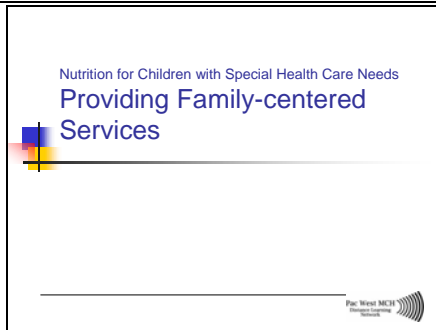


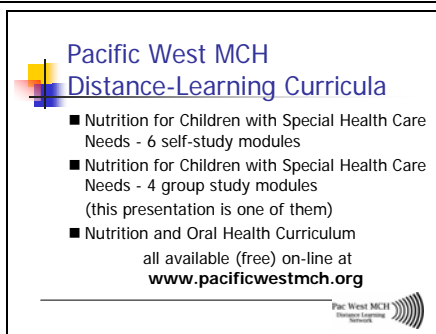
Pacific West Distance Learning Network Nutrition for Children with Special Health Care Needs Curriculum

Group Study Module 1: Providing Family-Centered Services Speaker's Notes

1



2

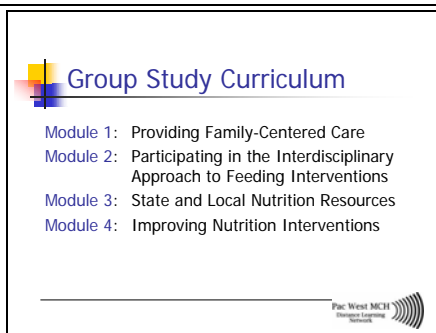


All of these materials are available free-of-charge on the website listed.

Participants may also be interested in the self-study curriculum.

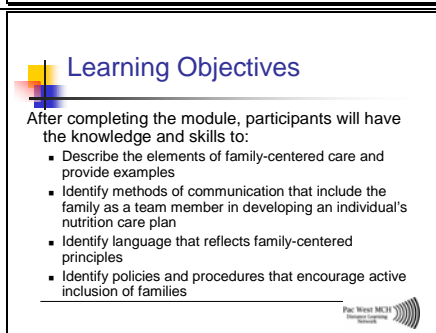
There may be a charge for continuing education credit.

3



These four modules are available as group-study topics for in-services and other meetings. The material in these modules is best learned through an interactive process between the group leader and amongst the group members. A Leaders' guide, PowerPoint presentations, handouts and video segments are available free-of-charge.

4



The point of this format is to facilitate discussion—and to learn from the discussion. We think this is a topic best learned by interaction. As we go through the material, think about how it applies to your practice...what can you implement...what is not reasonable to implement?

5



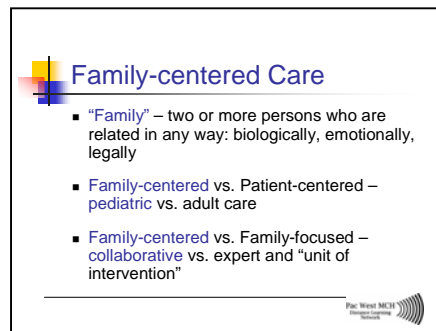
Family-centered Care

“Family-centered care is an approach to the planning, delivery, and evaluation of health care that is governed by mutually beneficial **partnerships between health care providers, patients, and families.**”

<http://www.familycenteredcare.org>

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Family-centered Care

- “Family” – two or more persons who are related in any way: biologically, emotionally, legally
- Family-centered vs. Patient-centered – pediatric vs. adult care
- Family-centered vs. Family-focused – collaborative vs. expert and “unit of intervention”

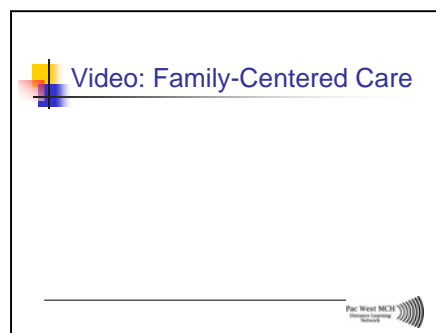
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Clarification...

The definition of family (and degree of family involvement in health care) is controlled by the patient, provided he/she is developmentally mature and competent to do so. In pediatrics, families define for themselves who their family members are.

Family-centered vs. family-focused: Both approaches acknowledge involvement with the family. In family-focused care, professionals provide care from the position of the “expert”...they tell families what to do. They consider the family the “unit of intervention.” Family-centered care is characterized by a collaborative approach to caregiving and decision-making. Each party respects the knowledge, skills, and experience the other brings to the health care encounter.

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Video: Family-Centered Care

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This 15-minute video was prepared for a teleconference held in 2001. Cam Lanier is an RD and the parent of a child with a metabolic disorder. She is the Parent Consultant for the Adolescent Health Transition Project and the LEND program at the University of Washington.

In the video segment Cam Lanier discusses the 8 elements of family-centered care. The handouts that she refers to are included in your materials. If you are not already familiar with the handout “Welcome to Holland” you can read this.

[After the video]: Cam has also included a handout called, “It Makes You Think Harder.” This was written by her son, the brother of her child with special needs. You might want to take a moment to read this perspective of an 8-year-old boy.

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Language...how are your words interpreted?

- "Family unavailable for interview"
- "Compliance is poor"
- "Presented the Chinese food summary, but dad claims the suggestions don't apply"
- "One of my cases is a 5 year old Down's kid"



Another thing to think about is family-centered language. These are examples of professionals' statements that are not very family-centered. Think about how they might be interpreted by the family or by other professionals:

- This was in a hospital chart 4 days in a row, at 1 pm. What the professional did not know was that the family spent most days (and nights) in the room, but left between 12:30 pm and 2 pm for lunch at the individual's request.
- The family was trying, blood glucose levels were improving, but not ideal.
- This was a posting on a listserve; it turned out that the family was from Japan.
- Think about how you would react if this statement was made about your child.

9

Family-centered Language

"...When we recognize that people with disabilities are people first, we can begin to see how people with disabilities are more like people without disabilities than they are different."

Kathie Snow, 1998



Kathie Snow has written about using "People-First Language." Some of her writing is in your handout material.

Does anybody have any thoughts about this statement? What do you think it means?

Some people view it as, "I am defined by who I am, not by what my disability is."

Kathy Snow says: "My son Benjamin, is 11 years old. He loves the Lone Ranger, ice cream, and playing on the computer. He has blonde hair, blue eyes, and cerebral palsy. His disability is only one small piece of his life."

**Family-centered Language:
"People-first language"**

- Focus on the individual, not the disability; do not refer to the disability unless it's relevant
- Avoid labeling people: "a Down's kid" vs. "a child who has Down syndrome"
- Emphasize abilities not limitations: "confined to a wheelchair" vs. "uses a wheelchair"
- Avoid negative or sensational descriptions (achieved a near-normal life despite suffering from...)
- Avoid using "normal" to describe people without disabilities

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- "When I introduce myself to people, I don't tell them I'll never be a prima ballerina. I focus on my strengths, not on what I can't do."

- Labeling is demeaning and doesn't reflect a person's individuality or equality...and does not convey respect. Other examples from Kathie Snow: A parent of a child who wears glasses doesn't say, "My

child is myopic". A person with a medical diagnosis of cancer doesn't say "I am cancerous."

- I don't say, "My son can't write with a pencil," I say, "My son uses a computer to write."
- Keep the disability in perspective. Avoid "making somebody a victim" (e.g., avoid "she suffers from Down syndrome" or "he is a tragic victim of blindness"). Avoid making people "superheroes."
- Instead of "normal" use "typical" or "without disability" or "without diabetes" etc.

Arguments against person-first language (& some rebuttal) [these discussion points may or may not come up; use them as time allows and depending on the audience]

"But we use non-person first language for things that aren't related to disability...you wouldn't say 'the person who provides nutrition services' or 'the person who grandmothers'." – It is appropriate for society to categorize people without person-first language in some cases, but not when referring to disabilities. Disabilities are not defining characteristics in which a profession (e.g., the nutritionist v. the person who provides nutrition services) or a role in society (the grandmother v. the person who grandmothers).

"We call people patients all the time...but that's what they are when they are in the hospital, right?" – This is often a judgment call. If you are working in a hospital, the people who are receiving the medical care are indeed patients. For some people, this "okays" the use of the term patient. Other people prefer to use a different term (the client's name?) when referring to an individual, reserving the use of "patient" to refer to a general group of people.


"But this is how we've always said it; nobody else uses that kind of language." – stereotypes die slowly

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People-first Language

Change the following from "language to avoid" to "people-first language"

- the handicapped
- normal kid
- he is autistic
- he's one of my cases
- a quadriplegic
- she is learning disabled
- a victim of epilepsy



Ask participants to "fix" the terms on this slide.

Suggested responses:


- People with disabilities
- Child who is developing typically
- He has autism
- I see him in clinic
- Person with quadriplegia
- Person with a learning disability
- Person with epilepsy

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HIPPA and the Privacy Rule

Guidelines for protection of patient privacy and information management:

- The Health Insurance Portability and Accountability Act of 1996 (HIPAA)
- Department of Health and Human Service's "Standards for Privacy of Individually Identifiable Health Information" regulation (Privacy Rule)




Most practitioners are aware of HIPPA, but some, especially those in community settings may not be.

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HIPPA and the Privacy Rule

- Patients must have access to their medical information
- A written consent must be completed before medical information is released
- More information:
 - <http://www.hhs.gov/ocr/hipaa>
 - <http://aspe.hhs.gov/admsimp>




Can you think of how this might have an impact on your practice?

Sharing information with other health care providers

Sharing information with school staff, other people involved in a child's life

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Barriers to Family-centered Care





We'd like to discuss some of the barriers to family-centered care. What barriers have you identified? Is family-centered practice valuable enough to figure out how to overcome those barriers? What are some strategies you have tried? Has anyone had the experience of saving time in the end because of increased trust, "buy-in," after the initial investment?

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Barriers to Family-centered Care

- TIME!
- "But we've always done it this way"
- Agency policies are not family-centered
- Regulations are prohibitive


These are some barriers that we came up with...any ideas for solutions?

(the participants do not have these answers in their handout)

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Case Study 1: Harold

- Harold is a 5 year old who requires a g-tube to meet his nutrient needs
- Was tolerating the standard pediatric formula
- Family began making blenderized formula (formula, whole milk, vegetables, egg) because they wanted to provide “real food.”
- RD told family: Harold’s nutrient needs are being met by his formula, and he doesn’t need the extra food. You should just use the prescribed formula.




The next few slides discuss 2 case examples. You’ll be asked to identify “what went right”...where family-centered care was practiced, and “what went wrong”...where care was not family-centered...and how it could be improved.

This is Harold.

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Case Study 1: What went right?




Ask participants to identify “what went right?”

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Case Study 1: What went right?


- Harold’s family was connected to appropriate health care services
Element #4 – appropriate policies and programs to meet the needs of families
- Harold’s family communicated with service providers
Element #2 – Facilitation of parent/professional collaboration
- Harold’s family cared about his nourishment



These are some suggested “right” responses. (the participants do not have these answers in their handout)

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Case Study 1: What went wrong?




Ask participants to identify “what went wrong?”

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Case Study 1: What went wrong?

- Ignored Element #2:
Facilitation of parent/ professional collaboration at all levels of health care
- Ignored Element #3:
Sharing of unbiased and complete information with parents about their child’s care on an ongoing basis in an appropriate and supportive manner
- Told family what to do instead of developing a plan together



These are some suggested “wrong” responses. (the participants do not have these answers in their handout)

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Case Study 1: Harold

RD realizes need for collaboration, and explains concerns about the homemade formula:

- raw egg is unsafe
- nutrient composition may not meet needs
- can have problems with contamination
- can have problems with tube clogging because of viscosity of formula



This is what happened...

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Case Study 1: Harold

Harold's parents would like to use the home-prepared formula, if possible. RD works with family to make it possible:

- Raw egg is unsafe; they agree to stop using it
- Recipe is adjusted to meet Harold's nutrient needs
- Family will watch for clogging problems and communicate them to RD



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Case Study 2: Martina

- Martina is a 2 year old with a rare disorder
- Clinician thought that Martina's family would benefit from the support that a mentor family could provide
- Clinician asked a mentor family to contact Martina's family



Now, Martina...

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Case Study 2: What went right?



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Case Study 2: What went right?

- Recognized Element #7: *Encouragement and facilitation of parent-to-parent support*



(the participants do not have these answers in their handout)

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Case Study 2: What went wrong?



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Case Study 2: What went wrong?



- Ignored Element # 5: *Recognition of family strengths and individuality and respect for different methods of coping*
- Shared medical information without family's consent



(the participants do not have these answers in their handout)

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Case Study 2: Martina



- Martina's family was upset by the unsolicited phone call
- The clinician decided to implement a new policy:
 - Offer phone call from mentor family
 - If call is accepted, obtain signed release of information
 - If call is declined, offer at a subsequent visit



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Further thought...



- Give an example of a time you practiced family-centered care
- Give an example of care you've received that was not family-centered...what could the clinician have done differently?
- How can you improve your practice?

