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Since its establishment in 1984, the Center for Practical Bioethics has dedicated itself to addressing real life issues in aging and end of life. Within the last decade we have honed those lessons well but a burgeoning concern that continues to challenge us is quality in long term care. For consumers, quality of care (QOC) and quality of life (QOL) are inextricably bound especially as disease progresses, chronicity and co-morbidity coalesce, age advances and end of life approaches. In systematic efforts to separate quality in discreet realms, this nation has provided professionals a construct to describe quality but misguided regulators in its measure and deprived consumers of its benefits. By segregating disparate views, we:

- Unwittingly focus on one measure at the expense of other,
- Ignore the essential and integrative aspects of palliative care critical to achieving quality and,
- Encourage an adversarial provider/regulator environment that virtually dismisses the role of the broader community as non-essential.

Families, surrogates, advocates, healthcare care professionals, administrators and regulators invest heavily in systematically classifying the myriad aspects of the traditional long term care recipient's life. When policy, practice, professional opinion and treatment plan collide with personal choice, quality often gets re-visioned through a lens of rules and regulation to reduce risk of harm. Initial assessment and the MDS, though clarifying, distract from ongoing resident-focused care when the data become

sacred and healthcare system dictates, facility protections, or surveying agency measures alone determine what's in the best interest of each resident. The resulting collision of values and needs for both recipient and system constructed to protect vulnerable persons often fails to elucidate or resolve, resulting instead in unavoidable conflict, defensive treatment and in some cases futile care. The Center's experience in applying a proven acute care model of addressing these conflicting ethical dilemmas brought this stark reality into clear view for us and initiated our journey into developing an innovative model that offers hope to improving the capacity of providers, the confidence of regulators and quality for consumers.

For the most part, the sole criteria for state and federal agencies to evaluate long term "quality of care" measures, deal exclusively with what bad things happened or what predetermined "harmful" outcomes should have been averted. For example, all eight of the CMS website MDS "quality measures" identify negative measures of physical care. The only positive quality of care measure that appears on the CMS sponsored consumer website page under "Overview" identifies the average time a resident spends with professional nursing staff. But even that item fails to measure up as the companion July 2003 *"Measures, Indicators, and Improvement of Quality of Life in Nursing Homes"* CMS final report by the University of Minnesota indicates "the number of *activities staff* was a stronger correlate with QOL than was the amount of *nursing staff* (professional, nonprofessional or both)," (emphasis mine).

If traditional long term care is meant to provide an aging in place experience for this nation's most fragile and aged population, we must recognize that dying well must at some point be viewed as a goal of care. While a primary focus on pain control and its accompanying symptoms must remain paramount, its amelioration must be set in the

context of the whole person encompassing the psycho-spiritual dimensions that no pharmacological panacea can address. Despite the need, we have no real way to measure the successful management of declining health in a holistic age-in-place environment.

Dying, as a process – not an unanticipated or imminently occurring event – needs to be incorporated into the American aging experience as a fundamental life task, one integral to the long term care experience and environment; essential to complete as the consumer’s wishes are honored. It should not be considered an optional and event must be recognized as hard work. Incumbent upon the regulatory environment is an obligation to not only tolerate this view, but codify its reality into the evaluation and survey process, allowing for it within the setting and without distinction of benefit election to hospice when prognosis is indeterminable.

As chronic conditions take undetectable tolls and disease progression diminishes capacities, goals of care change; expectations get reinterpreted. Values may remain stable but perceptions of a “full life” ebb and flow. The meaning of maintenance and intervention modify. We redefine what it means to “get better,” “get well” and “be cured”. Consumers have no idea how the intersection of compromised physical condition (often resulting from previous curative treatments), advanced age, multiple diagnoses, and chronic conditions affect life expectancy. Presumption that getting up or eating meals is always in everyone’s best interest can be no more certain than norms associated with spiritual support, privacy or social interaction.

While we may have no extant way to measure overall quality in long term care, we do have emerging research, new guidelines in palliative care, and innovation committed to consumer driven models. One such innovative model is a bi-state effort

under development in Kansas and Missouri that brings together regulators, providers, community volunteer and consumers into a quasi-public and private partnering aimed at continuous quality improvement, facility self-enhancement, ethics consults, and consumer focused policy development. This work cannot be successful, however, without federal peer review organization support and state departments on aging and health services commitments to de-construct a culture of mistrust focused on sanction and one size fits all definition of quality.

As this Commission continues its work, it is essential that you call for demonstration efforts that marry the interests of consumers with the imagination of the community tapping the skills of the industry and expanding the oversight role of surveying agencies. Relying on innovation from the independent sector such as the Center for Practical Bioethics represents will set us on a path of private and public partnership preparing for a much needed paradigm shift in quality long term care.