

Nutrition for Children with Special Health Care Needs

Module 1: Growth Assessment



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

The length and height of a child are measured on the same day. The length measurement will be ___ than the height.

- a. Longer *
- b. Shorter
- c. The same

QUESTION 2

A 6-year old girl has contractures of the arms and legs, cannot stand, but can sit upright. Which of the following measurements would be the most appropriate estimator of height?

- a. sitting height *
- b. arm span
- c. mid arm muscle circumference
- d. crown-rump length

QUESTION 3

True or false: Because the CDC growth charts are based on data from healthy children, it is not appropriate to use them with children with special health care needs.

- a. true
- b. false *

QUESTION 4

Measurements should be made with the same method that was used when the growth charts were developed. Thus, a 3-year-old child should be weighed:

- a. in light clothing and shoes
- b. with outer clothing and shoes removed *
- c. fully clothed
- d. dressed, in a parent's arms

QUESTION 5

Children with which of the following conditions are more likely to have short stature than a typically-developing child:

- a. Down syndrome
- b. Prader Willi syndrome
- c. both of the above *
- d. none of the above

QUESTION 6

An infant comes to your clinic with the following information: Weight for age plotted on growth chart <5th percentile. What other information would you want to have?

- a. mother's weight
- b. older brother's weight
- c. length *
- d. head circumference

QUESTION 7

You learn that this infant's length is also less than the 5th percentile for age. Which of the following tools will provide the BEST information about the child's nutritional status?

- a. head circumference
- b. mid-arm muscle circumference
- c. triceps skinfold
- d. weight-for-length percentile *

QUESTION 8

Jack is a 7-year, 10-month old male with myelomeningocele. His physical activity is limited, but he is able to use his arms and shoulders. He is unable to stand, so a stature measurement cannot be taken.

Which alternative to stature is most appropriate?

- a. crown-rump length
- b. arm span *
- c. knee height
- d. triceps skinfold



Introduction

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

- describe techniques to obtain accurate anthropometric data (weight, length, height, and head circumference) for children with special health care needs
- identify guidelines used for growth assessment and understand the origin of these guidelines
- describe the influence of specific conditions on growth
- use appropriate reference data and published information to interpret growth data

Growth information is used in nutritional assessment:

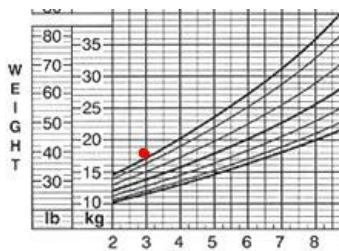
- to compare an individual's growth to the growth of his/her peers
- to evaluate an individual's growth pattern over time

In order for the information to be valuable:

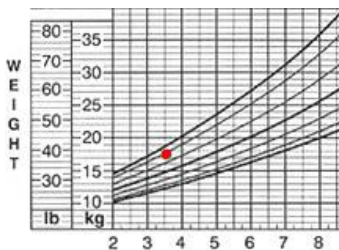
- The measurement must be **accurate**
- The data must be **plotted correctly**
- The **appropriate reference data** should be used for comparison

Take a look at what happens when errors are made:

This child was weighed. His weight was plotted above the 95th percentile for age. He is not overweight. What went wrong?



- 1) He was weighed wearing a coat and a bulky sweater and holding a full bottle
- 2) Age was calculated incorrectly...he is actually 3½-years old, not 3-years old.



After he was re-weighed, in light clothing, and his weight and age were plotted correctly, it became evident that he was growing appropriately. This case is probably an exaggeration of what happens in typical practice, but illustrates the importance of accurate technique and plotting.

Section 1: Measurement Techniques

This section will review the technique for measuring:

- Head circumference
- Weight
- Stature

The following measurements will also be discussed:

- Estimators of stature
- Body composition

Head Circumference

Head circumference is commonly referred to as OFC - occipital frontal circumference. It is generally the last anthropometric parameter to be affected by nutritional status.

1. Equipment:

Use a flexible, non-stretchable measuring tape. Plastic insertion tapes are available; they should be cleaned between uses. Paper tapes are also available. If paper tapes are used, care should be taken not to crease the paper.

2. Child and Positioning:

The child should be standing or sitting in the lap of his/her caregiver. Remove any barrettes or braids in the child's hair.

3. Measurement:

Place the measuring tape around the child's head: just above his/her eyebrows, ears, and around the occipit (the prominence at the back of the head). Pull the tape snugly. Repeat the measurement until two measurements agree to 0.1 cm or 1/16 inch.

Weight

Weight is used to make many important decisions about a child's nutritional status and clinical care plan. It is imperative that accurate weight measurements are made.

It is more important to have an accurate bi-annual weight than an inaccurate monthly weight. Children under the age of 2 years should be measured on a pan- or bucket seat-type scale.



1. Equipment:

Use a calibrated beam balance scale or digital scale with "strain gauge" mechanism that is accurate to 10 grams or 1/4 ounce. A clean cloth or pad is often used in the "bucket" of the scale. The scale should be calibrated before each use to reflect the weight of the cloth or pad.

2. Child and Positioning:

The infant's clothing and diaper should be removed and the infant centered on the scale. Take the measurement when the infant is lying quietly. Although it is possible to estimate an infant's weight by subtracting the weight of the parent alone from the weight of the parent holding the child, this is not recommended. The platform scale used for this type of measurement is typically accurate to 100 grams; weight changes less than 100 grams may be missed.

3. Measurement:

Measure the infant's weight to the nearest 10 grams or 1/4 ounce. Record any conditions that might have interfered with an accurate weight (e.g., infant was moving).

Children over the age of 2 years, who are cooperative and able to stand alone should be weighed using a platform scale.



1. Equipment:

Use a calibrated beam balance scale or a digital scale with "strain gauge" mechanism that is accurate to 100 grams or 1/4 pound. A spring-type bathroom scale should NOT be used... with repeated use, it will not maintain the necessary degree of accuracy.

2. Child and Positioning:

Bulky clothing, outer clothing, and shoes should be removed. (It is best if clothing is standardized; some clinicians have children wear a paper gown for weight measurements.) The child should be centered on the scale's platform, touching nothing.

3. Measurement:

Record the measurement to the nearest 100 grams or 1/4 pound and record any conditions that might have interfered with an accurate weight (e.g., child was moving).

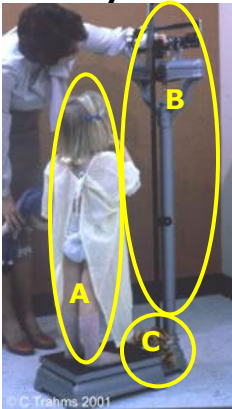
Considerations for children with special health care needs



For children who are too large for the infant scale, but cannot stand, use a platform scale on which a wheelchair can be placed, or a bed scale.

Because these specialty scales are not available in many communities, an alternative is to weigh the child's caregiver holding the child, weigh the caregiver alone, and subtract the caregiver's weight from the weight of both individuals. If this method is used, it is important to note this on the growth chart. If the child can sit independently, use a chair scale.

Identify the error in this picture: Where is proper technique NOT being used?



- The child is wearing light clothing (underclothes and a gown) and no shoes. She appears to be standing still. This is appropriate.
- A beam balance scale is being used to measure this child. This is appropriate.
- Correct! The toy on the scale is inappropriate.*

Stature

Stature (length and height) is measured in two ways:

- recumbent length for the child younger than 24 months
- standing height for children over the age of 24 months

It is important to plot (standing) height measurements on the growth charts for 2 to 20-year olds, because the percentiles are adjusted for the difference between length and height.

Recumbent length is sometimes measured when a child older than 24 months of age is unable to stand. If length is used for a child older than 2 years of age (and thus plotted on the growth charts for 2 to 20-year olds), this should be noted on the chart.



1. Equipment:

Use an infant lengthboard with a fixed headboard and moveable footboard that are perpendicular to the table. The lengthboard should have a measuring tape marked in millimeters, with the zero end at the end of the headboard.

2. Child and Positioning:

Clothing that might interfere (including diaper) is removed.

Two people are required to measure length accurately:

- Person A holds the child's head with the crown against the headboard (Frankfort Plane) and makes sure that the trunk and pelvis are aligned with the measuring device.
- Person B straightens the legs, holding the ankles together with toes pointed directly upward, moves the footboard firmly against the soles of both of the child's feet.

3. Measurement:

The measurement should be made to the nearest 0.1 centimeter.

Children over 2 years of age who are able to stand should be measured standing.



1. Equipment:

Use a measuring board with an attached, movable headboard (stadiometer). If this is not available, use a non-stretchable tape measure attached to a vertical, flat surface (e.g., wall or door jam with no baseboard) and equipment that will provide an accurate right angle to actually take the measurement.

The movable measuring rod that is attached to a platform scale is too unsteady to ensure accurate measurements.

2. Child and Positioning:

The child's shoes, hat, and bulky clothing (e.g., sweater, coat) should be removed and hair styles or hair accessories that might interfere with the measurement should be adjusted.

The child should stand with shoulders level, hands at sides, knees or thighs together, and weight evenly distributed on both feet. Head, back, buttocks, and heels should touch the wall/measuring surface if possible. If this is not possible, two contact points (head and buttocks or buttocks and heels) should touch the wall/measuring surface. The child should look straight ahead with line of vision perpendicular to the body.

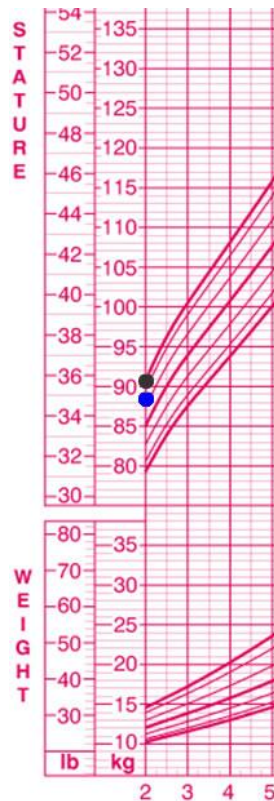
3. Measurement:

The measurement should be made to the nearest 0.1 centimeter.

Length is not equal to height—take a look at this example:

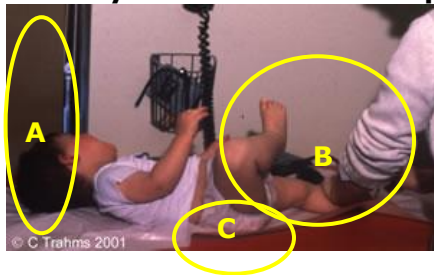
This 2-year old child's length (91.1 cm) was plotted on a growth chart for 2 to 20-year olds – stature-for-age at the 90th percentile (black dot).

When her height (measured on the same day) was plotted, stature-for-age was at the 75th percentile (blue dot).



Therefore, if a length measurement is taken (e.g., because an older child is unable to stand) it should be noted on his growth chart.

Identify the 3 errors in this picture: Where is proper technique NOT being used?



- a. There is only one measurer. She is not able to hold the infant's head in place while the measurement is being taken, and the infant's head is not in the Frankfort plane.
- b. The measurement is being taken with only one foot against the footboard; this can make an infant seem "longer" than he really is.
- c. The infant's diaper is interfering with an accurate measurement.

Considerations for children with special health care needs:

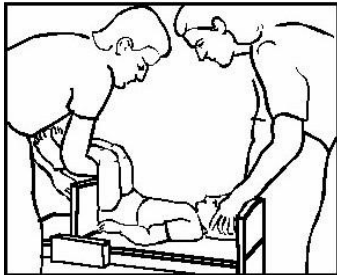
Contractures about the hips, knees, and ankles can interfere with an accurate stature measurement. Several measures are useful alternatives to length or height. These include crown-rump length, sitting height, arm span, and tibia length.

These measurements are discussed briefly in this module. More information, including how to obtain detailed information about measurement techniques can be found in [For More Information](#) at the end of this module.

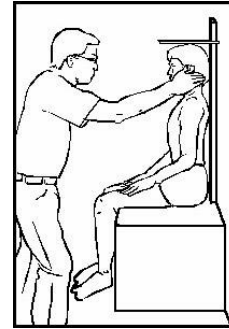
Crown-rump length and sitting height

Crown-rump length and sitting height measurements are often useful for children with contractures of the lower body.

These measurements will not correlate directly with height or length, but can indicate a child's rate of growth when plotted on CDC Growth Charts.



Crown-rump length

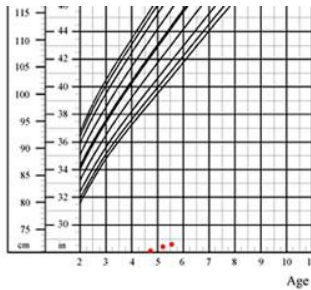


Sitting-height measurement

Although the measurements will be below the 5th percentile for age, they will show whether or not the child is following a consistent growth curve.

Sitting-height: an example

YE is a 5-year, 7-month old boy with developmental delay. He had a stroke in infancy, and the right side of his body is affected. He is not able to stand or extend his right arm.



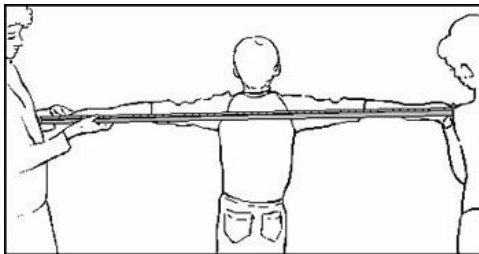
Sitting height measurements (along with weight) are used to monitor YE's growth. He is consistently measured sitting on a 40 cm box.

YE's sitting height measurements show that he is growing consistently on the height-for-age charts.

Together, with regular weight measurements, his sitting height-for-age measurements indicate that he is growing well.

Arm span measurement

The stature of children with involvement of the lower body only (e.g., some children with myelomeningocele or lower body paralysis) can be estimated by using arm-span measurements. This requires the use of a specialized anthropometer.



Note that arms must be perpendicular to body and the anthropometer is touching the extended middle fingers of the right and left hands.

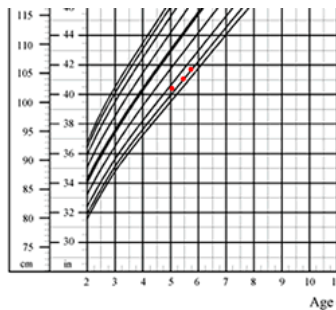
For children with contractures of the upper extremities such as in cerebral palsy, accurate arm span measurements can be difficult.

For typically-developing children, the ratio of arm span to height is about 1:1. This may not be the case for children with special health care needs. Monitoring an individual's arm span measurements over time can provide information about the rate of growth, also known as growth velocity.

Arm span cannot accurately estimate stature in young children (younger than 5 to 6 years) because the proportions of limb length and trunk length to total body length are different for younger than older children.

Arm span measurement: an example

VJ is a 5-year, 9-month old boy. He was born prematurely, has developmental delay, and has trouble standing on his own.



Because he is able to extend his arms, arm span is used to estimate his stature.

This measure is consistently performed by the same clinicians, who have experience with arm span measurement technique, and the use of arm span measure is noted on the chart. (VJ's arm span is measured by his physical therapist and the nurse who works with the therapist.)

Other segmental measurements (e.g., knee height and tibia length) are sometimes used as alternatives to stature measurements. These can provide some information about a child's growth, however their usefulness is limited. There are few data to support a relationship with the stature of typically-developing children, and even fewer data for children with special health care needs.

Choose an alternative height measurement for this 4-year old child:



- arm span
- crown rump
- knee height
- head circumference

Crown-rump length (or sitting height, if this child is able to sit unassisted) is the best alternative to height measurement.

Arm span measurements are not useful for children under the age of 5 to 6 years. There are few data to support the use of **knee height** to estimate stature for young children with special health care needs. **Head circumference** is not related to stature.

Body composition

Body composition can be estimated with a number of tools. One of the most common methods of assessing body composition is by measuring skinfolds (e.g., triceps and subscapular skinfolds), estimating the amount of body fat and muscle mass present, and comparing estimates to population reference data.



triceps skinfold
measurement

These secondary measurements are useful only if obtained with precise and accurate technique that is developed with training and practice. During training, the measurements must be validated by a person experienced with skinfold thickness measurement techniques. Only calibrated calipers should be used for measuring skinfold thickness; plastic calipers are not accurate.



subscapular
skinfold
measurement

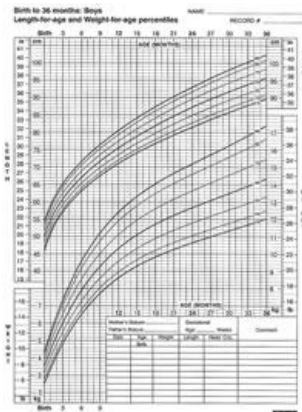
There are limited skinfold thickness data for young children and children with special health care needs. The best use of these measurements for children with special health care needs is for assessing changes over time. Skinfold measurements are not appropriate for children with subcutaneous edema.

More information, including how to obtain information about skinfold measurements and interpretation can be found in [For More Information](#) at the end of this module.

Section 2: Assessment Guidelines

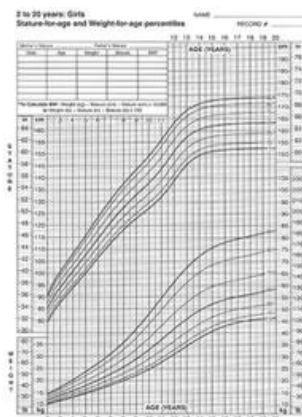
Once accurate measurements are made, the data are compared to growth charts that are based on the growth patterns of thousands of children in the United States (CDC Growth Charts) or charts based on thousands of measurements (WHO Growth Standards). This section reviews the development and use of these growth charts. These charts are a compilation of data—measurements of children who participated in the National Health and Nutrition Examination Surveys (NHANES): NHANES (1971-74), NHANES II (1976-80), and NHANES III (1988-94).

Information about the growth charts and downloadable versions of the charts can be found on the CDC website: www.cdc.gov/growthcharts.



WHO growth charts are available for children 0-24 months (weight-for-age, length-for-age, head circumference-for-age, weight-for-length)

- These charts were based on data from the WHO Multicentre Growth Reference Study (MGRS) – 18,973 observations for 882 children
- Children in the MGRS lived in environments believed to support what WHO researchers view as optimal growth of children
- Some of the inclusion criteria: predominantly breastfeeding at 4 months, breastfeeding at 12 months, complementary food introduced at mean age 5.4 months
- Some of the exclusion criteria: low socioeconomic status, birth at <37 weeks or >42 weeks, multiple birth, perinatal morbidities, child health conditions known to affect growth, weight-for-length >3 SD +/- study mean
- Weight-for-

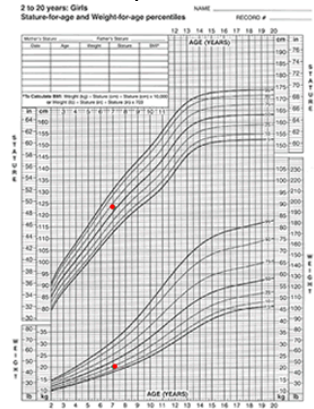


Charts for 2 to 20-year olds (weight-for-age, stature-for-age, Body Mass Index [BMI]-for-age, weight-for-stature [for children 77-121 cm only])

- These charts are based on data from the five previous NHANES surveys
- NHANES III data were not used for the weight-for-age and BMI-for-age percentiles for children over age 6 years
- Like the charts for younger children, these represent the racial/ethnic diversity of the US

Weight-for-age and stature-for-age charts can be used to describe a child's growth, relative to his or her peers.

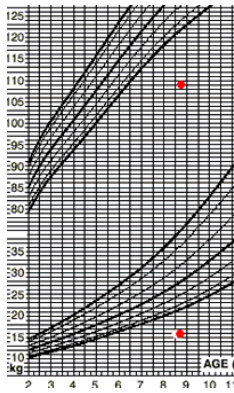
For example:



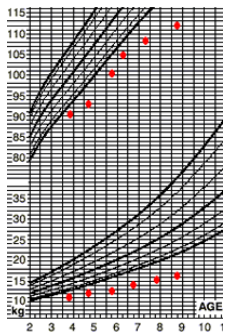
A 7-year old child's weight is 20 kg and her height is 123.5 cm. This weight is at the 25th percentile, which indicates that she is heavier than 25% of girls her age, and 75% of girls her age weigh more.

Her height is between the 50th and 75th percentiles, indicating that she is taller than 50 to 75% of girls her age.

These charts are also useful tools for monitoring growth over time.



When only one point in time is examined, this child appears to be at significant nutritional risk.



When previous growth data (that include multiple points paralleling the 5th percentile) are considered, it becomes evident that this child's growth rate has remained constant. (In fact, she has a medical condition sometimes associated with short stature.)

She remains at nutritional risk, but the data are less alarming when compared to previous measurements.

Weight-for-length and BMI-for-age

Weight-for-length, body mass index (BMI)-for-age, and weight-for-stature are all used to compare a child's weight to his or her height.

- **Weight-for-length** is used for infants and children under the age of 2 years

- **Body mass index (BMI)-for-age** is used for screening children between 2 and 20 years of age. The WHO charts also include a BMI-for-age option, however use of the BMI-for-age growth chart is not recommended for children younger than age 2 years at this time.

Weight-for-length

Weight-for-length is expressed as a percentile, and is an indicator of an individual's proportionality.

The WHO recommends cutoff values of 2 standard deviations (2.3rd and 97.7th percentiles). The WHO charts available on the CDC website label these values as the **2nd** and **98th** percentiles:

- Weight-for-length <2nd percentile indicates low weight-for-length
- Weight-for-length >98th percentile indicates high weight-for-length

Some organizations and institutions may have other cutoff values (e.g., outside the 5-10th or 90-95th percentiles) to trigger further assessment.

Changes in percentile channels (for example a sudden decrease from the 50th to the 10th percentile or increase from the 50th to the 95th percentile) can also indicate nutritional risk.

Use of z scores to quantify changes is becoming more common as more organizations move to computerized charting. A z score is more precise than a percentile.

Body Mass Index (BMI)-for-age

Body mass index (BMI) is a calculation used for children over age 2 years. It is expressed as a ratio of weight (in kg) to height (in m) squared:

$$\text{BMI} = \frac{\text{weight in kilograms}}{(\text{height in meters})^2}$$

BMI can be obtained with a number of methods:

- (weight in kg) / (height in m) / (height in m)
- [(weight in pounds) / (height in inches) / (height in inches)] x 703
- BMI tables, downloaded from the CDC website www.cdc.gov/nccdphp/dnpa/growthcharts/bmi_tools.htm
- BMI calculator, available on the CDC website www.cdc.gov/nccdphp/dnpa/bmi/calc-bmi.htm

BMI-for-age is plotted on sex-specific charts to describe a child's weight and height proportionality, and can be used to monitor changes over time.

BMI has been shown to be a good indicator of obesity and risk for obesity in children and adults.

- BMI-for-age between the 85th and 94th percentiles is indicative of overweight (previously noted as "at risk of overweight")

- BMI-for-age greater than the 95th percentile for age is indicative of obesity

There are fewer data to support the use of BMI for age as an indicator of underweight than overweight. The guideline is:

- Underweight is indicated by a BMI-for-age less than the 5th percentile

Changes in percentile channels can also indicate nutritional risk.

Specialty Growth Charts

It is important to use the CDC Growth Charts first and then evaluate whether or not it is appropriate to use a specialty growth chart along with the information provided by the CDC charts.

Specialty growth charts have been constructed with data from groups of children with a number of disabilities. These charts are sometimes used for comparing the growth (especially in stature) of children who have conditions that affect an individual's genetic growth potential.

There are some major drawbacks to the specialty charts, however:

- Most of the charts are based on small groups of children and there is no ethnic or racial mix.
- Although the children reflected in the growth chart share a diagnosis, their growth potential may not be similar. For example, some may have received tube feedings, or some children may have had concurrent or secondary medical conditions that interfered with growth. Those children whose growth (and growth potential) is most accurately reflected in specialty growth charts are those whose disorders have a genetic component.
- The children used to compile the charts may not have been ideally nourished. Thus, weights and heights may be lower or higher than what is ideal.
- Measuring techniques may have been inconsistent (in some cases, chart reviews were used to collect data; in other cases, the measurement techniques were not clearly defined).
- In general, the charts do not include all growth parameters (weight-for-age, stature-for-age, weight-for-stature); an assessment based only on a specialty chart is incomplete.

The charts based on the growth of children with Down syndrome (trisomy 21) provide some examples of these limitations. For these reasons (and others), the American Academy of Pediatrics recommends that clinicians NOT use the Down syndrome charts because they do not reflect the current population and body proportion.

The clinician using the specialty charts should be aware of potential limitations to specialty charts. Limitations to previously used charts for Down syndrome are included as an example:

- The children in the sample were of limited diversity with respect to race, ethnicity and the geographic location of their residence.

- The nutritional status of the children in the sample was not assessed, so it is difficult to ascertain whether or not the data represent a well-nourished group of children or reflect problems with nutritional status.
- The existence of secondary medical conditions affecting growth (congenital heart disease, which affects about 40% of children with Down syndrome, and feeding problems, which are present in up to 80% of children with Down syndrome) was not considered in developing the reference data.

Growth charts for children with cerebral palsy acknowledge the effect that different disease severities and feeding modalities can have on growth. One group constructed charts based on data from almost 25,000 children with cerebral palsy in California.

Sets of charts are available for different groups:

1. Walks well alone ≥ 20 feet, balances well
2. Walks with support or unsteadily alone ≥ 10 feet, but does not walk alone or balance well
3. Crawls, creeps, or scoots, does not walk
4. Does not walk, crawl, creep, or scoot; does not feed self, is not gastrostomy tube fed
5. As Group 4, but gastrostomy tube fed

Limitations include the use of measurements reported in medical records (not a standardized measurement technique).

Consider the following questions when using a specialty growth chart:

- Does the child have the same disorder as the children used to compile the chart?
For example:
Does he have achondroplasia or a different type of chondroplasia?
- Are there other differences between the individual and the group used to construct the chart? For example, feeding modality, use of growth hormone or other medications that might affect growth
- Was the source of the data reliable? How large was the sample? Is there a genetic basis for an atypical growth pattern?
- Are you using the same measurement techniques that were used to collect the data for the charts?

Section 3: Influence Of Special Health Care Needs

This section reviews the influence that medical conditions can have on growth patterns. Some general effects are described, and some specific conditions are reviewed.

Some medical conditions have specific effects on growth.

For instance, most children with Down syndrome are shorter than their age-matched peers who do not have Down syndrome.

When assessing the growth (and nutritional status) of a child with a special health care need, take the medical condition into consideration and look for medically-related factors that might explain atypical growth.

Effect on Growth Assessment: Short stature

Short stature is associated with several specific conditions. When assessing the growth of children with these conditions, it is important to recognize this. Some children with short stature have problems with overweight and obesity. While their energy needs are likely to be less than those of their taller, typically-developing peers, caregiver expectations of what they should eat and portion sizes offered may not be smaller. This will be covered in more detail in Module 2.

Children who are non-ambulatory may be shorter than their ambulatory peers because of a lack of weight-bearing (weight-bearing stimulates linear growth).

Growth delays are often associated with genetic disorders including Down syndrome, Prader-Willi syndrome, trisomy 13 and 18 syndromes, deLange syndrome, Hurler syndrome, Russell-Silver syndrome, Turner syndrome, Smith-Lemli-Opitz syndrome, and Williams syndrome. A few non-genetic conditions, such as fetal alcohol syndrome and spina bifida are also associated with short stature and/or growth delays depending on the severity of the condition.

Effect on Growth Assessment: Body composition and muscle tone

Body composition and muscle tone may influence the way weight-for-age and weight-for-stature (or body mass index-for-age) are interpreted. The data used to assess weight and stature proportionality (weight-for-length and body mass index-for-age) are based on children with typical body composition.

Low muscle tone is common among children with some disorders, and this must be taken into consideration. Disorders that are frequently associated with low muscle tone include cerebral palsy, Down syndrome, Prader-Willi syndrome, Fragile X syndrome, and muscular dystrophy. Children with paralysis (e.g., myelomeningocele) will also have altered body composition. Because fat weighs less than muscle, a child with decreased muscle mass and an "acceptable" weight-for-length, may be overfat.

Possible effects of *some* specific medical conditions on growth are summarized in this module.

Keep in mind that these are general effects; an individual's growth pattern may or may not follow what is described. Some general information about each of the following disorders is provided:

Conditions that alter a child's growth potential

Angelman syndrome
chondroplasias, e.g., achondroplasia
deLange syndrome
Down syndrome (trisomy 21)
Prader-Willi syndrome
Turner syndrome

Conditions that have the potential to alter growth

cerebral palsy
myelomeningocele (spina bifida)
muscular dystrophy

More information about the impact that specific conditions have on nutritional status is presented throughout this set of modules.

Angelman syndrome

Description

Angelman syndrome is a genetic defect caused by partial deletion of chromosome 15 (maternal) or disomy (paternal); children with Angelman syndrome have mental retardation, hyperactivity and unprovoked laughter.

Possible effects on growth

- Children with Angelman syndrome typically have problems with underweight.

Chondroplasias, e.g., achondroplasia

Description

Chondroplasias are disorders of cartilage growth. Achondroplasia is one type, an inherited problem that involves growth of cartilage in the long bones and skull. Persons with achondroplasia have short limbs, normal-sized trunks, large heads, and small faces and hands.

Possible effects on growth

- Children with chondroplasias have short stature and can have problems with excessive weight gain if nutrient intake is not carefully monitored.

deLange syndrome

Description

Children with deLange syndrome (also called Cornelia deLange syndrome and Brachmann-deLange syndrome) often have poor prenatal growth, cardiac defects, severe mental retardation, and dysmorphic features.

Possible effects on growth

- Short stature and problems with growth are common among children with deLange syndrome because of complications associated with the disorder.

Down syndrome (trisomy 21)

Description

Down syndrome is caused by an “extra” 21st chromosome. Children with Down syndrome often have mental retardation, cardiac defects, and hypotonia (decreased muscle tone). Duodenal atresia (blockage of the intestine) may be present. Oral problems can include oral hypotonia, small oral cavity causing tongue protrusion, and delayed and/or abnormal tooth eruption.

Possible effects on growth

- Children with Down syndrome have short stature.
- Initial problems in infancy with underweight may be present, however, problems with overweight can present as a child gets older.
- Hypotonia can be a barrier to physical activity, further contributing to undesirable weight gain.

Prader-Willi syndrome

Description

Prader-Willi syndrome is a genetic disorder caused by partial deletion of chromosome 15 (paternal) or disomy (maternal). Children with Prader-Willi syndrome have mental retardation and abnormal food-related behaviors. Prader-Willi syndrome is characterized by feeding problems during infancy, and hyperphagia, often resulting in obesity, in childhood and adolescence.

Possible effects on growth

- Children with Prader-Willi syndrome have short stature.
- Initial problems with poor feeding and poor weight gain occur during infancy.
- Abnormal behaviors related to food and eating (hyperphagia, stealing food) lead to obesity if not carefully managed.

Turner syndrome

Description

Turner syndrome is a genetic defect in females marked by the absence of one X chromosome. Individuals with Turner syndrome typically have ovarian failure, genital tissue defects, heart and circulation problems and short stature.

Possible effects on growth

- Girls with Turner syndrome typically have short stature.
- Some girls with Turner syndrome can have problems with excessive weight gain.

Cerebral palsy

Description

Cerebral palsy (CP) involves chronic, nonprogressive central nervous system (CNS) dysfunction leading to problems with tone and movement. Children with CP make up a very heterogeneous group. Depending on the original insult, this condition has many clinical manifestations, from very mild to very severe neurological involvement. Children with cerebral palsy may or may not be ambulatory and may or may not have mental retardation.

Possible effects on growth

- Growth impairments are seen in many children with CP. It is thought that the impairments are related to inadequate intake because of neurological problems that impact oral-motor function and ambulatory status.
- Many children with CP were born prematurely; it is important to correct for gestational age when assessing the growth of an infant with CP.

Myelomeningocele (Spina bifida)

Description

Myelomeningocele is caused by failure of the neural tube to close completely during fetal development, resulting in a lesion along the spinal cord. The level of muscle weakness and paralysis depends on the level of the lesion (high or low along the spinal cord). Children with myelomeningocele may or may not be ambulatory.

Possible effects on growth

- Children with myelomeningocele have short stature depending on the severity and location of the spinal lesion.
- Depending on the level of the lesion, muscle tone may be significantly affected. Problems with overweight and obesity are common among older children because of lack of ambulation. Problems with poor weight gain can be present in other children because of oral-motor problems and feeding difficulties.
- If the lesion has caused paralysis of the legs, stature may be affected because of the lack of load-bearing physical activity.

Muscular dystrophy

Description

Muscular dystrophy is the progressive degeneration of muscle function. The most common is a genetic form called Duchenne muscular dystrophy. Other types include spinal muscular atrophy (SMA), myasthenia gravis, and myotonic dystrophy.

Possible effects on growth

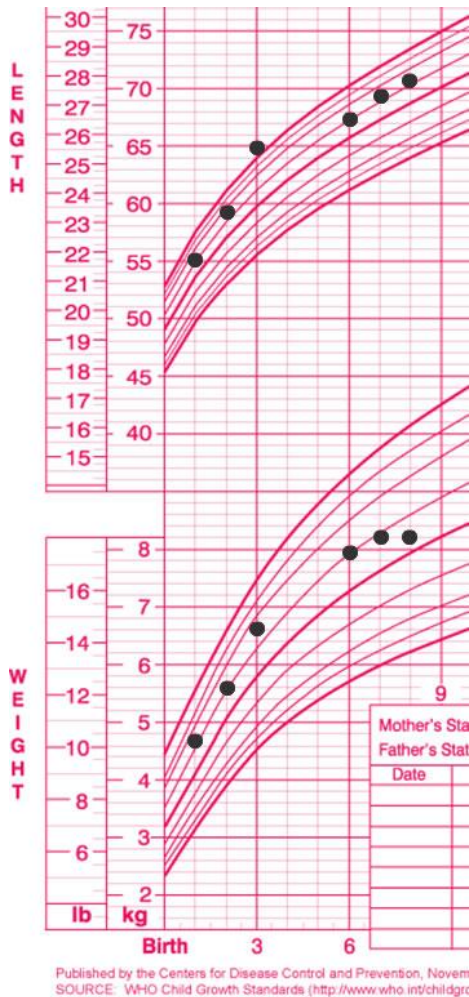
- Because muscle strength gradually decreases, there is a change in a child's body composition over time. Overweight and obesity can become problems later in childhood and in adolescence because of changes in energy needs and physical activity levels.

Section 4: Making Clinical Decisions

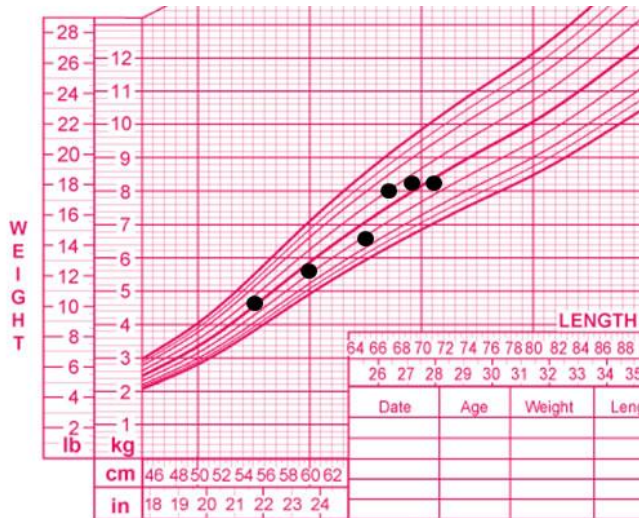
This section "walks" you through the decision-making process. The first scenario describes a case and one way to approach the growth data. In the second scenario, you will be asked to make clinical decisions based on the information presented. This section is not scored.

Scenario 1

Sarah is an 8-month old who is referred to you because of slow weight gain. Her mother is a meticulous record-keeper and brings Sarah's growth information to the visit.



You plot this information on the WHO chart for girls age 0 to 24 months, and see that Sarah's rate of weight gain has slowed since age 6 months. Her length-for-age has remained relatively stable.



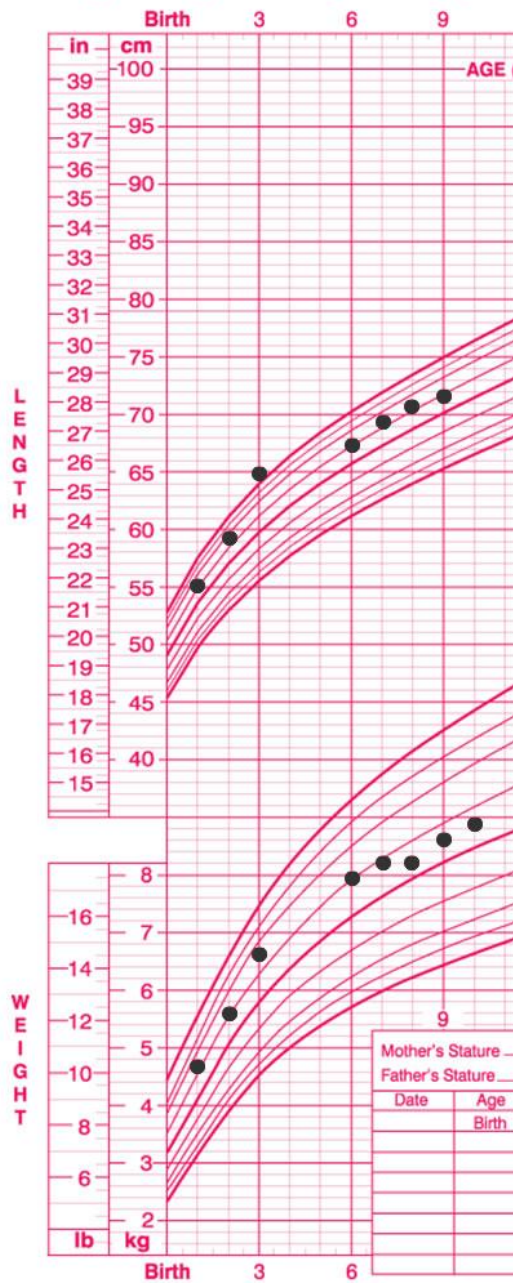
You see that Sarah's weight-for-length has gradually decreased as well.

Published by the Centers for Disease Control and Prevention, November 1, 2009
 SOURCE: WHO Child Growth Standards (<http://www.who.int/childgrowth/en>)

You explore reasons for Sarah's slow weight gain. Sarah's mother says that both she and her husband are slim. You explain that this may predispose Sarah to be slim, but that no weight gain for 3 months is concerning for an infant.

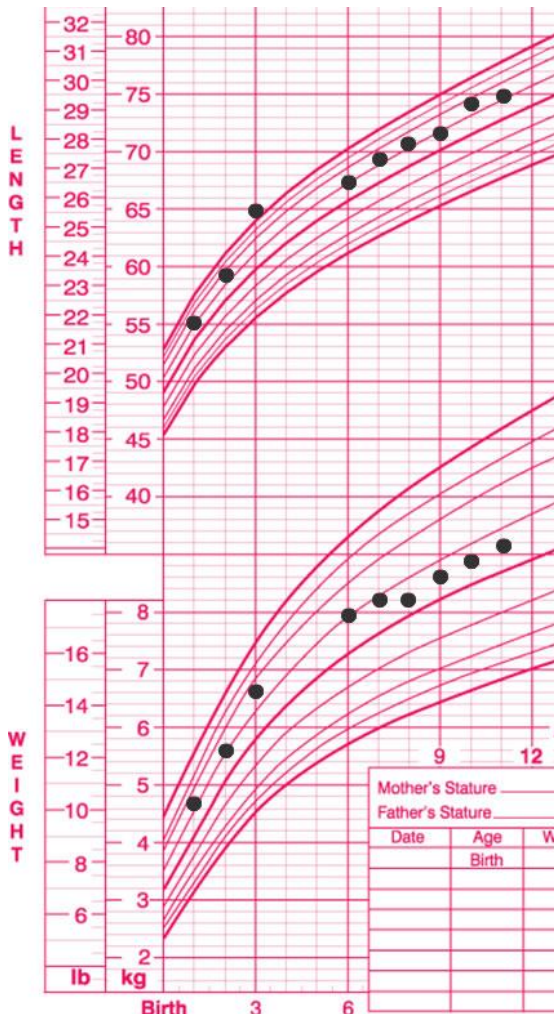
You learn that Sarah does not have a medical condition that is associated with problems with weight gain. The portion sizes offered to Sarah, however, are smaller than appropriate for an 8-month old. You provide information about appropriate portion sizes and eating patterns to Sarah's mother and suggest that they return in one month for a follow-up visit. This information is communicated to Sarah's primary care physician.

Birth to 24 months: Girls
Length-for-age and Weight-for-age perc



Published by the Centers for Disease Control and Prevention, November 1, 2006
 SOURCE: WHO Child Growth Standards (<http://www.who.int/childgrowth/en>)

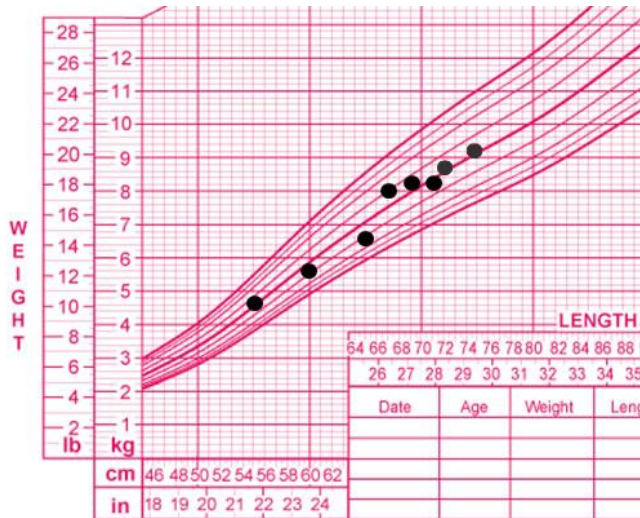
They return one month later, and Sarah has gained some weight. Her mother says that they are offering larger portion sizes and expanding Sarah's food repertoire. Because you are still concerned about growth, you suggest that the family return for brief monthly follow-up visits for a few months.



Sarah and her family return regularly and you are able to track her rate of growth.

Sarah's growth is consistently between the 50th and 75th percentiles for weight-for-age and remains between the 75th and 90th for length-for-age.

Published by the Centers for Disease Control and Prevention, November 1, 2009
 SOURCE: WHO Child Growth Standards (<http://www.who.int/childgrowth/en>)



Sarah's most recent weight-for-length is close to the 50th percentile. You recommend that Sarah's growth be monitored at well child check-ups and that a referral be made if further concerns arise.

Published by the Centers for Disease Control and Prevention, November 1, 2009
 SOURCE: WHO Child Growth Standards (<http://www.who.int/childgrowth/en>)

Scenario 2

Mary is an 8-year old. Her physician has referred her to you because he is worried that she is overweight. You weigh and measure Mary using proper technique. She weighs 32.9 kg and is 131.9 cm tall.

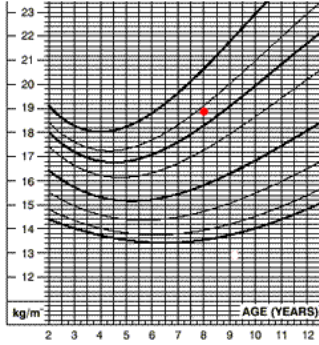
Print the growth chart for Girls 2 to 20 years, and plot her measurements. Click here <link> for an image of the growth chart. Or visit www.cdc.gov/growthcharts for a printable pdf.

How do her measurements compare to other children her age?

- a. Weight-for-age: 90th percentile, stature-for age: 75th percentile
 - b. Weight-for-age: 85th percentile, stature-for-age: 75th percentile
 - c. Weight-for-age: 90th-95th percentiles, stature-for-age: 50th percentile
 - d. Weight-for-age: 90th percentile, stature-for-age: 90th percentile
- The correct response is a. weight-for-age: 90th percentile, stature-for-age: 75th percentile.*

What is Mary's BMI?

- a. 22
 - b. 18.9
 - c. 18.7
 - d. 19.1
- The correct response is b 18.9.*



Mary's BMI is between the 85th and 90th percentiles for age. According to CDC guidelines, you assess Mary to be:

- a. Overweight
- b. At risk for overweight
- c. Underweight
- d. Within normal limits

The correct response is b. at risk for overweight.

According to the CDC guidelines, a BMI greater than the 85th percentile indicates overweight. BMI greater than the 95th percentile indicates obesity, and BMI less than the 5th percentile indicates underweight.

You realize that although Mary's BMI indicates overweight, screening parameters do not always tell the whole story. You learn that Mary is an active 8-year old, involved in sports activities almost year-round. You assess her food pattern, and it is reasonable for an 8-year old.

You tell Mary's parents that her growth parameters indicate the need for your further assessment, but that she seems well-muscled, is physically active, and has an appropriate food pattern. You provide the family with some recommendations for appropriate portion sizes and encourage them to continue to promote physical activity. You suggest that her growth (weight and height) be monitored regularly and that she be referred to a nutritionist if her BMI-for-age crosses the 95th percentile.

Post Test

QUESTION 1

Jason, an 8-year, 11-month old boy with Down syndrome (trisomy 21) comes to your clinic with his foster parents. They are concerned because his pediatrician says that he is small for his age. His weight and height are below the 5th percentile for age on the CDC charts. What do you tell his parents? (Select the BEST answer.)

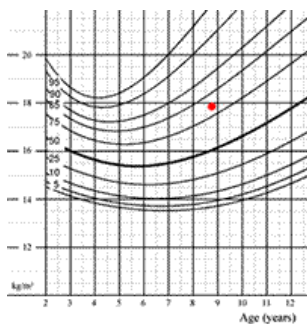
- He is shorter and weighs less than typically-developing children his age, but this is okay because he has Down syndrome. Children with Down syndrome are shorter and lighter than their peers.
- Jason is short for his age. He should be referred to an endocrinologist to evaluate the need for growth hormone therapy.
- Jason is shorter and weighs less than typically-developing children his age. His parents should offer energy-dense foods and give him a nutritional supplement.
- There is not enough information to assess the situation. *

QUESTION 2

The correct answer to the previous question was "d. there is not enough information to assess the situation." What should you do next to BEST evaluate Jason's current nutritional status?

- You should find out the height of his biological mother and his father to determine his genetic potential for growth.
- You should measure Jason's head circumference and plot head circumference-for-age.
- You should calculate and plot his BMI. *
- You should ask Jason and his family to come back in three months so that you can evaluate his growth pattern over time.

QUESTION 3



Jason's BMI is between the 75th and 85th percentiles for age. You tell his family that this indicates: (Choose the BEST answer)

- Jason is at risk for overweight. His intake should be monitored carefully.
- Jason's weight is proportionate to his height, however his growth should be monitored regularly. *
- Jason's weight is proportionate to his height. However, since his weight and height are less than the 5th percentile for age, he should receive nutritional supplements.
- Jason's BMI would be fine for a child without Down syndrome, but because you suspect he has low muscle tone, his BMI-for-age should be closer to the 95th percentile.

QUESTION 4

You remember that there are specialty growth charts for children with Down syndrome. Are these charts appropriate for Jason?

- yes, because Jason's measurements require further assessment
- yes, the charts should be used exclusively for all children with Down syndrome
- no, the charts are only for girls with Down syndrome
- no, the previously used charts no longer reflect the current population and body proportion *

You explain that children with Down syndrome often have different growth patterns than children without Down syndrome. The adolescent growth spurt is sometimes delayed or absent. Because of this difference in growth patterns, and because some children have low muscle tone that is related to the disorder (the decrease in tone can make physical activity difficult), children with Down syndrome can be at risk for becoming overweight.

You suggest that Jason's growth be monitored frequently (every 4 months or so) and plotted on growth charts.

Jason returns to clinic one year later at nearly 10 years of age. You weigh and measure Jason, and explain your interpretation of his measurements to his family:

- Weight-for-age: 10-25th percentiles on CDC charts (was <5th percentile)

Compared to typically-developing children, Jason's weight-for-age is between the 10th and 25th percentiles.

- Height-for-age: <5th percentile on CDC chart (was <5th percentile)

Compared to typically-developing children, Jason is in the "shortest" 5 percent. This makes sense, since children with Down syndrome are often shorter than typically-developing children.

QUESTION 5

Jason's BMI-for-age is between the 90th and 95th percentiles (was 75-85th percentiles)

What do you tell his family?

- "Don't worry. Children with Down syndrome tend to experience an adolescent growth spurt later than children without Down syndrome. Jason will 'grow into' his weight."
- "Jason's BMI-for-age indicates that he has gained too much weight for his height." *
- "Jason's height-for-age remains low. He must not be eating enough. He should have a feeding evaluation."
- "Jason is very overweight. You should enroll him in a special weight loss program immediately."

You learn that Jason drinks between 12 and 18 ounces of fruit juice each day. You recommend that Jason's family reduce the amount of juice he drinks or dilute the juice that he is offered. You also suggest that they encourage physical activity.

With the extra attention and the small changes, Jason's rate of weight gain slows, and his weight-for-age remains relatively stable after six months.

QUESTION 6

You are scheduled to see a 3-year old with Prader-Willi syndrome. She was referred by her endocrinologist who has prescribed growth hormone therapy. Which of the following charts is most appropriate to use to evaluate her growth?

- a. WHO growth charts (weight, length, weight-for-length, and head circumference)
- b. CDC growth charts (weight, height, and BMI-for-age) *
- c. Prader-Willi charts (weight, height, and BMI-for-age)
- d. Prader-Willi charts (height only) and CDC charts (weight and BMI-for-age)

QUESTION 7

Maria is a 6-year, 10-month old girl with Prader-Willi syndrome. Her weight-for-age is between the 75-90th percentiles, and her stature-for-age is at the 10th percentile.

Which assessment tool will provide the best information about Maria's nutritional status?

- a. weight-for-length
- b. BMI-for-age *
- c. sitting height
- d. triceps skinfold

QUESTION 8

Maria weighs 29.5 kg and is 110.5 cm tall. What is Maria's BMI?

- a. 26.7
- b. 26.3
- c. 24.2 *
- d. 21.9

For More Information About Measurement Techniques

Anthropometric Standardization Reference Manual. Lohman TG, Roche AF, Martorell R, eds. *Anthropometric Standardization Reference Manual*. Champaign, Ill: Human Kinetics Books, 1988. ISBN 0-87322-331-4. This book describes many measurement techniques. It is out of print, however, copies are sometimes available through college and university bookstores. Several online retailers, including <http://alibris.com> and <http://bookfinder.com>, sometimes have this book in stock.

CDC/MCHB Growth Chart Tutorials: Measurement Techniques. Centers for Disease Control and Prevention and the Maternal and Child Health Bureau. *Growth Charts Training*. 2001. The CDC and MCHB have developed tutorials to accompany the 2000 CDC Growth Charts. These tutorials are aimed at health care professionals. Modules cover equipment, measurement technique, and developing and rating your technique. For information about accessing the tutorials, visit <http://depts.washington.edu/growth>.

For More Information About Tools for Assessment

CDC Growth Charts. Centers for Disease Control and Prevention (CDC). Information about the 2000 CDC Growth Charts, and downloadable versions of the charts are available on the CDC website: <http://www.cdc.gov/growthcharts>.

Frequently Used Guidelines: Anthropometrics and growth. Guidelines for interpretation of growth are presented. <http://depts.washington.edu/nutrpeds/fug/growthtoc.htm>.

CDC/MCHB Growth Chart Tutorials: Growth Assessment. Centers for Disease Control and Prevention and the Maternal and Child Health Bureau. *Growth Charts Training*. 2001. The CDC and MCHB have developed tutorials to accompany the 2000 CDC Growth Charts. These tutorials are aimed at health care professionals. Modules cover use and interpretation of the charts, including BMI. For information about accessing the tutorials, visit <http://depts.washington.edu/growth>.

Crown-rump Length. Crown-rump length. McCammon RW, ed. *Human Growth and Development*. Springfield, Ill: Charles C Thomas, 1970. Longitudinal data from 75 females and 75 males are presented.

Prediction of Stature from Knee Height. Chumlea WC, Guo SS, Steinbaugh ML. Prediction of stature from knee height for black and white adults and children with applications to mobility-impaired or handicapped persons. *J Am Diet Assoc*. 1994; 94(12): 1385-1388. This article presents data collected during 1960-1970 from children 6-12 years of age. The population was 85% Caucasian.

Sitting Height. Hamill PV, et al. Body weight, stature and sitting height. *US Vital and Health Statistics, Series 11, #126*; Publication No. HSM 73-1606. Washington DC: US Government Printing Office, 1973. These tables (sitting height for age) are based on the NCHS 1977 population (age 1-18 years).

Triceps Skinfold and Upper Arm Circumference. Frisancho AR. New norms of upper limb fat and muscle areas for assessment of nutritional status. *Am J Clin Nutr*.

34: 2540-2545, 1981. This article provides age- and sex-specific percentiles for triceps skinfold, upper arm circumference, arm muscle area, and arm fat area based on a cross-sectional sample of 19,097 white subjects age 1 to 74 years.

Estimating body composition in children with Duchenne muscular dystrophy. Mok E, et al. Estimating body composition in children with Duchenne muscular dystrophy: comparison of bioelectric impedance analysis and skinfold-thickness measurement. *Am J Clin Nutr.* 2006; 83:65-69. This article highlights some of the problems with using reference data from typically-developing children when assessing the nutritional status of an individual with a special health care need. In this study, skinfold measurements overestimated fat-free mass and thus underestimated muscle mass in children with Duchenne muscular dystrophy.

World Health Organization (WHO) Child Growth Standards. This website includes growth charts for infants and children (ages 0-5 years), based on data from infants who were primarily breastfed and part of the WHO Multicentre Growth Reference Study. Charts for infants include length-for-age, weight-for-age, weight-for-length, and the site also includes training materials.
<http://www.who.int/childgrowth/en>.

For More Information About the Influence of Specific Conditions

Charts/Tables Used to Monitor Growth of Children with Special Health Care Needs. Reprinted with permission from: Yang Y, et al. *Nutrition Interventions for Children with Special Health Care Needs.* Washington State Department of Health. 2010. This table describes charts and tables that are often used to monitor the growth of children with special health care needs. It is available for download in pdf format here. This publication can be downloaded from the WA DOH website: <http://here.doh.wa.gov/materials/nutrition-interventions>.

For More Information About Using Growth Data to Make Clinical Decisions

Assessment of Growth: Equipment, techniques and growth charts. Feucht S. Assessment of growth: Part 1, equipment, technique and growth charts. *Nutrition Focus.* 26(6). 2011. To subscribe to Nutrition Focus, visit <http://depts.washington.edu/nutrifoc/webapps/>.

Assessment of Growth: Interpretation of growth. Ogata B, Feucht S. Assessment of growth: Part 2, interpretation of growth. *Nutrition Focus.* 27(1). 2012. This article presents case studies. To subscribe to Nutrition Focus, visit <http://depts.washington.edu/nutrifoc/webapps/>.

Expert committee recommendations regarding the prevention, assessment, and treatment of childhood overweight and obesity: summary report. Barlow SE and the Expert Committee. Expert committee recommendations regarding the prevention, assessment, and treatment of childhood overweight and obesity:

summary report. *Pediatrics*. 2007; 120:S164-S192. online:
http://www.pediatrics.org/cgi/content/full/120/Supplement_4/S164.

Anthropometrics. Murphy K. Anthropometrics. In: Yang Y, et al. *Nutrition Interventions for Children with Special Health Care Needs*. Washington State Department of Health. 2010. This chapter describes techniques for weighing and measuring children and presents some guidelines for interpreting measurements. This publication can be downloaded from the WA DOH website:
<http://here.doh.wa.gov/materials/nutrition-interventions>.