Person, Family Centered and Culturally Responsive Care

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Module Objectives

- Describe the philosophy and central ideas of person/family-centered care (PFCC).
- Understand the intersect of PFCC & cultural and linguistic competency (CALC)
- Understand cultural compassion and cultural humility
- Describe disparities in PFCC
- Recognize the family as a constant in the life of a child with a disability.
- Consider the family as the center of decision-making related to their child with a disability and that each family member has strengths and abilities that impact decision making.
- Recognize the importance of the family voice in every aspect of service from the provision of individual care to program development and evaluation.
- Learn strategies to use when working with families in order to understand a family's perspective
- Understand the importance of knowing your own biases

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Before starting the module

- Think about and define what family means to you
- You will be working with a child and family affected by Zika virus. Think about these questions as you engage with the material:
  - How will you prepare for the first interaction?
  - What strategies and tools will you use to start building an effective partnership?
  - Think about what any biases you might have that can hinder your meaningfully engaging with this family.

What is Person and Family Centered Care (PFCC)?

Person and family-centered care is an approach to the planning, delivery, and evaluation of health care whose cornerstone is active participation between families and professionals. Family-centered care recognizes that families are the ultimate decision makers for their children, with children gradually taking on more and more of this decision-making themselves.

National Survey of CSHCN (2014)

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In Family Centered Care:

- People are treated with dignity and respect
- Health care providers share information that is useful and affirming
- Plans and experiences build on individuals and families strengths
- Collaboration extends beyond care to include policy & program development, quality improvement (QI), & professional education

Hughes (2014)

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When care is family-centered, services:

- Meet the physical, emotional, developmental, and social needs of children, and
- Supports the family's relationship with the child's health care providers, and
- Recognizes the family's customs and values, and
- Providers recognize the family is the constant throughout the child's entire life

National Survey of CSHCN (2014)

PFCC/CALC improves

- Health
- Well-being
- Satisfaction
- Access
- Communication
- School attendance

Hughes (2014)

PFCC/CALC decreases

- Family strain
- Office visits
- Emergency visits
- Unmet family needs

Hughes (2014)

Health Care Disparities in PFCC

- Latino parents have ½ the odds of receiving PFCC than non-Latino white parents
- African American parents have 2/3 the odds of receiving PFCC than white parents
- Children from homes with non-English primary language received significantly less PFCC
- Families with low SES received significantly less PFCC

Hughes (2014); National Survey of CSHCN (2014)

Maternal and Child Health Bureau

The Maternal Child Health Bureau stresses cultural competence as a critical component of family-centered care; you cannot have one without the other.

Family-centered care and Zika Virus Video 1

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Family-centered care and Zika Virus Video 1 – Reflection

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Family-centered care and Zika Virus Video 2

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Family-centered care and Zika Virus Video 2 - Reflection

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The intersection of CALC and PFCC

Cultural competence can be seen as a necessary set of skills for nurses [service providers] to attain in order to render effective patient [and family centered care]”

Camphina-Bacote, 2011

What is Culturally Responsive Care?

"the ongoing process in which the healthcare professional continuously strives to achieve the ability and availability to work effectively within the cultural context of the patient (individual , family and community)"

Camphina-Bacote, 2011

In Culturally Responsive Care the provider:

- Spends enough time with the family;
- Listens carefully to the parents;
- Treats the parent like a partner in the child's care;
- Is sensitive to the family's values and customs; and
- Provides the specific information that the parent needs.

National Survey of CSHCN (2014)

Demonstrating Culturally Responsive Care

- Treating families with respect & dignity
- Listening to their voices and stories
- Recognizing & understanding cultural values
- Being sensitive to family's values
- Forming partnerships
- Supporting decision-making
- Knowing the cultural context
- Ensuring the meaningful participation of families in all aspects of care

Seek and Engage in Cultural Encounters

- Directly interact with diverse children/families
- Enhance and develop skills
- Develop ‘mindful intercultural communications’
- Understand that knowing about cultural groups is not at all the same as knowing an individual or family
- Cultivate compassion
- Develop cultural humility

Campinha-Bacote, 2011

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Cultivate Compassion

“Cultivating compassion requires that we understand situations from the other’s point of view and engage in self-reflection regarding how our actions are affecting the other person”

Gallagher (2007)

Understanding Cultural Humility

“The approach of cultural humility goes beyond the concept of cultural competence to encourage individuals to identify their own biases and to acknowledge that those biases must be recognized. Cultural competency implies that one can function with a thorough knowledge of the mores and beliefs of another culture; ***cultural humility acknowledges that it is impossible to be adequately knowledgeable about cultures other than one's own****. Another term often used when discussing working with others outside of our own culture is cultural sensitivity. Cultural humility requires us to take responsibility for our interactions with others beyond acknowledging or being sensitive to our differences.”*

Levi (2009)

Barriers to Culturally Responsive Care

"overall health of the American population has improved over the past few decades, but not all Americans have benefited equally from these improvements. Minority populations, in particular, continue to lag behind whites in a number of areas, including *quality of care, access to care, timeliness, and outcomes.* Other health care problems that disproportionately affect minorities include *provider biases, poor provider-patient communication, and health literacy issues.*"

(U.S. Agency for Healthcare and Research Quality, a division of the U.S. Department of Health and Human Services (HHS), 2013)

In the Aug. 11, 2015 issue of the Journal of the American Medical Association, a Viewpoint co-authored by The Joint Commission's medical director, Ronald Wyatt, MD, MHA, calls for immediate action to address racial bias throughout the U.S. health care system

Take Away Messages

- Disparities in who receives PFCC persist by race, disability, insurance, language, & SES
- Skills in being culturally responsive are crucial in being family-centered, you CANNOT be one without the other
- You must continually assess all your work through the lens of PFCC & CALC
- PFCC/CALC results in improved outcomes
- Family & children are essential partners in our work

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Additional Resources (not an exhaustive list)

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Additional Resources cont.

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Homer, C. J., Klatka, K., Romm, D., Kuhlthau, K., Bloom, S., Newacheck, P, J. Van Cleave, & Perrin, J. M. (2008). A review of the evidence for the medical home for children with special health care needs. *Pediatrics*, *122*(4), e922–e937.

Ngui, E. M., & Flores, G. (2006). Satisfaction with care and ease of using health care services among parents of children with special health care needs: the roles of race/ethnicity, insurance, language, and adequacy of family-centered care. *Pediatrics*, *117*(4), 1184–1196.

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