THE ETHICAL RESPONSIBILITY TO PERSON-CENTERED CARE
Serving Elders with Diminished Cognitive Ability
in Long-Term Care

For the aging population, a multidisciplinary team of medical professionals and social service providers are essential to provide holistic care in assessment, treatment decisions, goal setting and direct care. Care teams engage people in the helping process as partners. Person-centered care elicits individuals' values and preferences to guide all aspects of their health care, supporting their realistic health and life goals. "Person‑centered care is achieved through a dynamic relationship among individuals and all relevant providers. This collaboration informs decision‑making to the extent that the subject of care desires" (American Geriatrics Society Expert Panel, 2016). Each individual is more than a manifestation of a diagnosis, and everyone has a unique level of ability.

Historical Origins
The person-centered care philosophy originated in the work of psychotherapist Carl Rogers (Kirschenbaum, 2009). According to Rogers, patients' life histories, morality, and personal ideologies make them the experts on their own needs, and so they should be at the lead of their treatment teams. Rogers posited that person-centered care requires patients' recognition, respect, and trust in the care, and he considered decision-making without the expertise of the patient to be "arrogant, inefficient, and negligent" (Rogers, 1961). Moreover, Rogers recognized the individual's self-determination as the core component in the healing process. Rogers considered his role to be that of a professional with specialty knowledge and skill, as well as a provider of resources to facilitate the individual's self-determined goals.

In the late 1980s, the professor of gerontology Thomas Kitwood innovatively applied Roger's philosophy to dementia care (Kitwood, 1990). Kitwood recognized person-centered care as a way to provide care by focusing on personal strengths, uniqueness, and preferences, enabling healthcare professionals to enhance personhood and quality of life for people with dementia (Mitchell & Agnelli, 2015). Like Rogers, Kitwood argued that the person was much more than a set of symptoms and a diagnosis, and that depersonalization through invisibility in society undermines the personhood of individuals with dementia. Kitwood claimed that personhood is sacred and unique, and that every person has an ethical status and should be treated with deep respect. He developed a framework of care that encourages caregivers to focus not on what is done but more on how it is done. Kitwood's (1997) principles, "assist those who provide care to critically evaluate how programs and communication strategies can be adopted and implemented to support the multidimensional person with dementia".

The 1990s brought further research for understanding person-centered memory care through the work of Alzheimer's disease researchers (Sabat & Collins, 1999; Sabat &

Harré, 1992). Sabat and Collins (1999) wrote that, "there is a selfhood absent of memory and cognitive impairments that remains in all people even through the end of a disease progression—Intact autobiographical memory does not constitute the self or personal identity" (Sabat, 2002). Sabat and Collins (1999) suggested that the multidimensional self presented in public and in relationships can be lost, partly as a result of how others treat and view the person with cognitive decline. Sabat and Collins (1999) theorized that, "Losses in aspects of selfhood might be traced, in part, to dysfunctional social interactions rather than solely the neuropathology of Alzheimer's disease".

Ethics
Vulnerable people receiving care become marginalized when those with the position to make decisions for them choose not to make their autonomy paramount.

When a care team serves a client with cognitive decline that affects functioning, it is our ethical responsibility to continuously address and reexamine matters of safety versus autonomy. The National Association of Social Workers' Code of Ethics considers when a client's autonomy and safety are not congruent. "Social Workers are cognizant of their duel responsibility to clients and to the broader society. They seek to resolve conflicts between clients' interest in a socially responsible manner consistent with the values, ethical principles, and ethical standards of the profession". Weighing a person's right to self-determination and the larger community's right to safety is a heavy task, and never black and white. When imminent danger is possible for the person or the public, a person's competence or incompetence is determined by a court of law; we are charged with assessing a person's capacity to make informed decisions for care planning. Health care professionals often use competency and capacity interchangeably, yet these concepts are different. Competency implies a global ability to understand. Capacity is decision specific.

Humans have complex medical, psychological, and social needs. Assessing a person's capacity to be lead decision makers in their personal care involves a number of considerations. As advocates of person-centered care, we face unique challenges when calling for care teams to consider capacity and risk in a patient with compromised cognitive abilities. Individuals may be capable of making care decisions in one situation but not in another. The risk to slip into paternalism is a concern that must be addressed in decision-making with patients.

Decision making for an individual who is capable of making informed decisions is paternalistic even if well intentioned. Benevolence can be a camouflage for actions motivated by other interests (Graumann, 2012). An individual's autonomy should only be infringed upon with significant justification. The Alzheimer's Society (2015) reports that, people with dementia can face discrimination and treatment that contravene their human rights for three key reasons: ageism, the stigma and discrimination associated with the condition, and lack of capacity to challenge and report incidents that occur".

Risk

When not person-centered, risk management can easily lead to risk avoidance or risk aversion, because risk can become the center of an examination instead of the individual. This can encourage restriction and exclusion, and it can create barriers to social inclusion and a good quality of life. "The experience of many people who use support services is that "risk" is given to them as the reason why they are not able to do the things that other people are doing every day" (Neill et al., 2009). In contrast, a person-centered approach to risk takes a balanced approach, such that the purpose of any risk assessment is just as much about the happiness of the person, the family, and the community as it is about safety. The person-centered approach enables individuals and those involved in their treatment to focus on safety, yet also ensures opportunities to try new things and take risks that are a natural part of life. "Dignity of risk refers to a commitment to each person's right to control their own life, including both good and bad experiences" (Parsons et al., 2009). Identifying what the person's goals are distinguishes person-centered clinical risk assessment from traditional clinical risk assessment. A vision of what success could look like and what could be different or better for the person is put together from the perspective of the person, as well as those who support the person (Methven, 2012).

Protective Factors
Protective factors enhance the likelihood of positive outcomes and lessen the likelihood of negative consequences from exposure to risk. They can be defined as, "influences that modify, ameliorate, or alter a person's response to some environmental hazard that predisposes the individual to a maladaptive outcome" (Jessor et al., 1998). Research strongly suggests that protective factors may offset the effects of exposure to risk factors. Protective factors encompass and include social attachment to family, caregivers, community, and peers; morals and spirituality; and individual characteristics.

Movements
The physiological, social, and economic changes that commonly impact older adults with cognitive deficits frequently contribute to dependency and make them vulnerable to violation of their human rights. "By focusing on needs rather than rights, the human dignity, security, and autonomy of the individual can be easily ignored" (Cox & Pardasani, 2017).

The disability rights movement of the 1970s spoke to the many inequalities and unmet needs of disabled people and their inherent right to access and inclusion in society. This was a human rights movement modeled on the civil rights movement of the 1960s. Disability rights advocates posits that these rights are diagnosis neutral and do not distinguish between different illnesses or conditions. They define disability as the physical, psychological, and cognitive impairments that arise from illnesses, diseases, and health conditions—and how individuals and organizations must ensure that people with these impairments are not excluded or treated unfairly, and can be accommodated in the same way as non-disabled people (Mental Health Foundation, 2015).

The social model of disability, developed and framed by the disability movement, argues that the disabled person has an impairment as a result of a condition, and that such individuals are "disabled not by their impairment, but by a broad range of social, economic, attitudinal, physical, architectural, and environmental factors" (DeJong, 1979). But the human rights lens has not been widely applied to people with cognitive impairments. For example, "people with dementia frequently reside within a medical model where others often make decisions on behalf of the individual, prescribe a treatment regime (often only pharmacologically focused), and retain (often unintentionally) the power in the relationship, so that the person with dementia is often rendered a passive dependent" (Quinn, 2013). When applied to the common issue within the aging population of medical decision making in those with cognitive impairments, the Social Model of Disability requires the treatment team to seek alternative means to allow for the dignity and human rights of a person to be honored. The natural deterioration of the physical and mental capabilities due to aging should not strip a person of human dignity, right to self-determination, and autonomy.

Shared decision making is a process in which health care professionals empower consumers to make informed medical decisions. As a result of patients' dissatisfaction with lack of autonomy and passive role in their care, shared decision making seeks to address barriers to client participation such as insufficient knowledge, limited time with providers, lack of advocates, confusion, and misunderstanding. "This model is found to be very helpful in scenarios where an individual is being presented with a number of treatment options with varied risks and benefits" (Graumann, 2012).

Nursing Home Reform
In 1987, the Federal Nursing Home Reform Act (1987a, 1987b, 1987c) was enacted as part of the Omnibus Budget Reconciliation Act (OBRA) to address concerns about abuse, neglect, and inadequate care in nursing facilities. OBRA presented a minimum set of standards for care and health in Medicare and Medicaid certified nursing facilities and included a bill of rights for residents. The bill was intended to establish a baseline for improvement in care, with the expectation of increasing residents' happiness and fulfillment. OBRA's standards included inspectors' engaging consumers and families, not just staff and administrators.

The Culture Change Movement
The culture change movement was born out of the need for nursing home reform. Culture change's mission is to move long-term care facilities from health care institutions to person-centered community homes (Neill et al., 2009).

Culture change implicates the engagement of direct care staff as empowered partners of the community. Residents and staff are both self-determining members. This increases employee buy-in, satisfaction, and retention. The goal of the culture change movement is to create an environment that no longer expects "dependency and deterioration following admission to the facility but one that fosters growth, creativity, and rejuvenation" (Mitty, 2005).

The Eden Alternative nonprofit (https://www.edenalt.org) is a cornerstone in the culture change movement. The Eden Alternative recognizes that loneliness, helplessness, and boredom are reported by elders to be the root of most suffering in long-term care. The Eden Alternative believes that the antidote to these issues is an environment filled with unexpected, unpredictable interactions, specifically with humans and animals. Among the principles of the Eden Alternative are the following: "Medical treatment should be the servant of genuine human caring, as opposed to its master, and decision making authority should rest with the elders and those closest to them rather than in the hands of a bureaucratic hierarchy". The Pioneer Network is another program within the culture change movement that highlights providing privacy, comfort, and personalization. The Pioneer Network (https://www.pioneernetwork.net) offers support and roadmaps for administrators who wish to adopt person-centered care within their organizations. In 2003, The Green House Project developed a philosophy of person-centered care by partnering with providers to erect 300 non-institutional elder care homes. These Green Homes are in communities and serve residents in a family-style environment, staffed with nursing staff but functioning as closely as possible to in-home care. The Green House Project's goal is to bring meaning and purpose to the lives of the residents (https://www.thegreenhouseproject.org).

References

Alzheimer's Society. (2015). *Alzheimer's Society's view on equality, discrimination, and human rights*. https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/equality-discrimination-human-rights

American Geriatrics Society Expert Panel on Person-Centered Care. (2016). Person-centered care: A definition and essential elements. *Journal of the American Geratrics Society*, *64*(1), 15–18. https://doi.org/10.1111/jgs.13866

Cox, C., & Pardasani, M. (2017). Aging and human rights: A rights-based approach to social work with older adults. *Journal of Human Rights and Social Work*, *2*(3), 98–106. https://doi.org/10.1007/s41134-017-0037-0

DeJong, G. (1979). Independent living: From social movement to analytic paradigm. *Archives of Physical Medicine and Rehabilitation*, *60*(10), 435–446. PMID: 496597

Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *The Gerontologist*, *58*(Suppl. 1), S10–S19. https://doi.org/10.1093/geront/gnx122

Federal Nursing Home Reform Act. (1987a). 42 C.F.R. 483. Requirements for states and long term care facilities. https://www.ecfr.gov/cgi-bin/text-idx?SID=d134af3cf13616941322bfec715312bb&mc=true&node=pt42.5.483&rgn=div5

Federal Nursing Home Reform Act. (1987b). 42 U.S.C. § 1395i–3. Requirements for, and assuring quality of care in, skilled nursing facilities. https://www.law.cornell.edu/uscode/text/42/1395i-3

Federal Nursing Home Reform Act. (1987c). 42 U.S.C. § 1396r. Requirements for nursing facilities. https://www.law.cornell.edu/uscode/text/42/1396r

Graumann, S. (2012). Social services ethics, overview. In R. Chadwick (Ed.), *Encyclopedia of applied ethics* (2nd ed., pp. 175–181). Academic Press. https://doi.org/10.1016/B978-0-12-373932-2.00398-7

Jessor, R., Turbin, M. S., & Costa, F. M. (1998). Risk and protection in successful outcomes among disadvantaged adolescents. *Applied Developmental Science*, *2*(4), 194–208. https://doi.org/10.1207/s1532480xads0204_3

Kirschenbaum, H. (2009). *The life and work of Carl Rogers*. Alexandria, VA: American Counseling Association. Also published by PCCS Books, Ross-on-Wye, UK, 2007.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Open University Press.

Kitwood, T.(1990). The dialectics of dementia: With particular reference to Alzheimer's disease. *Ageing and Society*,10,177–196.

Mental Health Foundation. (2015). *Dementia, rights, and the model of disability: A new direction for policy and practice?* https://www.mentalhealth.org.uk/sites/default/files/dementia-rights-policy-discussion.pdf

Methven, S. (2012). Enabling risk. In S. Stirk & H. Sanderson (Eds.), *Creating person-centred organisations: Strategies and tools for managing change in health, social care and the voluntary sector* (pp. 240–256). Jessica Kingsley Publishers.

Mitchell, G., & Agnelli, J. (2015). Person-centered care for people with dementia: Kitwood reconsidered. *Nursing Standard*, *30*(7), 46–50. https://doi.org/10.7748/ns.30.7.46.s47

Mitty, E. L. (2005). Culture change in nursing homes: An ethical perspective. *Annals of Long-Term Care*, *13*(3). https://www.managedhealthcareconnect.com/article/3870

National Association of Social Workers. (2017). *NASW code of ethics*. https://www.socialworkers.org/About/Ethics/Code-of-Ethics/Code-of-Ethics-English

Neill, M., Sanderson, H., Allen, J., Reid, S., Woodhead, N., & Irwin, L. (2009). A positive approach to risk requires person centred thinking. *Tizard Learning Disability Review*, *14*(4), 16–23. https://www.academia.edu/5602568

Parsons, L., Cocks, E., & Williamson, M. (2009). *A review of best practice in individual needs planning*. Curtin University of Technology, School of Occupational Therapy and Social Work. https://espace.curtin.edu.au/handle/20.500.11937/46262

Rogers, C. R. (1961). *On becoming a person: A therapist's view of psychotherapy*. Houghton Mifflin.

Sabat, S. R. (2002). Surviving manifestations of selfhood in Alzheimer's disease: A case study. *Dementia*, *1*(1), 25–36. https://doi.org/10.1177/147130120200100101

Sabat, S. R., & Collins, M. (1999). Intact social, cognitive ability, and selfhood: A case study of Alzheimer's disease. *American Journal of Alzheimer's Disease*, *14*(1), 11–19. https://doi.org/10.1177/153331759901400108

Sabat, S. R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing & Society*, *12*(4), 443–461. https://doi.org/10.1017/S0144686X00005262

Quinn, G. (2013). *Age: From human deficits to human rights—reflections on a changing field*. Paper presented at the launch of the Human Rights and Older People Policy Paper, Dublin.