflected in the PC plan.
6. Meaningful Life and Engagement • Meaningful choices exist for every individual on a regular basis and reflect their preferences and interests. • Processes exist to collect and implement these choices.	• Any staff member can articulate what things residents for whom they are consistently assigned find interesting and engaging, which are reflected in the PC plan. • Any staff member can show how this information is collected and implemented, as applicable to his/her role. • Residents can describe things they do that make their life meaningful and engaging. • The organization can provide documentation of the residents' preferences and interests.
7. Services	• The PC plan reflects resident preferences related to service schedules, and such preferences are implemented.

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General HCBS Domains and Attributes [1]	Initial AL Indicators [2]
• The organization's policies and practices allow individual preference to determine service schedules. • Services are designed to empower the individual receiving services to maximize independence, choice and control. • Services are delivered in a PC relationship-based manner.	• Any staff member can articulate the strengths and capabilities of residents for whom they are assigned. • Any staff member can articulate how he/she uses a resident's strengths and capabilities, for whom they are assigned, to help maximize his/her independence, choice and control. • Residents respond affirmatively that staff providing services take the time to get to know them. • Residents respond affirmatively that staff providing services do so at a time and in a manner that the resident prefers.
8. Environment • The setting looks and feels like home, with private living space that individuals can furnish and decorate with their own belongings; home-style furniture, furnishings, and lighting are used in community spaces (personal, warm and comfortable). • An accessible, usable environment is designed to empower the individual receiving services to maximize independence. • Visitors of the individual's choosing may visit 24 hours a day.	• Residents have choice of a private room (see earlier comment pertaining to 1e, privacy). • Residents report that the environment looks and feels like home. • Residents report the environment is free of obstacles to independence. • Residents report being able to receive visitors at times of their choosing.
9. Accountability • A process is in place to ensure that PC outcomes are actually being achieved.	• A process is in place to determine whether PC outcomes are actually being achieved.

[1] Bold text denotes the domains for the listed attributes.

[2] These indicators have been modified based on the literature review and ongoing efforts (see text).

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Table 2

Search Terms and Sources for Literature Review

Literature Review Search Terms[1]	Grey Literature Sources
Person-centered	CMS/HCBS division
Resident-centered	FutureAge
Patient-centered	Provider
Family-centered	LTC Living
Person-centered care	Eden Alternative
Resident-centered care	Commission on Accreditation of Rehabilitation Facilities
Patient-centered care	Institute for Caregiver Education
Family-centered care	Kansas Foundation for Medical Care
Person-directed care	Colorado Foundation for Medical Care
Resident-directed care	Green House Project
Patient-directed care	Wellspring
Family-directed care	Planetree
Person-centeredness	American College of Health Care Administrators
Resident-centeredness	Center for Excellence in Assisted Living
Patient-centeredness	National Resource Center for Participant-Directed Services
Family-centeredness	PC experts[2]
Personhood	Council on Quality and Leadership
Culture change	Institute for Patient & Family-Centered Care
Eden Alternative	
Green House Homes	
Wellspring	
Planetree	
Artifacts (of Culture Change)	
Patient-Environment Transaction	
Experience of Home (EOM)	
Meaningful life	

[1] Each of these terms were combined with terms assisted living, long-term care, and nursing home. Both American and British variants of centered (i.e., centred) were used as search terms.

[2] Twenty-seven individuals known to be expert in the field of PC were searched for by name; identified resources were then reviewed against those identified by the literature review, and duplicates were excluded.

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Table 3

Importance of Person-Centered (PC) Domains Based on Expert Panel Rating

Domain	Number (%) of Attributes		Rating[1]	
	Retained	Omitted	Unadjusted	Adjusted[2]
Core Values and Philosophy				
Personhood	13 (76%)	4 (24%)	8.5	8.8
Respect and Dignity	9 (90%)	1 (10%)	8.6	8.7
Autonomy, Independence, and Choice[3]	13 (72%)	5 (28%)	8.6	9.1
Privacy	7 (88%)	1 (12%)	8.9	9.1
Relationships and Community				
Belonging	9 (69%)	4 (31%)	8.3	8.6
Family[4]	13 (81%)	3 (19%)	8.4	8.9
Ownership/Governance	18 (95%)	1 (5%)	9.2	9.3
Leadership	28 (82%)	6 (18%)	8.5	8.7
Workforce Practices	24 (80%)	6 (20%)	8.5	8.8
Meaningful Life and Engagement	19 (79%)	5 (21%)	8.6	9.0
Services	25 (93%)	2 (7%)	8.8	8.9
Environment	21 (95%)	1 (5%)	8.6	8.7
Accountability	12 (100%)	0 (0%)	8.7	8.7

[1] Experts rated literature-based indicators within each domain (not shown) from 1 (least important) to 10 (most important).

[2] Adjusted to remove the attributes with importance ratings less than 8.0.

[3] Subdomains 1c and 1d were combined due to the similarity in related indicators.

[4] Based on the literature review, an additional domain, Family, was identified.