

Concept Paper

Changing Care: Applying the Transtheoretical Model of Change to Embed Equity, Diversity, and Inclusion in Long-Term Care Research in Canada

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Abstract: Healthcare policy reform is evident when considering the past, present and future of long-term care (LTC) in Canada. Some of the most pressing issues facing the LTC sector include the changing demographic composition in Canadian LTC homes, minimal consideration for the role of intersectionality in LTC data collection and analysis, and the expanding need to engage diverse participants and knowledge users. Using the Transtheoretical Model of Change (TTMC) as a framework, we consider opportunities to address intersectionality in LTC research. Engaging diverse knowledge users in LTC (e.g., unpaid caregivers, paid care staff), community (e.g., advocacy groups, service providers) and policy decision-makers (e.g., provincial government) is crucial. Empowering individuals to participate, modifying environments to support engagement, and facilitating ongoing partnerships with knowledge users are critical aspects of change efforts. Addressing structural barriers (e.g., accessibility, capacity, jurisdictional policies, and mandates) to research in LTC is also essential. The TTMC offers a framework for planning and enacting individual, organizational, and system-level changes for the future of LTC.

Keywords: ageism; caregiving; classism; (dis)ablism; diversity; equity; inclusion; nursing homes; retirement homes; teams



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1. Introduction

To understand Canada's LTC system's present and future, we must first look to its past. Thus, in this concept paper, we consider the historical influences, including systems of oppression, that have shaped today's long-term care systems before offering potential opportunities for changing these policies and practices using the transtheoretical model of change (TTMC) [1–3]. The TTMC is used as a means of empowering knowledge users with a vested interest in LTC research to integrate meaningful changes. We hope that knowledge users can use these stages and processes of change to re-imagine LTC policies and practices in a more equitable, diverse, and inclusive manner. To facilitate this process of re-imagining, we outline and comment on our team's movement through each stage of the TTMC.

1.1. Past Is Prologue

Little research has been conducted on the specific history of LTC systems in Canada, but Barbara Emodi [4] offers a detailed account. According to Emodi, in the 19th century, aging populations in Canada were not recognized as a distinct group of individuals nor

were they excluded solely to isolated and institutionalized care. This period was devoid of institutions which exclusively offered services to older adults and, instead, institutions offered services to individuals with special needs (i.e., physical or mental illness) or from specific social groups (i.e., (dis)abled) [4]. Although these institutions often housed older adults, it was not until the end of the 19th century that the intention of these institutions was solidified and the terminology describing these institutions as homes for older adults was established [4]. Eurocentric perspectives of wellness, reason, and civility shaped these institutions [5]. That is, in line with European religious ideology, such as the Christian ordinance towards custodial care for vulnerable and at-risk populations, the first Canadian institutions that specifically housed aging populations were funded by Christian organizations [4]. The type of care offered in these institutions has been described as deeply compassionate, often leading to a lack of rehabilitative efforts and an acceptance of patients as ‘handicapped’, ‘insane’, or ‘disabled’. In the 20th century, older adults with little economical means were frequently subjected to live in these charitably-based, often impoverished, institutions [4]. This approach highlighted the economic considerations placed on these institutions and the ideology of the “undeserving poor” ([1], p. 6). This perspective is emulated in “Madness and Civilization”, where Michel Foucault [6] describes the confinement of individuals by the state under the auspices of health and social care. According to Foucault [6], rather than a moral or social response, confinement represented a solution to economic issues associated with unemployment and poverty. That is, the loss of ability or earning power with which to contribute to society was translated into a loss of autonomy and independence. Emodi [4] explains that this notion of the “undeserving poor” led to the confinement of older adults to institutions with impoverished living conditions that were located outside of urban areas and, therefore, isolated from society.

1.2. Social Exclusion & Institutionalization

As illustrated through the history of Canadian LTC systems, ageism (and, particularly, ageism as it intersects with classism and (dis)ablism) is the foundation upon which Canadian LTC systems were built [7,8]. Ageism upholds a system of oppression that (re)produces stereotypes (i.e., how we think about), prejudice (i.e., how we feel about), and discrimination (i.e., how we act toward) with respect to ourselves or others based on age [9–11]. Ageism is associated with worse physical and mental health outcomes, including reduced longevity, greater presence of chronic conditions, increased number of acute medical events and hospitalizations, increased cognitive and functional impairment, onset and worsening of depression, and inappropriate prescribing [12]. From a socioeconomic standpoint, it is associated with reduced quality of life, increased social isolation and loneliness, restricted sexuality, increased risk of violence and financial abuse, and increased poverty and financial insecurity [12]. For example, ageism can result in chronic social rejection and age-based discriminatory practices that result in the exclusion of older adults from participating in social spaces and, subsequently, contribute to increased rates of loneliness and social isolation. Moreover, ageism is closely linked to (dis)ablism; that is, (dis)abilities among older adults are often (inaccurately) portrayed as a normal part of aging and—due, in part, to beliefs that an inevitable decline in functioning and loss of independence comes with increasing age—that institutionalization in long-term care homes is an acceptable solution to age-related (dis)abilities [13,14]. In fact, the segregation of older adults from society into LTC institutions has been classified as a fundamental form of discrimination [14].

Taken together, these historical influences and systems of oppression (i.e., ageism, classism, (dis)ablism) produce the conditions in which the institutionalization of older adults with (dis)abilities (e.g., Alzheimer’s disease and other dementias, Parkinson’s disease, multiple sclerosis) who may have fewer economic resources within LTC systems seems natural, neutral, and normal. In fact, prior to the COVID-19 pandemic, the harms caused by LTC institutions went largely unnoticed within Canadian society; during the first and ensuing waves of the COVID-19 pandemic, however, it became almost impossible for these harms

to continue to go unnoticed [15,16]. For example, the Royal Society of Canada—which recognizes excellence across the arts, humanities, sciences, and social sciences—brought together a team of exceptional researchers to prepare a policy briefing on the future of long-term care within the context of the COVID-19 pandemic [15]. With this policy briefing, it became apparent that, despite the commitment to provide comprehensive care across the Canadian LTC sector, the continuum of LTC services in its current form is unlikely to meet the needs of aging populations with an array of service needs [17,18]. Calls for reform or abolishment of LTC systems were, and continue to be, prominently voiced [19]. While these calls for change might be commonly recognized and recited across Canadian jurisdictions, the legacy of colonialism and the systems of oppression that maintain LTC institutions need to be deconstructed and/or dismantled in a way that allows for the enactment of genuine change. We urgently need to deconstruct/dismantle and, subsequently, rebuild Canadian LTC systems before our society collectively forgets the ongoing harms that were perpetrated during the COVID-19 pandemic.

2. Methods & Results

2.1. *Transtheoretical Model of Change*

Change is a slow, often ambiguous, progression which unravels with time, requiring frequent, small commitments to behavioral and emotional change [20]. The TTMC offers a framework to describe how such behavioral and emotional commitments to change occur through a five-stage progression (i.e., precontemplation, contemplation, preparation, action, maintenance) [1,2]. Although initially designed to conceptualize individual change [1,2], the TTMC has been applied to organizational and group-based change [3,21]. For example, members of a community-based research team described how they moved through the stages of change to conduct a research project to support health policy reform regarding the integration of pharmacists in collaborative care practices in Alabama [22]. The authors noted several important lessons learned, including the need for a “collective mission”, “diverse knowledge, perspectives and skills”, and “mutual learning”. Ongoing communication between team members and consideration for maintaining engagement over time were also mentioned as key ingredients for maintaining change. In the current concept paper, methods and results were guided by previous literature on TTMC using a “participant observer” approach in which team members provided feedback on the stages of development and processes of change while also being involved in the work itself.

Ten processes have been identified to characterize change throughout the five stages of the TTMC [22] (see Table 1). Consciousness raising (e.g., advocacy efforts, policy briefs, evidence syntheses) and dramatic relief (e.g., feelings of horror and disgust related to conditions in LTC) promote contemplation [23]. Self-liberation (e.g., belief in the value and possibility of change) in addition to re-evaluations of self (e.g., identity as a caregiver) and of the environment (e.g., workplace culture) can help to promote movement from contemplation to preparation [23]. Contingency management (e.g., motivations of knowledge users), counterconditioning (e.g., changes in workflow), and stimulus control (e.g., modified working environments) help to move through preparation to action and maintenance stages. Social liberation (e.g., empowerment of individuals within the (dis)ability community) and helping relationships (e.g., diverse knowledge user networks, leadership) are essential throughout the change process [24]. Three additional processes have been identified for organizational change (i.e., team, thinking about commitment, commitment) [22].

Table 1. Applying the Transtheoretical Model of Change to Long-Term Care (LTC).

Stages of Change	Processes of Change	Examples
Pre-Contemplation to Contemplation	Consciousness Raising	- Commission reports (e.g., Ontario’s LTC COVID-19 Report) - Groups (e.g., Healthcare Excellence Canada’s LTC + Acting on Pandemic Learning Together; Supporting Diversity and Inclusion in LTC Advisory Committee’s Embracing Diversity Toolkit) - Reflecting on observations (e.g., meetings, news stories) and opportunities to improve (e.g., feedback from unpaid caregivers, resident & family councils, town halls)
	Dramatic Relief	- Acknowledging, reflecting, and sharing feelings (e.g., anger, fear, loss) - Empathizing with the hardships experienced by others (e.g., residents, family members)
Preparation	Self-Reevaluation	- Recognizing the purpose and value of change for oneself (e.g., providing inclusive person- or family-centered care; supporting wellbeing of residents, unpaid caregivers, and paid care staff) - Associating change with growth rather than loss
	Self-Liberation	- Gathering ideas of intersectionality (e.g., equity, diversity, inclusion, and accessibility) - Wanting to be part of change - Seeing self as change actor and beneficiary of change
	Environmental Re-evaluation	- Fostering a sense of optimism for meaningful culture change and policy reform in LTC - Identifying common interests with those in the public sector and research community - Reflecting on the community by considering the full range of social identities and locations - Having a positive impact on the broader work environment
Action & Maintenance	Contingency Management	- Compensating individuals for their time and effort (e.g., participants, residents, unpaid caregivers) - Spreading awareness on structural and systemic issues (e.g., celebrating incremental successes) - Regular feedback channels through a range of communication methods (e.g., emails, newsletters, message boards, town halls, resident & family councils) - Incorporating intersectionality into paid care staff performance reviews and hiring decisions
	Counter Conditioning	- Standardizing quality improvement projects with emphasis on diverse knowledge user perspectives - Adding time into every paid care staff member’s schedule for research so participating becomes part of expectations rather than additional volunteer time
	Stimulus Control	- Arrangements to support culture change (e.g., protected time for staff, compensation for all participants including residents & unpaid caregivers, flexible meeting times, translation services & other accommodations, regular opportunities for sharing & learning) - Restructuring channels to identify gaps and initiate change (i.e., avoiding traditional views of change requests as “complaints”) - Actively maintaining partnerships with researchers, resident, unpaid caregivers, paid care staff, healthcare groups, community providers, and policy makers - Ensuring knowledge sharing is easy and accessible

Table 1. Cont.

Stages of Change	Processes of Change	Examples
Throughout the Stages of Change	Social Liberation	• Embracing person- and family-centered approaches that promote accessibility and autonomy • Encouraging and empowering residents, unpaid caregivers, and paid care staff to lead research and quality improvement projects • Offering requested information and additional resources and information (e.g., Ontario Disability Support Program) • Supporting the continuum of care needs in the community (e.g., home and community care, pharmacare, assistive devices)
	Helping Relationships	• Connecting researchers, residents, unpaid caregivers, and paid care staff • Providing supports to facilitate participation from under-represented groups, including residents with mental illness (e.g., pairing resident with unpaid caregiver or paid care staff member), residents with no regular caregiver (e.g., involving volunteers), and non-White individuals (e.g., engaging with broader community to establish best practices) • Ensuring any group is represented by multiple voices (i.e., not just one person representing a whole group) • Recognizing it may be more appropriate to consult one group at a time then bring all the perspectives together in a summary • Offering many different formats for participation instead of a “one size fits all” (e.g., smaller & larger group meetings, individual interviews, surveys, informal 1-on-1 meetings, virtual & in-person options) • Building strong relationships rooted in trust • Recognizing difficult and emotional stories will likely be shared and committing to creating a safe space and offering appropriate follow-up for sharing stories • Identifying a point person for questions and comments • Keeping all individuals informed of progress and decisions • Engaging existing structures (e.g., senior leadership, resident & family councils)

Using the TTMC as a theoretical framework, the present concept paper considers opportunities to make meaningful changes within LTC systems by moving individuals and organizations through the stages of precontemplation, contemplation, preparation, action, and maintenance (see Table 1). Co-authors drew from knowledge and experiences as a research team to illustrate each of these stages. Specifically, the first author presented the concept at a team meeting, developed a preliminary table with a few examples, and asked for input on a shared (electronic) document over a period of several months; co-authors added examples from their experiences as well as discussions with stakeholders (i.e., LTC staff, family members of older adults in LTC).

2.1.1. Precontemplation & Contemplation: Consciousness Raising & Dramatic Relief

Our team arose from collaborations established through the Canadian Institutes of Health Research (CIHR) Health System Impact (HSI) Fellowship. Recipients of the CIHR HSI Fellowship are doctoral and postdoctoral trainees who receive extensive training and experiential learning opportunities as embedded researchers within health system organizations [25,26]. With support from an academic mentor and a health system mentor, CIHR HSI fellows are empowered to make high-impact contributions within learning health systems. With support from Healthcare Excellence Canada (Ottawa, Canada) and funding from the Canadian Institutes for Health Research (Ottawa, Canada) and Saskatchewan Health Research Foundation (Saskatoon, Canada), our Implementation Science Team was formed. As reports of rising COVID-19 infections and deaths in long-term care (LTC) homes were brought to light at the beginning of the COVID-19 pandemic, a group of current and past CIHR HSI fellows joined forces to find ways of producing impact-oriented

research to support LTC homes during the COVID-19 pandemic and beyond. This process embodied our movement from the stage of precontemplation to the stage of contemplation (see Table 1).

Through the process of consciousness raising, the COVID-19 pandemic was a catalyst from which we moved from ignorance to awareness. Increased awareness of structural and systemic issues within current LTC systems inspired us to evoke much needed change. More specifically, during the first wave of the COVID-19 pandemic, and because of the disproportionate effect that the COVID-19 pandemic had on residents living in LTC homes, bans on in-person visits by unpaid caregivers were enacted across Canada [27]. Although these measures were understandably adopted to reduce the risk of COVID-19 infection and death among LTC residents, they were also associated with adverse—albeit unintended—consequences for LTC residents, unpaid caregivers, and paid care staff (e.g., [15,28]). By the end of the first wave of the COVID-19 pandemic, high-profile researchers began to highlight the need for evidence-based approaches to transform and restore trust in LTC systems through research and, subsequently, evidence-based policies and practices [15]. Becoming aware of the structural and systemic issues underlying our current LTC system, reflected in the oppressive history of LTC, allowed us to reflect on our feelings towards the hardships experienced by LTC residents, unpaid caregivers, and paid care staff. Through a process of dramatic relief, we allowed the emotional arousal and turmoil from these issues to fuel our desire for change in LTC policies and practices.

2.1.2. Preparation: Self-Liberation & Re-Evaluation of Self and Environment

After weeks of lockdown during the first wave of the COVID-19 pandemic, many Canadian residential long-term care settings reported serious declines in residents' physical, cognitive, and mental health [29]. In preparation for the second wave of the COVID-19 pandemic, funding opportunities for research related to mitigating the adverse effects of the COVID-19 pandemic on Canada's LTC sector became readily available [30]. To act on our desire for change, we prepared an application for the Implementation Science Teams: Strengthening Pandemic Preparedness in Long-Term Care funding opportunity. In preparing our application for this funding opportunity, we conducted a rapid review of interventions aimed at involving unpaid caregivers in the care of LTC residents. Given the relation between social exclusion and institutionalization, we observed that each of the studies included in the rapid review reported on group-level demographic characteristics for residents and/or unpaid caregivers; however, these demographic characteristics were often limited to age, gender identity, and (dis)ability status without consideration for other social identities (e.g., class, race, religion, sexual identity) that are known to differentially affect health outcomes [31,32]. Furthermore, by not examining the ways in which these social identities intersected (e.g., older women, older women of colour, older women with a diagnosis of dementia) [33], differences in experiences across social locations were not acknowledged. Thus, the importance of intersectionality became a core feature of our change efforts (see Table 1).

Once this impetus for change became apparent, and once we started to prepare our application for the funding opportunity, we needed to reflect on our roles and environment to develop a plan of action. Our Implementation Science Team was primarily composed of early-, mid-, and late-career researchers across several Canadian jurisdictions (i.e., Saskatchewan, Manitoba, Ontario, Quebec, Nova Scotia, New Brunswick). About half of the early career researchers are situated within academia, whereas the other half are embedded scientists within health system organizations. Early career researchers provide leadership using a collaborative governance structure. Mid- and late-career researchers provide early-career researchers with guidance and mentorship on an as-needed basis. The team receives input from relevant knowledge users on a regular and as-needed basis. At any one time, the team is supported by two or three trainees. In preparing our grant application, we spent time discussing the most effective ways for us to approach intersectionality as a team. We recognized the inherent systemic challenges confronting certain members

of our research communities and we believed that we could make a difference through recruitment of trainees and researchers from underrepresented groups, a governance structure that supported opportunities for co-learning across our highly diverse team, and by incorporating intersectionality into training activities.

2.1.3. Action & Maintenance: Contingency Management, Counterconditioning & Stimulus Control

Following the preparation stage, several processes were (and continue to be) needed to support change actions and maintain change efforts. Action and maintenance require significant commitment, time, and effort. Within the context of research, for example, compensating participants was and is a crucial aspect of supporting and maintaining change efforts. Paying individuals for their time and effort positively reinforces engagement. For example, in a move to conduct more person-oriented research, we have been holding monthly advisory council meetings with LTC residents, unpaid caregivers, and paid care staff since the beginning of our project. In line with the SPOR Evidence Alliance's Patient Partner Appreciation Policy and Protocol [34], all resident and family partners are compensated at a rate of \$25 per hour.

Beyond compensation, recognizing and highlighting contributions of participants and caregivers is another form of positive reinforcement. Furthermore, attention to contingency management and feedback processes support other processes of change (e.g., self-liberation, thinking about commitment). Stimulus control may include efforts to ensure research is accessible to everyone by restructuring the LTC environment. Hosting monthly advisory council meetings, for instance, has allowed us to actively establish and maintain partnerships with LTC residents, unpaid caregivers, and paid care staff. We have also met with knowledge users (e.g., government stakeholders) to establish mutually beneficial relationships. Finally, counterconditioning requires changing the culture within LTC settings so that it is more amenable to research efforts. As an example, having dedicated staff time for participating in and/or leading research projects would be vitally important. We have observed that collaborating on this research project was facilitated when LTC homes had a designated staff member leading research and/or quality improvement initiatives. See Table 1 for more details.

2.1.4. Throughout the Stages of Change: Social Liberation & Helping Relationships

The importance of empowering and supportive relationships cannot be overstated. Change agents need to feel capable and supported throughout the change process. By providing more choices and resources, individuals feel empowered and capable of making meaningful change. One of the key elements of intersectional research is ensuring the inclusion of diverse and underrepresented voices (e.g., individuals who have communication challenges and may need accessibility support and accommodations to participate in LTC research; for example, older residents with dementia and/or sensory loss). By mobilizing and empowering early-, mid-, and late-career researchers from across Canada to address challenges in the LTC sector, our IST moved from a state of contemplation into preparation and action.

Our IST was able to engage key knowledge users in the LTC sector, conduct a rapid review of the literature, and develop a funding proposal to support the presence of unpaid caregivers in LTC homes with emphasis on intersectionality. Cultivating new and existing relationships with policy workers and decision makers was essential to plan for knowledge translation. Policy-related knowledge translation has been crucial for engaging and empowering LTC staff and unpaid caregivers. Ongoing actions related to unpaid caregivers and intersectionality (e.g., advice to government) and maintenance of change efforts (e.g., advocacy, implementing changes in homes) will also require empowered knowledge users working together. See Table 1 for more details.

2.1.5. Organizational Change: Thinking about Commitment, Commitment & Teams

Organizational and system-level changes require individuals to work together. In addition to individual stages and processes of change identified by Prochaska and colleagues (TTM) [1], Prochaska and colleagues [22] identified three additional processes of change specific to organizations: thinking about commitment (e.g., identifying time, resources, expertise, leadership needed to support culture change), commitment (e.g., investing in new roles dedicated to change), and teams (e.g., partnership with stakeholders, engaging diverse perspectives). As evidenced by the current paper, co-authors have identified resources to support change efforts and are committed to continue to work together as a team to support the future of LTC.

3. Discussion

Our current health systems, including LTC systems, need to adapt to this societal awareness of structural and systemic barriers for aging populations across social identities and locations, including intersections of gender, race, ethnicity, religion, spoken language, socioeconomic status, and (dis)ability status, to name a few [35]. Many gaps in understanding these intersecting identities and locations exist, including the oversimplification of variables in unrepresentative data sets [36], highlighting the need for research in this area to comprehensively examine such variables. Using the TTMC framework outlined in this manuscript, researchers and knowledge users of LTC systems can begin to ponder and reflect on the Canadian LTC system and ways to work towards meaningful, intersectional engagement in LTC research. Our research team plans to continue to use the TTMC to frame planning, action, and maintenance of change efforts related to LTC.

The COVID-19 pandemic exposed and exacerbated these pre-existing vulnerabilities in legislation [16]. Changes to the LTC sector are clearly needed; for example, healthcare policy decisions aimed at increasing equitable access to home care and community-based housing with health services, as well as changes to “institutional” care [37]. Two approaches have been highlighted in literature as frameworks to reform or drastically alter the current LTC system and its often-overlooked colonial history. Abolitionist movements (e.g., Disability Justice Network Ontario) emphasize the need to dismantle existing structures and develop voluntary, accessible, community-run services and public infrastructure that is not tied to employment [37]. De-institutionalization and access to “just care work” are key components of abolition. Rather than separating older adults and individuals with care needs from their communities, abolitionists emphasize adaptations to environments within communities. In contrast, reform movements tend to focus on changing the current LTC system to be more inclusive and intersectional while promoting a need for more LTC homes and an increased level of staffing and care within institutional settings [37]. Although different approaches to change, both movements recognize and support the need for transformation through mobilization of key knowledge users and decision-makers (i.e., policymakers, researchers, cooperation of jurisdictional bodies).

Cross-sector partnerships are also essential in the pursuit of changes to complex social and healthcare systems [38]. Research on community coalitions highlights the importance of engaging diverse knowledge users throughout the change process [24,39–41]. Our team has begun this process by engaging with key residents, unpaid caregivers, paid care staff, policymakers, and decision makers in each of our jurisdictions of focus (i.e., Saskatchewan, Ontario, New Brunswick). While we have begun this process, much more work is needed in cultivating meaningful connections across sectors. We need to have a better understanding of the ways in which different sectors (e.g., acute care, home care) uphold systems of oppression (e.g., ageism) that may impact aging populations. We need to examine how ageism intersects with other systems of oppression and social exclusion (e.g., classism, disablism, racism, sexism) in ways similar to, and different from, the LTC sector. Finally, we need to find solutions that allow us to eliminate (i.e., abolish) or mitigate the effects (i.e., reform) of these systems of oppression.

4. Future Directions for Applying the TTMC in LTC Research

Although evidence suggests the TTMC can be applied across different populations and settings [40], we highlight key considerations for its use within the context of LTC research. First, it is critical to determine how the differing cultures within LTC homes interact with the application of this model. For example, LTC culture varies across jurisdictions in Canada due to regulatory bodies and the type of revenue model that supports LTC homes (i.e., public vs. private). Therefore, the application of TTMC in each LTC home requires a well-devised planning and implementation process that considers the unique adaptations specific to the LTC culture. Another key consideration is the duration of time it takes to progress between the stages of the TTMC within LTC settings, while maintaining awareness of the differing LTC cultures across jurisdictions and regulations.

Further, given the diverse population of residents and caring staff in LTC (i.e., ethnicity, race, gender, etc.), it is vital to pursue future research on TTM-tailored interventions which address and embed intersectionality in LTC research and policy work. Lastly, a limitation of this model is its assumption that the decision-making process is coherent and logical, which is often not true, especially for those with limited cognitive abilities (i.e., Alzheimer's disease). Despite these limitations, the potential adaptations of the TTMC in LTC research and policy could shed light on how best to promote intersectionality in LTC and the harmonization of LTC systems across jurisdictions and regulatory bodies. The future of LTC depends on our collective ability to recognize the mistakes of the past and move through the stages of change to create an inclusive, supportive, and engaging environment for individuals to receive long-term care.

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