

A RESIDENT'S DEFINITION OF QUALITY

Quality is something we all pursue in life. We can define it as excellence. CMS' Nursing Home Compare 5-star rating system includes health inspections, staffing and quality measures. The focus is primarily on physical and clinical quality as proxies for overall quality. Since care and life in nursing homes are complex and multidimensional, the expertise from residents' lived experience should be used for a more comprehensive list of quality indicators - skilled care, a real home, resident-direction, and compassion.

SKILLED CARE

Residents want high-quality care, so their physicians, nurses and rehabilitation staff must be knowledgeable, skilled, and experienced. They must deliver the full range of clinical care for medical, physical, cognitive and emotional needs. Physicians and nurses must work to prevent serious care problems including falls, pressure ulcers, infections, dehydration, weight-loss, pain and elopement. The ability to manage complex care, prevent unnecessary secondary complications, avoid inappropriate treatments and unnecessary drugs, restore function, manage chronic pain, detect changes in physical and mental status and avoid adverse events and harm are all essential. Physicians and nurses must also ensure residents' rights to self-determination in medical care, to informed consent, to refuse treatment and to choose a personal attending physician.

CNAs have a critical role as providers of direct care. They must keep residents clean and comfortable, monitor for skin breakdown, make sure residents are properly fed and hydrated, and assist with ambulation and safe transfers. They must also make sure residents have their assistive devices - glasses, hearing aids and dentures; provide some engagement to reduce agitation, as well as protect clothes and other possessions from loss and damage. There must be adequate staff to take care of residents properly and respond to call lights in a timely manner. A strong positive relationship between total direct-care staff and quality care has been shown.

Skilled rehabilitation services across the continuum of physical, occupational, speech and respiratory must be provided to maintain and improve functioning, promote independence and comfort through devices and equipment such as individualized manual and power wheelchairs.

A REAL HOME

Facilities are residents' homes where they might live for a long time. A home should be a place where they feel they belong, feel comfortable, secure and happy. Quality experiences depend upon the contributions of staff from all departments who support residents making their own daily life choices based on their preferences and priorities. Kitchen staff must see that residents get their favorite food and that dining is an enjoyable time to socialize. Activities staff must see that residents have engaging, interesting, fun activities based on their interests, strengths and real needs. In addition to providing distraction and leisure, being with other residents at activities can support forming friendships and feeling part of a community. Without this purpose and meaning there are days of boredom, loneliness, unhappiness.

Social workers must help residents access facility services and past associations, like their faith communities, to promote the continuity of each person before and now. Maintenance must provide a comfortable calming pleasant home environment, free of hazards. Maintenance must also assist in helping to make residents' rooms spaces that promote preservation of individual selves and identities by providing furniture and places for cherished possessions. Management must provide access to outdoor areas where residents can walk and wheel for pleasure as they did before. Housekeeping must keep the environment sanitary. Laundry must make sure units are stocked with clean linen to save CNAs' time, and that residents' clothes don't get damaged or lost, ensuring residents feel secure about their belongings.

The director of staff training must keep staff's skills current and can serve as a general resource. The hairdresser must make residents look kept. The receptionist has an important role in greeting residents and, perhaps, ensuring mail is not lost and seeing that residents get their spending money. Central supply has a role in the quality of life of residents, and must keep units stocked so direct-care workers can be efficient and spend their time with residents, not chasing supplies. The administrator must set the tone for the work of all departments so residents' days are made good, and their expectations met that they are living in their real home.

RESIDENT- DIRECTION

Residents, or their legal representatives, are in the best position to identify residents' unique needs and goals, as well as direct and manage services. Facilities must accommodate each resident's individuality by respecting their right of choice. Independence and a dignified existence can only occur when residents have self-determination and autonomy in decision-making regarding every aspect of their lives, balanced against safety standards. Personal control, the ability to be effective in getting significant choices, and autonomy, the innate desire to experience freedom and to be one's own true self as the origins of one's actions, are both essential. Even residents determined incompetent, should be able to assert this right based on their capacity.

The resident-direction process for staff includes knowing the person's own unique life story, culture, personality, wishes, experiences, feelings and perceptions, then respecting the person's expertise and supporting their decisions. The positive psychological impacts for residents of autonomy and control are numerous - having a sense of agency, getting individual needs and preferences met, flattening hierarchy with staff, experiencing freedom, being more involved and empowered, feeling joyful, interested, optimistic, improving self-esteem, leading authentic lives, retaining one's own identity. Preserving residents' self-determination, agency and autonomy also benefits staff. There is less conflict. Physicians will listen to residents or their proxies, with regard to administration of medications and treatments. Nurses and CNAs will be less affronted, no longer misinterpreting requests as signs that residents do not respect their expertise.

Without resident-choice there is paternalism which discounts the individual, thwarts a basic need for control resulting in negative effects on mental health. Feelings of powerlessness, loss of self-efficacy, decreased motivation and engagement, poor adaptation, more emotional distress, increased pessimism, retreat, passivity and fear are the cumulative set of reactions referred to as

learned-helplessness. A self-directed model of care and life as practiced in written care plans, should thus be the gold standard.

COMPASSION

Technical task-oriented care and services alone are insufficient. Compassion is needed. Compassionate staff respond to the central human need for connection, psychological care of the whole person - empathy. Empathy is the ability to understand the emotional state of another person, be kind, humane, gentle, involved and comforting. Compassionate staff listen actively and attentively, recognize, understand, acknowledge and respond to anxiety, worries, distress, pain, suffering and vulnerability. Compassionate staff go above and beyond with significant acts of kindness, from the gift of a simple can of favorite soda to a resident to emotional support for family members during a vigil. Management must have staffing patterns that allow sufficient time for staff and residents to develop these quality interactions so critical for vulnerable residents.

Management's role is to also provide leadership and organizational support for compassion. They must have an open-door policy for both residents and family members, seeking them out, valuing them, making them feel comfortable speaking up and being involved, be good listeners and be open-minded. They must address any and all problems identified and solve them, creating mutual respect. Daily compassionate interactions have the power to alter lives, enhance health outcomes, create trust, prevent emotional harm, provide hope, and remind us of our common humanity.

OUTCOMES

Quality matters. Providers can assure quality facilities by being committed to service excellence, and by creating a dynamic system of continuous adaptation and improvement in planning, preventing, identifying and correcting problems. Quality experiences will provide quality outcomes for residents, transforming their lives, boosting satisfaction, and assuring they achieve not only their personal goals and outcomes, but their highest practicable levels of physical, mental and psychosocial well-being.

Penelope Ann Shaw, PhD

Board Member. Massachusetts Advocates for Nursing Home Reform. Member. Citizens Advisory Committee. Massachusetts Executive Office of Elder Affairs.