Person Centered Care and the Nursing Home Regulations
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The Concept of Person Centered Care

Physicians and nurses have always considered that they provided medical care individually to a person, thus it was Person Centered Care.

This conceptual model assumes a distinction from a **public health practitioner** who provided health care improvement and innovation to a population.
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• This distinction between individual care and public health is not what is meant.

• The concept of person centered care began with the mental health community.

• The history of care for the mentally ill is a complex and dismal story of misunderstanding the spectrum of congenital and acquired disease as well as frustration with the lack of effective treatment.
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• In the 1840s, Dorothea Dix, a self made teacher and social activist from Massachusetts, lobbied for better living conditions for the mentally ill after witnessing the dangerous and unhealthy conditions under which many patients lived.
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• Over a 40-year period, her efforts successfully persuaded the U.S. government and states to fund the building of 32 state psychiatric hospitals.

• She was appointed superintendent of nurses during the Civil War. She was responsible for setting up field hospitals and first-aid stations, recruiting nurses, managing supplies and setting up training programs.
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• The inpatient institutional care model developed during this time, in which most patients lived in hospitals and were treated by professional staff.
• This was considered the most effective way to care for the mentally ill.
• Institutionalization was also welcomed by families and communities struggling to care for the mentally ill.
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• Although institutionalized care increased patient access to mental health services, the state hospitals were often underfunded and understaffed, and the institutional care system drew harsh criticism following a number of high-profile reports of poor living conditions and human rights violations.
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• Patient consent for treatment has been required since 1906.

• During the 1950's and 1960's, humanistic psychology was born.

• Carl Rogers and Abraham Maslow theorized that all people are motivated to fulfill a hierarchy of needs to achieve "self actualization" or full capacity and that the role of therapists/physician is to facilitate this growth.
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• In *The Origin and Nature of Our Institutional Models* Wolfensberger (1969) used an intellectual history of mental retardation services to vividly sketch the powerful and mutually reinforcing connection between

• How society sees people with disabilities,

• How this shapes the services professionals consequently offer, and

• The impact of these services on the lives of people who rely on services.
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- The work of researcher-practitioners like Marc Gold (1972), Lou Brown (1976), and Tom Bellamy (1979) and others clearly demonstrated that the capacity to learn and to work for people with severe disabilities were: habitually, reflexively, and profoundly underestimated by almost all of the professionals who assessed them.
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• **1955:** Congress authorized the *Mental Health Study Act of 1955* and called for “an objective, thorough, nationwide analysis and reevaluation of the human and economic problems of mental health.”

• The act provided the basis for the study conducted by the Joint Commission on Mental Illness and Health, *Action for Mental Health*, released in 1961.
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The **Community Mental Health Act** of 1963 was an act to provide federal funding for community mental health centers in the United States. This legislation was passed as part of [John F. Kennedy's New Frontier](https://en.wikipedia.org/wiki/New_Frontier) (also known as the Community Mental Health Centers Construction Act, Mental Retardation Facilities and Construction Act, Public Law 88-164, or the Mental Retardation and Community Mental Health Centers Construction Act of 1963)

This Act led to considerable [deinstitutionalization](https://en.wikipedia.org/wiki/Deinstitutionalization).
The Concept of Person Centered Nursing Home Care

• In the early 1980s, work by the National Citizens’ Coalition for Nursing Home Reform, with the support of the AARP and other consumer advocacy groups concerned about substandard care in nursing homes, emphasized residents’ rights and the importance of resident assessment.

• They produced a landmark report:
The Concept of Person Centered Nursing Home Care

*Holder, Elma L., Frank, Barbara W. Consumer statement of principles for the nursing home regulatory system.*

Washington (DC): National Citizens’ Coalition for Nursing Home Reform (NCCNHR); 1983

This was endorsed by more than sixty national organizations, presented to the U.S. Department of Health and Human Services, and distributed to all congressional offices.
The Concept of Person Centered Nursing Home Care

• In 1986 the Institute of Medicine published *Improving the Quality of Care in Nursing Homes*, which recommended changes in regulatory policies and procedures necessary to ensure that nursing home residents (a term that first appeared in this report) received satisfactory care.
The Concept of Person Centered Nursing Home Care

• In 1987, Congress passed the Nursing Home Reform Act (OBRA ‘87) that **required** facilities to provide individualized, or "person-centered," care.
Person Centered Care as projected by the Pioneer Network

- In 1997, leaders in the industry along with consumer advocates, researchers, and regulators, formed the Pioneer Group to advocate for person-centered care and create a movement for "culture change" in the nation's nursing homes. The Pioneer Network eventually took the lead in fostering the culture-change movement within nursing homes.
Person Centered Care as put forward by the Pioneer Network

• Taken from their Web site information:

• As a result of this law, providers began to move away from the institutional model of nursing home care and toward a more homelike environment.
Person Centered Care as projected by the Pioneer Network

- **Person-centered care** is driven by the individual’s needs and preferences, meaning that the resident can decide what treatment is provided, when to rise, when and what to eat, what social activities are appealing or how their living environment should look.

- Living independently = **being in control of your life regardless of how much assistance you need to do so**
Person Centered Care as projected by the Pioneer Network

• You are in control!

• While staying at a nursing home, it should feel like home to you, regardless of whether your needs require a short or long stay. Your nursing home will work with you and your loved ones (if you wish) to design care that supports you, builds on your strengths, promotes quality of life, and honors your preferences, choices, abilities and culture. Person-centered care means that your voice is listened to and respected. You have the right to choice, dignity, independence, respect and a purposeful life.
While staying in a nursing home, your caregivers will work with you to develop a written plan that details the care you need and want. This brochure can be used to help bring your voice to the care plan meeting. Caregivers have the jobs that they do because they CARE about people! They want to hear from you!

Your care plan is:

- Specific to you;
- Supports your well-being and rights;
- Written in a manner you can understand; and
- Updated as your goals, needs and preferences change.
Person Centered Care as projected by the Pioneer Network

• Proponents of culture change do not recommend a specific model or set of practices. Instead, they support principles shaping resident care practices; organizational and human resource practices; and the design of the physical facility.

• According to these principles, an ideal culture change facility would feature:
Person Centered Care as projected by the Pioneer Network

- **Resident direction.** Residents should be offered choices and encouraged to make their own decision about personal issues like what to wear or when to go to bed.
Person Centered Care as projected by the Pioneer Network

• **Homelike atmosphere.** Practices and structures should be more homelike and less institutional. For example, replacing larger nursing units with smaller "households" of 10 to 15 residents. Residents would have access to refrigerators for snacks, and overhead public address systems would be eliminated.
Person Centered Care as projected by the Pioneer Network

• **Close relationships.** To foster strong bonds, the same nurse aides should always provide care to a resident.

• **Staff empowerment.** Staff should have the authority, and the necessary training, to respond on their own to residents’ needs. The use of care teams should also be encouraged.
Person Centered Care as projected by the Pioneer Network

• **Collaborative decision-making.** The traditional management hierarchy should be flattened, with frontline staff given the authority to make decisions regarding residents’ care.

• **Quality improvement processes.** Culture change should be treated as an ongoing process of overall performance improvement, not just as a superficial change or provision of amenities.
Person Centered Care as projected by the Pioneer Network

- It promotes person-centered care through reorientation of the facility’s culture—its values, attitudes, and norms—along with its supporting core systems (such as breaking down departmental hierarchies, creating flexible job descriptions, and giving front-line workers more control over work environments).
Person Centered Care as projected by the Pioneer Network

- It strives to **honor residents’ individual rights**, offering them quality of life and quality of care in equal measure. Culture change also recognizes the importance of all staff members’ contributions to the pursuit of excellence.
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• The Commonwealth Fund’s 2007 National Survey of Nursing Homes\(^{26}\) found that only 5 percent of nursing directors said that their facilities completely met the description of a nursing home transformed through culture change.

• Doty M, Koren MJ, Sturla EL
  
  *Culture change in nursing homes: how far have we come? Findings from the Commonwealth Fund 2007 national survey of nursing homes* [Internet]. New York (NY): Commonwealth Fund; 2008 May9 [cited 2009 Dec 4].
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- Staff failed to offer choice during morning ADL care delivery for at least 1 of 3 ADL care activities in all 20 NHs. Observational data showed residents were not offered choice about when to get out of bed (11%), what to wear (25%), and breakfast dining location (39%).

- In comparison, survey staff issued only 2 deficiencies in all 20 NHs relevant to choice in the targeted ADL care activities, and neither deficiency was based on observational data.

*The Gerontologist* 2009

*Resident Choice and the Survey Process: The Need for Standardized Observation and Transparency*

John F. Schnelle, PhD, Rosanna Bertrand, PhD, Donna Hurd, MSN, Alan White, PhD, David Squires, BS, Marvin Feuerberg, PhD, Kelly Hickey, BS and Sandra F. Simmons, PhD
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• CFR§483.10 Resident Rights

• The resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility. A facility must protect and promote the rights of each resident, including each of the following rights:
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- F151
- §483.10(a) Exercise of Rights
- §483.10(a)(1) The resident has the right to exercise his or her rights as a resident of the facility and as a citizen or resident of the United States.

- §483.10(a)(2) The resident has the right to be free of interference, coercion, discrimination, and reprisal from the facility in exercising his or her rights.
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• F153

• §483.10(b)(2) -- The resident or his or her legal representative has the right--

• (i) Upon an oral or written request, to access all records pertaining to himself or herself including current clinical records within 24 hours (excluding weekends and holidays);
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- F154

- §483.10(b)(3) -- The resident has the right to be fully informed in language that he or she can understand of his or her total health status, including but not limited to, his or her medical condition;
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• F155

• (Rev. 127, Issued: 11-26-14, Effective: 11-26-14, Implementation: 11-26-14)

• § 483.10(b)(4) – The resident has the right to refuse treatment, to refuse to participate in experimental research, and to formulate an advance directive as specified in paragraph (8) of this section; and
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• Whenever there appears to be a conflict between a resident’s right and the resident’s health or safety, determine if the facility attempted to accommodate both the exercise of the resident’s rights and the resident’s health, including exploration of care alternatives through a thorough care planning process in which the resident may participate.
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• F156

• §483.10(b)(1) -- The facility must inform the resident both orally and in writing in a language that the resident understands of his or her rights and all rules and regulations governing resident conduct and responsibilities during the stay in the facility.
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- F157
- §483.10(b)(11) -- Notification of changes.

(i) A facility must immediately inform the resident; consult with the resident’s physician; and if known, notify the resident’s legal representative or an interested family member when there is--

(A) An accident involving the resident which results in injury and has the potential for requiring physician intervention;
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(B) A significant change in the resident’s physical, mental, or psychosocial status (i.e., a deterioration in health, mental, or psychosocial status in either life-threatening conditions or clinical complications);

(C) A need to alter treatment significantly (i.e., a need to discontinue an existing form of treatment due to adverse consequences, or to commence a new form of treatment); or

(D) A decision to transfer or discharge the resident from the facility as specified in §483.12(a).
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• (ii) The facility must also promptly notify the resident and, if known, the resident’s legal representative or interested family member when there is--

• (A) A change in room or roommate assignment as specified in §483.15(e)(2); or

• (B) A change in resident rights under Federal or State law or regulations as specified in paragraph (b)(1) of this section.
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- F158
- §483.10(c)(1) Protection of Resident Funds
- The resident has the right to manage his or her financial affairs, and the facility may not require residents to deposit their personal funds with the facility.
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F162

• §483.10(c)(8) Limitation on Charges to Personal Funds

• The facility may not impose a charge against the personal funds of a resident for any item or services for which payment is made under Medicaid or Medicare (except for applicable deductible and coinsurance amounts) (e.g. Nursing, dietary, laundry, activity services, etc....)
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• Listed below are general categories and examples of items and services that the facility may charge to residents’ funds if they are requested by a resident, if the facility informs the resident that there will be a charge, and if payment is not made by Medicare or Medicaid:

• (A) Telephone;
• (B) Television/radio for personal use;
• (C) Personal comfort items, including smoking materials, notions and novelties, and confections;
• (D) Cosmetic and grooming items and services in excess of those for which payment is made under Medicaid or Medicare;
• (E) Personal clothing;
• (F) Personal reading matter;
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- (G) Gifts purchased on behalf of a resident;
- (H) Flowers and plants; and
- (I) Social events and entertainment offered outside the scope of the activities program, provided under §483.15(f) of this subpart.
- (J) Noncovered special care services such as privately hired nurses or aides.
- (K) Private room, except when therapeutically required (for example, isolation for infection control).
- (L) Specially prepared or alternative food requested instead of the food generally prepared by the facility, as required by §483.35 of this subpart.
The resident has the right to personal privacy and confidentiality of his or her personal and clinical records.

(1) Personal privacy includes accommodations, medical treatment, written and telephone communications, personal care, visits, and meetings of family and resident groups, but this does not require the facility to provide a private room for each resident;
• (2) Except as provided in paragraph (e)(3) of this section, the resident may approve or refuse the release of personal and clinical records to any individual outside the facility;

• (3) The resident’s right to refuse release of personal and clinical records does not apply when--

• (i) The resident is transferred to another health care institution; or

• (ii) Record release is required by law
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- F174
- §483.10(k) Telephone
- §483.10(l) Personal Property
- The resident has the right to retain and use personal possessions, including some furnishings, and appropriate clothing, as space permits, unless to do so would infringe upon the rights or health and safety of other residents.
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- F240
- §483.15 Quality of Life
- A facility must care for its residents in a manner and in an environment that promotes maintenance or enhancement of each resident’s quality of life.
- Interpretive Guidelines §483.15
- The intention of the quality of life requirements is to specify the facility’s responsibilities toward creating and sustaining an environment that humanizes and individualizes each resident. Compliance decisions here are driven by the quality of life each resident experiences.
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- F241
- §483.15(a) - Dignity
- The facility must promote care for residents in a manner and in an environment that maintains or enhances each resident’s dignity and respect in full recognition of his or her individuality.

- Interpretive Guidelines: §483.15(a)
- “Dignity” means that in their interactions with residents, staff carries out activities that assist the resident to maintain and enhance his/her self-esteem and self-worth.
Some examples include (but are not limited to):

**Grooming residents** as they wish to be groomed (e.g., hair combed and styled, beards shaved/trimmed, nails clean and clipped);

**Encouraging and assisting residents to dress in their own clothes** appropriate to the time of day and individual preferences rather than hospital-type gowns;

**Assisting residents to attend activities** of their own choosing;
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• F241 (continued)

Labeling each resident’s clothing in a way that respects his or her dignity (e.g., placing labeling on the inside of shoes and clothing);

Staff interacting/conversing only with each other rather than with residents while assisting residents;

Respecting residents’ private space and property (e.g., not changing radio or television station without resident’s permission, knocking on doors and requesting permission to enter, closing doors as requested by the resident, not moving or inspecting resident’s personal possessions without permission);
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1. F241 (continued)

Promoting resident independence and dignity in dining such as avoidance of:

Day-to-day use of plastic cutlery and paper/plastic dishware;

Bibs (also known as clothing protectors) instead of napkins (except by resident choice);

Staff standing over residents while assisting them to eat;
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• F241 (continued)

Respecting residents by speaking respectfully, addressing the resident with a name of the resident’s choice;

avoiding use of labels for residents such as “feeders,”

not excluding residents from conversations or discussing residents in community settings in which others can overhear private information;
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• F241 (continued)

• Focusing on residents as individuals when they talk to them and addressing residents as individuals when providing care and services;
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• F241 (continued)

Maintaining an environment in which there are no signs posted in residents’ rooms or in staff work areas able to be seen by other residents and/or visitors that include confidential clinical or personal information (such as information about incontinence, cognitive status).
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• F241 (continued)

• An exception can be made in an individual case if a resident or responsible family member insists on the posting of care information at the bedside (e.g., do not take blood pressure in right arm).
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• F241 (continued)

• [This does not prohibit the display of resident names on their doors nor does it prohibit display of resident memorabilia and/or biographical information in or outside their rooms with their consent or the consent of the responsible party if the resident is unable to give consent.]
CMS Directed Person Centered Care

• F241 Continued

Maintaining resident privacy of body including keeping residents sufficiently covered, such as with a robe, while being taken to areas outside their room, such as the bathing area (one method of ensuring resident privacy and dignity is to transport residents while they are dressed and assist them to dress and undress in the bathing room).
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F241 (continued)

Refraining from practices demeaning to residents such as keeping urinary catheter bags uncovered, refusing to comply with a resident’s request for toileting assistance during meal times, and restricting residents from use of common areas open to the general public such as lobbies and restrooms, unless they are on transmission based isolation precautions or are restricted according to their care planned needs.

[An exception can be made for certain restrooms that are not equipped with call cords for safety.]
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• F242
  • (Rev. 48, Issued: 06-12-09, Effective: 06-12-09 Implementation: 06-12-09)
  • §483.15(b) - Self-Determination and Participation
  • The resident has the right to--
  • (1) Choose activities, schedules, and health care consistent with his or her interests, assessments, and plans of care;
  • (2) Interact with members of the community both inside and outside the facility; and
  • (3) Make choices about aspects of his or her life in the facility that are significant to the resident.
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• F 242 continued

Residents have the right to have a choice over their schedules, consistent with their interests, assessments and plans of care. Choice over “schedules” includes (but is not limited to) choices that are important to the resident, such as daily waking, eating, bathing, and the time for going to bed at night. Residents have the right to choose health care schedules consistent with their interests and preferences, and the facility should gather this information in order to be proactive in assisting residents to fulfill their choices.
If the resident refuses a bath because he or she prefers a shower or a different bathing method such as in-bed bathing, prefers it at a different time of day or on a different day, does not feel well that day, is uneasy about the aide assigned to help or is worried about falling, the staff member should make the necessary adjustments realizing that the resident is not refusing to be clean but refusing the bath under the circumstance provided. The facility staff should meet with the Resident to make adjustments in the care plan to accommodate his or her preferences.
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• F 242 Continued

• According to this requirement at §483.15(b)(3), residents have the right to make choices about aspects of their lives that are significant to them. One example includes the right to choose to room with a person of the resident’s choice if both parties are residents of the facility, and both consent to the choice.
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- F246
- §483.15(e) - Accommodation of Needs
- A resident has the right to --
- §483.15(e)(1) - Reside and receive services in the facility with reasonable accommodation of individual needs and preferences, except when the health or safety of the individual or other residents would be endangered;
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The facility is responsible for evaluating each resident’s unique needs and preferences and ensuring that the environment accommodates the resident to the extent reasonable and does not endanger the health or safety of individuals or other residents. This includes making adaptations of the resident’s bedroom and bathroom furniture and fixtures, as necessary to ensure that the resident can (if able):
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Open and close drawers and turn faucets on and off; See her/himself in a mirror and have toiletry articles easily within reach while using the sink;

Open and close bedroom and bathroom doors, easily access areas of their room and bath, and operate room lighting;

Use bathroom facilities as independently as possible with access to assistive devices (such as grab bars within reach) if needed; and

Perform other desired tasks such as turning a table light on and off, using the call bell; etc
CMS Directed Person Centered Care

- The bedroom should include comfortable seating for the resident and task lighting that is sufficient and appropriate for the resident’s chosen activities. The facility should accommodate the resident’s preferences for arrangement of furniture to the extent space allows, including facilitating resident choice about where to place their bed in their room (as long as the roommate, if any, concurs). There may be some limitations on furniture arrangement, such as not placing a bed over a heat register, or not placing a bed far from the call cord so as to make it unreachable from the bedside.
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• The facility should also ensure that furniture and fixtures in common areas frequented by residents are accommodating of physical limitations of residents. Furnishings in common areas should enhance residents’ abilities to maintain their independence, such as being able to arise from living room furniture. The facility should provide seating with appropriate seat height, depth, firmness, and with arms that assist residents to arise to a standing position.
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- F257
- §483.15(h)(6) Comfortable and safe temperature levels. Facilities initially certified after October 1, 1990 must maintain a temperature range of 71 - 81° F; and
- F258
- §483.15(h)(7) For the maintenance of comfortable sound levels.
- Interpretive Guidelines §483.15(h)(7)
- “Comfortable” sound levels do not interfere with resident’s hearing and enhance privacy when privacy is desired, and encourage interaction when social participation is desired. Of particular concern to comfortable sound levels is the resident’s control over unwanted noise.
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CARE PLANNING

• §483.20 Resident Assessment
• The facility must conduct initially and periodically a comprehensive, accurate, standardized reproducible assessment of each resident’s functional capacity.
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• F280

• §483.10(d)(3) – The resident has the right to - unless adjudged incompetent or otherwise found to be incapacitated under the laws of the State, participate in planning care and treatment or changes in care and treatment.
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• F 280 continued
• “Participates in planning care and treatment” means that the resident is afforded the opportunity to select from alternative treatments. This applies both to initial decisions about care and treatment and to decisions about changes in care and treatment.
CMS Directed Person Centered Care

• F 280 continued

• A resident whose ability to make decisions about care and treatment is impaired, or a resident who has been formally declared incompetent by a court, should, to the extent practicable, be kept informed and be consulted on personal preferences.
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• F 280 continued

• Whenever there appears to be a conflict between a resident’s right and the resident’s health or safety, determine if the facility attempted to accommodate both the exercise of the resident’s rights and the resident’s health, including exploration of care alternatives through a thorough care planning process in which the resident may participate.
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- F246
- §483.15(e) - Accommodation of Needs
- A resident has the right to --
- §483.15(e)(1) - Reside and receive services in the facility with reasonable accommodation of individual needs and preferences, except when the health or safety of the individual or other residents would be endangered;
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• What do the surveyors expect to see and hear and find documented when the resident engages in actions that seem to endanger his/her health - refuses treatment, refuses to cooperate with staff interventions, consistently refuses medications, or engages in potentially dangerous activities?
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1. To the extent possible, engage and involve the resident in the overall care plan process.

2. To the extent possible, engage and involve the family/legal representative in the overall care planning process.

3. Ask why – why the resident is not cooperating with physician orders for treatment, refusing medications and staff interventions for care, etc....
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4. Ask: “What would be acceptable to you?” possibly some compromise or alternative to the current arrangement.

5. Offer alternatives and choices.

6. Inform the resident and family of the potential bad outcomes.

7. Monitor for decline in health and review this with the resident and family.
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- F248
- §483.15(f) Activities
- (1) The facility must provide for an ongoing program of activities designed to meet, in accordance with the comprehensive assessment, the interests and the physical, mental, and psychosocial well-being of each resident.
- “Activities” refer to any endeavor, other than routine ADLs, in which a resident participates that is intended to enhance her/his sense of well-being and to promote or enhance physical, cognitive, and emotional health. These include, but are not limited to, activities that promote self-esteem, pleasure, comfort, education, creativity, success, and independence.
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• F248 continued

• “One-to-One Programming” refers to programming provided to residents who will not, or cannot, effectively plan their own activity pursuits, or residents needing specialized or extended programs to enhance their overall daily routine and activity pursuit needs.
CMS Directed Person Centered Care

• F248 continued

• “Person Appropriate” refers to the idea that each resident has a personal identity and history that involves more than just their medical illnesses or functional impairments. Activities should be relevant to the specific needs, interests, culture, background, etc. of the individual for whom they are developed.
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• F248 continued

Surveyors need to be aware that some facilities may take a non traditional approach to activities. In neighborhoods/households, all staff may be trained as nurse aides and are responsible to provide activities, and activities may resemble those of a private home. Residents, staff, and families may interact in ways that reflect daily life, instead of in formal activities programs. Residents may be more involved in the ongoing activities in their living area, such as care-planned approaches including chores, preparing foods, meeting with other residents to choose spontaneous activities, and leading an activity.
CMS Directed Person Centered Care

• F248 continued

• It has been reported that, “some culture changed homes might not have a traditional activities calendar, and instead focus on community life to include activities. Instead of an “activities director,” some homes have a Community Life Coordinator, a Community Developer, or other title for the individual directing the activities program.
Some medications, such as diuretics, or conditions such as pain, incontinence, etc. may affect the resident’s participation in activities. Therefore, additional steps may be needed to facilitate the resident’s participation in activities, such as:
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• F248 continued

• If not contraindicated, timing the administration of medications, to the extent possible, to avoid interfering with the resident’s ability to participate or to remain at a scheduled activity; or

• If not contraindicated, modifying the administration time of pain medication to allow the medication to take effect prior to an activity the resident enjoys.
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F248 continued

A continuation of life roles, consistent with resident preferences and functional capacity (e.g., to continue work or hobbies such as cooking, table setting, repairing small appliances);

Encouraging and supporting the development of new interests, hobbies, and skills (e.g., training on using the Internet); and

Connecting with the community, such as places of worship, veterans’ groups, volunteer groups, support groups, wellness groups, athletic or educational connections (via outings or invitations to outside groups to visit the facility).
Information from other Culture Change Organizations

- ALABAMA COALITION FOR CULTURE CHANGE
- Alabamaculturechange.org
- C/O K Hughes 601 Nwoodburn Drive Dothan, AL 36301
- EIN: 26-4540863
AL Coalition for Culture Change

• The Alabama Coalition for Culture Change advocates and facilitates deep system change and transformation in our culture of aging. To achieve this, we:
• Create communication, networking and learning opportunities
• Build and support relationships and community
• Identify and promote transformations in practice, services, public policy and research
• Develop and provide access to resources and leader
• Community is the antidote to institutionalization
Person Centered Care OHIO

- Ohio Person-Centered Care Coalition

- “The mission of the Ohio Person-Centered Care Coalition is to influence and support transformational culture change in the long-term care environments where all individuals can experience meaning and purpose.”
Person Centered Care OHIO

• Ohio Person-Centered Care Coalition

• While staying at a nursing home, it should feel like home to you, regardless of whether your needs require a short or long stay. Your nursing home will work with you and your loved ones (if you wish) to design care that supports you, builds on your strengths, promotes quality of life, and honors your preferences, choices, abilities and culture. Person-centered care means that your voice is listened to and respected. You have the right to choice, dignity, independence, respect and a purposeful life.
• You don’t lose control when you move into a nursing home. As you always have, you decide how your day flows. You wake up at the time you want to get up and go to bed when you are ready. It is your choice whether you receive a bath or a shower, and you will decide when and how often either will happen. The nursing home will give you food choices that you enjoy, in a setting and at a time that you prefer. Your caregivers should know all of these preferences and be familiar with you. If the offered activities aren’t of interest to you, let your caregivers know of an activity that you would enjoy.
• Unfortunately, with Alzheimer’s disease and other dementias, a stigma remains that people with dementia are not fully “here,” that they are no longer themselves. Caregivers often treat them accordingly—as a diagnosis, not a person.
Person Centered Care Kansas

PEAK 2.0 (Promoting Excellent Alternatives in Kansas)

• Person-centered care is a philosophy that changes the focus of caregiving from accomplishing tasks to emphasizing the person.

• As a result, the personal preferences of residents become as important as providing the services and supports they need.

• Person-centered care requires a shift in an organization’s values and beliefs about quality. Traditionally, high quality clinical care is seen as the pinnacle of a high quality nursing home. With person-centered care, high quality clinical care remains critically important, but quality of life is valued as equally important.

• We need to do both.
Person Centered Care Kansas

The PEAK 2.0 (Promoting Excellent Alternatives in Kansas) program focuses on five domains essential to person-centered care:

• The Foundation,
• Resident Choice,
• Staff Empowerment,
• Home Environment, and
• Meaningful Life.
Person Centered Care Kansas

• All residents in long term care facilities have rights guaranteed to them under Federal and State law. Requirements concerning resident rights are specified in §§483.10, 483.12, 483.13, and 483.15. Section 483.10 is intended to lay the foundation for the remaining resident’s rights requirements which cover more specific areas.
Person Centered Care Kansas

• Residents have the right to what is legal, healthy and safe.
• Honor the choices that people make. This tells people that you know them, you know what they like and are meeting those choices.
• Choices and preferences must be considered
• People have the right to make choices even if it might not be the best choice for them.
Person Centered Care: The Beginning

Now: what happened to JFK’s New Frontier that started 50 years ago -- and **person centered care** for those with congenital and acquired mental health issues who were residents of those institutional care facilities for
Person Centered Care

- The chronically mentally ill patients who were essentially unable or unprepared to handle the outside world were released into adult homes, group homes, foster homes, supervised residences, “hotels,” and nursing homes. As patients aged, many of them have been transferred to nursing homes from lesser care settings. A number of patients have become homeless as a result, and the number of mentally ill persons in the prison population also increased significantly. Approximately 750,000 patients with chronic mental illness have been placed in nursing homes by the late 1980s.

See more at: http://www.annalsoflongtermcare.com/article/7712#sthash.k0ZQ7q1v.dpuf
Person Centered Care

• More Mentally Ill Persons Are in Jails and Prisons Than Hospitals: A Survey of the States ---- May 2010

• Using 2004–2005 data not previously published, we found that in the United States there are now greater than three times more seriously mentally ill persons in jails and prisons than in hospitals. Looked at by individual states, in North Dakota there are approximately an equal number of mentally ill persons in jails and prisons compared to hospitals. By contrast, Arizona and Nevada have almost ten times more mentally ill persons in jails and prisons than in hospitals.
Person Centered Care

• More Mentally Ill Persons Are in Jails and Prisons Than Hospitals: A Survey of the States ---- May 2010

• It is thus fact, not hyperbole, that America’s jails and prisons have become our new mental hospitals.
More Mentally Ill Persons Are in Jails and Prisons Than Hospitals: A Survey of the States ---- May 2010

- E. Fuller Torrey, M.D., Executive Director, Stanley Medical Research Institute, and Board Member, Treatment Advocacy Center
- Sheriff Aaron D. Kennard (retired), M.P.A., Executive Director, National Sheriffs’ Association
- Sheriff Don Eslinger, Seminole County (Fla.) Sheriff’s Office, and Board Member, Treatment Advocacy Center
- Richard Lamb, M.D., Professor of Psychiatry, University of Southern California Keck School of Medicine, and Board Member, Treatment Advocacy Center
- James Pavle Executive Director, Treatment Advocacy Center
Person Centered Care

- Eighty-nine percent of the older people with serious mental illness who are institutionalized reside in nursing homes. Pilgrim State Hospital in New York, which was considered to be the largest mental hospital in the world, once cared for about 10,000 patients. The bed capacity has now shrunk to about 650.

- See more at: http://www.annalsoflongtermcare.com/article/7712#sthash.k0ZQ7qlv.dpuf
Person Centered Care

- States have saved a significant amount of money by these maneuvers, but is this a real saving in terms of true costs, or is it just a shift of fiscal burden from the state to the federal government?
- What about the consequences—the human suffering and quality-of-life issues—for this underrepresented segment of our population? The taxpayer is still responsible for the monetary burden as a result of the revolving-door situation of these patients.

See more at: http://www.annalsoflongtermcare.com/article/7712#sthash.k0ZQ7qlv.dpuf
Person Centered Care

• Could this happen to skilled nursing home care?

• 50 years from the implementation of OBRA 87 is 2042.

• How old will you and your relatives be in 2042?
Person Centered Care

The DOJ has filed several suites against Alabama Medicaid for failure to provide Home and Community Based Waiver services for nursing home residents who wanted to go home.
Person Centered Care

Home vs Institution: Which Setting Yields Better Functional Outcomes?

Researchers conducted a retrospective cohort study that included a sample of 22,557 older adults who received either nursing home care (n=11,678) or home care (n=10,879) over a period of 1 year.

DOI: http://dx.doi.org/10.1016/j.jamda.2014.07.013

See more at: http://www.annalsoflongtermcare.com/content/home-vs-institution-which-setting-yields-better-functional-outcomes#sthash.wDxZJvtL.dpuf
Person Centered Care

• Functionality was assessed based on change in activities of daily living (ADLs) at 1 year. Covariates included geographical location, level of long-term care services, age, sex, primary caregiver, beneficiary status, bedridden status, cognitive function, nursing and special treatment, rehabilitation needs, and medical diagnoses.

DOI: http://dx.doi.org/10.1016/j.jamda.2014.07.013

See more at: http://www.annalsoflongtermcare.com/content/home-vs-institution-which-setting-yields-better-functional-outcomes#sthash.wDxZJvtL.dpuf
Person Centered Care

• The results showed that among all unmatched patients (N=22,557), those who received nursing home care experienced greater loss of functionality after 1 year compared to home care patients ($\beta=0.44108$, $P<.0001$)

DOI: http://dx.doi.org/10.1016/j.jamda.2014.07.013

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Person Centered Care

• In propensity-score matching, the paired $t$-test analysis found similar results, as ADLs of older adults had deteriorated less in the home care group compared with the nursing home group after 1 year ($P<.0001$).

DOI: http://dx.doi.org/10.1016/j.jamda.2014.07.013

See more at: http://www.annalsoflongtermcare.com/content/home-vs-institution-which-setting-yields-better-functional-outcomes#sthash.wDxZJvtL.dpuf
Person Centered Care

Based on these findings, the study authors concluded that ADLs of older adults could differ according to the type of long-term care received, but that home care likely results in better maintenance of functionality than in nursing home care.

DOI: http://dx.doi.org/10.1016/j.jamda.2014.07.013
See more at: http://www.annalsoflongtermcare.com/content/home-vs-institution-which-setting-yields-better-functional-outcomes#sthash.wDxZJvtL.dpuf
World Congress

• World Congress Leadership Summit on Medicaid Managed Care

• February 24 - 25, 2015 • Washington, DC

See more at: http://worldcongress.com/common/pricing.cfm?confcode=HW15037#sthash.e1rDVGs0.dpuf

• CASE STUDY: Make the Change to Community-Based Care for Long Term Medicaid Patients
World Congress

• CASE STUDY: Make the Change to Community-Based Care for Long Term Medicaid Patients

Hear how the state of Florida is transitioning its long term care patients to a community based setting. Understand the managed care organization’s role in this shift and how they work with providers to ensure high levels of care while reducing costs. Learn how managed care organizations:
World Congress

- Manage providers
- Reduce costs for states
- Improve quality of care
- Collaborate with states and providers to make community-based long term care a reality in the state of Florida
Person Centered Care

• Unless residents and families are treated with dignity and respect and have genuine person centered care, there is such a momentum to abolish “institutional residential care” that traditional nursing homes may become a thing of the past.

• Where would all of the elderly and infirm folks go? Discharge to home care with a sitter and a visiting nurse.
Person Centered Care

Home care is often suboptimal:
No regulatory oversight of care and environment
No socialization with folks of the same age
No formal activity program
Care provided by a high school graduate with minimal medical training
High risk for exploitation and abuse – especially by family
Person Centered Care

• Can the nursing homes in Alabama become the kind of place that elderly folks want to go and live?
• 9600 people in Alabama now pay (a lot!) to live in assisted living and specialty care assisted living.
• Many move to independent living facilities.
• Many more are in unlicensed facilities.
Person Centered Care and Culture Change in Alabama

• I believe it can be done!