

## Defining Quality in Long-Term, Home and Community Care: A Working Paper

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How do we measure the quality of care provided to individuals living with chronic illness, disability or limitations due to aging who have their long-term care needs met in the community, often at home? Defining quality in long-term, community care is an essential step toward defining what a system of care should look like. Long-term, community care has some important elements in common with acute care, but it is not the same. We have therefore chosen to begin with the framework proposed by the Institute of Medicine “Crossing the Quality Chasm” which consists of six elements of quality healthcare<sup>i</sup>, and add additional elements to better address the unique nature of long-term care in the community. We are indebted to many others working in this field, but would particularly like to cite the work of Ed Wagner and his colleagues at the MacColl Institute for Healthcare Innovation<sup>ii</sup> and that of Jim Gardner and colleagues at the Council on Quality and Leadership.<sup>iii</sup> Throughout, we have used the term “care-receiver” instead of “patient” to distinguish the individual receiving long-term care services from the individual receiving acute care services. We believe that quality long-term care in the community is:

- 1) **Safe** - avoiding injuries to care-receiver (and caregivers... our additions in parentheses) from the care that is intended to help them;
- 2) **Effective** - providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit. (We don't know if “overuse” is a serious problem in long-term care although there are clearly questions of effectiveness of many long-term care interventions)
- 3) **Personalized** - providing care that is respectful of and responsive to individual care-receiver (and caregiver) preferences, needs and values and ensuring that care-receiver (and caregiver) values guide all clinical decisions.
- 4) **Timely**: reducing waits and harmful delays for both those who receive and those who give care.
- 5) **Efficient**: avoiding waste, including waste of equipment, supplies, ideas and energy.
- 6) **Equitable** – providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

We think these six parameters suggested by the IOM report can be usefully applied to long-term and chronic care in the community as well as acute care in medical settings. Quality long-term care in the community should also be safe, effective, patient-centered, timely, efficient and equitable.

However, there are **special considerations** for assessing quality in long-term care resulting from a number of factors including the setting of care, who is involved in providing care and their roles and responsibilities<sup>iv</sup>, and the length and goals of care. Therefore, we suggest adding an additional four dimensions of quality to address these unique considerations.

For example, in long-term, community care, the individual receiving care is typically not removed from the setting in which they live to receive care; rather, either they receive care in their home, or the setting in which they receive care *becomes* their primary residence. The type of care provided often has a primary goal of facilitating adaptation to home and community settings by helping the care recipient accomplish the normal activities of daily living (eating, dressing, bathing, etc.). As a result, the setting of care is integrated into the care plan as a vehicle for rehabilitation, treatment and support. Additionally, the individuals who provide care are often family members and para-professionals, not medical professionals. Finally, individuals who receive long-term care often receive care for extended periods of time; even for a lifetime.

All these unique features mean that long-term care activities need to facilitate participation in the community, the continuation of positive daily routines and the achievement of personal goals for both the individual being cared for and the primary caregiver. Long term care provision should not overwhelm the individual's (or the caregiver's) need for leisure, recreation, intimacy, connectedness, privacy and self-determination. We refer to this dimension of quality in long-term care as **"Balanced"**. Quality community care should provide an optimum mix of rehabilitation, education, and support balanced with the needs for "normalcy" in family life, with the goal of allowing a rich quality of life in the community for both patient and caregiver.

In addition, long-term care in the community should be provided as a **"Shared"** function of family, professional providers and the community. Care in the community should not be entirely shouldered by family and friends in isolation. Instead, quality care in the community should integrate the efforts of professional and family systems of care, provide adequate respite and assistance to family caregivers, and encourage participation in effective community programs. Quality care in the community involves sharing the actual objective burden of care including the financial and time-related burden between professional caregivers, family caregivers, and community supports including trained volunteers, voluntary health associations and similar groups whenever possible. Effective community programs, supports and services should be integrated into the care plan.

Third, the *way* in which professional and family caregivers work together with the receiver of care and with one another is of great importance to the overall quality of care.

The roles of care-receiver, family caregivers and professional providers must be carefully defined and tasks distributed appropriately; they must act together as a “team”. Professional caregivers should be supportive of family caregivers and the integration of their work should be seamless, consistent, and complementary. They should be partners with the care-receiver and family caregiver. This quality we term “**Collaborative**” reflecting our view that professional and family caregivers should respect the skill, effort, and knowledge of the other. In addition, and perhaps most importantly, collaboration requires that the care-receiver play a key role in self management, goal setting, problem solving and evaluation of care as much as possible. Professional caregivers should recognize that their work is supplementary to the fundamental contribution of family and friends and assessment of the needs, knowledge and skills of care-receiver and family caregiver should be an essential step in planning professional services. Family caregivers and care-receivers, in turn, should be assisted in integrating the special skills, knowledge and assistance of professional providers into family routines and a holistic care plan.

Finally, quality long-term care should be “**Developmental**”. Because of the extended time frame over which care is often provided, the care plan should include attention to the long term, developmental needs of the individual receiving care. In addition, because the lives of caregivers and care receivers are typically closely entwined in long-term care, developmental considerations should also be extended to family caregivers, professional caregivers and the family as a whole. Neither the care-receiver nor caregiver should have to put their lives entirely “on hold” because they are receiving or providing long-term care services. Instead, supports should be designed to allow and facilitate personal development, learning, and the achievement of developmental milestones and personal goals important to members of the long-term care team.

We therefore suggest adding four new dimensions to the IOM’s six in order to fully capture the requirements for quality long-term care in the community:

- 7) **Balanced** - providing care that is integrated into the daily life of care-receiver and caregiver and that facilitates self-determination and a rich life in the community.
- 8) **Shared** - providing adequate support, respite and assistance to family caregivers so that the objective burdens of care, including financial and time - related burdens, are shared as much as possible between professional caregivers, family caregivers and others in the community.
- 9) **Collaborative** - integrating the work of family, professional caregivers and the community in a way that maximizes their unique contributions, skills and knowledge.
- 10) **Developmental** - providing a range of services and supports in a manner that facilitates development, learning and the achievement of personal goals for the care-receiver and members of the long-term care team.

We think these ten dimensions are a useful beginning point from which to launch a discussion of how to evaluate and construct a Quality long-term care system in the community. We welcome discussion and comment on this framework from all interested parties. Comments should be addressed to: [rbirkel@canes.gsw.edu](mailto:rbirkel@canes.gsw.edu)

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<sup>i</sup> Crossing the Quality Chasm: A New Health System for the 21st Century, The Institute of Medicine, National Academies Press, 2001

<sup>ii</sup> Bodenheimer, Thomas; Wagner, Edward H.; Grumbach, Kevin, Improving Primary Care for Patients With Chronic Illness. JAMA: Journal of the American Medical Association 2002-10-09, 288:14, 1775(5)

<sup>iii</sup> Quality Performance in Human Services : Leadership, Values, and Vision, Edited by James F. Gardner, , & Sylvia Nudler, Paul H. Brookes Publishing Co., Baltimore, MD, 1999

<sup>iv</sup> In referring to “caregivers” we have chosen the following language: family, friends, neighbors who provide care are referred to as “family caregivers” (whether they are “paid” or not); individuals who provide care as a profession including so-called “para-professionals”, are called “professional caregivers”. Finally, individuals who provide care as part of an organized community effort (e.g. faith-based programs), voluntary health association, or primarily as a personal vocation, are referred to as “volunteer caregivers”. We recognize that these divisions and distinctions are imperfect, but we hope they are nonetheless useful in the current discussion.