Maternal and Child Health Bureau
Division of Services for Children with Special Health Needs

DEFINITION OF FAMILY-CENTERED CARE

Family-Centered Care assures the health and well-being of children and Their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services.

PRINCIPLES OF FAMILY-CENTERED CARE FOR CHILDREN

The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following principles:

- **Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.**
- **Everyone respects the skills and expertise brought to the relationship.**
- **Trust is acknowledged as fundamental.**
- **Communication and information sharing are open and objective.**
- **Participants make decisions together.**
- **There is a willingness to negotiate.**

Based on this partnership, family-centered care:

1. **Acknowledges the family as the constant in a child's life.**
2. **Builds on family strengths.**
3. **Supports the child in learning about and participating in his/her care and decision-making.**
4. **Honors cultural diversity and family traditions.**
5. **Recognizes the importance of community-based services.**
6. **Promotes an individual and developmental approach.**
7. **Encourages family-to-family and peer support.**
8. **Supports youth as they transition to adulthood.**
9. **Develops policies, practices, and systems that are family-friendly and family-centered in all settings.**
10. **Celebrates successes.**

Sources: **National Center for Family-Centered Care. *Family-Centered Care for Children with Special Health Care Needs.* (1989). Bethesda, MD: Association for the Care of Children's Health.**

Bishop, Woll and Arango (1993). *Family/Professional Collaboration for Children with Special Health Care Needs and their Families.* Burlington, VT: University of Vermont, Department of Social Work.

Family-Centered Care Projects 1 and 2 (2002-2004). Bishop, Woll, Arango. Algodones, NM; Algodones Associates

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THE ROLE OF CULTURAL COMPETENCE IN FAMILY-CENTERED CARE

Cultural Competence is intricately linked to the concept and practice of "family-centered care". Family-Centered Care honors the strengths, cultures, traditions and expertise that everyone brings to a respectful family/professional partnership, where families feel they can be decision makers with providers at different levels - in the care of their own children and as advocates for systems and policies supportive of children and youth with special health care needs. It requires culturally competent attitudes and practices in order to develop and nurture those partnerships and to have the knowledge and skills that will enable you to be "family-centered" with the many diverse families that exist. It also often requires building relationships with community cultural brokers, who can assist you in understanding community norms and link you with other families and organizations, such as churches, beauty shops, social clubs, etc. that can help promote your message or conduct outreach for services.

DEFINITION OF CULTURAL/LINGUISTIC COMPETENCE

Cultural competence is defined as a set of values, behaviors, attitudes, and practices within a system, organization, program or among individuals and which enables them to work effectively cross culturally. Further, it refers to the ability to honor and respect the beliefs, language, interpersonal styles and behaviors of individuals and families receiving services, as well as staff who are providing such services. At a systems, organizational, or program level, cultural competence requires a comprehensive and coordinated plan that includes interventions at all the levels from policy-making to the individual, and is a dynamic, ongoing, process that requires a long-term commitment. A component of cultural competence is linguistic competence, the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who are not literate or have low literacy skills, and individuals with disabilities.

PRINCIPLES OF CULTRUAL COMPETENCE

An organization should:

1) **Value diversity in families, staff, providers and communities;**
2) **Have the capacity for cultural self-assessment;**
3) **Be conscious of the dynamics inherent when cultures interact, e.g.families and providers;**
4) **institutionalize culture knowledge; and**
5) **Develop adaptations to service delivery and partnership building reflecting an understanding of cultural diversity.**

An individual should:

1) **Examine one's own attitude and values;**
2) **Acquire the values, knowledge, and skills for working in cross cultural situations; and**
3) **Remember that every one has a culture.**

Sources: Maternal and Child Health Bureau (MCHB), Guidance and Performance Measures for Discretionary Grants, Health Resources and Services Administration, U.S. Department of Health and Human Services, Denboba and Goode, 1999 and 2004.

Cross, Bazron, Dennis and Isaacs, Towards a Culturally Competent System of Care, 1989.

Goode and Jones, Definition of Linguistic Competence, National Center for Cultural Competence, Revised 2004.

Denboba, "Federal Viewpoint", Special Additions Newsletter for Children with Special Health Care Needs, Spring/Summer 2005.

What is my risk of breaking a bone?

As you get older, your risk of breaking a bone, often through a fall, increases. This increased risk may be due to weakened bones or ***osteoporosis***.

Your risk is estimated primarily by:
Your age: _____
Your Bone Mineral Density (T score): ______

It is also affected by:
- ☐ If you have had a fracture
- ☐ If a parent had a fracture
- ☐ If you currently smoke
- ☐ If you drink more than 2 drinks of alcohol a day
- ☐ If you have taken prescription steroid medications

Based on these risk factors, we estimate your risk is
<10%   10-30%   >30%

Your fracture risk can be lowered with medications called ***bisphosphonates***, which work to reduce bone loss. This decision aid will walk you through the benefits and downsides of bisphosphonates, so that we can make an informed choice about whether or not they are right for you.

Prepared for: ______________________________

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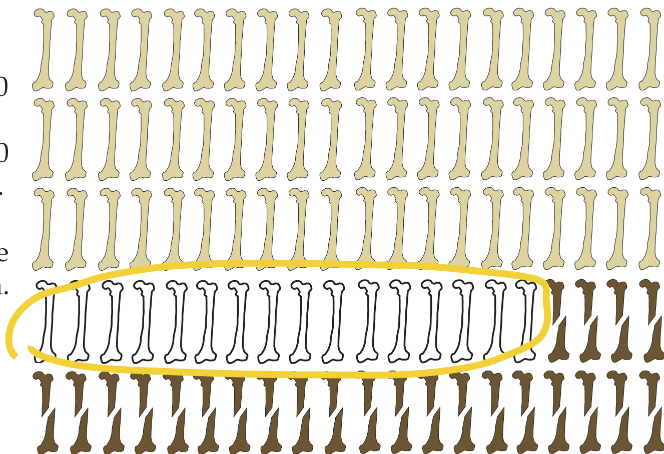
Benefits

Without Medication
Roughly 40 in 100 have a fracture within the next 10 years. 60 will not.

With Medication
Roughly 24 in 100 have a fracture within the next 10 years. 76 will not. 16 have avoided a fracture because of the medication.



Downsides

Directions
This medication must be taken
- Once a week
- On an empty stomach in the morning
- With 8 oz of water
- While upright (sitting or standing for 30 min)
- 30 minutes before eating

Possible Harms

Abdominal Problems
About 1 in 4 people will have heartburn, nausea, or belly pain. However, it may not be from the medication. If the medication is the cause, the problem will go away if you stop taking it.

Osteonecrosis of the Jaw
Fewer than 1 in 10,000 (over the next 10 years) will have bone sores of the jaw that may need surgery.

Out of Pocket Cost
with insurance $30 | without insurance $70-90

What would you like to do?

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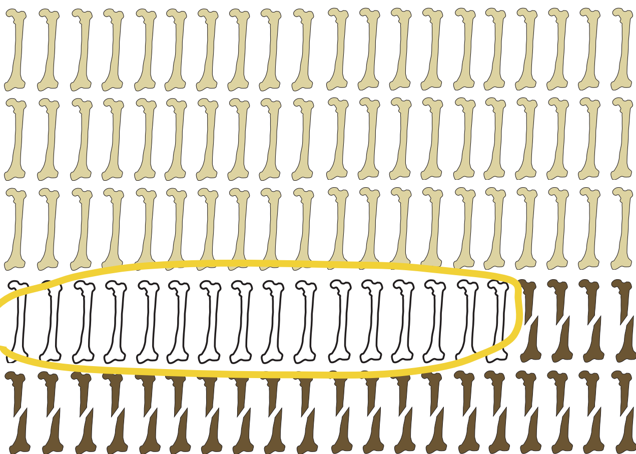

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National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health Care

Culturally Competent Care:

1. ***Health care organizations should ensure that patients/consumers receive from all staff members effective, understandable, and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language.***
2. ***Health care organizations should implement strategies to recruit, retain, and promote at all levels of the organization a diverse staff and leadership that are representative of the demographic characteristics of the service area.***
3. ***Health care organizations should ensure that staff at all levels and across all disciplines receive ongoing education and training in culturally and linguistically appropriate service delivery.***

Language Access Services:

4. ***Health care organizations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation.***
5. ***Health care organizations must provide to patients/consumers in their preferred language both verbal offers and written notices informing them of their right to receive language assistance services.***
6. ***Health care organizations must assure the competence of language assistance provided to limited English proficient patients/consumers by interpreters and bilingual staff. Family and friends should not be used to provide interpretation services (except on request by the patient/ consumer).***
7. ***Health care organizations must make available easily understood patient-related materials and post signage in the languages of the commonly encountered groups and/or groups represented in the service area.***

Organizational Supports:

8. ***Health care organizations should develop, implement, and promote a written strategic plan that outlines clear goals, policies, operational plans, and management accountability/oversight mechanisms to provide culturally and linguistically appropriate services.***
9. ***Health care organizations should conduct initial and ongoing organizational self-assessments of CLAS-related activities and are encouraged to integrate cultural and linguistic competence-related measures into their internal audits, performance improvement programs, patient satisfaction Assessments, and Outcomes-Based Evaluations.***
10. ***Health care organizations should ensure that data on the individual patient's/consumer's race, ethnicity, and spoken and written language are collected in health records, integrated into the organization's management information systems, and periodically updated.***
11. ***Health care organizations should maintain a current demographic, cultural, and epidemiological profile of the community as well as a needs assessment to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area.***
12. ***Health care organizations should develop participatory, collaborative partnerships with communities and utilize a variety of formal and informal mechanisms to facilitate community and patient/ consumer involvement in designing and implementing CLAS-related activities.***
13. ***Health care organizations should ensure that conflict and grievance resolution processes are culturally and linguistically sensitive and capable of identifying, preventing, and resolving cross-cultural conflicts or complaints by patients/consumers.***
14. ***Health care organizations are encouraged to regularly make available to the public information about their progress and successful innovations in implementing the CLAS Standards and to provide public notice in their communities about the availability of this information.***

Office of Minority Health, U.S. Department of Health and Human Services. (2000).National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health Care. Federal Register, 65(247), 80865-80879.
http://www.omhrc.gov/clas/finalcultural1a.htm

Communicating With and About People with Disabilities

About 50 million Americans report having a disability. Most Americans will experience a disability some time during the course of their lives. Disabilities can affect people in different ways, even when one person has the same type of disability as another person. Some disabilities may be hidden or not easy to see.

People First Language

People first language is used to speak appropriately and respectfully about an individual with a disability. People first language emphasizes the person first not the disability. For example, when referring to a person with a disability, refer to the person first by using phrases such as: "a person who …", "a person with …" or, "person who has…"

Here are suggestions on how to communicate with and about people with disabilities.

People First Language	Language to Avoid
Person with a disability	The disabled, handicapped
Person without a disability	Normal person, healthy person
Person with an intellectual, cognitive, developmental disability	Retarded, slow, simple, moronic, defective or retarded, afflicted, special person
Person with an emotional or behavioral disability, person with a mental health or a psychiatric disability	Insane, crazy, psycho, maniac, nuts
Person who is hard of hearing	Hearing impaired, suffers a hearing loss
Person who is deaf	Deaf and dumb, mute
Person who is blind/visually impaired	The blind
Person who has a communication disorder, is unable to speak, or uses a device to speak	Mute, dumb
Person who uses a wheelchair	Confined or restricted to a wheelchair, wheelchair bound
Person with a physical disability, physically disabled	Crippled, lame, deformed, invalid, spastic
Person with autism	Autistic
Person with epilepsy or seizure disorder	Epileptic
Person with multiple sclerosis	Afflicted by MS
Person with cerebral palsy	CP victim
Accessible parking or bathrooms	Handicapped parking or bathroom
Person of short stature	Midget
Person with a congenital disability	Birth defect
Person with Down syndrome	Mongoloid
Person who is successful, productive	Has overcome his/her disability, is courageous

For more information about disability and health, visit www.cdc.gov/disabilities

National Center on Birth Defects and Developmental Disabilities
Office of the Director

DEPARTMENT OF HEALTH & HUMAN SERVICES·USA CDC

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