



PennState

Ross and Carol Nese
College of Nursing

Tressa Nese and Helen Diskevich
Center of Geriatric Nursing Excellence



PROGRAM FOR PERSON-CENTERED LIVING SYSTEMS OF CARE IMPACT REPORT: 2019-2021

**A Program of the Tressa Nese and Helen Diskevich Center of Geriatric Nursing Excellence,
Ross and Carol Nese College of Nursing, Penn State University
and Polisher Research Institute, Abramson Senior Care**

This report offers an overview of the Program for Person Centered Living Systems of Care's (PPCLSC) recent accomplishments translating evidence-based research into practice, policy, and education to improve the well-being of older adults.

As we consider our achievements from 2019 to 2021, we are especially proud of:

- Ongoing research to better meet the needs and preferences of traditionally under-served older adults, including people who identify as LGBTQ+ and older adults living with dementia or communication challenges.
- Quickly pivoting during COVID-19 to develop research and resources to support older adults and care partners.
- Developing and enhancing training for the next generation of gerontological scholars and practitioners.

The PPCLSC team and its collaborators lead pragmatic research, provide educational and training resources, and promote collaborative opportunities, all with a common goal: to spur innovation and improvements in the practice and quality of long-term services and supports (LTSS). We disseminate our work broadly, leading to adoption among scholars, practitioners, and policy makers to advance person-centered care.

We offer our sincere thanks to PPCLSC's philanthropic partners for investing in our work to advance personalized care as the standard of care for older adults in all settings. We are deeply grateful to Dr. Donald Ford, Carol Irvine and Abramson Senior Care for their ongoing support and commitment to this vision.

POLICY INFLUENCE

The pandemic highlighted persistent weaknesses in the nation's systems of LTSS. Our research studies, and our work with LTSS providers and other stakeholders across the care continuum, directly address these problems and test new solutions. This experience informs our recommendations for state and federal policy that promotes preference-based, person-centered care.

Accomplishments:

- Kimberly VanHaitsma, PPCLSC's director, gave an invited presentation on the state-of-the-science of person-centered care at the 2020 National Institute on Aging's Research Virtual Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers. Her review of effective evidence-based pragmatic approaches contributed to the summit's influential recommendations for future national scientific research and policy priorities for person-centered care.
- The PPCLSC team and its collaborators contributed to three policy papers published in leading journals addressing (see Appendix A):
 - Dementia care topics related to research priorities and outcomes, models of person-centered care, and competency-based training for care partners.
 - Lessons learned from Ohio's use of the Preferences for Everyday Living Inventory (PELI) and the potential future application of this tool as a pay-for-performance (P4P) metric in statewide initiatives.
 - Use of the new field of implementation science to advance equity and person-centered care to influence and improve the quality of care in nursing homes.

In other policy-related activities, VanHaitsma serves as a member of the Pennsylvania Long-Term Care Council and collaborates with the Institute for Healthcare Improvement and other partners to shape national and state-level dementia and age-friendly initiatives that are models for national policy. Also, Rabbi Erica Steelman serves on the Long-Term Care Equality Index Advisory Council, a joint project of the Human Rights Campaign and SAGE.

RESEARCH IMPACT

Our research focus supports the development of theory, measurement methods, and clinical interventions that enhance the physical and psychological wellbeing of older adults, particularly those living with dementia. We test innovative methods using preference-based approaches to improve older adults' quality of life through numerous studies in the U.S. and internationally in a variety of settings.

By the Numbers for 2019-2021:

- We are fortunate that the work has been supported by 10 grants, including 4 federal grants from the National Institute on Aging, National Institute for Nursing Research and Health Resources and Service Administration; 3 grants from state government (Ohio and Tennessee); 2 grants from private foundations; and 1 through Penn State University (see Appendix C).
- During 2019 through 2021, a total of 52 articles were published in leading journals (cited 215 times per Google Scholar). The article *Optimizing Effective Communication While Wearing a Mask During the Covid-19 Pandemic* was the second-most viewed article in the *Journal of Gerontological Nursing, November 2020 issue*. In addition, we disseminated our work via 42 symposia and presentations to the Gerontological Society and other scientific and provider organizations (see Appendix C).
- Our collective research spanned the continuum of LTSS care settings, including: 100+ nursing homes, 45+ primary care sites and 10+ home and community-based service providers in Maryland, Ohio, Pennsylvania, Arizona, Michigan, Missouri, Texas and Canada.

Accomplishments:

- Developed and published a new integrative model of person-centered living systems of care that has helped advance the field of person-centered care. This theoretical model can be used to test how meeting individual preferences affects psychological wellbeing among older adults receiving LTSS. *The Gerontologist, 2020*.
- Extended preference assessment and preference-based care into home and primary care settings:
 - The new PELI subscale aims to strengthen communication between older adults receiving home health services and care providers. This timely addition to the PELI asks older adults about their preferences for using technology and helps providers match their communication preferences to each individual's needs.
 - The Age-Friendly Care PA initiative (a HRSA-funded Geriatric Workforce Enhancement Grant), housed within the Ross and Carol Nese College of Nursing at Penn State, provides training, and seeks to infuse person-centered care processes in primary care practices in rural, under-served communities statewide. Partners on the project are Primary Health Network (PHN), the state's largest Federally Qualified Health Center; Institute for Healthcare Improvement; Area Agencies on Aging; and Alzheimer's Association.
- Created preliminary versions of the PELI for special populations: one for older adults with language, reading or comprehension challenges and a new stakeholder-driven project to refine the PELI for older adults identifying as LGBTQ+.
- Collaborated with German researchers to develop and test the first version of the PELI for international use in home, community-based and residential settings. Similar culturally sensitive translations of the PELI into Korean and Mandarin also are underway.
- With a team from Miami University Scripps Gerontology Center, we worked with nursing home providers in 11 states to co-create new tools and interventions to promote preference-based, person-centered care and study the systemic factors that promote or hinder uptake of these evidence-based practices in LTSS (see next section).

- With a team from the University of Maryland and Penn State University, conducted a randomized pragmatic clinical trial designed to enable nursing home staff to reduce behavioral and psychological symptoms of distress associated with dementia among nursing home residents and improve their quality of life using person-centered approaches.
- During the period from 2015 to 2019, the Ohio Department of Medicaid implemented a mandate that nursing homes use the PELI to enhance person-centered care. A grant examining this data will answer questions about the factors that impede or facilitate adoption of the PELI assessment tool.

Research Honors:

- *Individualized Positive Psychosocial Intervention Value Proposition (IPPI) -- National Institute on Aging IMPACT Collaboratory*, recognizes the IPPI as an exemplar of an evidence-based dementia care program.
- *Innovative Research on Aging Award – Mather Institute, 2019* -- for our research using machine learning to analyze and predict nursing home residents’ preferred activities.
- *Excellence in Quality Award -- Pennsylvania Health Care Association, 2019* -- for the “All About Me Project” to enhance transitions from the home to nursing home setting.

PRACTICE IMPACT

Through ongoing, collaborative research partnerships with providers and Miami University, we created training videos, tip sheets, webinars, newsletters and Agile-based Quality Assurance and Performance Improvement programs. With provider input, we tested and refined each resource to assure ease of use by a diverse workforce that includes administrators, activity and life enrichment directors, social workers, nurses, physicians, direct care workers, and advocates.

We developed and tested many of our tools first in the nursing home setting; yet they hold promise for home and community-based services providers as well. (See Appendix D for resources developed from 2019 to 2021, available free to providers at PreferenceBasedLiving.com.)

Accomplishments:

- Developed 100+ new resources to enhance provider capabilities to deliver person-centered care. These include 60 Individualized Positive Psychosocial Intervention (IPPI) activity kits, 30 person-centered care tip sheets, 14 training videos and webinars, and 5 new and revised assessment tools addressed to a broad range of nursing home and other LTSS providers.
- Created Covid-19 resources to help nursing homes support stressed, often short-staffed care partners as they cared for older adults during the pandemic. Topics cover: innovative ways to honor resident preferences during quarantine, how to convert group activities to 1-to-1 during quarantine, ways to combat isolation, and tips for communicating effectively while wearing a mask.
- Launched a 2½ -hour online Emotion-Focused Communication training course to build direct care worker skills in communicating effectively with people living with dementia. We’ve had a strong positive response to the course, with the first group of graduates reporting high levels of satisfaction with the training and a statistically significant increase in knowledge of recognizing emotions and confidence in using skills such as redirection.
- Introduced the ComPASS web-based app, now used by 63 nursing homes to assess resident preferences and improve person-centered care quality (339 residents assessed since the mobile app launched).
- Led three multi-state performance improvement projects with nursing home, assisted living and adult day care providers. We developed and provided participating organizations with supports that include training, instructional videos, toolkits, tip sheets, and monthly virtual coaching:
 - The first two projects introduced nursing homes to Preferences for Activity and Leisure (PAL) cards that give staff an easy way to learn about a resident’s background and communicate their most important preferences. PAL cards aided staff in providing person-centered care and promoted meaningful engagement for residents

during rapidly changing times in the nursing home setting. The two projects took place in Ohio and Tennessee, serving 23 residential communities.

- The third project, Individualized Positive Psychosocial Intervention (IPPI), is an evidence-based program that builds relationships and enhances person-centered care for older adults living with dementia. This project started recruiting providers in 2021 and is scheduled for completion in 2022. Participating providers receive specially designed IPPI activity kits for 60+ preference-based activities, along with virtual coaching and other resources to support implementation during the pandemic.
- [The Preference Based Living website](#) drew a global audience, with 7,869 new users and 33,520 page views this year. Visitors were from all 50 states and 31% of website visitors were from outside the US.

EMERGING LEADERS IN PERSON-CENTERED CARE:

Tressa Nese and Helen Diskevich Center of Geriatric Nursing Excellence
Ross and Carol Nese College of Nursing, Penn State University

Education for the current and future LTSS workforce is integral to our mission. These four early career Penn State Ross and Carol Nese College of Nursing scholars exemplify our goal to build a cadre of person-centered care experts:

- Liza Behrens, PhD, RN – Assistant Professor, Ross and Carol Nese College of Nursing, Penn State University (2019 graduate, Penn State). Research interests: implementation of preference-based, person-centered care in nursing homes to improve the physical and psychological well-being of residents living with dementia. In the fall of 2022, Behrens will teach the PPCLSC graduate-level course, *Person Centered Care: An Interdisciplinary Approach Applied to Older Adults*.
- Caroline Madrigal, PhD, RN – Advanced Fellow in Health Services Research, US Department of Veterans Affairs (2019 graduate, Penn State). Research interests: working to understand and implement person-centered care practices to improve the quality of care for Veterans in the nursing home setting.
- Andrea Yevchak Sillner, PhD, GCNS-BC, RN – Assistant Professor, Ross and Carol Nese College of Nursing, Penn State University (2013 graduate, Penn State). Research interests: developing a person-centered assessment tool to determine preferences for timing, frequency and content for technology-assisted communication among community dwelling older adults with multiple chronic conditions.
- Britney Wardecker, PhD – Assistant Professor, Ross and Carol Nese College of Nursing, Penn State University (NIA T32 fellow, Penn State). Research interests: investigating lesbian, gay, bisexual, transgender, and queer (LGBTQ+) older adults' psychological and physical health outcomes.

Next generation research impact: Behrens, Madrigal and Sillner co-authored *Person-Centered Gerontological Nursing: An Overview Across Care Settings*, published in the *Journal of Gerontological Nursing* in February, 2021.

Preference-Based Living Work Group

The Preference-Based Living Work Group is a diverse team of clinicians and researchers focused on advancing the science of preference-based care for older adults. Comprised of new and seasoned researchers and clinicians, the group provides a forum for brainstorming, planning, problem-solving, decision-making and collaboration in support of preference-based researchers in academic and service settings across the U.S.

FUNDERS AND SUPPORTERS

We are deeply grateful to the funders who have supported this work and made these accomplishments possible.

Donors: Abramson Senior Care and Carol Irvine, Dr. Donald Ford

Funders: National Institute on Aging, National Institute of Nursing Research, Health Resources and Services Administration, Ohio Department of Medicaid, Tennessee Department of Health, Gordon and Betty Moore Foundation, Penn State Clinical and Translational Science Institute, and The Patrick and Catherine Weldon Donaghue Medical Research Foundation.