

## **Nutrition for Children with Special Health Care Needs**

### **Module 6: Putting It All Together ... developing a family-centered plan**

## Pre Test

This Pre Test contains 8 multiple-choice questions. It is intended to provide you with some information about material that might require particular attention.

### QUESTION 1

True or False: The following is an example of a measurable outcome: Jessica's weight-for-length will remain between the 10th and 50th percentiles for the next 6 months.

- a. true
- b. false

### QUESTION 2

The answer to the previous question was true. Jessica's weight-for-length will remain between the 10th and 50th percentiles for the next 6 months is a measurable outcome. Why is it a measurable outcome?

- a. because a specific growth pattern is described
- b. because a time period is specified
- c. all of the above
- d. none of the above

### QUESTION 3

Is the following nutrition outcome measurable? Franklin's feeding problems will be addressed in the next 6 months.

- a. Yes, because a time period is specified
- b. Yes, because the outcome describes what will happen and when it will happen
- c. No, because "feeding problems will be addressed" is too general
- d. No, because 6 months is not enough time to address a feeding problem

### QUESTION 4

Which of the following is NOT an example of an element of family-centered care incorporated into practice?

- a. Therapists at the public health department are writing a grant to fund the development of a feeding team. They have asked Jeremy's father to be a parent consultant for the project.
- b. Samantha needs a feeding tube. The RD and physician met with her family, described all of the options and then explained why they selected the type of tube that will be placed.
- c. The RD at the local health department is aware of local and state programs that provide services and/or funding and provides this information to families as needed.

- d. None of the above; they are all examples of family-centered practice.

#### QUESTION 5

Which of the following is NOT an example of an element of family-centered care incorporated into practice?

- a. When Melanie was diagnosed with autism, her family wanted to meet families with children with autism. Richard's family did not. Their physician recognized that the families were different, and provided appropriate support to each family.
- b. Because her practice was small, one RD found it difficult to introduce families with similar disorders. Recognizing the importance of family-to-family support, she found resources for parent support services in her state and referred families to these services.
- c. Jessica's naptime was 1-2 pm, the hour that the WIC RD set aside to see children with special health care needs. The WIC RD adjusted her schedule on days Jessica needed to be seen.
- d. None of the above; they are all examples of family-centered care.

#### QUESTION 6

Which of the following interventions is complete, as part of a plan to address the following outcome for Kenny, a 11-year old who is overweight?

Nutrition Outcome: Kenny will maintain his current weight until his BMI-for-age is at the 85th percentile.

- a. Kenny will eat fewer foods at meal and snack times.
- b. Kenny will eat a piece of fruit instead of a cookie or treat at 5 morning snacks per week.
- c. Kenny will eat fruit instead of cookies.
- d. Kenny will consume fewer than 2000 kilocalories per day.

#### QUESTION 7

Nutrition Outcome: Sylvia's estimated calcium needs will be met by her next clinic visit.

This intervention is not very strong. Which of the following statements is better?

- a. Sylvia's family will offer 8 ounces of milk at breakfast, lunch and dinner each day.
- b. Sylvia will consume more calcium-rich foods (milk, yogurt, cheese) each day.
- c. Sylvia's family will give her a calcium supplement each day.
- d. Sylvia's family will give her a calcium supplement and offer more calcium-rich foods each day.

## QUESTION 8

The strongest intervention in the previous question was a. Sylvia's family will offer 8 ounces of milk at breakfast, lunch and dinner each day. Why was this the best response?

- a. Because calcium from food is absorbed better than calcium from a supplement
- b. Because Sylvia's family might not have enough money to purchase a calcium supplement
- c. Because that response included the amount of calcium Sylvia should consume (three 8-ounce servings of milk)
- d. Because that response specified how and when the intervention would be carried out

## Introduction

After completing this module, you will have the skills and resources to:

- Use growth, medical, and intake data to formulate a nutrition care plan
- Incorporate measurable outcomes for evaluation of the plan
- Include community services and programs in a nutrition care plan

Nutritional care is a process:

- Assessing status
- Identifying problems/needs
- Planning objectives
- Implementing interventions
- Evaluating outcomes

Modules 1 through 4 focused on assessing nutritional status and identifying problems. Interventions related to specific problems (for example, constipation and diarrhea) were also discussed.

Module 5 presented some of the resources that might be useful to help families put nutrition recommendations into practice.

This Module looks more closely at the development of a nutrition care plan. Although each nutrition intervention must be tailored to the needs of the individual and his/her family, an effective nutrition care plan has interventions that are:

- Specific – who, what, where, how are defined
- Outcome-based – criteria for determining whether or not the intervention was effective are outlined
- Family-centered – the family is a partner in the health care team providing care and is integral in developing the intervention

## Section 1: Family-centered Practice

This section reviews some of the principles that are critical to providing family-centered care.

### Elements of Family-centered Care

Eight “Elements of Family-centered Care” were presented in a 1987 document. These are listed in the several pages, with examples of how they might be incorporated into an RD’s clinical practice.

#### 1. Recognition that the family is the constant in the child’s life while the service systems and personnel within those systems fluctuate

Jorge, a child with myelomeningocele, has many people involved in his medical care:

- Primary care physician
- Family resource coordinator
- Speech therapist
- Case manager
- Occupational therapist
- WIC nutritionist
- Physical therapist
- Interpreters
- Teachers
- Public health nurse
- School nurse
- Early intervention nutritionist
- Social worker
- Home health care assistants

The case manager and the family have developed a plan to minimize the number of appointments that the family must attend. During at least two of the public health nurse’s home visits each year, a telephone discussion between the early intervention nutritionist, Jorge’s mother, the public health nurse, and the interpreter addresses nutrition-related issues. Jorge has in-person appointments with the nutritionist two times per year.

#### 2. Facilitation of parent/professional collaboration at all levels of health care: care of an individual child; program development, implementation, and evaluation; and policy formation

Julia’s father was encouraged to be very involved with the development of Julia’s medical care plan. This led to an interest in improving the therapy program that she attended, and he became active in fundraising for the center. As he spent more time at the center, he recognized a need for an interdisciplinary feeding team, and worked with the therapists to develop the team. Today, he is the parent consultant for the therapy center and is involved in expanding services for children with special health care needs at the state level.

#### 3. Sharing of unbiased and complete information with parents about their child’s care on an ongoing basis in an appropriate and supportive manner.

Samantha needed a feeding tube. The RD and physician met with Samantha's family and described all of the options. They presented risks and benefits for each type of feeding tube. As a group, they decided which type of tube to place and developed a feeding regimen that fit into the family's schedule.

**4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families**

The RD at the local public health department is aware of local and state programs that provide services and/or funding. He has a good relationship with the social worker and can contact her for more information about resources. He attends the local interagency coordinating council (ICC) meetings, where decisions about early intervention services are made.

**5. Recognition of family strengths and individuality and respect for different methods of coping**

When Melanie was diagnosed with autism, her family wanted to meet as many families with children with autism as soon as possible. Richard's family, however, did not want to meet other families right away. Their physician recognized that the families were coping with the diagnosis in different ways, and provided appropriate support to each family.

**6. Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care delivery systems**

Cameron has a metabolic disorder that requires the use of a specialized formula. As he got older, the RD and his family helped him to learn the skills needed to manage his disorder. When he was in high school, ordering the formula became his responsibility. He and his family wrote a "script" that included all of the necessary information.

**7. Encouragement and facilitation of parent-to-parent support**

Because her practice was small, one RD found it difficult to introduce families with similar disorders. Recognizing the importance of family-to-family support, she found resources for parent support services in her state and referred families to these services.

**8. Assurance that the design of health care delivery systems is flexible, accessible, and responsive to family needs**

In the few days after each nutrition visit, Rebecca's mother would think of feeding-related questions for the RD. She and the RD agreed that the questions could be sent by email, and would be answered within a week. This way, Rebecca's mother could ask questions as she thought of them, and the RD could answer them when it was convenient. Rebecca's mother used this service judiciously. These email messages became part of Rebecca's medical record.

Elements of Family-centered Care from: Shelton, T.L., Jeppson, E.S., and Johnson, B.H. (1987). *Family-centered care for children with special health care needs*. Washington, D.C.: Association for the Care of Children's Health.

### **Principles of Family/Professional Collaboration**

In a 1993 publication, seven principles of family/professional collaboration are described.

#### **Family/professional collaboration:**

- Promotes a relationship in which family members and professionals work together to ensure the best services for the child and the family
- Recognizes and respects the knowledge, skills, and experience that families and professionals bring to the relationship
- Acknowledges that the development of trust is an integral part of a collaborative relationship
- Facilitates open communication so that families and professionals feel free to express themselves
- Creates an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored
- Recognizes that negotiation is essential in a collaborative relationship
- Brings to the relationship the mutual commitment of families, professionals, and communities to meet the needs of children with special health care needs and their families

### **HIPAA and the Privacy Rule**

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Department of Health and Human Service's "Standards for Privacy of Individually Identifiable Health Information" regulation (Privacy Rule) provide specific guidelines for protection of patient privacy and management of information.

The new regulations require that patients have access to their medical information. Also, a written consent must be completed before medical information is released.

Health care organizations must be in compliance with these regulations by April 14, 2003 (or April 13, 2004, for small health plans).

More information about HIPAA can be found on the HHS website:  
<http://www.hhs.gov/ocr/hipaa> and <http://aspe.hhs.gov/admsimp>



## Section 2: Measurable Outcomes

An effective nutrition care plan includes goals (or outcomes) and interventions.

The goals or outcomes are the “results” ... what will happen as a result of the intervention. Examples of outcomes include:

- Weight-for-age between the 10th and 50th percentiles for age
- Intake of foods that have crunchy textures
- Intake that provides 15 g fiber per day

The interventions are the “actions” ... what will be done differently? Examples of interventions include:

- Family will offer energy-dense foods at meal and snack times
- Family will offer 2 foods with crunchy textures at each meal
- Whole grain bread will be used instead of white bread

This section examines nutrition outcomes. Interventions are reviewed in Section 3, Formulating a Nutrition Care Plan.

Some nutrition outcomes are long-term outcomes... for example, weight maintenance for an adolescent or an adequate calcium intake for a child between 4-8 years of age.

Other nutrition outcomes are short-term...for example, re-gain of weight lost during an acute illness or energy provided by a tube feeding when the transition to oral eating is made

Nutrition outcomes should be:

- Measurable
- Specific
- Evaluated

### An example of a care plan:

Carla is a 2-year old with cerebral palsy. Oral-motor delays make it difficult for her to eat. Over the past few months, Carla’s rate of weight gain has slowed, and laboratory measures indicate that she is malnourished. The nutritionist has identified problems that should be addressed and incorporated these as 2 goals in Carla’s medical plan:

- Carla will be well-nourished
- Carla’s feeding problems will be addressed

These goals are too general to be effective. How will the clinician determine whether or not the interventions are effective?

The clinician re-thought the goals, and changed them so that they could be measured:

1. Carla's prealbumin will be in the normal range in 6 weeks
2. Carla's weight-for-length will be at or above the 10th percentile in 6 months
3. Carla will be referred to a feeding therapist for further assessment and intervention by her next clinic visit

Then, Carla's RD formulated a set of interventions that would help to make the goals attainable:

- **GOAL 1: Carla's prealbumin will be in the normal range in 6 weeks**
- **GOAL 2: Carla's weight-for-length will be at or above the 10th percentile in 6 months**

For these goals to be met, the RD recognized that Carla's energy and protein needs would have to be met. She estimated that Carla would need, on average, an additional 200 kilocalories and 10 grams protein per day.

**Intervention: One food with added energy and protein will be offered at each meal and snack.** A list of foods and additives that add 25 kilocalories and 2 grams protein each was reviewed with Carla's mother. Specific energy and protein goals were not discussed. Instead, Carla's mother agreed to add one food per meal and snack.

**Evaluation: Carla's prealbumin will be in the normal range in 6 weeks.** Blood was drawn 6 weeks after the nutrition interventions were started. Carla's prealbumin was in the normal range.

The nutrition outcome was modified: Carla's prealbumin and albumin will be in the normal range in 6 months. Because the intervention was working, it did not change.

**Evaluation: Carla's weight-for-length will be at or above the 10th percentile in 6 months.** After 6 months, Carla's weight-for-length was at the 10th percentile. Her rate of weight gain was appropriate, and her weight-for-age and length-for-age continued "in channel." (Length-for-age was at the 25th percentile, and weight-for-age was between the 5th and 10th percentiles; both parameters followed the general shape of the growth curve.)

The nutrition outcome was modified: Carla's weight-for-age will continue between the 5th and 25th percentiles for age, length-for-age between the 10th and 50th percentiles, and weight-for-length between the 10th and 50th percentiles for age. Again, the nutrition intervention was effective, so this "action" did not change.

- **GOAL 3: Carla will be referred to a feeding therapist for further assessment and intervention by her next clinic visit**

**Intervention: The nutritionist will contact Carla's primary care physician to initiate the referral.** The RD also provided Carla's mother with the names and contact information for therapists in their community. Release of information consents were signed by Carla's mother, permitting communication of medical information between the RD and Carla's primary care physician.

**Evaluation:** At Carla's first follow-up visit, her mother reported that a referral to a feeding therapist had been made and that the first appointment went well.

The outcome was modified: Carla will receive feeding therapy. The intervention was changed as well: The nutritionist will communicate with the feeding therapist as needed. Again, a consent for release of information was needed and obtained.

The next few pages present several outcomes that are not measurable. In the text box, type the changes you would make so that they could be measured. Then, click the "Submit" button to read a short explanation and the suggested response.

### **Claudia**

Claudia is a 16-year old with Prader-Willi syndrome. Her BMI-for-age is now greater than the 95th percentile.

#### **Nutrition Outcome: Claudia will lose weight.**

In the text box, type the changes you would make so that they could be measured. Then, click the "Submit" button to read a short explanation and the suggested response.

RESPONSE: Technically, the original outcome is measurable. It is not very useful, however. If Claudia loses 20 grams in 6 months, was the intervention effective? Or, if Claudia does not lose any weight in 2 weeks, was the intervention ineffective? What if Claudia loses too much weight?

If the goal is for Claudia to lose weight, the following statement would be a more measurable outcome: **Claudia will lose 1 kilogram in 2 months.** The amount of weight to be lost is defined, and a time period is specified.

After 2 months, Claudia's weight increased. Discussion between the RD, Claudia, and her mother indicated that the nutrition intervention was not being carried out. The intervention was modified, and the nutrition outcome remained the same.

### **Aaron**

Aaron is an 8-year old with Down syndrome. In nine months, Aaron has gained 7 kilograms. His BMI-for-age is now at the 95th percentile.

#### **Nutrition Outcome: Aaron will maintain a healthy weight.**

In the text box, type the changes you would make so that they could be measured. Then, click the "Submit" button to read a short explanation and the suggested response.

RESPONSE: Although a healthy weight is the desired overall result, the original outcome is not useful in a nutrition care plan. What weight is healthy? Should he not gain any weight for a period of time? How does his stature affect this goal? How will Aaron's family know whether or not the intervention was successful?

The following statement would be a more measurable outcome: Aaron will maintain his current weight (32 kilograms) until his BMI-for-age is at the 75th percentile.

Aaron returned for follow-up every 4 months. His weight remained between 32 to 34 kilograms for several visits, and his family and clinician agreed that the intervention was appropriate. After one year, he has grown tall enough that his BMI-for-age is at the 75th percentile, and it is time to develop a new outcome.

### **Matthew**

Matthew is a 3-year old with autism. His intake is very limited; he eats yogurt, potatoes, carrots and drinks about 56 ounces of milk each day. His family is trying to expand the number of foods that Matthew will eat.

#### **Nutrition Outcome: Matthew will eat more foods.**

In the text box, type the changes you would make so that they could be measured. Then, click the "Submit" button to read a short explanation and the suggested response.

RESPONSE: The original outcome does not provide enough detail. Will the intervention have been successful if Matthew eats more food in general? What if he simply drinks more milk? What is the timeline? If Matthew does not eat more foods by next week, was the intervention a failure?

The following statement would be a more measurable outcome: Matthew will eat three new foods in the next four months.

After four months, Matthew is eating two new foods. His family is pleased with this progress, and the nutrition intervention is continued.

### **Sheldon**

Sheldon is a 9-month old with Prader-Willi syndrome. His weight-for-age, length-for-age, and weight-for length are below the 5th percentile. Weight-for-age had been at the 10th percentile until 6 weeks ago. He lost some weight at that time because of illness.

Because he has hypotonia, it may not be reasonable to expect his weight-for-length to be in the "upper percentiles" (e.g., 75th to 90th), but below the 5th percentile is not appropriate.

#### **Nutrition Outcome: Sheldon's weight-for-length will increase.**

In the text box, type the changes you would make so that they could be measured. Then, click the "Submit" button to read a short explanation and the suggested response.

RESPONSE: The original outcome does not provide enough detail. Is an increase to slightly above the 5th percentile appropriate? What about an increase to the 95th percentile? What is the timeline? If Sheldon's weight loss was a result of an illness, and he regains weight quickly, is it appropriate to encourage even more weight gain?

The following statement would be a more measurable outcome: Sheldon's weight-for-length will increase to above the 5th percentile in 6 weeks. At that time, his growth will be re-evaluated.

After 6 weeks, Sheldon is weighed and measured. His weight-for-age is again at the 10th percentile, and weight-for-length is near the 25th percentile.

To prevent excessive weight gain, the nutrition intervention is stopped and a new outcome is developed: Sheldon's weight-for-age and weight-for-length will continue between the 10th and 50th percentiles. His growth will be evaluated every 2 months.

## Section 3: Formulating Nutrition Interventions

The nutrition care plan includes interventions...the “actions”

From Section 1:

Examples of nutrition interventions include:

### Outcome/Goal

Weight-for-age between the 10th and 50th percentiles

Intake of foods with crunchy textures

Intake that provides 15 grams fiber per day

### Interventions

Family will offer energy-dense foods at meal and snack times

Family will offer 2 foods with crunchy textures at each meal

Family will offer whole grain bread instead of white bread

An effective intervention is specific. It specifies:

- **What** will be done to achieve the desired outcome
- **How** it will be carried out
- **Who** will do it
- **When** it will happen
- And, when appropriate, **Where** it will happen

Take a closer look at the examples:

**Family** will offer energy-dense foods at meal and snack times.

**Family** will offer 2 foods with crunchy textures at each meal

**Family** will offer whole grain bread instead of white bread at meals and snacks

The few pages present several interventions that are incomplete or inappropriate.

In the text box, type the changes you would make so that the intervention is stronger. Then, click the “Submit” button to read a short explanation and the suggested response.

### Aaron

Aaron is an 8-year old with Down syndrome. In 9 months, Aaron has gained 7 kilograms. His BMI-for-age is now at the 95th percentile.

Outcome: Aaron will maintain his current weight (32 kg) until his BMI-for-age is at the 75th percentile.

**Intervention: Aaron will eat foods with fewer kilocalories.**

In the text box, type the changes you would make so that the intervention is stronger. Then, click the “Submit” button to read a short explanation and the suggested response.

RESPONSE: This intervention is not specific. Fewer kilocalories will help Aaron to maintain his current weight, but the intervention does not provide enough information about how to carry it out to make it effective.

A more effective intervention is: Aaron's family will substitute foods with fewer kilocalories for energy-dense foods. (nonfat milk instead of whole milk, reduced fat salad dressing and mayonnaise instead of regular, artificially sweetened juice or diluted juice for regular juice)

Aaron's family and the RD developed the following interventions:

- Aaron's family will substitute foods with fewer kilocalories for energy-dense foods at meal and snack time. (nonfat milk instead of whole milk, reduced fat salad dressing and mayonnaise instead of regular, artificially sweetened juice or diluted juice for regular juice)
- Aaron will walk to school with his older brother 3 days each week

### **Matthew**

Matthew is a 3-year old with autism. His intake is very limited; he eats yogurt, potatoes, carrots, and drinks about 56 ounces of milk each day. His family is trying to expand the number of foods that Matthew will eat and would like him to eat vegetables.

Outcome: Matthew will eat three new foods in the next four months.

### **Intervention: Matthew will be offered vegetables.**

In the text box, type the changes you would make so that the intervention is stronger. Then, click the "Submit" button to read a short explanation and the suggested response.

RESPONSE: This intervention describes what will be done, but it does not specify who will carry it out, or when or where it will happen.

A more effective intervention is: Matthew's family will offer vegetables to Matthew at each dinner and provide praise when he touches, tastes, or eats the vegetable.

Matthew's family has a good relationship with his preschool teachers, and incorporated this nutrition goal into his educational plan. His teachers also offer a vegetable (from the list of vegetables provided by Matthew's family) at lunch each day. They praise Matthew when he touches, tastes, or eats the vegetable.

### **Sheldon**

Sheldon is a 9-month old with Prader-Willi syndrome. His weight-for-age, length-for-age, and weight-for-length are below the 5th percentile. He has lost some weight with a recent illness.

Outcome: Sheldon's weight-for-length will increase to above the 5th percentile in 6 weeks. At that time his growth will be re-evaluated.

**Intervention: Sheldon's family should offer infant formula that is concentrated to provide more energy and protein to Sheldon.**

In the text box, type the changes you would make so that the intervention is stronger. Then, click the "Submit" button to read a short explanation and the suggested response.

RESPONSE: Again, this intervention is not specific enough.

A more effective intervention: Sheldon's family should offer infant formula that is concentrated to provide 24 kilocalories per ounce. Sheldon's family should receive a written recipe for this special formula.

After 6 weeks, Sheldon's weight-for-length was between the 5<sup>th</sup> and 10<sup>th</sup> percentiles. The RD recommended that Sheldon's family continue to concentrate his formula, and his growth was monitored every 6 to 8 weeks as his intake of solid foods increased and formula decreased. Milk was introduced at about 13 months of age, and gradually replaced formula. Sheldon's growth continued appropriately.

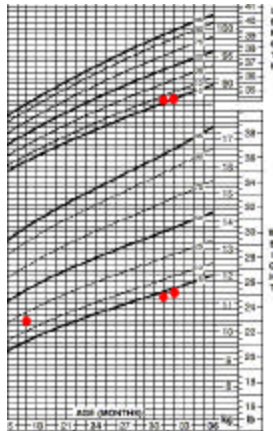
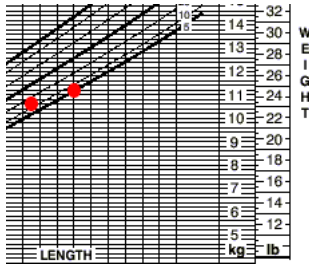


## Post Test

### Scenario 1

Darren is a 32-month old with developmental delay and reflux that is treated with medication. He has a seizure disorder, and takes anticonvulsant medications. Darren receives physical, occupational, and vision therapy, in addition to seeing a feeding therapist once per month. The feeding therapist gives recommendations to the family at each visit, based on Darren's progress. He is very sensitive to textures and only eats smooth, pureed foods.

Darren takes four 4-ounce bottles of soy milk and eats three meals (pureed fruits, vegetables, meat) each day.



Darren's growth chart:

- Length-for-age (top) is at the 5th percentile and weight-for-age (bottom) is below the 5th percentile.
- Weight-for-length is between the 5th and 10th percentiles; 15 months ago weight-for-length was between the 10th and 25th percentiles.

### QUESTION 1

Based on this information, what concerns do you have about Darren's nutritional status?

- a. growth
- b. dietary intake
- c. feeding skills
- d. all of the above

### QUESTION 2

You decide to present each of your 3 concerns to Darren's family, and then get more information to help you prioritize and develop a nutrition care plan with the family's input. What statement about growth do you make to Darren's family?

- a. Darren's weight-for-length has decreased over the past 15 months. Although his growth pattern may not be the same as typically-developing children, this decrease is a concern.
- b. Darren's weight-for-length has decreased over the past 15 months. This is concerning; a more appropriate weight-for-length would be at the 75th percentile.

- c. Darren's weight-for-length has decreased over the past 15 months, but that is okay. Children with developmental delay grow more slowly than children who are developing typically.
- d. Darren's decrease in weight-for-length is concerning, but as long as his length-for-age continues "in channel," his growth is not concerning.

### QUESTION 3

Because you are concerned about Darren's growth, you want to determine the amount of energy, protein, vitamins and minerals provided by his food pattern. You ask his family to keep a 5-day food record.

You want to provide Darren's family with some suggestions at this visit (instead of putting everything off until the food record is received). To do this, you want to get a general idea about the types and amounts of foods that Darren is eating, you decide to use another tool. Which of the following tools will provide general information about Darren's intake right now?

- a. Food Frequency Questionnaire
- b. feeding history
- c. 24-hour diet recall
- d. none of the above

### QUESTION 4

Darren takes four 4-ounce bottles of soy milk and eats three meals (pureed fruits, vegetables, meat) each day. He is a 32-month old with developmental delay and reflux that is treated with medication. Darren has a seizure disorder, and takes anticonvulsant medications. He is very sensitive to textures and only eats smooth, pureed foods.

What concerns do you have about Darren's dietary intake?

- a. 4 bottles and 3 meals is inappropriate; Darren should be offered food or milk only 6 times per day.
- b. Soy milk is inappropriate; Darren should be offered cow's milk.
- c. There is a potential medication-nutrient interaction with the anti-reflux medication and potassium.
- d. There is a potential medication-nutrient interaction with the anticonvulsant medication and vitamin D.

You ask Darren's mother why soy milk is offered. She explains that they suspect Darren has lactose intolerance. Darren's father has lactose intolerance, and Darren has symptoms that are similar to his father's when he drinks milk.

You explain your concerns about feeding skills to Darren's family. Children who have problems with reflux can develop aversions to feeding, even when the reflux is treated. Darren's sensitivity to texture is also a concern.

Darren's family and therapists are pleased with the progress he is making, and the system that is in place seems to be effective. You tell Darren's family that you are willing to collaborate with his other therapists, and can provide information about the types of foods that will meet Darren's nutrient needs.

### QUESTION 5

After presenting your concerns to Darren's family, you develop a nutrition care plan with their input.

**Concern 1: Darren's weight-for-length has decreased; you feel he needs more energy from food.**

Which of the following nutrition outcomes best addresses this concern?

- Darren will eat energy-dense foods for the next 6 months.
- Darren's weight-for-length will increase to 10-25th percentiles in the next 6 months
- Darren's weight-for-length will increase to 10th-25th percentiles.
- Darren's weight-for-age will be in the normal range in the next 6 months.

### QUESTION 6

**Nutrition Outcome: Darren's weight-for-length will increase to between the 10th and 25th percentiles in the next 6 months.**

Several nutrition interventions were developed for this outcome:

- Darren's family will continue to offer small, frequent meals and snacks (6-7 per day) to Darren
- Darren's family will purchase the most energy-dense soy milk available. (The RD reviewed label-reading with his family.)

Which of the following nutrition interventions is most appropriate?

- Darren's family will purchase soy milk that is fortified with calcium and vitamin D.
- Darren should take a multiple vitamin with iron supplement.
- Darren's family will add approximately 50 kilocalories to each meal.
- Darren's family will increase the energy and protein density of foods offered to Darren.

### QUESTION 7

**Concern 2: Darren's calcium and vitamin D intake may be inadequate because of the use of anticonvulsants and because he may not be using a soy milk that is fortified with vitamin D and calcium.**

Which of the following nutrition outcomes best addresses this concern?

- a. Darren should take a multiple vitamin with iron supplement.
- b. Darren should take a calcium and vitamin D supplement every day.
- c. Darren's estimated calcium and vitamin D needs will be met.
- d. Darren's estimated calcium and vitamin D needs will be met by his next clinic visit.

**Nutrition Outcome: Darren's estimated calcium and vitamin D needs will be met by his next clinic visit.**

The intervention for this outcome was developed:

The RD estimated Darren's calcium and vitamin D needs. Because the mineral and vitamin composition of soy milk is not listed on the label in milligrams per serving, she knew that providing his family with a goal intake of calcium and vitamin D (e.g., 500 mg calcium and 5 ug vitamin D) would not be helpful. She provided the family with information they could use to estimate the adequacy of Darren's calcium and vitamin D intake.

Since Darren's drank 16 ounces of soy milk per day, she estimated that his calcium and vitamin D needs could be met if each 8-ounce serving provided 30% of the Daily Allowance. (This is the terminology on the soy milk label.)

**Concern 3: Darren's feeding skills put him at nutritional risk.**

The RD agreed that Darren's problems with feeding were being addressed, but wanted to make it clear that these skills placed Darren at nutritional risk. Feeding skills were included in his nutrition care plan:

**Nutrition outcome: Darren's feeding skills will continue to be addressed by a feeding therapist until no further therapy is needed.**

Intervention: The RD will be available for consultation to the feeding therapist as goals are developed.

## QUESTION 8

Which of the following is NOT an example of an element of family-centered care incorporated into clinical practice?

- a. Harold's feeding tube leaked, and his skin was irritated. His mother talked with a friend whose son had a different kind tube. She asked the RD and Harold's physician about this tube, and they agreed with a change to a new tube.
- b. Martina's family did not express a desire to meet other families with children with Martina's diagnosis. The clinician thought that they didn't understand all of benefits that a "mentor" family could provide, so initiated contact between Martina's family and a "mentor" family.
- c. The WIC RD saw children with special health care needs between noon and 3 pm. Janine's naptime was always 1:00-2:30 pm, making nutrition appointments difficult. Janine's mother relayed this to the RD and the schedule was revised on days Janine needed to be seen.
- d. None of the above; they are all examples of family-centered practice.

## For More Information about Developing a Plan

### **Providing Nutrition Services for Infants, Children and Adults with Developmental Disabilities and Special Health Care Needs: Position Paper.**

Cloud HH, Posthauer ME. Providing nutrition services for infants, children and adults with developmental disabilities and special health care needs. *J Am Diet Assoc.* 104: 97-107. This position paper documents why nutrition services are essential and gives factors to consider when providing and planning nutrition services. It is available on-line to ADA members at:

[http://www.eatright.org/Public/GovernmentAffairs/92\\_18463.cfm](http://www.eatright.org/Public/GovernmentAffairs/92_18463.cfm)

### **Nutrition in Comprehensive Program Planning for Persons with Developmental Disabilities: Position Paper.**

Lucas BL, Blyler EM. Position of the American Dietetic Association: Nutrition in comprehensive program planning for persons with developmental disabilities. *J Am Diet Assoc* 97(2): 189-193. This position paper provides guidance regarding the provision of clinical nutrition services for persons with developmental disabilities and presents program planning recommendations. It is available on-line to ADA members at:

[http://www.eatright.org/Public/GovernmentAffairs/92\\_adap0297b.cfm](http://www.eatright.org/Public/GovernmentAffairs/92_adap0297b.cfm)

**Pediatric Manual of Clinical Dietetics.** Nevin-Follino N, ed. *Pediatric Manual of Clinical Dietetics, 2e.* American Dietetic Association. 2003. This diet manual provides practice guidance for the nutrition care of pediatric patients. The manual is available through ADA's on-line catalog:

[http://www.eatright.org/Public/ProductCatalog/SearchableProducts/104\\_8444.cfm](http://www.eatright.org/Public/ProductCatalog/SearchableProducts/104_8444.cfm).

## For More Information about Family-Centered Care

**Institute for Family-Centered Care.** This non-profit organization is a resource for policy makers, administrators, program planners, direct service providers, educators, and family members. The website includes information about resources related to family-centered care, including publications and videos, newsletters, seminars, and presentations. The website also features a bulletin board to promote discussion about issues related to family-centered care. <http://www.familycenteredcare.org/>.

**Family/Professional Collaboration.** Bishop KK, Woll J, Arango P. *Family/Professional Collaboration.* Department of Social Work, University of Vermont. This 48-page document describes the seven principles of family/ professional partnerships. Available from the Available through the HRSA Information Center <http://www.ask.hrsa.gov> Inventory Code: MCHG017.

**Family Voices.** Family Voices works toward addressing the common challenges that all children with special health care needs face. Their advocacy efforts revolve around three basic principles that the organization believes should be part of health care reform: family-centered care, community-based services, and parent-professional collaboration. The site serves as a national clearinghouse for information and resources. <http://www.familyvoices.org>.

**Family Village.** This easy-to-navigate site describes itself as a global community on the Internet for families of persons who have disabilities. It has a wealth of

information, resources, and web site connections for people with disabilities and their families and service providers. <http://familyvillage.wisc.edu>.