Center *for*
Public Service

Advocacy Needs for Improving the Long-Term Care Sector

A Position Paper

January 2023

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Acknowledgements

The Center for Public Service greatly appreciates all those who generously gave their time to inform this advocacy framework and position paper. Special thanks go to Ana Sofia Castellanos, PhD candidate; Mike Austin, PhD, MSW; Marcus Ingle, PhD; Trisha Kumar, MPH; and Barbara Kohnen Adriance, MPP and CEO of The Malden Collective that owns and operates the LiveWell Method (TM) and program. Additional thanks to Cat McGinnis, MS, for editing this report. Funding for CPS was provided by The Malden Collective as part of the Oregon Department of Human Services' support to scale up LiveWell—Oregon's Quality Assurance and Performance Improvement Program for Long Term Care Facilities.

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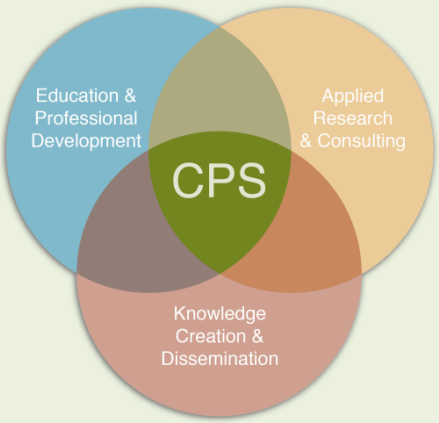
About the Center for Public Service

The Center for Public Service empowers people from a diverse array of industries with new ways of creating robust, human-centered solutions in Oregon and beyond. The center believes that public service is a legitimate, proud, and essential calling and that public servants and institutions are needed to serve as catalysts for innovation, to protect and promote justice and democracy, and to balance liberty and equity. The center provides teaching, research, public engagement, and applies practical knowledge to build leadership and improve the effectiveness of public service professionals and organizations.



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1.0. EXECUTIVE SUMMARY

Oregon is well-known for its commitment to improving the health, quality of life, and quality of care for older adults and persons with disabilities, which is reflected in the state's organization of long-term care (LTC). Despite Oregon's well-deserved reputation as a pioneer in the development of long-term care facilities (LTCFs), current evidence identifies emerging challenges facing the LTC sector. Oregon ranked fourth overall in the Long-Term Services and Supports State Scorecard as of 2020. However, the state ranked 23rd in quality of life and care, and 24th for its affordability and access.

Given these historic strengths and emerging challenges facing Oregon's LTCFs and the residents, staff, and volunteers within them, the Center for Public Service at Portland State University was charged with developing and implementing an Ecosystem Hub, in this case, a network of institutions or organizations providing and working to improve LTC. The hub recognizes the enormous challenges ODHS will face in terms of access, cost, quality of care, and quality of life for those living and working within LTCFs. The hub provides planning and identifies ways to address these challenges. This study is an outgrowth of the Ecosystem Hub.

1.1. Objectives

This paper examines challenges facing the LTC sector in Oregon and provides recommendations. The following are the main objectives of the paper:

- The identification of cross-cutting needs facing Oregon's aging adults and adults with disabilities and the needs of public and private organizations focused on LTCFs.
- The presentation of a comprehensive advocacy agenda and framework that identifies diverse paths forward for the Oregon Department of Human Services (ODHS) and its partners to ensure quality of care and quality of life for those living in LTCFs.

1.2. Methods

Our research included a review of relevant literature and an analysis of qualitative data from 28 interviews conducted between March and May 2022 with key leaders involved in providing care for older adults in Oregon and nationally. Basic questions for reviewing the literature included:

- What ongoing and new service delivery challenges do LTC providers face at an organizational level, and what opportunities do they identify in response to these organizational challenges?
- Political, economic, social, technological, legal, and environmental factors influence the ecosystem of LTC institutionally?

- What strategies are needed to address these complex organizational and institutional opportunities and challenges?

Interviews included the following questions:

- In reflecting on the current organization of care for older adults and adults with disabilities, what's been working well and what could be improved? What are the current challenges, threats and opportunities? What steps have been taken to address these issues, challenges or threats?
- Looking forward, what should the future of care for older adults and adults with disabilities look like? What practices, programs, or policies, or all of these, are needed to go from the present to the future? What advocacy strategies will be needed to support these future efforts, in order to make the future of care happen?

1.3. Findings

Key findings are grouped thematically and summarized below.

1.3.1. Perspectives on service users and care partners

- Users have insufficient access to quality care.
- Users lack knowledge about home-like and other community care and need more publicly subsidized non-institutional care.
- Funding for mental health and substance abuse treatment for users is lacking.
- Families need caregiving support.
- Opportunities are limited for intergenerational engagement of users.
- LTCF staff need higher wages, career opportunities, funding for training, and a culture of caring and respect.

1.3.2. Perspectives on providers

- Workforce supports are needed to increase and keep staff.
- Increases in reimbursement for community-based care have been insufficient.
- State matching of federal funds for community care has been insufficient.
- Some providers emphasize profits over patient care.

1.3.3. Perspectives on ODHS leadership

- ODHS has insufficient opportunities to train LTCFs.
- There are tensions related to process and organizational culture at ODHS.
- Organizational silos hamper collective problem-solving and public accountability.

1.3.4. Perspectives on changes needed for future care

1.3.4.1. Supporting and monitoring quality of care effectively

- Service delivery should reflect user perspectives, including language and gender.
- Community-based services should be integrated to address wellness and food security.
- Contracting and payment systems should support holistic person-centered care.
- LTC providers should optimize the use of data to inform quality improvement.

1.3.4.2. Greater oversight and regulation of the LTC sector

- Regulatory oversight and compliance should be strengthened for publicly funded and private LTC.
- ODHS and the Oregon Office of the Long-Term Care Ombudsman (ombudsperson) need to be more involved in policy and program implementation.
- ODHS needs a more collaborative model with sufficient staff to oversee the volume of providers.
- Collaborative performance measurement is needed for any regulatory effort, including transparent quality care metrics.

1.3.4.3. Needed advocacy strategies

- A more robust advocacy agenda for users and care partners is needed.
- New advocacy leadership is needed that presents a compelling public vision.
- Consumer views need to be integrated into the LTC system.
- A lobbying instruction guide for laypersons is needed.
- Advocate, user, and staff fears of speaking up about care need to be allayed.
- Leadership values and vision should support advocacy for consumers and workers.
- Deliberative space is needed for public and private groups to identify solutions.
- Leadership needs to address real or perceived power imbalances between users and providers.
- More structured opportunities are needed for community leaders to convey needs to policymakers and public administrators.
- Sufficient public funding is needed to support advocacy.
- Evidence-informed advocacy is needed to educate policymakers, public funders, and public agencies about the needs of users, policy gaps, fiscal challenges, and potential solutions.
- Outreach is needed for media elites, facility owners and operators, and communities .

- Transformations in healthcare rates and pay for value-based care should inform a potential alliance between stakeholders to align payments, service delivery, and quality of care.
- Small-scale initiatives and projects are needed to address needs through a partnership between ODHS, providers, associations, and advocates, using federal and state quality care metrics, to improve user safety, quality of care, and service delivery.

1.3.4.4. Recognizing that interpretations of advocacy success differ

- Naming problems and having shared understanding are needed to enhance awareness.
- Close relational work between stakeholders is needed to sustain ongoing collaboration.
- Advocacy needs to be grounded in a well-used strategic or policy framework.
- Harmful proposed legislation needs to be averted to allow for improving existing laws.
- Knowledge should be shared strategically to foster new policy advocacy communities.

1.4. Recommendations

A summary of recommendations for addressing LTC follows:

1.4.1. Conduct public outreach and engagement

- Engage with critical groups via public awareness campaigns, public forums, and leadership engagement and education.
- Develop a webpage with white papers, policy and practice resources, and case studies of organizations that exemplify promising avenues for the future of LTC.
- Develop a speaker series focused on innovations in LTC.
- Develop a leadership roundtable that designs new ways forward for LTC.
- Convene major leaders in Oregon and nationally to advocate for improved LTC.

1.4.2. Construct an advocacy framework that includes leadership development for users, provider training, and model development and testing through pilot demonstrations.

1.4.3. Use a management support organization to address organizational capacity building and promote practice, program, and policy initiatives among LTCFs.

1.4.4. Use knowledge development strategies and share best practices for person-centered care and structuring services within institutional and community-based environments.

1.4.5. Use a shared decision-making framework for advocates who seek to meet needs by the following means:

Evidence-informed issue identification, reflecting needs assessments, literature reviews, and cultural evidence.

- Discussion of how best to structure advocacy involvement.
- Clarification of assumptions, by identifying what is possible versus what is impossible, and what is desired versus what is needed.
- Selecting the most viable implementation options and providing the selection criteria.
- Implementing the options and articulating outcomes and timelines.
- Evaluating the overall process using specified criteria and timeframes.

1.4.6. Identify key organizational supports for advocacy within the LTC sector that draw upon community building, membership development, skilled leadership, and strategic planning.

1.5. Conclusion

This paper examined the enormous challenges ODHS and the LTC sector will face in coming years in terms of access, cost, quality of care, and quality of life for those living and working in LTCFs. Some of the best hopes—in the literature and in our interviews—for pre-empting or resolving these challenges involve shaping organizational values, culture, and leadership approaches to promote collaboration between those who have a stake in LTC; establishing sustainable funding for LTC services; creating frameworks that support effective outreach and engagement while harnessing the voices of LTC users and workers; strengthening advocacy for LTC users; professionalizing the caregiving profession; and enhancing monitoring and oversight of care quality. Oregon has proven its commitment to improving the health, quality of life, and quality of care for older adults and persons with disabilities. It is our belief that adoption of recommendations highlighted in this paper will move Oregon even further along the spectrum of high quality, person-centered care.

2.0. INTRODUCTION

The federal government and states dedicate over $270 billion annually to ensure the safety and health of 14 million older adults and adults with disabilities needing long-term care (LTC) services and supports (80). Recent evidence suggests that demand and costs for long-term care facilities (LTCFs)—including assisted living, residential care, memory care, and nursing facilities that are largely funded by Medicaid and Medicare—are expected to rise substantially (80). Because the supply of such facilities is not expected to rise as quickly as demand, federal and state policymakers, leaders of departments of human services and provider associations, and researchers have identified the need to address the changing organization of LTC (79, 80, 81).

Oregon's commitment to improving the health, quality of life, and quality of care for older adults and persons with disabilities is well-known and is reflected in the state's organization of LTC for older adults and people with disabilities as well as its prominence in national policy and practice circles (43, 57). Yet while the state has a well-deserved reputation as a pioneer in the development of LTCFs, recent evidence identifies emerging challenges facing Oregon's LTC sector. Specifically, as of 2020, Oregon ranked fourth overall in the Long-Term Services and Supports State Scorecard (reflecting the state's top-five rankings for its support for family caregivers, effective transitions, and choices for community-based settings and providers). However, the state ranked 23rd for its quality of life and quality of care, and 24th for its affordability and access (84).

3.0. ECOSYSTEM HUB

Given these historic strengths and emerging challenges facing Oregon's LTCFs and the residents, staff, and volunteers within them, the Center for Public Service at Portland State University was charged with developing an Ecosystem Hub. For the purposes of this paper, an Ecosystem Hub is a network of institutions or organizations providing LTC services, and more importantly, maintaining overall connectivity as hubs to improve these services.

Development of the Ecosystem Hub had two aims:

- The identification of cross-cutting needs facing Oregon's aging adults and adults with disabilities as well as those public and private organizations focused on LTCFs.
- The presentation of a comprehensive advocacy agenda and framework that identifies diverse paths forward for the Oregon Department of Human Services (ODHS) and its partners to ensure quality of care and quality of life for those living in LTCFs.

The Ecosystem Hub addresses these two aims by using an *organizational and institutional analytic lens*. Organizationally, the Ecosystem Hub focuses upon those formal organizations and groups providing LTC in response to service gaps, community needs, and under-addressed issues facing Oregon adult residents. These include public organizations tasked with the immediate oversight of LTCFs, private for-profit and nonprofit organizations delivering services to residents and those public and nonprofit groups that advocate on behalf of underserved adults and communities.

From an organizational perspective, the efforts of public and private administrators responsible for LTC can be seen in practices, programs, and policies. For example, public management activities can include efforts to improve monitoring of private providers via performance measurement of LTCFs, in response to public rules, policy requirements, and advocacy demands. Private management activities can reflect an effort to improve organizational culture and climate (e.g., developing and sustaining a culture of caring) as well as workforce retention in order to promote the health and well-being of adults in home- and community-based settings.

Institutionally, the Ecosystem Hub concerns issues of public governance and accountability in structuring the marketplace of LTC. A major aspect of this paper identifies collaborative opportunities for public policymakers, funders, regulators, large providers, and industry associations to note and address common issues and core concerns of Oregon's aging adults and adults with disabilities. A complementary aspect of institutional analysis involves attending to the perspectives of those organizations and groups that are often underrepresented in the institutional ecosystem of LTC in Oregon. In particular, the Ecosystem Hub acknowledges the important role of smaller public and private organizations, notably advocacy organizations, that can offer essential insights on how to improve the quality of care and quality of life for those within LTCFs.

This organizational and institutional lens focuses specifically on *PESTLE* (Political, Economic, Social, Technological, Legal, and Environmental) factors that shape the ecosystem of the LTC sector. These factors can impact the organization of community-based care for older adults and adults with disabilities, as summarized in table 1.

In sum, the Ecosystem Hub recognizes the enormous challenges ODHS will face in the future in terms of access, cost, quality of care, and quality of life for those living and working within LTCFs. The Ecosystem Hub identifies diverse ways to address these challenges by bringing more visibility to traditional and non-traditional organizational leaders, so that effective planning may begin. This study is an outgrowth of the Ecosystem Hub.

4.0. LITERATURE REVIEW

4.1. Methods

For the Ecosystem Hub, the completion of the needs assessment and advocacy agenda and plan first involved the review of the peer-reviewed and grey literatures. In particular, a *scoping literature review* reflected the following search keywords: long-term care; aging; adults with disabilities; nursing home; services; quality of care; workforce; staff; improvement; nonprofit; for-profit; policy; funding, fiscal, or cost; and advocacy. Although most of the literature review reflected scholarly journal articles and books, we also reviewed non-scholarly sources such as trade journals and policy reports.

The literature review addressed these basic questions:

- Organizationally, what ongoing and new service delivery challenges do LTC providers face, and what opportunities do they identify in response to these organizational challenges?
- Institutionally, what PESTLE factors influence the ecosystem of LTC? and
- What strategies are needed to address these complex organizational and institutional opportunities and challenges?

4.2. Results of the literature review

4.2.1. Challenges in delivering care

In regard to the first question, challenges that LTCFs face in delivering care include: social isolation of residents and other behavioral and mental health needs of adult residents (42); family-related issues regarding special care requirements or financial challenges (26); and workforce difficulties that relate to staffing levels, morale, and turnover (2, 10, 27, 28, 32, 33). Studies also noted that fiscal, organizational, staff, and technological barriers can negatively impact person-centered care (14, 29), even among high-performing facilities (16). In addition, research identified for-profit providers as being less effective in serving residents, as compared to nonprofit providers (26, 39, 49). In response to these challenges, studies identified various organizational methods for improving the delivery of LTC (14), including efforts to promote worker empowerment, participation, and quality of care (5, 9, 29); support for interdisciplinary and interprofessional teams (47); facilitative leadership and participatory management (5, 25); and an organizational culture of safety (11) and a person-centered climate (17, 31).

4.2.2. Policy, political, and legal factors in LTC

Concerning the second question, policy, political, and legal factors that structure the ecosystem of LTC include the federal use of Medicaid home- and community-based service waivers (46);

state administrative rules and programs, particularly involving the development and use of statewide performance measures (e.g., report cards) (3, 11, 15, 22); the need for greater state-based regulatory involvement involving minimum nurse staffing levels (6) and stronger performance audits (22); and the development and implementation of new employment and healthcare policies and administrative laws at state and national levels (10, 12).

4.2.3. Economic and fiscal factors in LTC

Economic and fiscal factors informing the external context of LTC include changes in public financing such as Medicaid reimbursement rates (12) or the financing of LTC insurance (7); experimentation with performance-based contracting (4); and local competition for skilled and less-skilled staff (12).

4.2.4. Social and cultural factos in LTC

Social and cultural factors impacting the organization of LTC include racial/ethnic disparities in access to and use of care (40, 41); and a looming need for geriatricians and their education and training (21).

4.2.5. Technological factors in LTC

Technological factors influencing the organization of LTC include: the use of social media to rate provider performance and quality of care (18); the use of simulation to support staff training (20); and efforts to address ageism and the lack of staff and resident supports for technology use (23, 45).

4.2.6. Environmental factors in LTC

Finally*, environmental factors* influencing the ecosystem of LTC include initiatives designed to make facilities more home-like (37, 38); and the architecture, development, and retrofitting of urban residential communities (8).

4.2.7. Strategies needed to address opportunities and challenges in LTC

Regarding the third question, scholarship has documented needed changes for the LTC sector (involving promising LTC practices, programs, or policies). The need for sectorwide or systemic change initiatives can be seen in calls for national quality care frameworks (15); more information on nursing home prices and quality of care (19); more consistent performance audits (22); more state experimentation (e.g., via state waiver demonstrations) (46); the design and testing of innovative health system infrastructural approaches (50); stronger public-private coordination to support collective action (13, 44); innovations in cross-provider coordination

(24, 44) and interprofessional teaming (43, 47, 48); more staff compensation, including health benefits (39); and greater use of volunteers and social workers (34).

As it pertains to the third question, the literature has primarily offered prescriptive statements in an effort to spur needed policy and administrative reforms (as can be seen in the efforts of blue-ribbon panels and task forces). However, no generally approved methodology exists for addressing the organizational and institutional challenges of LTC. To date, research on the question of how public and private leaders effect change in improving LTCFs and systems has drawn primarily from case-based methods and expert interviews. While studies have been essential in identifying the need for future leadership to promote organizational change and system reform, too little evidence exists concerning successful and unsuccessful change strategies for advancing LTC.

We therefore drew upon complementary literature on strategic change management and advocacy to promote system reform in the human services. This literature also relies upon qualitative case-based research and the reflections of academic experts and leading practitioners. This scholarship identifies the role of internal advocacy (in proposing and sustaining changes in service users and the organization overall) and external advocacy (in working with coalition partners to advance legislation and support funding requests) (58, 68, 69, 70, 75).

As it pertains to internal advocacy, two orientations are noted. The first is service-user-centered organizational improvement and transformation. The effort focuses upon the improvement of patient care and involves careful assessment of resident needs in order to address new problems and issues (64). Change-makers include administrators, staff, and caregivers, who develop and sustain trust-based, collaborative relationships (66). The second approach concerns organizational change management, led primarily by administrative leaders who bring the needed qualities of creativity and innovation, external awareness, flexibility, strategic thinking, and envisioning as they propose one or more key organizational changes. Such leadership involves engaging and getting buy-in from key staff members as the change process is being explored (85).

In regard to external advocacy, approaches include legislative advocacy, involving lobbying for a bill or policy, testifying in hearings, and releasing research reports; and administrative advocacy, including meeting with government officials, working in a planning or advisory group, responding to requests for information, and networking with government officials (58, 67). Both approaches are collaborative and involve advocacy organizations using and sharing relevant research evidence and personal narratives in an effort to persuade key elites and

decisionmakers. These strategies involve combined elite, empowerment, and mass strategies to advance advocacy campaigns. Finally, the literature underscores the need for financial and other organizational infrastructural resources in order to start and maintain internal and external advocacy efforts (13, 24).

5.0. QUALITATIVE INTERVIEWS

5.1. Methods

The second stage of this study involved *interviews with 28 key leaders who have current organizational expertise in the LTC sector*. Specifically, a purposive sample of state or national senior administrators was identified, and then invited to participate in semi-structured interviews via Zoom. In order for the sample to reflect diverse organizational and institutional contexts of LTC, the purposive sample included public policymakers and regulators, nonprofit and for-profit providers and operators, associations representing LTCFs, and advocacy organizations representing residents, caregivers, and staff in LTC settings.

Recruitment of the purposive sample of organizational leaders involved individual outreach from January through February 2022. Among Oregon leaders, outreach involved contacting senior administrators from state agencies responsible for the oversight and regulation of aging or disability services, state policymakers responsible for health and human service legislation, executives from nonprofit and for-profit providers, and leaders of associations (notably LeadingAge Oregon and the Oregon Health Care Association) and advocacy groups (such as the Governor's Commission on Senior Services and the Oregon Association of Area Agencies on Aging & Disabilities). Outreach to national leaders involved contacting senior administrators of national associations and advocacy groups that are actively involved in congressional aging- and disabilities-focused policymaking and administrative lobbying with federal health and human service agencies (e.g., Centers for Medicare and Medicaid Services).

Recruitment followed a standard procedure. An invitational email explained the study aims and research questions, and the study's relevance and importance for policy and practice improvement. The email also provided an overview of study procedures and an invitation to participate voluntarily and confidentially in the study. The email explained that interviewees would not be asked to reflect on their specific organization or on their work performance or their organization's work performance. Rather, interviewees were encouraged to speak broadly about the context, challenges, and opportunities of LTC, and the strategies needed to advance the future of care in Oregon and nationally. Finally, the invitational email noted that

interviewees would be provided with an executive summary that reflects major study themes, and that identifies recommendations and implications for the future of LTC.

The 28 interviews were completed from March through May 2022 and included these questions:

- In reflecting on the current organization of care for older adults and adults with disabilities, what's been working well; and what could be improved? What current challenges or threats and opportunities exist? What has been done to address these challenges or threats?
- Looking forward, what should be the future of care for older adults and adults with disabilities? What practices, programs, or policies are needed to go from the present to the future? What advocacy strategies will be needed to support these future efforts, in order to make the future of care happen?

These basic questions, and follow-up questions, asked interviewees to help translate ideas into action. Interviewees were asked to wrestle with the questions of "What is needed? How do you make change happen? And what is the place of advocacy in your efforts?"

The interviews ranged from 15 minutes to over one hour in length, and averaged around 45 minutes each. In total, interviews reflected: nine leaders from national associations or advocacy organizations; eight public administrators of state agencies; six leaders from state associations or advocacy organizations; three state policymakers; and two state LTC providers or operators. The large number of interviews was designed to prevent the singling out of specific leaders or organizational types.

Interviews were de-identified before being transcribed and transcripts were then read to support qualitative analysis. Analysis focused on whether specific themes (based upon the literature review) were noted. We also engaged in inductive analysis in an effort to identify themes that had not been raised in the literature review.

5.2. Results from the qualitative interviews

In reporting main themes from the 28 interviews, we organize the results via three domains:

- Current challenges impacting the organization of long-term care;
- Needed changes for the future of care; and
- Advocacy strategies to make needed changes happen.

5.2.1. Current challenges impacting the organization of long-term care

We first summarize challenges from the perspective of service users and care partners, providers, and ODHS. We then note a set of challenges that reflect the broader institutional political economic context of LTC. To most interviewees, the identified challenges had existed prior to the pandemic but were exacerbated by it. As a state policymaker said, “Everything is in a state of flux and crisis.”

5.2.1.1. Perspectives on service users and care partners

Four themes were raised in regard to the needs of residents and their care partners. First, interviewees suggested that seniors and adults with disabilities have insufficient access to quality care—particularly low-income payers and those in marginalized communities. Specifically, several interviewees stated that consumers do not have enough information to evaluate their care options. In addition, some interviewees noted that providers may not accept Medicaid-eligible adults, even if they are required to.

Second, many interviewees argued for more family caregiving supports. A leader of a national association/advocacy organization argued, “We are currently moving towards non-institutional care options. However, we are not doing enough to have infrastructure to support family caregivers and caregiving.”

Third, interviewees identified limited opportunities for intergenerational engagement between older adults and other community members. A state administrator stated, “We're missing out on that wisdom and the experience that our older adults hold by creating living environments for them— (older adults) really aren't integrated into the larger community.”

Fourth, interviewees overwhelmingly noted that staff of LTCFs need higher wages, promotional career opportunities (involving training and professional development), and a culture of caring and respect. Interviewees also noted that there are insufficient protections for staff of color, who can be traumatized by racist residents.

5.2.1.2. Perspectives on providers

Three main themes emerged in regard to LTC providers. First, interviewees overwhelmingly identified the need for workforce supports to address shortages of facility staff (e.g., CNAs, RNs, LPNs) in order to retain providers.

Second, insufficient funding was noted consistently. This theme reflects the perspective that providers are financially unable to train staff appropriately, such as in adult foster home settings. The need for further funding was also identified as a way to address payment

disparities, depending on the requisite type and level of care. For example, an interviewee suggested that in community-based care facilities (as compared to skilled nursing facilities), the reimbursement rate does not increase with cost. Funding was also noted as a way to address increasing and often overlapping service user needs. For example, several interviewees stated that funding for mental health and substance abuse treatment services among elders is lacking. Finally, some interviewees suggested that public funding increases are needed to address state-level needs in different federal entitlement programs. In particular, state and national interviewees noted that the level of state matching funds for home- and community-based services differs by state, as does the need for such federal services. A leader of a national association/advocacy organization said, “Medicaid (is) the biggest funder but it covers the small percentage of those who need it…there's a lot of unmet need. We don't even have a good measure of all of the unmet needs in states.”

Third, several interviewees argued that some types of providers can place a greater emphasis on financial performance than patient care. For example, one leader of a national association/advocacy organization suggested that assisted living facilities after the pandemic have increased their rates over 10 percent to 15 percent per month. Other individuals identified the existence of a profit perspective— “greed and profit,” as noted by a leader of a state association/advocacy organization—involving for-profit facilities.

5.2.1.3. Perspectives on ODHS

Interviews with state-level leaders identified a number of challenges facing ODHS as it seeks to articulate and implement its mission clearly. First, interviewees saw insufficient opportunities for ODHS to train LTCFs, and for post-training follow-up to assess whether providers are incorporating needed knowledge.

Second, tensions within ODHS were noted. One general tension reflects the difficulty ODHS faces in incorporating new values into an existing organizational culture. For example, several interviewees suggested that ODHS is experiencing growing pains as it seeks to become more anti-oppressive. An additional general tension reflects the bureaucratic complexity that ODHS faces in implementing new policies and regulations. In particular, some interviewees identified the challenges involved in developing new initiatives and managing them across state, county, and district levels. A final tension reflects the licensing and regulatory functions of ODHS in its interactions with LTCFs. A state administrator said, “We are partnering with providers and making sure that they're succeeding; and on the other hand, we are essentially disciplining providers when they aren’t making it work. So, there is a little bit of tension there.”

Third, state interviewees suggested that the existence of inter-institutional silos can limit opportunities for collective problem-solving. A state administrator said, "We begin to silo so much that we become paralyzed…And then, when we become paralyzed, we stop doing what we need to do." For example, several interviewees noted that ODHS and the Oregon Health Authority faced difficulties as they developed a collaborative initiative to address the health and behavioral health needs of seniors, and some of these interviewees noted that the needs of seniors remain inadequate. This institutional siloing was viewed as reflecting different types of public funding and different types of providers. For instance, several interviewees stated that nursing home oversight reflects federal regulations, yet the oversight of assisted living facilities—involving quality indicators such as worker ratios, quality aims, and safety goals—is more state-based. Overall, interviewees implied that inter-institutional siloing can negatively impact the ability of state agencies to ensure public accountability.

5.2.1.4. Perspectives on the broader institutional context of LTC

A final set of perspectives reflected the challenges raised by associations of LTC providers, the need for more robust consumer-centered advocacy, and the need for statewide leadership for older adults and adults with disabilities. First, several national and state interviewees noted that the primary rationale of industry associations is the protection of its members. Yet it was also suggested that LTC associations can protect poorly performing facilities. For example, a leader of a national association/advocacy organization suggested that industry lobbyists support "poor providers…There's this push to not have rules or regulations and to not have those that exist implemented or enforced." Similarly, a state policymaker asked, "How do you enforce things when there are facilities that are well-funded and will just contest penalties?" Another leader of a national association/advocacy organization suggested that industry associations can coopt academic investigations by funding policy research while dedicating less attention to consumer and worker rights.

A few state interviewees focused specifically on the Oregon Health Care Association (OHCA), which they implied holds substantial political power through its direct and indirect influence on state politicians and administrators. For example, one state administrator noted, "I felt I was having to explain myself to them instead of them having to explain themselves to me." This administrator stated that ODHS faced pushback from OHCA when ODHS tried to add training requirements or reprimands when harm occurred. Similarly, another state administrator suggested that adult foster home providers are unable to lobby for rate increases, unlike OHCA, which advocates for community-based care providers and skilled nursing facilities. However, it should be noted that few state interviewees made specific reference to OHCA or its sister association LeadingAge.

Second, interviewees overwhelmingly said that too little service-user-centered advocacy exists. It was suggested that it is easier to advocate for pets or children than older adults and adults with disabilities. For example, a LTC provider or operator argued, “It costs more to board your dog in Florida than Medicaid reimburses for 24 hours of care for humans in some instances.” In addition, some interviewees noted that the infrastructure for political advocacy can be limited, as advocacy is a staff- and time-intensive enterprise that is not available to most residents and community members. It was also noted that interorganizational competition exists among industry associations and advocates for funding and political influence, thereby implying that the space for service user advocacy is further constrained. Finally, a few national and state advocates questioned whether the advocacy pipeline can be sustained, particularly as Baby Boomer-era advocates may be retiring or passing on.

Third, a few interviewees identified the need for new leaders, who can present a clear and compelling public vision, and then bring in other leaders to articulate and implement the vision. This need was aligned with a need for more advocacy and with a desire for public leaders to make change to improve practice.

5.2.2. Needed changes for the future of care

In response to the identified challenges impacting the organization of LTC, interviewees offered several needed changes. These changes reflect the need for more public access, knowledge, options, and professionalization; the importance of expecting and paying for quality care, and monitoring care more carefully and consistently; and greater oversight and regulation of the LTC sector.

5.2.2.1. More public access, knowledge, options, and professionalization

Four main themes emerged that reflected the need for more public knowledge, access, and options. First, interviewees overwhelmingly suggested that older adults and adults with disabilities require greater access to publicly-supported, noninstitutional care. A leader of a national association/advocacy organization suggested that states should seek to “get more people at subsidized cost into smaller assisted living facilities and community-based, less institutional settings.” This emphasis reflects a turn away from long-term supportive services and towards home- and community-based services, as reflected in federal and state priorities.

Second, several interviewees identified the need for greater public knowledge of what is available for those wanting to be in home-like settings. A leader of a national association/advocacy organization identified the importance of “community awareness and access to home- and community-based services…to help people do anything they can do to

avoid nursing homes." Some interviewees also identified that most LTC is provided in family, voluntary settings and outside of licensed LTCFs.

Third, interviewees noted that the LTC sector needs to be financed differently in order to support more home-based care. Some interviewees identified the need for novel LTC financing mechanisms that provide more options for middle-class seniors and involve public and private insurers. A leader of a state association/advocacy organization stated, "Those who are impoverished and those who are rich have funding. Middle-income options are to impoverish yourselves to pay for housing." For example, it was noted by a few interviewees that while Washington state has developed an innovative approach to the financing of LTC insurance, the approach is still very much in development. As a leader of another state association/advocacy organization argued, "Long-term care insurance is not the solution."

Fourth, most interviewees identified the need for greater efforts to professionalize caregiving in LTCFs, by promoting worker pay and benefits and by increasing reimbursement rates among providers. A leader of a state association/advocacy organization argued that the LTC sector has been ineffective in trying to address COVID-19 and workforce issues simultaneously, and should stop "having feet in two canoes."

5.2.2.2. Expecting and supporting quality care and monitoring care more carefully and consistently

Four themes concerned the importance of quality care, with particular emphasis on how providers support access to care and quality of care as well as and how quality care is funded and monitored. First, interviewees identified the importance of centering service delivery in the service user perspective. Specifically, a number of interviewees noted that the overarching goal of LTC and community-based care is giving consumers choices for what services to get and where those services are delivered. Some interviewees also mentioned that services need to be equitable and inclusive, for example by reducing barriers to care for seniors whose first language is not English and for LGBTQ+ seniors. As a state policymaker noted, a tenet of LTC should be "quality care no matter where."

Second, suggestions were offered regarding methods to advance service user- and person-centered care at an organizational and institutional level. For example, community-based service integration was raised as a method to ensure that adults can access wellness visits and have their food security needs addressed. In addition, a few interviewees argued that service equity considerations need to be incorporated into how state agencies monitor LTCFs and how individual providers deliver (or do not deliver) care.

Third, several interviewees suggested that contracting and payment systems, and evaluation methods, need to support holistic and person-centered care. Some interviewees noted tethering value-based care to pay-for-performance financial approaches. In particular, it was suggested that efforts to incentivize overall quality of care might include giving per-resident bonuses for LTCFs that reduce hospitalizations; giving bonuses for employee retention; and giving bonuses to facilities that gather data on staff trainings, resident falls, and other quality care metrics.

Fourth, several interviewees stated that among LTC providers, individual facilities need to collect and use data more carefully and consistently to inform their quality improvement efforts. Interviewees also suggested that state administrators and private facility operators need to understand how and why training matters for service improvement and the promotion of person-centered care. An LTC provider or operator asked, "Do we know why this training exists? Do we know what happens when people don't do this training?"

5.2.2.3. Greater oversight and regulation of the LTC sector

Four themes were identified that concern the need to provide greater oversight and regulation of the LTC sector. First, interviewees overwhelmingly identified the importance of regulatory oversight and compliance at the organizational and institutional levels. Organizationally, public regulation was seen as essential for supporting consumer rights and quality of care for residents and their families. A state administrator stated, "We need a regulatory system that functions with a consumer protection focus rather than a provider support focus." Institutionally, regulation in the form of "watchdogs" (as noted by a leader of a state association/advocacy organization) was viewed as necessary for supporting the careful review of program implementation in response to policy requirements. Regulation was also seen as advancing financial transparency in the sector. Overall, regulation was viewed as fundamental for ensuring public accountability for the delivery of publicly funded and privately-provided services to residents and communities. A leader of a national association/advocacy organization argued, "To have a robust industry that is going to survive and flourish, you should be trustworthy."

Second, many interviewees suggested that for regulation and compliance efforts to succeed, ODHS and the state ombudsman need to be more actively involved in policy and program implementation. For example, a state legislator suggested that a regulatory aim needs to be the enforcement of penalties for noncompliance in order to avoid "gaming the system." Interviewees noted that such efforts should involve legislative committees on human services and healthcare and the Oregon Governor's Office in tandem with relevant state agencies and groups responsible for consumer protection.

Third, it was noted that for such regulatory efforts to be effective, ODHS needs to be set up to succeed, not to fail. For example, given that the number of LTCFs has expanded rapidly since 2020 (to its current level of 1,356 adult foster homes, 569 community-based care facilities, and 130 skilled nursing facilities), a few interviewees questioned whether ODHS had sufficient staff and needed organizational capacity to regulate LTCFs while managing pandemic-related crises.

In addition, several interviewees identified the role of ODHS in providing more assistance to new providers and poorly performing facilities. Interviewees stated that as a result of House Bill 3359 (instituting a progressive discipline approach with LTCFs), ODHS has a facility enhancement and oversight supervisory program, in which residential care facilities receive training (e.g., webinars) and technical assistance in response to licensing complaints. Yet it was suggested that ODHS should explore the adoption of a more tailored support model, in which fledgling providers are coached to be successful, as opposed to fined for noncompliance and violations. As a state administrator noted, "It's easier to teach (LTCFs) to be strong providers than it is to unlearn bad habits." The overall goal of the model is to be more collaborative and less adversarial, by creating venues and forums for joint problem-solving.

Fourth, many interviewees stated that collaborative performance measurement is essential for any regulatory effort involving policy and program implementation. Interviewees commonly suggested that transparency in the definition and measurement of quality care metrics is critical, given that providers may have very different interpretations of policies and other public directives. To support the consistent and careful tracking of facilities' efforts in response to state administrative rules and regulations and other public mandates, interviewees suggested that transparent and collaborative efforts should address the following:

- Issues of technical nomenclature involving community-based care, LTC, and residential care facilities.
- The alignment of quality care metrics with actual resident outcomes.
- Pockets of inequitable access to care (specifically identifying where people of color, LGBTQ+ individuals, and rural communities are being underserved).

5.2.3. Advocacy strategies to make needed changes happen

Finally, interviewees proposed several strategies that are intended to address the needed changes. Themes relate to the importance of centering the advocacy agenda in service users and care partners, and vesting the advocacy agenda in new leadership and a new institutional platform. Other themes identify a methodology for the development of an advocacy portfolio that reflects the institutional context of LTC. Finally, themes reflect upon how success in

advocacy can look different to different advocacy organizations and in different institutional settings.

5.2.3.1. Centering the advocacy agenda in service users and care partners

Interviewees uniformly identified the importance of an advocacy orientation that is centered in service users and care partners who bring their lived experiences—as opposed to those providers and other public and private organizations that speak on their behalf. As suggested by a state policymaker, "Consumers' views and needs need to be integrated into the system and the development of the policies that are going to affect them."

To advance this advocacy orientation, interviewees suggested that new advocates need to be identified, educated, and then given active opportunities to express their unmet needs in policy and administrative spaces. A leader of a state association/advocacy organization suggested that local organizations should develop and share a "Lobbying 101" instruction guide for laypersons. It was also noted that this advocacy orientation needs to incorporate an emphasis on diversity, equity, and inclusion that dignifies residents and staff equally, that is non-tokenizing, and that affirms the perspectives of persons of color and other traditionally marginalized groups.

Yet while interviewees stated that residents, families, and staff need to be at the table more regularly in the public policy and regulatory sphere, some also worried that advocates may fear retaliation. For example, a state administrator asked how to bring advocates to the table so that they do not perceive adverse consequences (such as residents who worry that their identification of unmet care needs may result in threat of eviction, or staff who fear that their service concerns may hurt their employment status).

5.2.3.2. Vesting the advocacy agenda in new leadership and a new institutional platform

Several interviewees identified the formal leadership needed to support advocacy for service users and workers. Specifically, interviewees argued for a different type of leadership that can dedicate significant attention to consumer protection, in which more prominence is given to issues of quality of care and quality of life for older adults and adults with disabilities. For example, a leader of a state association/advocacy organization stated, "We need an executive leader of the state that values older people and people with disabilities." The interviewee then suggested that the future leader needs to create a collaborative and deliberative space that invites executives of major public and private groups to discuss problems and issues and explore solutions. In addition, the interviewee suggested that the leader needs to have sufficient experience, authority, evidence, social capital, and the ability to mediate. Finally, the interviewee stated that the leader needs to use their educative and consultative abilities as they work with different public and private organizations.

Other state interviewees raised the need for a future platform for leadership to advance a clear strategic vision and plan. Yet no interviewee could identify the specific institutional platform that would be needed. Several interviewees noted that while state agencies are able to support advocacy efforts, state administrators have little authority or leverage to advocate, whereas industry associations advocate primarily for their organizational members. As noted by a state administrator, "ODHS is the fulcrum of a very unbalanced seesaw, where patients, their families, and direct care workers are on one side with very little power, and industry and their organizations are on the other side with a lot of money and power."

However, two dimensions of the needed institutional platform were highlighted. First, interviewees regularly noted the importance of creating more structured opportunities for community leaders to present their needs-based requests to policymakers and public administrators. It was implied that such requests need to be separate from the adult protective service complaints that are submitted to ODHS and the state ombudsperson. Second, many interviewees suggested that more collaborative opportunities are needed between local providers, clinicians, community-based organizations, relevant cabinet-level state administrative entities (e.g., ODHS, Oregon Health Authority, Oregon Disabilities Commission), insurers, and health plans.

Finally, several interviewees noted that sufficient public funding and organizational infrastructure is needed to support any advocacy platform. An LTC provider or operator said that "your budget is your moral document," and a leader of a national association/advocacy organization argued that "funding is at the heart of all advocacy work." Interviewees also suggested that requests for public funding need to showcase how advocacy efforts lead to programs that enhance service accessibility and effectiveness and quality of life.

5.2.3.3. Developing an advocacy portfolio that reflects the institutional context of LTC

Interviewees noted several strategies that can be used to shape an advocacy portfolio, and that reflect the institutional ecosystem of LTC. Leaders of national and state associations/advocacy organizations identified the following essential factors that are summarized in table 2. The factors reflect engagement in evidence-informed advocacy by educating policymakers, public funders, and public agencies about the needs of large groups of service users, existing policy gaps and fiscal challenges, what needs to be done, and how to do it. These factors also recognize the importance of outreach to other relevant stakeholders, including media elites, state and local leaders, facility owners and operators, and community residents and their families.

In addition to the examples provided in table 2, interviewees identified other methods for developing an advocacy portfolio. Some interviewees suggested that a coalition or alliance of state funders, providers, and service users' needs be explored in an effort to align payments, service delivery, and quality of care. For example, a leader of a national association/advocacy organization highlighted the importance of "efforts around transformational change in healthcare rates and paying for value-based care." Finally, a few state administrators suggested that small-scale model initiatives and demonstration projects can often support larger changes, particularly if they address major unmet needs. Such innovations may need to involve a partnership between ODHS, leading providers, associations, and advocates. They may also require federal and state waivers, and evaluations that examine whether the innovation is more cost-effective (using federal and state quality care metrics and other standardized measures) as compared to as-usual care. For instance, a state administrator suggested that a future initiative might seek to determine whether the effort improves resident safety and quality of care as well as efficiency in service delivery.

5.2.3.4. Recognizing that interpretations of advocacy success differ

Finally, interviewees were asked to consider what success in advocacy looks like. In response to this question, several elements of successful advocacy were identified. These are summarized in table 3.

6.0. IDENTIFICATION OF MAJOR CHALLENGES AND NEEDS IN OREGON

Based upon a synthesis of results from the literature review and qualitative interviews, we identify the major challenges and needs facing Oregon's aging adults and adults with disabilities as well as those public and private organizations focused upon LTC. This identification of challenges and needs reflects the organizational and institutional lens that informs the Ecosystem Hub.

6.1. Major challenges

Among the population of older adults and adults with disabilities, a major challenge concerns the lack of opportunities for service users to self-advocate and advocate for their communities. This involves older adults and adults with disabilities not being given enough opportunities to register their demands and those of members of their community, using inclusive and accessible methods. Service user advocacy is clearly identified as being insufficient at the organizational level (within LTCFs) and institutionally (with policymakers and state agencies). Other challenges facing older adults and adults with disabilities include insufficient access to

quality care; social isolation and insufficient family caregiving supports; and insufficient opportunities for intergenerational engagement.

Among the population of LTC providers, major challenges are identified at the staff, management, and agency levels. At the staff level, challenges include high staff turnover and low staff morale, insufficient staff wages, and few promotional career opportunities. At the management level, we note the limited use of participatory management and facilitative leadership, and few opportunities for managers to empower staff. At the overall organizational level, we identify the following challenges:

- Few opportunities and insufficient resources to incorporate a person-centered care framework.
- Insufficient use of evidence to support service improvement and organizational performance.
- Limited use of interdisciplinary and interprofessional teams.
- Few opportunities to create an organizational culture of caring and safety and person-centered climate among staff.

Finally, at the institutional level, challenges include the following:

- Insufficient funding for LTCFs.
- Organizational complexity at ODHS.
- Siloing between ODHS and other state agencies.
- Insufficient opportunities for ODHS to train LTCFs.
- The protection of ineffective providers.
- A lack of statewide leadership that prioritizes the sharing of opportunities for service user-centered advocacy.

6.2. Major needs

In response to these major challenges, we identify three sets of needed changes. These reflect the following major types of organizations comprising the ecosystem of LTC:

- Providers that are responsible for the delivery of accessible, timely, and quality LTC, and the industry associations that represent them.
- Public agencies that are directly or indirectly involved in the oversight, funding, and regulation of the LTC sector and policymakers that are tasked with policy development, evaluation, and improvement that involves publicly-funded services to older adults and adults with disabilities.

- Advocacy organizations that register ongoing and emerging service user needs, propose sensible ways to address them, and then monitor existing and new initiatives from a service user self-determination perspective.

6.2.1. Major needs of LTC providers

Major needs for LTC providers relate to the delivery of high quality, affordable care that meets the specific needs of residents. A core element concerns the need for further professionalization of the LTC workforce, involving increased pay, staff training (notably involving staff of adult foster homes), and expanded opportunities for professional growth and development. Another element involves the importance of managers and administrators collaborating with staff and service users to use various forms of evidence to address core service delivery and operational problems. A related element concerns the need for organizational leaders to promote a culture of learning and improvement. These elements are intended to ensure that LTCF structures and processes attend to the needs of residents and care partners.

6.2.2. Major needs of ODHS, other public agencies, and policy bodies

Within ODHS, the major need concerns the strengthening of public regulation through careful and consistent performance measurement and management. This involves ensuring that ODHS has sufficient staff to monitor and support service improvement and organizational performance, particularly involving at-risk and poorly performing providers. A related need concerns the importance of coaching fledgling LTCFs via an organizational support model. It also concerns the exploration of methods that align performance measurement with contracting and procurement systems (such as value-based payments).

To address these needs, ODHS may need to explore small-scale initiatives that are designed to enhance service accessibility and service quality. It may also need to create structured opportunities for conveying lessons learned internally and externally. The development of internal forums could involve ODHS units that are responsible for different types of providers (i.e., adult foster homes, community-based care facilities, skilled nursing facilities) and that work at different levels of the agency (i.e., state, county, district). External forums could involve the sharing of promising practices and programs with industry associations and state agencies in Oregon and outside Oregon.

Externally, ODHS needs to reduce siloing with the state ombudsman, the Oregon Health Authority, and sister public agencies and commissions. Service integration opportunities can be explored, particularly if they can address the comorbidities, intersecting service needs, and

service-related costs of residents. A related need involves ODHS coordinating more closely with relevant policy committees, notably involving human services and healthcare, in order to align evidence-based policymaking and evidence-based public management. Specifically, the development and evaluation of new policies and statutes should include ongoing assessment of policy implementation and effectiveness.

6.2.3. Major needs of advocacy organizations

The major need of advocacy organizations is clear: More leaders and advocacy organizations are needed in order to advance the call for greater access to home- and community-based services and greater public knowledge of what is available for those wanting to be in home-like settings. Another need involves the need to reimagine advocacy leadership as a collective activity that involves the social and political efforts of community members. This can be exemplified by the need to coach cohorts of new advocates using an "Advocacy 101" training to identify unmet needs for LTCFs in middle-income communities and in low-income communities where few Medicaid-reimbursable LTCFs are available, and then conveying the needs to relevant state agencies, policymakers, and media sources. A related element is the need for organizational financing and development to support the maintenance of advocacy efforts.

7.0. RECOMMENDED ADVOCACY AGENDA FOR ODHS AND PARTNER ORGANIZATIONS

In response to the identified challenges and needs, we propose a comprehensive advocacy agenda that identifies diverse paths forward for ODHS and partner organizations to ensure the quality of care and quality of life for those living in LTCFs. The agenda recognizes the enormous challenges ODHS will face in the future in terms of access, cost, quality of care, and quality of life for those living and working within LTCFs. It also acknowledges the essential and evolving role of providers, and the needed emergence of more robust advocacy organizations. The proposed agenda lays out a framework that identifies diverse ways to address these challenges and needs by bringing more visibility to them so that effective planning may begin.

7.1. Framework of an advocacy agenda

Table 4 frames a proposed advocacy agenda. The table columns distinguish between proposed efforts that are internal to ODHS versus those that involve partnerships with external organizations (notably providers and associations, other state agencies and public policy committees, and advocacy groups). In contrast, the table rows differentiate between a focus on organizational improvement that supports adaptation and planned change versus

organizational transformation that supports reform and corrective action. The overall aim of the framework is the identification of possible methods to strengthen accountability for the overall LTC sector, ranging from more modest to more intensive in scope.

Before the elements of the advocacy agenda are described, some limitations should be acknowledged. First, the proposed elements identified in table 4 may not reflect all current and planned efforts by ODHS. Specifically, while many interviewees identified needed opportunities for ODHS, interviewees were generally encouraged to speak broadly about the context, challenges, and opportunities of LTC, as opposed to organizational needs specific to ODHS. Second, the qualitative interviews likely omitted the perspectives of additional staff in ODHS and additional community partners. Third, the literature review was drawn largely from non-Oregon sources, thereby limiting the potential applicability of main findings.

Despite these limitations, the literature review and qualitative interviews provide complementary evidence concerning the need for ODHS to partner internally and externally to strengthen service accessibility and quality. We therefore draw specific implications for policy, organizational improvement and management and leadership development, and community building, as seen below.

7.2. Internal organizational improvement methods

The upper left-hand quadrant of table 4 concerns organizational improvement efforts that are internal to ODHS. First, ODHS should create opportunities for ODHS staff to discuss the needs of service users, at the district, county, and state levels. Such listening structures are designed to identify ways to better serve residents of LTCFs and care partners. Second, ODHS should explore opportunities to incorporate a specific focus on accessible and quality care into its existing practices, programs, and policies. This effort should involve consideration of lessons learned for ODHS staff who are charged with the oversight of specific practice initiatives, ongoing and new programming, and policy implementation. Reflection upon what has worked well and what has worked poorly is intended to foster a culture of learning and quality improvement for ODHS as it contracts for LTC services and supports.

Third, ODHS should seek to align its emphasis on performance measurement (as embodied in the use of quality care metrics) with a focus on the performance management of providers. Poor performing providers, and new providers, will likely require organizational capacity assessment and leadership coaching led by ODHS staff. These efforts will involve ODHS staff being ready to assess and then train providers, in order to improve service quality. Thus, a fourth effort involves ODHS assessing its current and anticipated level of unmet needs pertaining to its oversight and regulation of LTCFs. It will be especially important to ensure that

ODHS has sufficient staff in response to the rising need for the licensing, regulation, and support of community-based care facilities.

7.3. External organizational improvement methods

The upper right-hand quadrant of table 4 concerns external organizational improvement efforts, which involve needed partnerships with relevant organizations. First, ODHS should share knowledge of available options for LTC, particularly in service deserts (such as rural areas). The knowledge should be viewed as used and useful from the perspective of older adults and adults with disabilities. In particular, knowledge navigation assistance may be needed from knowledge brokers. For example, leaders of culturally-specific communities may need to translate and then convey electronic documents written in English into a more accessible format. A second effort involves ODHS providing leadership development opportunities to community leaders and residents of LTCFs. The aim is for leaders and residents to give input and feedback as to their experiences and needs. This aim is intended to advance an emphasis on quality care among service users and providers.

Third, ODHS should promote the training of providers at different organizational levels. Management and leadership training should begin with a focus on quality improvement and the development of a culture of learning among frontline staff, supervisors, and administrators. Training should also involve methods for the support of family caregivers and consumer education. Fourth, ODHS should engage in the development and testing of new, small-scale innovations. Such innovations may involve public agencies and leading providers, in an effort to assess cost-effectiveness of a pilot initiative vis-à-vis as-usual care. The testing and scaling of promising initiatives may need to be limited to a specific provider pool or geographic area. Most importantly, service user leadership should be involved in the selection and management of any specific demonstration.

7.4. Internal organizational transformation methods

Two elements constitute the lower left-hand quadrant of table 4 concerning internal organizational transformation efforts. The first involves a shift designed to rebalance the culture of ODHS from one that is principally focused on organizational compliance to one that is also strongly focused on organizational innovation. The effort may involve the development of positions and units focused on the promotion of service access and the development and testing of new enterprises. Such an effort may become more prominent as ODHS explores less-institutional pathways for the delivery of accessible and quality care and the continued promotion of resident safety and wellbeing.

The second transformational shift concerns how ODHS will need to support and staff service user advocacy. Infrastructure supports for service user advocacy may be provided in a manner comparable to the infusion of DEI throughout all operations of ODHS. For both elements to proceed, the shift in organizational culture will require substantial time and financial investments, talent identification and leadership development, and the consistent use of various forms of evidence.

7.5. External organizational transformation methods

Finally, three elements constitute the lower right-hand quadrant of table 4 that concern external organizational transformation. First, as identified in the literature review and the qualitative interviews, ODHS should strengthen its focus upon consumer protection. Such external efforts will need to involve collaboration with other public agencies, to advance regulation on the fundamental issues of access, quality care, and cost. In regards to the issue of cost, ODHS and its public agency partners may need to gather information on the financial transparency of LTCFs. It may also be important for ODHS to explore the use of value-based care and other performance-based contracting methods that tether payments to actual performance (as opposed to per-diem cost-reimbursement contracting).

Second, we identify the need for systemwide workforce supports designed to promote service-user-centered advocacy in LTCFs. On the matter of private human service workforce issues, public human service organizations have few levers of governance. Specifically, public human service agencies can sanction providers that are unable to retain direct care workers and that do not comply with staff training requirements. They can also support mergers and acquisitions of providers in response to one or both providers losing sufficient trained staff.
Because private workforce issues are essential yet differ by local labor market, ODHS may need to cosponsor private sector initiatives that support the retention and advancement of direct care staff in a specific labor market. Such initiatives will need to involve specific providers, and may provide an opportunity to partner with industry associations and advocacy organizations.

Third, ODHS should invest additional resources in identifying innovative LTC policies and programs. ODHS has a deserved positive reputation for its support for family caregivers, effective transitions, and choices for community-based settings and providers. Further innovations in these areas should be pursued. Yet ODHS's future innovations may be in response to ongoing concerns of affordability and access, and quality of life and quality of care. For instance, innovations may involve the collaboration of local authorities, private owners, and private operators in supporting the development of residential care facilities for middle-income adults.

One way to support public sector innovations in policymaking and programming is through public service incubators. These can involve the lead public organization supporting the design, testing, evaluation, and improvement of innovations in partnership with other public or private sector organizations. The model policies and demonstration programs we have referred to might be organized under the umbrella of an "ODHS LTC incubator." The development and branding of such an incubator would distinguish ODHS Adults and People with Disabilities in relation to its other service divisions as well as in relation to other state human service agencies.

8.0. REFLECTIONS, QUESTIONS, AND RECOMMENDATIONS

We conclude by first providing reflections and questions that require additional information from ODHS and other leaders of the LTC sector. We then offer general recommendations for ODHS that reflect the literature review and qualitative interviews.

8.1. Reflections and questions

In synthesizing the literature review and qualitative interviews, we noted the substantial gap between the current institutional structure of LTC and what may be needed for the future of LTC. This discrepancy reflects a tendency of our interviewees to focus attention on here-and-now considerations that involve current organizational demands and dilemmas.

However, when they were asked to engage in a brief thought experiment about what needs to change in LTC practices, programs, and policies, several interviewees identified the need for leadership and an overarching institutional platform that can implement the leader's vision. Unfortunately, they were unable to identify the specific shape of the leadership profile and institutional platform.

We therefore list basic questions designed to prompt strategic visioning. First, what might be involved in proposing a "state czar for aging and disabilities" and vesting the leader in a cabinet-level position that is responsible for the development and implementation of a master plan for older adults and adults with disabilities (86, 87)? Second, how might the position be viewed by existing institutional parties in Oregon and nationally? Third, what economic and political resources might be attached to the position? Fourth, in the absence of new leadership and overarching institutional platform, what can ODHS do to better address the needs of older adults and adults with disabilities? Specifically, are there ways for ODHS to express more leadership, by monitoring need levels across geographical areas; supporting interorganizational coordination and collaboration in improving existing systems of care; advancing diversity,

equity and inclusion in publicly funded and privately provided human services; and strengthening regulation and innovation in quality care initiatives?

These questions are not hypothetical. In the course of conducting the interviews, we learned from a leader of a state association/advocacy organization that a comprehensive aging and disability assessment and plan is being finalized. The assessment and plan will refer to LTCFs but is designed to be broader than the LTC sector. An aim is to identify the needs of low- and middle-income seniors and seniors with disabilities for healthy aging in Oregon. A particular emphasis will be the need for community-based care supports in non-metropolitan communities.

8.2. Recommendations

We offer several general recommendations to ODHS.

8.2.1. Provide outreach and engagement

Provide public outreach and engagement to critical groups—via public awareness campaigns, public forums, and leadership engagement and education—to further the development of an Ecosystem Hub. This outreach and education could include the following:

- Developing, populating, and updating a webpage that includes relevant white papers and policy briefs, other practice, program, and policy resources, and case studies of organizations that exemplify promising avenues for the future of LTC.
- Developing and coordinating a speaker series focused on innovations in practice, programming, and policy.
- Developing and coordinating a leadership roundtable that designs a new way forward for LTC.
- Convening major leaders in Oregon and nationally via a conference cosponsored by ODHS.

8.2.2. Establish an advocacy framework

Consider several elements of the advocacy framework (seen in table 4) as ODHS advances its strategic partnership. These relate to the need for the leadership development of service users, the training of providers, and model development and testing through pilot demonstrations.

8.2.3. Use a decision-making framework

Use a common decision-making framework for advocates who seek to address unmet needs. This framework includes the following:

- Evidence-informed issue identification that reflects needs assessments, literature reviews, and the use of available administrative, community, and cultural evidence.
- Discussion of how to structure advocacy involvement (i.e., who sits around the table to engage in issue identification and prioritization?).
- Clarifications of assumptions by identifying what is possible versus what is impossible and what is desired versus what is needed.
- Identification of viable options to address a given issue.
- Selection of the most viable implementation option along with an explanation of the selection criteria.
- Implementation of the selected option and articulation of specified outcomes and timelines.
- Evaluation of the overall process using specified criteria and timeframes.

8.2.4. Establish organizational supports for advocacy

Establish several organizational supports as ODHS identifies new ways to support advocacy of the LTC sector. These recommended supports are quoted below from the Wilder Collaboration Factors Inventory (88) and include the following items:

Community Building:

- History of collaboration or cooperation in community
- Collaborative group seen as a legitimate leader in the community
- Favorable political and social climate
- Mutual respect, understanding and trust

Membership Development:

- Appropriate cross-section of members
- Members see their collaboration as in their self-interest
- Ability to compromise
- Members share a stake in both process and outcome
- Multiple layers of participation

Skilled Leadership:

- Promoting flexibility
- Developing clear roles and policy guidelines
- Adaptability
- Appropriate pace of development
- Open and frequent communication
- Established informal relationships and communication links

Strategic Planning:

- Concrete, attainable goals and objectives
- Shared vision
- Unique purpose
- Sufficient funds, staff, materials, and time

9.0. CONCLUSION

This paper examined the enormous challenges ODHS and the LTC sector will face in coming years in terms of access, cost, quality of care, and quality of life for those living and working in LTCFs. Some of the best hopes—in the literature and in our interviews—for pre-empting or resolving these challenges involve shaping organizational values, culture, and leadership approaches to promote collaboration between those who have a stake in LTC; establishing sustainable funding for LTC services; creating frameworks that support effective outreach and engagement while harnessing the voices of LTC users and workers; strengthening advocacy for LTC users; professionalizing the caregiving profession; and enhancing monitoring and oversight of care quality. Oregon has proven its commitment to improving the health, quality of life, and quality of care for older adults and persons with disabilities. It is our belief that adoption of recommendations highlighted in this paper will move Oregon even further along the spectrum of high quality, person-centered care.

APPENDICES

Table 1. PESTLE Factors Impacting the Organization of Long-Term Care

PESTLE factors	Descriptors
Political and policy factors	Public and private organizational responses to federal and state legislation, public policies, and regulations that involve long-term supportive services and home- and community-based services; and the proposing of new policy initiatives by LTC leaders in response to existing policy hurdles and mandates
Economic and fiscal factors	LTC providers and associations anticipating and addressing public financing issues, contracting difficulties, and competition for market share, staff, and influence
Social and cultural factors	LTC leaders responding to the need for providers and staff members, particularly in underserved communities and in response to racial/ethnic disparities in access to and use of care
Technological factors	The adoption and diffusion of new technology-based efforts to support providers and staff members that are intended to enhance service access, workplace effectiveness, and quality of care
Legal factors	Opportunities and concerns facing LTC leaders that reflect existing and new rules and regulations, including liabilities and exemptions from class action lawsuits
Environmental factors	The design of LTCFs to be less institutional and more home- and community-based

Table 2. General Methodology for Developing an Advocacy Portfolio

Essential factors	Examples or quotes
Listening to service users and community leaders about the needs of older adults, via community-based organizations across the state that are focused on elder rights (e.g., local area associations for aging).	"Engage at a local level, where you understand and know your community…there's more power there and more impact" (state administrator).
Collaborating with established advocacy partners while finding ways to work with less-traditional allies.	Partnering with the Department of Labor on long-term care workforce issues.
Drawing upon core knowledge with public policies, programs, and practice efforts.	Having subject matter expertise in the field by "sweating the details" (leader of a national association/advocacy organization).
Careful assessment of specific rules, laws, regulations, and existing standards of care within state industries/systems.	Performance measurement focused on quality of care and quality of living. Formal evaluation of the implementation of new policies/programs in long-term care facilities.
Identifying policy-fiscal opportunities that are attentive to cost calculations.	Recognizing that Medicaid managed care plans are starting to contract with provider networks to address the social determinants of health, analogous to Medicare Advantage plans. "I think there has to be a bridge to better funding and services, but that can't all come from increased rates from taxpayers. Some of that is going to have to come from decreased profits in for-profit organizations and…that's really hard for people to understand" (state policymaker).
The development of research and evaluation studies, and their dissemination via forums, the sharing fact sheets and other consumer-focused briefs.	"We do research…we do blogs, we do fact sheets…for states, so every state can plug in what they know that's the most valuable thing" (leader of a national association/advocacy organization). "We let data inform our efforts and actions" (leader of a state association/advocacy organization).
Service user-led education of policymakers and public administrators.	Public testimonials and policy/administrative stories that capture the experiences and unmet needs of service users in a novel way to represent a population. "Whining is not advocacy" (leader of a national association/advocacy organization).

Table 3. What Does Successful Advocacy Look Like?

Elements of successful advocacy	Examples or quotes
Creating awareness by naming a problem and developing a common understanding of it.	"If you haven't named the problem, then how are you going to even start to (address) it? So it's like explaining to everyone what the problem is" (leader of a national association/advocacy organization).
Close relational work involving key staff and stakeholders, that builds upon ongoing collaboration with partner organizations.	"You don't have to know everyone. You just have to know the people who are on the committees that affect your work and your population" (leader of a national association/advocacy organization).
Rooting the advocacy effort in a common and well-used strategic or policy framework.	The expert use of a social determinants of health framework or a social impact model.
Preventing or slowing down the more dangerous aspects of proposed legislation, and proposing improvements on existing laws.	"Playing defense in a Republican Congress, or passing better laws with a Democratic Congress" (leader of a national association/advocacy organization). "Successful advocacy is a policy that accurately reflects the consumers' perspective, wants, and needs" (leader of a national association/advocacy organization).
Sharing knowledge strategically, to broaden networking into new policy advocacy communities.	Conveying the possible benefits and costs of a proposed workforce development initiative to state and local policymakers as well as to advocacy organizations focused upon long-term care facilities.
Empowering workers and community members, particularly in support of culture change.	"It's a movement to change the culture of nursing homes, to be more resident- and direct care worker-centered" (leader of a national association/advocacy organization).
Creating and sustaining opportunities for service user leadership in community, public and private administrative, and legislative advocacy.	"Getting a place at the legislative policymaking table" (leader of a national association/advocacy organization).
Searching for increased funding as well as more diverse sources of funding for one's advocacy agenda.	Not relying on an angel investor (e.g., Mackenzie Scott, who gave grants to two of the national associations/organizations groups being interviewed) or a sole public funding source.

Table 4. Organizational Improvement and Transformation by Internal and External Methods

Impact	Internal relations & development	External relations & development
Organizational Improvement	• Building listening structures to hear ODHS staff and their experiences with service users and community members. • Centering ODHS practices, programs, and policies in accessible and quality care. • Alignment of quality care metrics with performance management. • Assessing unmet needs among ODHS staff.	• More stakeholder awareness of available options. • Leadership development of service users. • Training of providers. • Model development and testing through pilot demonstrations.
Organizational Transformation	• Rebalancing compliance activity with the capacity to innovate. • Promoting advocacy infrastructure development .	• More focus on consumer protection. • Systemwide workforce supports. • More focus on innovations in long-term care policy and programming.

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