

Dr. Diana White

Senior Research Associate
Institute on Aging
Portland State University
Portland, Oregon

Before the

Senate Special Committee on Aging

Hearing on

**Person-Centered Care:
Reforming Services and Bringing Older Citizens Back to the Heart of Society**

July 23, 2008

Good morning Senator Casey, Ranking Member Smith, and members of the Committee; I very much appreciate the opportunity to participate in this hearing on person-centered care. I have been participating in efforts to create more person-centered long-term care practices since 2001. For most of that time I worked for the Oregon Health & Science University's Hartford Center of Geriatric Nursing Excellence and I am continuing that work at Portland State University. The Hartford Center partnered with the State's Unit on Aging, Seniors & People with Disabilities, and 10 long-term care facilities (nursing homes, assisted living, residential care) to develop person-centered care practices. In 2003, the partnership expanded when Oregon received a Better Jobs Better Care Demonstration grant from the Robert Wood Johnson Foundation and Atlantic Philanthropies. Our partners included 8 provider organizations (nursing homes, home care, assisted living, residential care), the long-term care trade associations (Oregon Health Care Association, and the Oregon Alliance of Senior and Health Services), the Oregon State Board of Nursing, and many others. Through BJBC, we worked to improve living and working environments for direct care workers and residents through person-centered care practices. I was the local evaluator of that project.

One of our first challenges was to clarify and define what we meant by "person-centered care." We went through a rigorous and systematic process to create a definition and then a measurement tool we could use in our evaluation. As our own thinking and experience evolved, we began to use the term "person-directed" rather than "person-centered" because we wanted to emphasize that residents, even those with severe cognitive and physical impairments, need to be in charge of their care. **Person-Directed Care** is a way of thinking about care that honors and values the person receiving support. Well-being and quality of life are what the person receiving services says they are. Supporting people the way they want to be supported is more important

than completing a list of care tasks. The elements comprising person-directed care are: personhood, knowing the person, choice and autonomy, comfort, and relationships. Definitions of each of these elements are attached to this statement. I should note that developing consensus on the definition of person-centered and person-directed care is an ongoing process in the field. To implement these practices, organizational systems must be in place. For all staff, this means:

- adequate education and training
- ability to be an advocate for residents
- ability to make decisions about care with residents
- having the time to work with residents
- teamwork
- skilled supervisors
- adequate staffing

I would like to provide some examples from two nursing homes who participated in the BJBC project as well as the earlier project. At Mennonite Village, a nursing home in Albany, Oregon, residents go to a dining room of their choice at any time of day and order from a menu, which is different every day. If they don't see something they like, they know they can request a sandwich or eggs, or some other favorite food. Certified Nursing Assistants, or CNAs, have food handler permits, so dining hours are extended to all hours of the day or night. If someone wants a hamburger at 1:00 AM, they can get it. Food waste has almost been eliminated, residents are no longer parked dozing in the hallways waiting for meals, the dining areas are quieter and more conducive to conversation, resident and family satisfaction with food has increased, and direct care staff point to this program with pride.

At Rogue Valley Manor in Medford, Oregon, a nursing assistant meets with each new resident to learn how and when they like to get clean. If the person is used to showers at night, they continue to get showers at night. If they prefer a bath in the morning, they can get that, too. If bathing or showering is painful or frightening, a towel bath might be a comforting solution.

The CNA also learns what kinds of soaps, shampoos, or lotions are preferred, whether hair should be washed during the bath or shower or at a different time. Sometimes a resident with dementia can't describe preferences or routines. The CNAs get what information they can from the resident, they ask family members, they talk to each other, and, most importantly, they pay a lot of attention to the behaviors of the resident to figure out the rest. During this process, they also identify what kind of music or conversation would be pleasurable to the person to help put them at ease. The shower or bathing schedule is then built around resident preferences. Staff have the flexibility to "go with the flow" if a resident does not feel like following their routine on a particular day or requests a different routine. This person-directed bathing practice has resulted in reduced stress and increased pleasure for staff and residents.

At both these and at many other facilities throughout Oregon, person-centered care practices have not stopped with dining or bathing programs described here. Each led to new activities as staff and residents experienced successes and saw different areas that needed a person-centered approach. For example, with flexible dining and bathing schedules, at both of these facilities, residents get up and go to bed when they want, some residents go to breakfast in their pajamas if that was their routine in the past. Some facilities have started therapeutic gardening programs, and almost all are experimenting with ways to build team and leadership among direct care staff. Many facilities have experimented successfully with worker-directed care teams. These teams make their own assignments to residents, mentor new staff, and do their own scheduling. Building renovations are occurring, beginning with eliminating nursing stations to create living room areas. All of the organizations most engaged in these activities report more satisfied and vibrant elders, and more satisfied and empowered staff.

We have learned that the ability of organizations to develop and sustain person-directed care practices is related to four areas: first, an organizational culture compatible with a person-centered care philosophy is necessary. We found that those who were most successful in making changes were open to doing things differently and considered this work to be core to their mission rather than a project to be completed. Second, top management must be engaged and committed, but able to delegate leadership to others. Support from corporate leaders is critical. Third, all staff must be a part of the change and committed to making things work. They must have a real voice and meet regularly to plan and evaluate their activities. Many organizations need help in learning how to lead effective meetings and hold one another accountable for following through on team decisions. Finally, successful organizations create person-directed care practices that make sense for their settings, the residents or clients receiving support, and for the staff who work there. As a result, details vary, but new practices are more likely to become integrated into operation of the organization. A DVD on transforming dining practices recently produced in Oregon provides an example. Four facilities radically changed dining practices, but all did it differently, including family style, buffet, and 2 different restaurant-style approaches.

Although exciting and rewarding, the process of culture change is not easy, even when organizations are committed to making these changes. Long-term care has many challenges, most associated with limited resources of time, staff, and funding. We would like more investment in the organizations that are working toward person-directed care practice changes. An example is a partnership between Oregon's Seniors & People with Disabilities and 12 nursing homes using civil penalties funds. We would like a formal certification program that recognizes those organizations that meet specific benchmarks reflecting person-directed care practices. The magnet program managed by the American Nurses Credentialing Center and

North Carolina's NOVA program provide models. The ability to implement and grow person-directed care practices depends on a strong and stable workforce. I echo the recommendations provided by Robyn Stone, John Rowe, and others to this committee last April on "Impending Shortages of Health Professionals." Education of the workforce needs to emphasize person-directed care principles. The trade associations in Oregon prominently feature culture change at their annual conventions. The ECLEPs project educating nursing students, and Better Jobs Better Care and the Jobs to Careers initiatives for direct care workers are other examples as is development of universal workers that allows flexibility in staffing. Most regulations governing long-term care do not contradict person-directed care practices; however, review mechanisms are needed to assure that they support both safety and person-centered care practices. In all of these efforts, we need to continue to clarify what we mean by person-centered or person-directed care and continue to develop ways to define, measure, and sustain these practices. More research can inform us about best practices for implementing culture change activities and determine the extent to which they help the people they are meant to serve. We need to learn directly from residents how well these changes are meeting their own needs, values, and preferences, and the extent to which they feel honored, respected, and part of their communities.

Person-directed care practices continue to evolve in Oregon. I will leave you with a Philosophy Statement that has been adopted by key stakeholders, including government and provider organizations, and information about several ongoing person-directed care initiatives. All involve statewide coalitions composed of multiple partners. Again, thank you for this opportunity to share our experiences and our hopes to transform long-term care.

Domains of Person-Directed Care

Developed for the Oregon Better Jobs Better Care Demonstration Project

Person-Directed Care is a philosophy of care that requires thinking about and planning with and for people who require assistance in their daily lives and providing that assistance in such a way that the person is honored and valued and is not lost in the tasks of caregiving. The emphasis of care is on well-being and quality of life as defined by the person. Six domains comprise person-directed care; 5 address care and support issues directly and the sixth addresses systems needed to support person-directed care

1. Personhood. Each person has inherent value, and is therefore worthy of respect and honor regardless of disease or disability. Care centers on the individual (in contrast to the provider or caregiver) through a) consideration of strengths, abilities, possibilities, and the social contributions of the person in the present; and b) sensitivity to the person's perspective about his/her care experiences and meanings the person has constructed about his/her situation.

2. Knowing the Person. Each person is unique with his/her own life story, cultural experiences, personality, and pattern of daily living—or daily habits, values, needs, preferences. Knowing the person includes knowing what is important to that person. Care involves supporting continuity between who the person has been and who the person is now by providing care in a manner consistent with that person's biography. Knowing the person is essential to understanding the meaning of behavioral symptoms in persons with dementia or other cognitive impairment.

3. Autonomy/choice. Care is supportive of personal or mastery; it assumes that independence enhances competence. Care emphasizes a balance between freedom and choice on the one hand with safety on the other. The right of individuals to take risks and, in some case, to make poor decisions is emphasized. With PCC, individuals have maximum control over their own care and environments.

4. Comfort. Physical and emotional care needs are attended to using highest standards of practice (e.g., pain control, alternatives to restraints, appropriate medications, exercise, bathing, dressing, eating, toileting, skin care, wheelchair seating, appropriate touch).

5. Relating to others. Each person lives and function within a web of relationships: (e.g., person-family, person-care provider, person-family-provider, person-peer, person- external community, care provider-supervisor). Intentional relationships between care providers and the person (and family) emphasize and promote communication, consistency, trust, attachment, friendship, and partnership, and minimize isolation and conflict.

Supportive Environment. The ability to provide PDC is dependent upon characteristics of the system in which care is provided. These include the resident's environment (e.g., personalized living space, interesting activities, pleasurable places that are accessible, privacy) and the organizational environment. Organizational environment includes support for staff to work with residents (e.g., adequate information, advocacy role, problem solving, policies and procedures that support worker autonomy). It also involves structural characteristics such as staffing, workload, training, supervisory support, and teamwork.

White, D. L., Newton-Curtis, L., & Lyons, K. S. (2008). Development and initial testing of a measure of person-directed care. *The Gerontologist*.

BJBC Policy Goal: Better interpretation of Oregon Revised Statutes regarding Seniors and People with Disabilities ORS 410.020

Oregon citizens can be justifiably proud of the system of care that has developed over the past twenty-five years. The number of community based care choices, and the availability of home care, hospice and other services have been at the forefront of national efforts to develop a diversified system. However, recent fiscal challenges have slowed system development efforts and the state now faces the looming challenges of a growing population of elders and disabled citizens and an environment of limited resources. To continue to improve the system of care and the ability of that system to recruit and retain front line workers, a coalition of 19 organizations sought and received funding as a Better Jobs Better Care (BJBC) demonstration project from the Robert Wood Johnson Foundation, Atlantic Philanthropies, and the Northwest Health Foundation. BJBC has focused significantly upon policy development to continue to promote Oregon's system development and to promote the culture change to a person-centered care model which has emerged as a key underpinning of the project's efforts.

The language of Oregon Revised Statutes focused on interpreting state policy may be interpreted as supportive to the philosophy of person-centered care and with the values of independence and personal responsibility (e.g. 410.020 Section 2. "Assure that older citizens and disabled citizens retain the right of free choice in planning and managing their lives... maximize self care and independent living within the mainstream of life." Section 10. "Involve older citizens and disabled citizens in the decision making process for programs affecting their lives." Section 16. "Recognize that older citizens who retire should be able to do so in honor and dignity.") However, the state policy for seniors and persons with disability as enacted in Oregon Revised Statutes, while not inconsistent with the culture change now occurring in long-term care, does not speak directly to some important concepts.

The opportunity now exists to better interpret state statutes to reflect this culture change of person-centered services and personal responsibility. Oregon's Department of Human Resources has assembled a Task Force on Long-Term Care, which is a public policy forum endorsed by the Governor, to examine and recommend system change. The BJBC coalition believes that the goal of a fully-integrated long-term care system in the future should be the product of a public-private partnership and should reflect person-centered care and personal responsibility. If this common goal can be agreed upon by the members of the Task Force and the public and private partners in the BJBC coalition, it can lead to statutory and administrative rule changes that promote person-centered services. The development of workforce competencies related to person-centered care will also be crucial to this policy change.

Definitions

A fully developed system of care is a continuum of services including: family education and support; case management; personal capacity building; in-home care; community based care services (day services, foster care, residential care, assisted living); intermediate and skilled nursing.

Person-Centered Care (PCC). PCC is a philosophy recognizing the inherent value of each individual and is focused on supporting strengths and abilities; capacity for social

contribution; unique values, preferences and living habits; and autonomy and choice. Quality is measured in terms of both physical and emotional care. PCC recognizes that quality of care is built on healthy relationships and strives to create systems that support relationships between care receivers and direct care workers. It requires an intentional approach of relationship building between people giving and receiving services and recognizing the importance of direct care workers to these relationships. It requires organizational commitment to the adaptation of treatment plans, organizational protocols, and policies and practices to enhance relationship and autonomy so that decision making can occur to meet individual needs and goals. It necessitates the adaptation of both living and treatment environments and staff orientation and training.

Person-Directed Care (PDC). A philosophy of PDC strives to implement and support the choices that the person being assisted makes and to keep all decision-making as close to them as possible. It recognizes that some individuals lack the physical or cognitive abilities to tell us with words what their wishes are, but that within their past choices and present behaviors lies the key to what will most honor their current wishes. In these cases, those who work with them on a daily basis (the family or other direct caregivers) need to have the ability to adapt routines to fit their expressed and implied wishes. It recognizes the inherent value of each individual focused on supporting their strengths and abilities, capacity for social contribution, unique values, preferences and living habits, promoting autonomy and choice.

Promotion of Personal Responsibility – Helping people to maximize their knowledge, skills and abilities in order to foster independent lives and decision making ability; bolstering support systems which promote the capacity to continue to operate with as much autonomy and self sufficiency as possible.

Public Private Partnership – A philosophy of collaboration of governmental, private for profit and not for profit providers of service, foundations, philanthropists, advocates and faith based organizations to develop resources, programs and facilities to achieve agreed upon social goals.

Policy Proposal

The BJBC coalition recommends that the state and its partners *develop and sustain a private public partnership to fully develop a system of care with an emphasis on person centered and person directed care and services and promotion of personal responsibility.*

To implement the proposed partnership DHS should include person centered care and workforce development in current planning efforts regarding the Future of Long Term Care in Oregon. DHS should collaborate with private providers, long term care workers, advocates, consumers, philanthropic and faith based organizations to develop and promote common goals for person-centered care, person-directed care, personal responsibility and capabilities, and family support. Collaborative efforts should focus on workforce development and training.

Partnerships should be strengthened and this statement endorsed through other organizations such as Acumentra Health, MOVE, the Oregon Alliance for Senior and Health Services, Oregon

Health Care Association, AARP, Home Care Commission, colleges and universities, and labor unions.

Roles

While all partners shall seek to develop and mutually fund innovative services to fully develop the continuum of care, specific roles for public and private sector partners merits clarification.

Public Sector:

- Develop and implement regulatory standards reflecting PCC and PDC values.
- Develop policies balancing health and safety concerns within a context promoting personal responsibility, independence and individual choice.
- Allocate resources to support staff training and development regarding PCC and PDC.
- Allocate resources to fund concrete services to assist elders and disabled Oregonians to remain autonomous.

Private Sector:

- Develop the continuum of housing options, services and care system for elders and disabled Oregonians within the PCC and PDC standards.
- Develop proactive strengths based early intervention and support services that foster elder and disabled friendly communities and promote PCC and PDC goals.
- Implement workforce development strategies and programs to assure competency in delivering PCC and PDC services.
- Provision of health promotion, planning assistance, education and fitness services to clients to support the goals of individual planning and personal responsibility.
- Solicitation of private philanthropy and resources to further the implementation of the continuum of care and PCC and PDC innovations.

Educational Sector:

- Conduct research to establish evidence-based best practices consistent with PCC and PDC goals in long-term care.
- Facilitate translation of research into practice.
- Educate and train the long-term care workforce.
- Incorporate PCC and PDC concepts into educational curricula.

Philanthropy, Advocates, Consumers and Faith Based Community:

- Active participation in planning and development of PCC and PDC service innovations and service development that fosters personal responsibility.
- Financial participation in program and project development.
- Participation in qualitative assessment of efforts to implement system improvements.

Labor:

- Promote education and implementation of programs promoting PCC and PDC standards and workforce issues for individuals represented by organized labor.

Culture Change & Person-Directed Care Initiatives in Oregon

- 1. M.O.V.E.** stands for *Making Oregon Vital for Elders*, and is a network of organizations and individuals committed to facilitating and supporting culture change in long-term care. Members are dedicated to reexamining current practices and policies in health care delivery regardless of setting and assuring a person-directed, value-based system. M.O.V.E. holds quarterly educational meetings featuring leaders in the culture change movement from all over the country. MOVE also develops resources to support organizations on their culture change. An example is a DVD, “Transforming Your Dining Services,” that features four facilities that have successfully implemented four different types of person-centered dining practices, developing the programs to meet the needs and preferences of the residents served. For more information, www.orculturechange.org
- 2. CCMU Culture Change Teams.** The State Unit on Aging (i.e., Seniors and People with Disabilities) has developed partnerships with 12 nursing homes. Using civil penalty funds, each nursing home established a culture change team that includes direct care workers. A state surveyor, who does not have responsibility for surveying that particular facility, is an outside team member. The surveyors are resource persons for the facility. They can emphasize that the survey requirements are consistent with person-directed care, debunk myths about what can’t be done, and offer suggestions for how to accomplish what the team wants to accomplish for residents within the regulatory requirements. Through this process, surveyors are also learning about person-directed care and sharing that information with their colleagues. A geriatric nurse practitioner, who is a leader in person-directed care practice has been contracted with by the State to provide coaching and consultation to these 12 teams.

- 3. Nursing Home Collaborative.** The Hartford Center of Geriatric Nursing Excellence at Oregon Health & Science University is one of 5 Hartford Centers participating in the Collaborative to address quality care for frail older adults in nursing homes. Funded by the Atlantic Philanthropies, nurse leaders in geriatric nursing are working together to find a research-based professional nursing practice model that can be widely implemented and translated to a national standard. The Hartford Centers are building on existing relationships; in Oregon this includes MOVE.
- 4. Enriched Clinical Learning Environments through Partnerships in Long-Term Care (ECLEPs).** This project builds capacity for long-term care (LTC) facilities to be excellent clinical learning sites for nursing students in the Oregon Consortium for Nursing Education (OCNE). Through community-academic partnerships, this model training and support program provides LTC staffs with essential knowledge and skills to enhance their practice setting and support students' learning. This project is developing four enriched LTC clinical education sites for nursing students, including nursing facilities and assisted living. The program will be available for replication by other schools and LTC facilities throughout Oregon and the Northwest. This project is funded by the Northwest Health Foundation (NWHF).
- 5. Jobs to Careers,** is a work-based learning project targeting direct care workers in assisted living settings. The grantee is Portland Community College and funding comes from the Robert Wood Johnson Foundation. This project is governed by multiple partners. Five assisted living facilities are participating. Trainers have been trained and are teaching incumbent and new workers 26 modules that will help workers meet occupational competencies to be residential care assistants. Person-centered care

practices have been built into the modules and stressed at train-the-trainer sessions.

Completion of all modules will result in college credits and opportunities for career advancement.

- 6. Leading Edge** was a partnership led by Oregon's Quality Improvement Organization for the CMS 8th Scope of Work which included person-centered care initiatives. Tools to assist nursing homes map their person-centered care journey were developed through that project (see <http://www.acumentra.org/healthcare-settings/nursing-homes/index.htm>).
- 7. Advancing Excellence.** Oregon is participating in this national campaign. To date, the group has focused on training to create person-centered work environments to retain direct care staff, and on improving care transitions between hospitals, home, and nursing facilities to reduce risk and incidence of pressure ulcers. Attached is a summary of the staff retention training teleconference series held last spring.
- 8.** The Oregon Health Care Association, the Oregon Alliance for Senior & Health Services, as well as multiple other professional organizations have sponsored training on person-directed care practices for their members. Attached is a partial list of content covered in their conferences and conventions. Resources also are highlighted in their newsletters.