Chapter 101
Growth Charts for Children with Cerebral Palsy: Weight and Stature Percentiles by Age, Gender, and Level of Disability

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Abstract Growth charts for the general population, whether reference charts from the CDC or standards for healthy children developed by the WHO, are of limited use for children with cerebral palsy (CP), whose weight-for-age and stature-for-age often track below the 5th percentiles on such charts. In this chapter we review previous work on CP-specific growth patterns and growth charts and present new weight-for-age and stature-for-age growth charts for CP. The new charts are based on data comprising over 100,000 measurements of weight and height of children with CP who received services from the California Department of Developmental Services from 1988 to 2002. The charts are stratified by Gross Motor Function Classification System (GMFCS) level. The percentile curves in the new charts are based on methodology recommended by the WHO (the Box–Cox power-exponential distribution with four parameters was used to construct the percentile curves). The resulting curves show 5th, 10th, 25th, 50th, 75th, 90th, and 95th percentiles of weight-for-age and stature-for-age separately for boys and girls and GMFCS levels I–V, with level V further separated according to presence of a feeding tube. Very low percentiles of weight (5th or 20th percentile, depending on GMFCS level), below which mortality rates are elevated, are identified in the charts. The format of the charts is similar to that of the CDC general population reference charts for children aged 2–20. The new charts confirm earlier work showing that percentiles of weight-for-age and stature-for-age in CP are substantially lower than corresponding percentiles in the general population. The charts also confirm that weight and stature in CP are strongly associated with level of gross motor functioning. Among the most severely affected children with CP (GMFCS level V), weight and stature percentiles are higher for those with feeding tubes. The chapter reviews evidence from earlier studies linking very high or very low weights in CP to other health outcomes and examines these links relative to percentiles of weight-for-age on the new GMFCS-level-specific growth charts. Practical considerations for using the new charts are discussed and cautionary notes provided. The chapter includes a brief discussion of how the information presented here might apply to other neurological disorders or medical conditions.

Abbreviations

AAMD	American Association on Mental Deficiency
BMI	Body mass index
CDC	Centers for Disease Control and Prevention

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CDER	Client Development Evaluation Report
CP	Cerebral palsy
DDS	Department of Developmental Services
GAMLSS	Generalized additive models for location, scale, and shape
GMFCS	Gross Motor Function Classification System
NCHS	National Center for Health Statistics
WHO	World Health Organization

101.1 Introduction

Monitoring growth has been standard practice in pediatric care for decades (Dibley et al., 1987). Plotting anthropomorphic measurements on reference charts is a quick and effective means of alerting care givers and parents to possible nutritional or other health concerns.

For the general population, reference charts for growth based on a large national sample of data in the United States were first developed and published by the US National Center for Health Statistics (NCHS) (Hamill et al., 1977). These NCHS charts were revised and modified by the World Health Organization (WHO) and published in 1979 as an international reference for pediatric growth (Hamill et al., 1979). The original NCHS growth charts were revised and expanded by the Centers for Disease Control and Prevention (CDC) in 2000 (Kuczmarski et al., 2000) and were for a time adopted by the WHO as an international reference. Eventually the WHO completed a comprehensive review of the NCHS and CDC charts and concluded that they were inadequate as representations of healthy growth, especially in infancy and early childhood. The WHO published new growth charts for healthy children in 2006 (World Health Organization, 2006).

Neither the WHO charts for healthy, well-nourished children nor the CDC charts are representative of the patterns of growth of children with cerebral palsy (CP – see Table 101.1). For the WHO charts, children with "chronic neurological disease that influences daily activity" were excluded, and as the CDC charts were based on random samples of non-institutionalized civilians in the USA, only a very small number could have had CP given that its prevalence is on the order of 2 in 1000 overall.

Growth patterns for children with CP are known to deviate significantly from those of the general population (Fung et al., 2002; Henderson et al., 2002; Krick et al., 1996; Krick and Van Duyn, 1984; Motion et al., 2002; Shapiro et al., 1986; Stallings et al., 1993a, b, 1995; Stevenson et al., 1994, 1995,

Table 101.1 Cerebral palsy facts

1. Cerebral palsy (CP) has been defined as a group of permanent disorders of the development of movement and posture, causing activity limitation(s) that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication and behavior; by epilepsy; and by secondary musculoskeletal problems (Rosenbaum et al., 2007).
2. CP is the most common childhood motor impairment disorder, with a prevalence on the order of 2 in 1000.
3. CP may be caused by a number of different mechanisms, including brain malformations, antenatal brain damage, very pre-term birth, oxygen deprivation around the time of birth, bacterial or viral infection before or after birth, neonatal stroke, and brain trauma. In many cases a specific cause is never identified.
4. Activity limitations generally accompany a diagnosis of CP, but the severity of these varies widely, from mild problems with hand use or walking to complete immobility.
5. Feeding difficulties and nutritional impairment are commonly seen in individuals with CP.
6. The ramifications of having CP vary as widely as the condition itself.
7. Life expectancy of persons with CP may be very much lower than normal in severe cases or near normal in very mild cases.
8. Growth patterns of persons with CP also vary widely as the charts presented in this chapter demonstrate.

2006b; Tobis et al., 1961; Zainah et al., 2001). Children with CP have lower weights (Fung et al., 2002; Krick et al., 1996; Stallings et al., 1993b; Stevenson et al., 2006b), smaller stature (Fung et al., 2002; Zainah et al., 2001), lower muscle mass (Fung et al., 2002), and lower fat stores (Fung et al., 2002) than their peers in the general population. Bone mass density is also below national averages, especially among those who are non-ambulatory (Henderson et al., 2002). It is not unusual for children with cerebral palsy to have weights that fall below the 3rd percentile on standard growth charts (Stewart and McKaig, 2009).

Feeding difficulties and resulting nutritional problems are partly responsible for observed deficits in growth of children with CP (Fung et al., 2002; Krick and Van Duyn, 1984; Motion et al., 2002; Shapiro et al., 1986; Stallings et al., 1993a, b). Non-nutritional factors also contribute (Shapiro et al., 1986; Stallings et al., 1993b; Stevenson et al., 1995). For example, some children with hemiplegic CP and normal stature and tricep skin-fold measurements nevertheless had length and girth measurements on their affected sides that were smaller than on their unaffected sides (Stevenson et al., 1995). Other studies similarly found involved limbs to have delayed skeletal maturation (Roberts et al., 1994) and reduced bone density (Lin and Henderson, 1996) compared with uninvolved limbs. Thus it appears that muscular atrophy in affected limbs may impede growth independently of nutritional intake. Children with brain damage involving the pituitary may have impaired endocrine function. This has raised the question of whether growth hormone treatment may be beneficial to some children with cerebral palsy (Shim et al., 2004). In addition a small number of children with CP demonstrate features of precocious puberty. In association with this there can be an early plateau of growth with consequent short stature.

It has been suggested that prior to the development of CP-specific growth charts, common practice for children with CP was to view growth that followed a given percentile curve on standard charts (WHO, CDC, or other) as being appropriate (Stewart and McKaig, 2009). However, it is now clear that percentiles of weight and height for children with CP deviate further and further from those of CDC charts with advancing age (Day et al., 2007; Krick et al., 1996; Stevenson et al., 2006b). For example, median weights for children with severe CP who had very limited gross motor functioning and were fed by gastrostomy were at the 10th percentile on CDC growth charts at age 5, at the 3rd percentile by age 10, and dramatically below the 3rd percentile by age 15 (Day et al., 2007). This is likely to be partly a consequence of increased nutritional requirements of adolescents with CP not being adequately met.

For an individual child with CP, it has been unclear how large the deviations from CDC percentile curves must be to raise serious concerns. Reference curves based on growth of children with CP, stratified by level of severity, would be more useful than CDC or WHO charts in this context.

101.2 Parameters of Growth for Children with Cerebral Palsy

Growth charts for the general population of children and adolescents typically track weight and height for age and sometimes weight for height or body mass index. For infants, weight, length, and head circumference are commonly tracked. For children with cerebral palsy, in principle the same measurements can and should be tracked. However, in some cases fixed joint contractures, the presence of scoliosis, involuntary muscle spasms, or poor cooperation due to cognitive deficits can make height difficult to measure in a consistent, repeatable way. Weight measurements may also be problematic, though relatively simple devices to assist with this are available (e.g., wheelchair scales).

Body mass index (BMI) is a commonly reported measure of weight for height and is often considered a reasonable proxy for body-fat composition in the general population. BMI is obtained by dividing weight, in kilograms, by the square of height in meters. As such, BMI may be problematic for children with cerebral palsy due to the difficulties in measuring height.

A number of approaches have been proposed to deal with the complication of measuring stature in children with more severe CP. Formulae have been developed for estimating height based on measurements of upper arm length, tibial length, and knee height. Each of these can be obtained in a more consistent manner than head-to-heal height in children with severe CP (Stevenson, 1995). Caution is required when relying on measurements of lower limbs, such as tibial length, as a surrogate for overall stature in children with the diplegic form of CP, as the neurological deficit primarily involves the lower limbs and may impair their growth disproportionately. Much of the work in this area has been strictly descriptive, but Stevenson et al. (2006b) have linked some of these alternative measurements to the children's overall health and social participation.

Other easily obtained measurements of growth that have been studied in CP include tricep or subscapular skinfold thickness (Henderson et al., 2007; Spender et al., 1988; Stallings et al., 1993b, 1995; Stevenson et al., 2006b; Zainah et al., 2001), mid-upper-arm muscle area (Henderson et al., 2007; Stevenson et al., 2006b), upper-arm length (Stevenson et al., 2006b), and mid-arm circumference (Zainah et al., 2001).

101.3 History of Growth Charts for Children with CP

Studies going back to the 1950s have demonstrated that heights and weights of children with CP are often significantly below accepted norms for the general population. A good summary of earlier literature on this subject, together with what were apparently the first CP-specific growth charts, was provided by Krick et al. (1996). The charts provided curves for 10th, 50th, and 90th percentiles of weight-for-age, length-for-age, and weight-for-length, smoothed by way of cubic splines (Koenker et al., 1994). They were based on 1,630 observations of 360 children with relatively severe quadriplegic CP. Percentiles of weight and height/length for this population were significantly lower than age- and sex-matched percentiles from the (then available) 1979 NCHS references (Hamill et al., 1979). These CP growth charts have since been widely cited and are available on the Internet at the Kennedy Krieger institute web site (Kennedy Krieger Institute, 2009).

To what extent the Krick et al. (1996) charts might be representative of all children with cerebral palsy was unknown. The authors noted a number of factors that were worthy of further investigation as to their possible impact on growth in quadriplegic CP. These included prenatal and perinatal factors, familial growth patterns, endocrine status, role of nutrient intake, number and type of surgical procedures, overall health status, body composition, use of medication, socioeconomic status, and place of residence. Conspicuously absent from this list was level of independent gross motor functioning or feeding ability (though these may have been thought to fall under the umbrella of overall health status). The study (Krick et al., 1996) was based on growth of children with quadriplegic CP who were "unable to initiate movement" and who had "limited physical activity." Roughly 40% received nutrition via a feeding tube. Common sense would suggest that children with very mild CP (even if involving all four limbs) might follow a pattern of growth above the norms provided in the Kennedy Krieger Institute's charts. More recent studies have confirmed this (Day et al., 2007; Stevenson et al., 2006b).

In 2006, Stevenson et al. conducted a study of growth and its association with health in children with moderate to severe cerebral palsy (Stevenson et al., 2006b). The study group was stratified by Gross Motor Classification System (GMFCS) levels (Palisano et al., 2008). The GMFCS is a validated system to classify persons with cerebral palsy according to their level of independent gross motor functioning. The levels are summarized briefly in Table 101.2.

Table 101.2 Gross Motor Function Classification System (GMFCS)

GMFCS level	Brief description
I	Walks without limitations
II	Walks with limitations
III	Walks using a hand-held mobility device
IV	Self-mobility with limitations; may use powered mobility
V	Transported in a manual wheelchair

Children in the Stevenson et al. study were of GMFCS levels III–V, and approximately 40% of those at GMFCS level V had feeding tubes. Children with higher levels of gross motor functioning tended to have greater weights and lengths for age. Among the lowest functioning group (GMFCS V), those with feeding tubes were, on average, heavier.

Another question raised in this study was whether the curves they developed, or indeed any growth curves for cerebral palsy, should be used clinically to track the growth of children with cerebral palsy. They ultimately decided against making their own charts available for this purpose, observing that:

> . . . because the representative sample of children with CP used to develop the curves likely included children with confounding secondary conditions of acute and chronic malnutrition and growth hormone deficiency, we decided against the idea. We were concerned that clinicians might use these growth curves as 'prescriptive' for the population.

In their view further research was needed before their curves (and perhaps any available curves) could be meaningfully used in a clinical setting.

In 2007 reference curves for percentiles of weight, height, and BMI for children with cerebral palsy from age 2 to 20 based on a very large database from the California Department of Developmental Services (DDS) were published (Day et al., 2007). These charts were stratified by level of gross motor function and feeding ability and have added to the evidence that growth of children with CP varies considerably depending on the level of severity. As would be expected, the resulting charts showed that children with less severe CP have growth percentiles closer to those of the general population (as represented by national or international reference charts), while those with the most severe CP have growth percentiles below even those published previously for children with relatively severe quadriplegic CP (Krick et al., 1996). The charts were based on cross-sectional data and illustrated percentiles of weight-, height-, and BMI-for-age.

At the time of publication of the Day et al. study, it was noted that although the charts were certainly of some value, further research would be needed to link easy-to-obtain, reliable, and inexpensive body measurements with markers of health (Stevenson and Conaway, 2007). In spite of the lack of such an evidence-based link and to encourage the undertaking of research to identify one, the authors made the full set of charts available for download at www.LifeExpectancy.org/Articles/GrowthCharts.shtml. The charts have been used by a number of nutritionists and other health-care professionals, and some have provided valuable feedback to the authors. The charts have recently been included in an appendix in the textbook by Sullivan (2009).

101.4 New Growth Charts for CP

We have now revised the growth charts described in the previous section and present them in this chapter (Figs. 101.1–101.24). The new charts are based on the same source data as described previously (Day et al., 2007), but the analysis and presentation of the data have been modified as we will describe shortly.

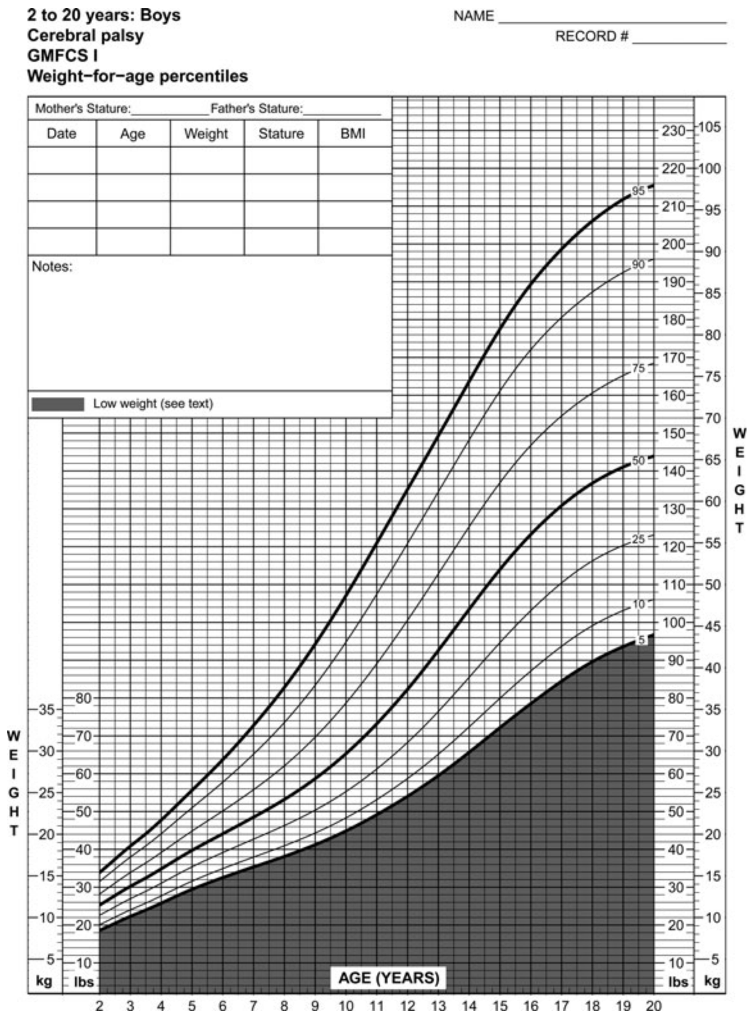

Fig. 101.1 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Boys GMFCS I weight-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services and California Bureau of Vital Statistics. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

The data are measurements of height and weight and calculated BMI of children with cerebral palsy ages 2–20 years who received services from the State of California's Department of Developmental Disabilities (DDS) between January 1, 1988 and December 31, 2002. The DDS provides early intervention, occupational and physical therapy, equipment, case management, and respite and social services for all state residents with cerebral palsy who have a substantial disability (California Department of Developmental Services, 2010a). Cerebral palsy is defined for this purpose as "(1) a non-progressive lesion or disorder in the brain occurring during intrauterine life or the perinatal period and characterized by paralysis, spasticity, or abnormal control of movement or posture which is manifest prior to 2–3 years of age and (2) other significant motor dysfunction appearing prior to age 18." (California Department of Developmental Services, 2010b) Children with diagnoses suggesting cerebral palsy of postnatal origin (e.g., traumatic brain injury, near drowning, motor vehicle accident, brain tumor, or other injuries or illnesses acquired at older ages) and children

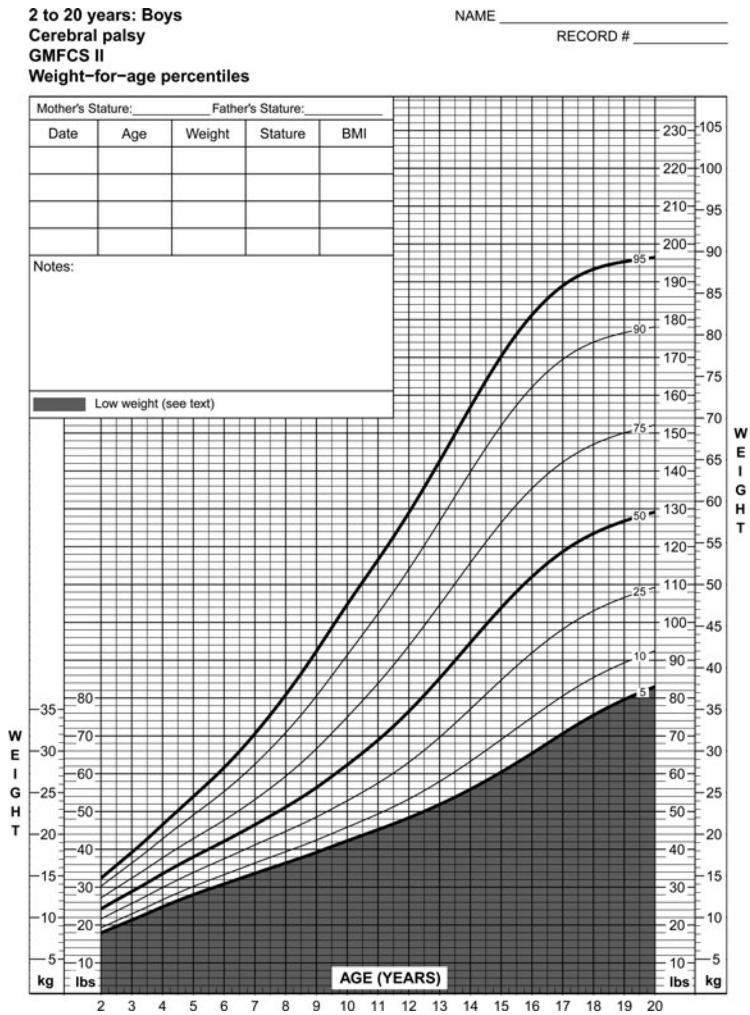

Fig. 101.2 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Boys GMFCS II weight-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services and California Bureau of Vital Statistics. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

with significant concomitant diagnoses (e.g., autism, Down syndrome, degenerative disorders) were excluded from the analyses. Data on each child receiving services from the DDS, including information on height, weight, and gross motor functional abilities, are recorded annually on an instrument called the Client Development Evaluation Report (CDER). Various sets of data from these CDERs have been the basis for many previous studies of CP, including studies of growth, likelihood of future ambulatory ability, mortality, and causes of death.

The charts presented here differ from those published previously (Day et al., 2007) in the following ways.

1. The percentile curves illustrated in the new charts are based on methodology recommended by the WHO (2006) The Box–Cox power-exponential distribution with four parameters – μ (for the median), σ (coefficient of variation), ν (Box–Cox transformation power), and τ (parameter

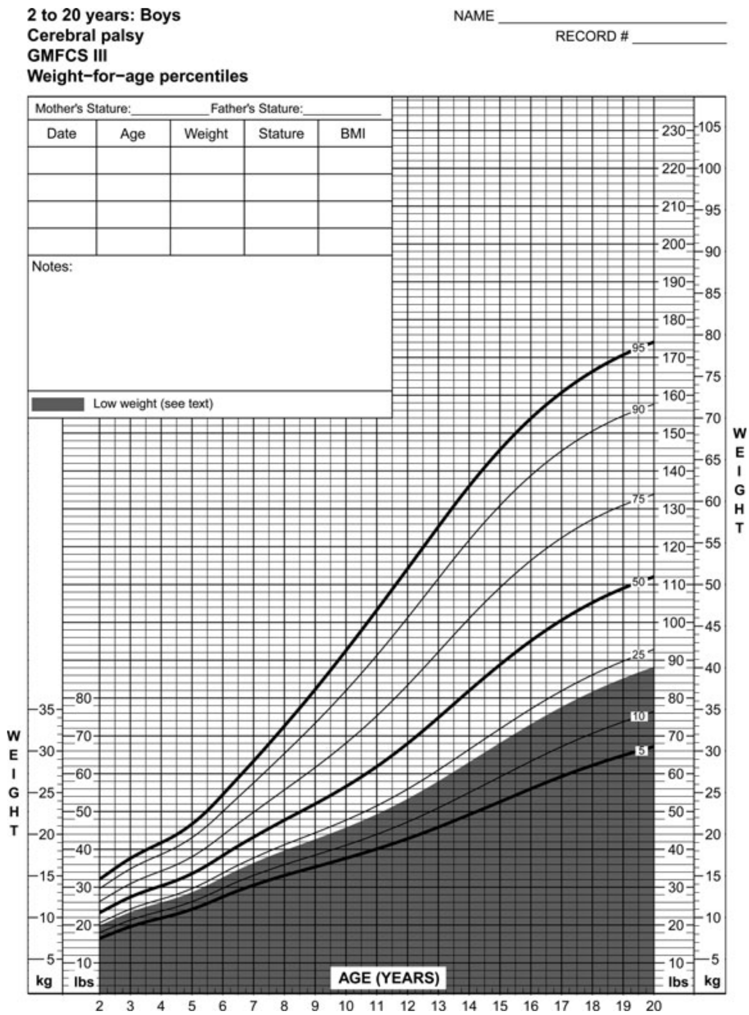

Fig. 101.3 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Boys GMFCS III weight-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services and California Bureau of Vital Statistics. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

related to kurtosis) was used to construct the percentile curves. We used this same method for all growth parameters (weight, height, and BMI). This method is part of a more general methodology, GAMLSS (Generalized Additive Models for Location, Scale and Shape), which includes a broad framework for known methods of constructing growth curves (Rigby and Stasinopoulos, 2004). The methodology is explained and discussed in detail in the references (Rigby and Stasinopoulos, 2004; World Health Organization. Nutrition for Health and Development, 2007).

2. The new charts are stratified by GMFCS level. Because the CDER items do not include a GMFCS score, we approximated GMFCS based on available CDER gross motor function elements. Full details of the algorithm for determining GMFCS from CDER elements are available from the corresponding author of this chapter. GMFCS level V is stratified further according to presence

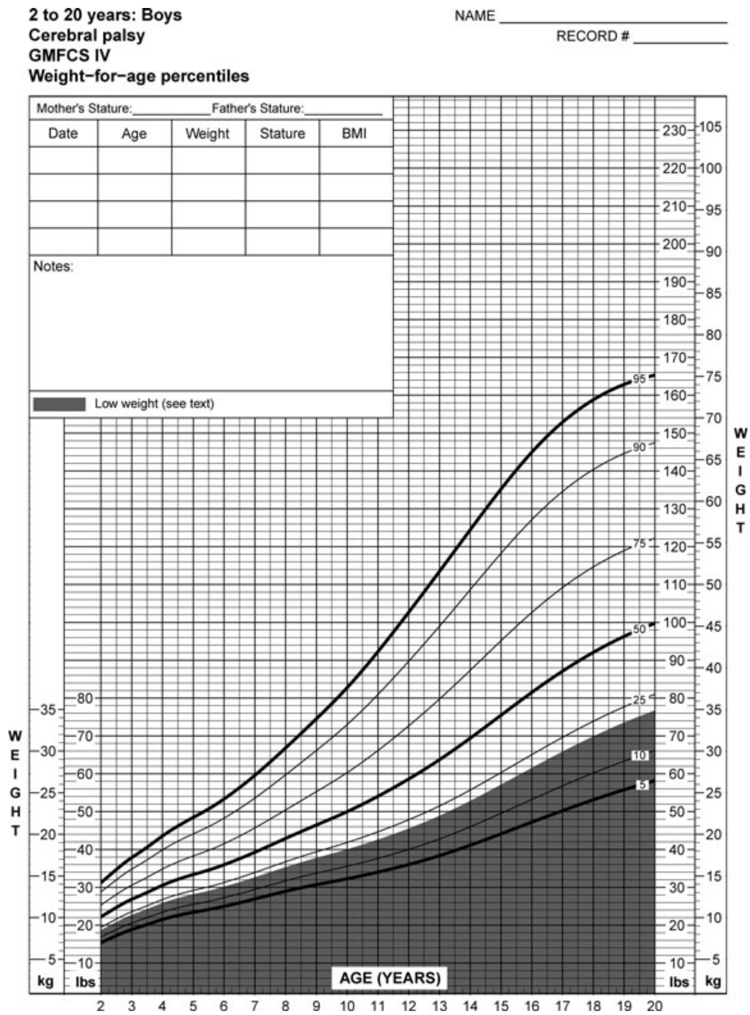

Fig. 101.4 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Boys GMFCS IV weight-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services and California Bureau of Vital Statistics. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

of feeding tube. Numbers of children falling into each GMFCS category by age and sex are shown in Table 101.3.

3. The new charts have been modified to have the same look and features as CDC charts which are familiar to many clinicians and parents.
4. The new weight-for-age charts include an indicator of weight percentiles below which mortality risk is increased (Figs. 101.1–101.12). The analyses involved in determining these low weight zones are discussed further in a subsequent section of this chapter.

The resulting charts showing percentiles of weight-for-age and height-for-age are presented in Figs. 101.1–101.24. The charts show that children with the mildest CP (GMFCS level I) have patterns of growth that are not very different from those of the general population (e.g., as represented

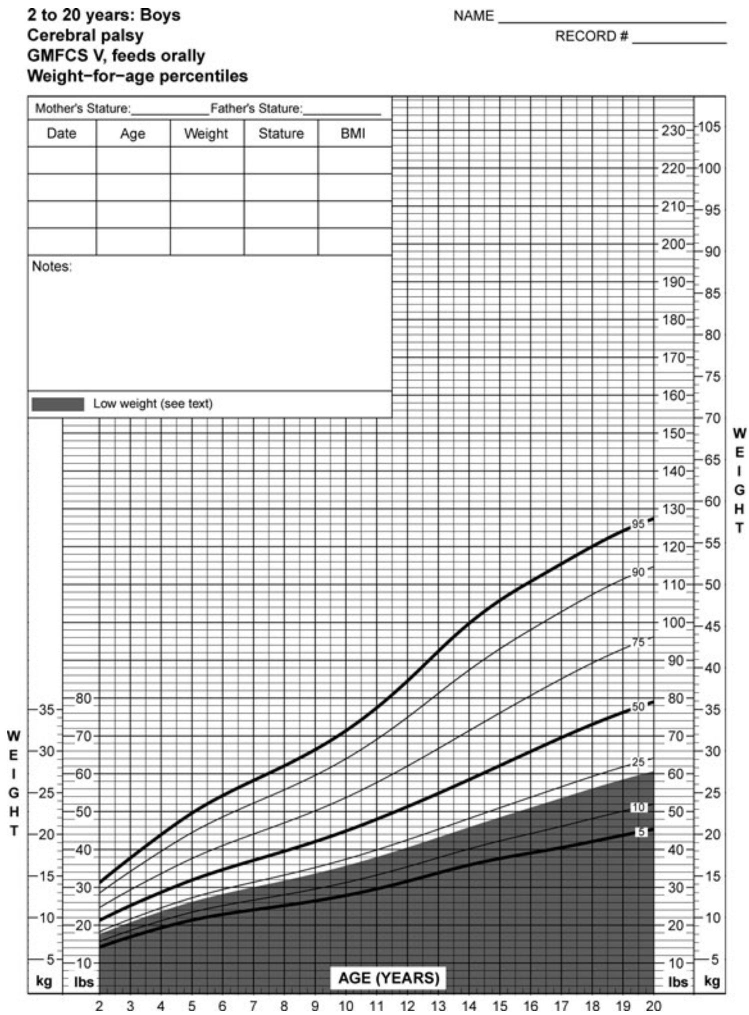

Fig. 101.5 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Boys GMFCS V, feeds orally weight-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services and California Bureau of Vital Statistics. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

by CDC or WHO charts). Children with progressively more severe limitations in gross motor function have progressively lower weights and heights. Among those with the most severe limitations (GMFCS level V), percentiles of weight and height are somewhat higher for those fed by a feeding tube. This is likely to represent an impaired nutritional status in a proportion of orally fed children and might suggest that optimal nutritional status in these very severely impaired individuals is better represented by the weights of those who are tube fed. However, in clinical practice a small number of tube-fed children are significantly overweight and this may have affected the results to a degree.

Full color versions of the new growth charts for CP, including charts of percentiles of BMI-for-age (not shown in this chapter), are available at: http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml.

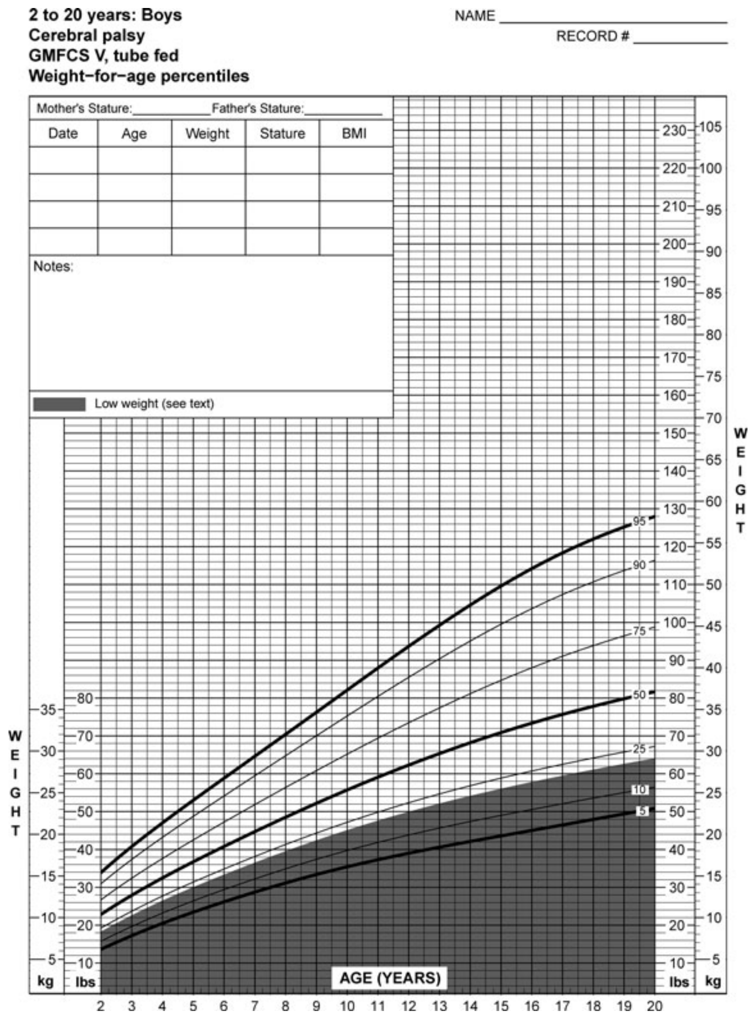

Fig. 101.6 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Boys GMFCS V, tube fed weight-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services and California Bureau of Vital Statistics. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

101.5 Links Between Growth and Other Health Outcomes

It would be helpful to know whether growth that is tracking below or above a certain percentile on available growth charts for CP should, in and of itself, raise concerns regarding overall health or even a narrow aspect of health for an individual. Toward this end a number of studies have identified links between health outcomes and growth in CP. Evidence now suggests that among children with cerebral palsy of a given level of gross motor functioning, those with lower weights, smaller stature, or less fat, muscle, or bone density have poorer health. The link between such outcomes and percentiles on available growth charts is only beginning to emerge.

Stevenson et al. studied the association of growth (measurements including weight, knee height, upper arm length, mid-upper arm muscle area, triceps skinfold, and subscapular skinfold) with

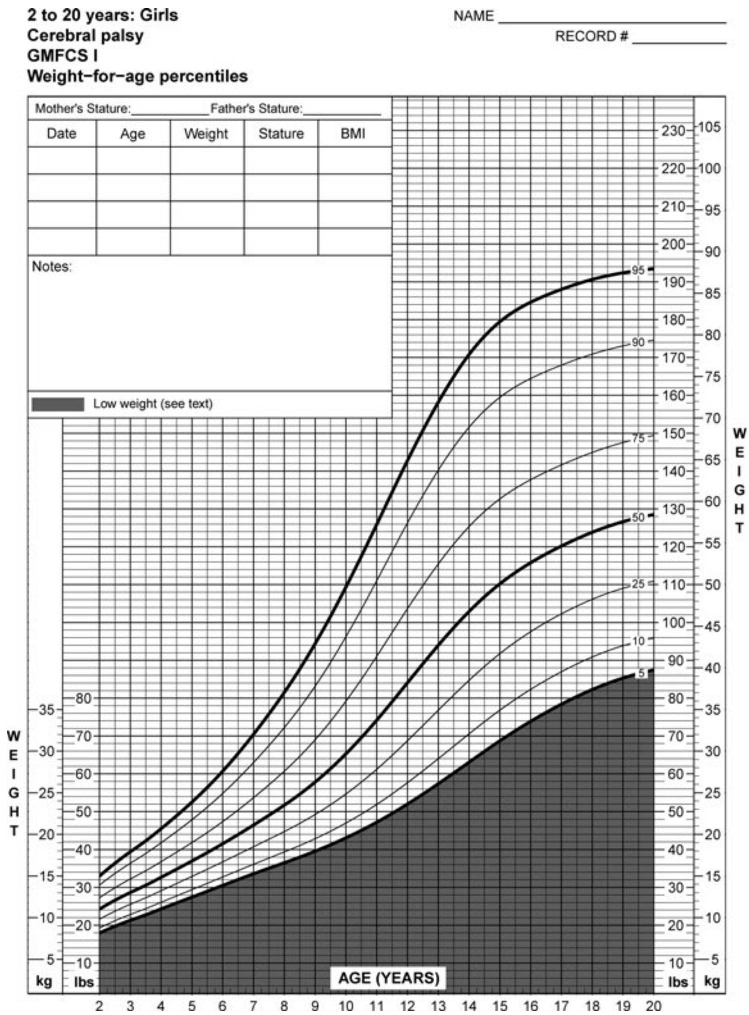

Fig. 101.7 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Girls GMFCS I weight-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services and California Bureau of Vital Statistics. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

health-care use and social participation (Stevenson et al., 2006b). They concluded that "Bigger children with CP had better health and social participation than similar smaller children." Though the authors did present charts of weight and knee height in this study, no direct link was made between measurements on the growth charts and the health outcomes studied.

A significant association between mid-upper arm fat area and subscapular skinfold thickness with health-care utilization, child's social participation, and the impact on family activities has been reported (Samson-Fang et al., 2002). For example, 1 SD decrease in mid-upper arm fat area was associated with a 28% increase in doctor visits, a 31% increase in days missed from school, and a 51% increase in missed activities for the family throughout the preceding 4 weeks.

Stevenson et al. (2006a) showed that greater body fat (as measured by triceps skinfold thickness) is associated with greater risk of bone fractures in children with moderate to severe CP. Currently

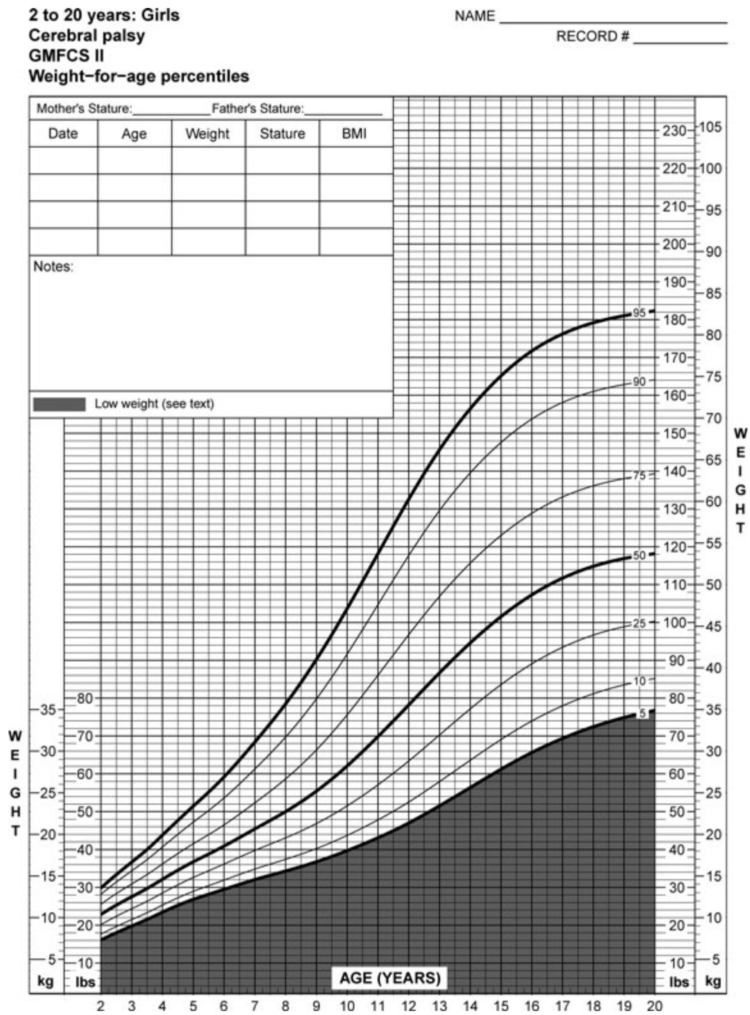

Fig. 101.8 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Girls GMFCS II weight-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services and California Bureau of Vital Statistics. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

these authors and others at the North American Growth in Cerebral Palsy Project are investigating a number of alternative measurements of growth and body composition for CP and their relationships to health outcomes.

101.6 Low or High Weight-for-Age and Health in CP: Preliminary Findings

We have thus far only preliminary findings on the association of general health measures with weight percentiles illustrated in Figs. 101.25 and 101.26. On the CDERs that are the source of data for the current growth charts, *chronic major medical conditions* are those "that limit or impede the client or significantly impact the provision of service" (California Department of Developmental Services, 1986). Excluded from this category of chronic major medical conditions are CP itself; any

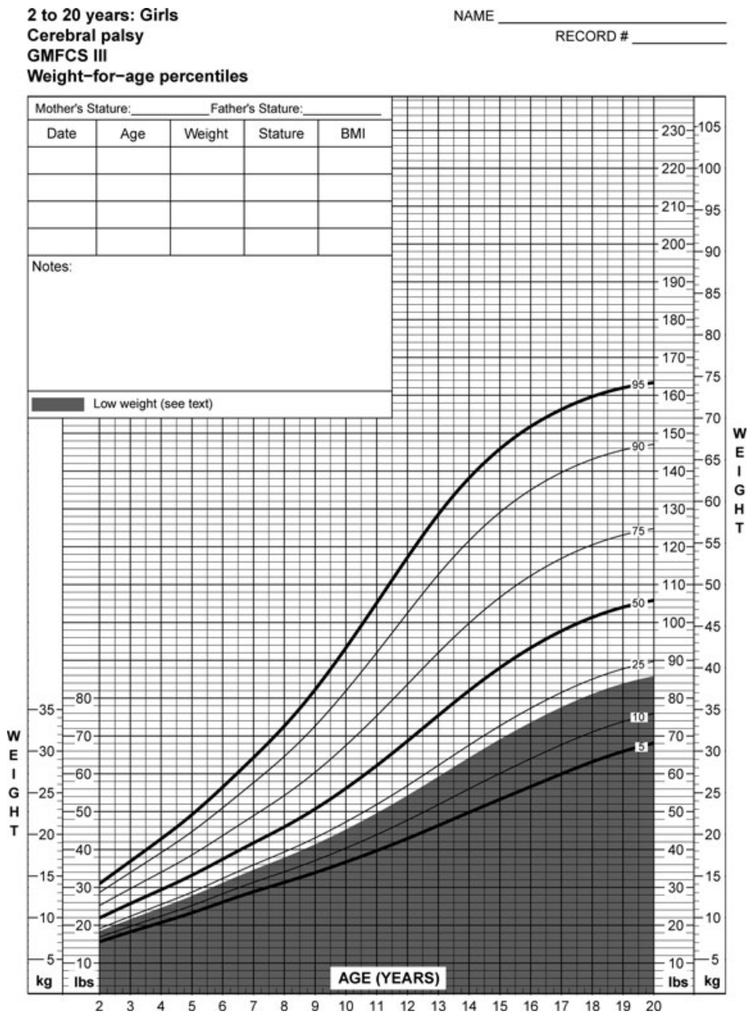

Fig. 101.9 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Girls GMFCS III weight-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services and California Bureau of Vital Statistics. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

American Association on Mental Deficiency (AAMD) diagnosis; acute and self-limiting illnesses (e.g., pneumonia, measles, etc.); and chronic but non-limiting conditions (e.g., acne). Examples of conditions that *are* considered chronic major medical conditions for purposes of the CDER are diabetes mellitus, chronic hypertension, atherosclerotic heart disease, and chronic upper respiratory infections.

Figure 101.25 shows proportions of persons contributing to the weight-for-age charts in Figs. 101.1–101.12 who have at least one chronic major medical condition, stratified by GMFCS level and quintile of weight. Figure 101.26 shows the mean number of major medical conditions for each GMFCS level and quintile of weight. Both the proportion of children with any chronic major medical conditions and the mean number of chronic major medical conditions are significantly higher for the lowest quintile of weight in GMFCS levels I–IV and for those at GMFCS level V who are orally fed. For those at GMFCS level V who have feeding tubes the lowest quintile was

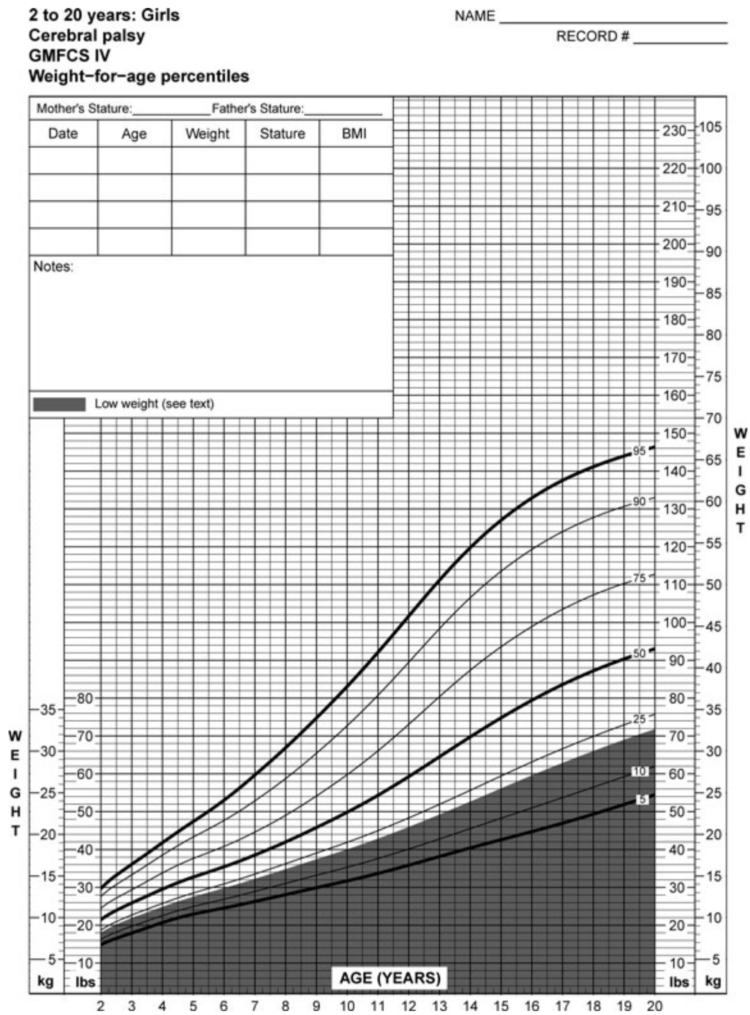

Fig. 101.10 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Girls GMFCS IV weight-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services and California Bureau of Vital Statistics. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

associated with significantly fewer major medical conditions than the middle three quintiles. Neither the presence nor number of major medical conditions was significantly different for the highest quintile of weight compared to the middle three. Further investigation will be required before any definitive conclusions about these relationships can be drawn or recommendations made.

101.7 Very Low Weight Is Associated with Increased Risk of Mortality

To our knowledge, the question of whether poor growth might be associated with an increased risk of mortality in CP has not been addressed previously in the literature. To explore this question we calculated mortality rates for various percentiles of weight and levels of GMFCS (Fig. 101.27). Weights

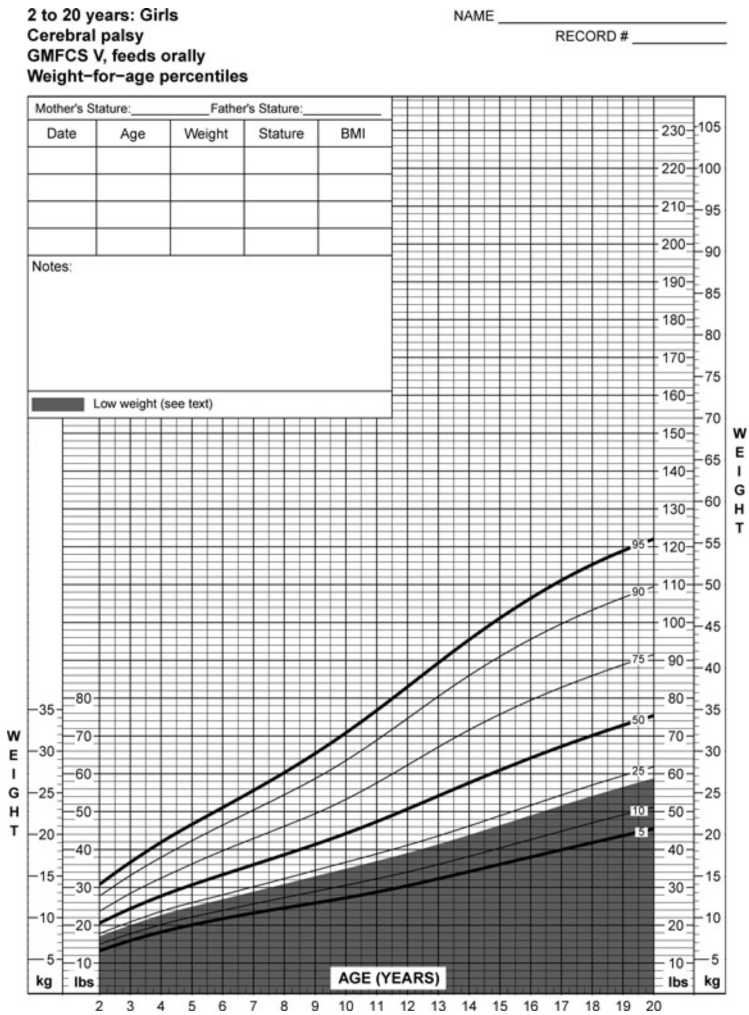

Fig. 101.11 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Girls GMFCS V, feeds orally weight-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services and California Bureau of Vital Statistics. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

below the 20th percentile were significantly associated with increased mortality rates for GMFCS levels II–IV and level V with or without feeding tubes. We subsequently used Cox proportional hazards regression to determine whether the association of low weight with increased mortality risk was independent of other possible predictors, such as level of gross motor functioning, feeding ability, age, and sex. Cutoff percentiles of weight were eventually determined for each GMFCS level such that weights below these cutoffs were associated with increased mortality. The areas beneath the cutoffs are indicated with shading in Figs. 101.1–101.12.

It may seem that BMI should have been a better choice for determining a cutoff for increased mortality risk. If fair numbers of persons were of very low weight due in part to being of very low stature, this may have diluted the association of very low weight with mortality risk. Interestingly, however, very low weight proved to be a stronger predictor of increased mortality than very low BMI in multivariate Cox models.

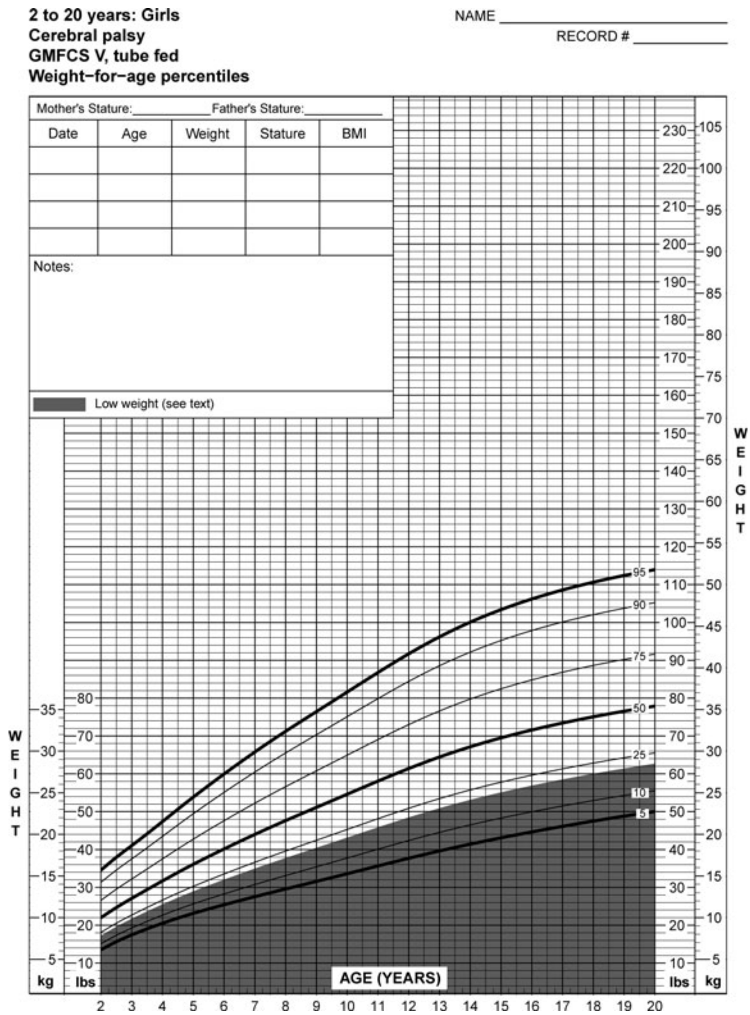

Fig. 101.12 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Girls GMFCS V, tube fed weight-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services and California Bureau of Vital Statistics. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

These analyses were recently presented at the 63rd annual meeting of the American Academy of Cerebral Palsy and Developmental Medicine, and a more complete description of them has been published in *Pediatrics* (Brooks et al., 2011).

101.8 Overweight and Obesity in Cerebral Palsy

For children in the general population, obesity is often defined to be a BMI at or above the 95th percentile on CDC growth charts for a given age and gender. A person is overweight if BMI is between the 85th and 95th percentile. For the general population, it is well documented that obesity in childhood is associated with a number of morbidities and increases the risk of obesity in adulthood (Whitlock et al., 2005). It is unclear whether the same definitions of overweight and obesity make sense for children or adolescents with CP or whether the same should apply at all levels of GMFCS.

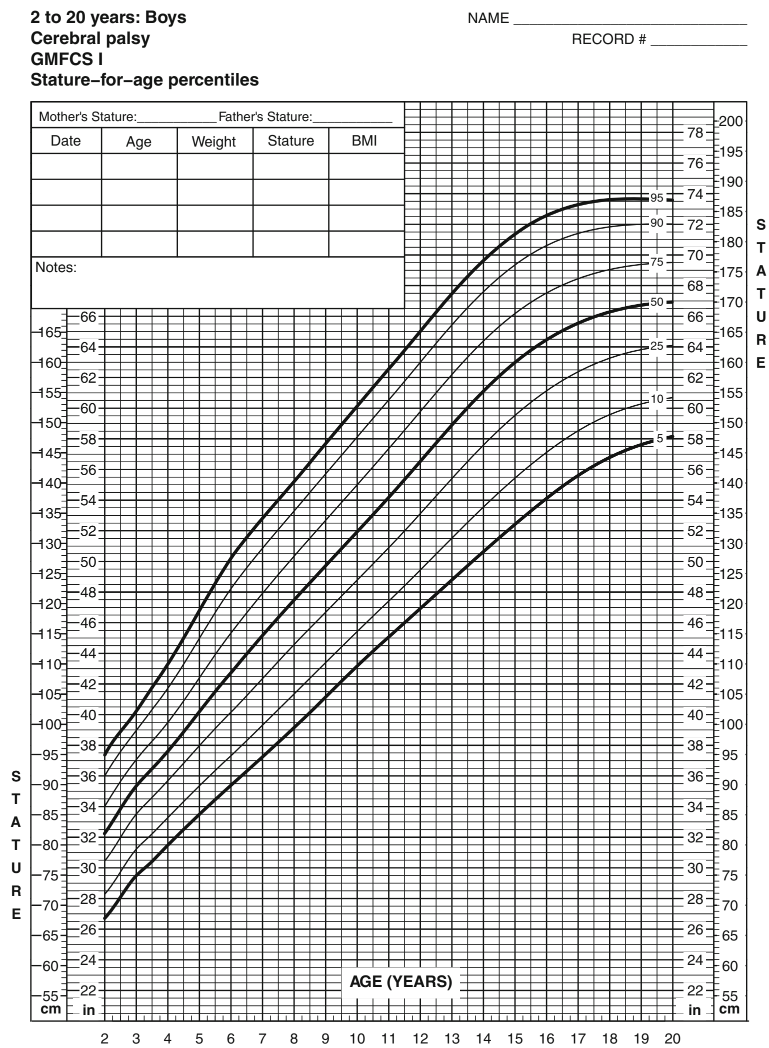

Fig. 101.13 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Boys GMFCS I stature-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

The prevalence of obesity, according to the foregoing definition, in ambulatory children with cerebral palsy has been estimated (Rogozinski et al., 2007). This study found that the prevalence of obesity in this population increased from 8% in 1994–1997 to 17% in 2003–2004. Children with higher levels of functioning had a greater chance of being obese in all time periods studied. A higher prevalence of obesity in ambulatory children with CP (GMFCS levels I and II) compared with non-ambulatory children (GMFCS levels IV and V) has been reported elsewhere as well (Hurvitz et al., 2008).

A number of complications arise when considering the possible health implications of obesity in CP. First, the definition of obesity must be considered. In the general population, the definitions of obesity and of overweight are based on evidence that when BMI falls in these categories risks of

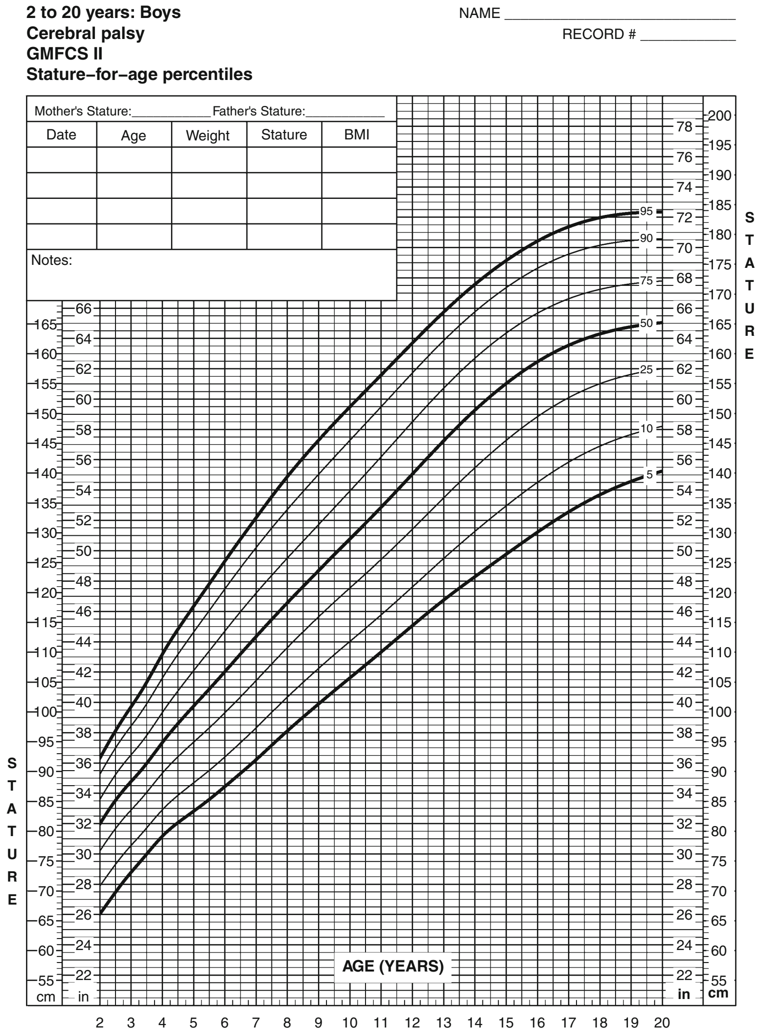

Fig. 101.14 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Boys GMFCS II stature-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

various negative health outcomes are increased. According to the definition of obesity used in the studies discussed above, i.e., that obesity is a BMI greater than the 95th percentile on CDC charts, ambulatory children with CP (GMFCS levels I and II) are reportedly more likely to be obese than persons in the general population (Hurvitz et al., 2008; Rogozinski et al., 2007). The new BMI-for-age charts for CP (http://www.LifeExpectancy.org/NewGrowthCharts.shtml) confirm this. On these charts, the 95th percentiles of BMI for GMFCS levels I and II are significantly higher than the 95th percentiles in the GP. On these charts, patterns of BMI-for-age for other GMFCS levels are markedly different than for the GP, with percentile curves being basically flat. This raises serious questions about using general population definitions of obesity in these more involved groups of

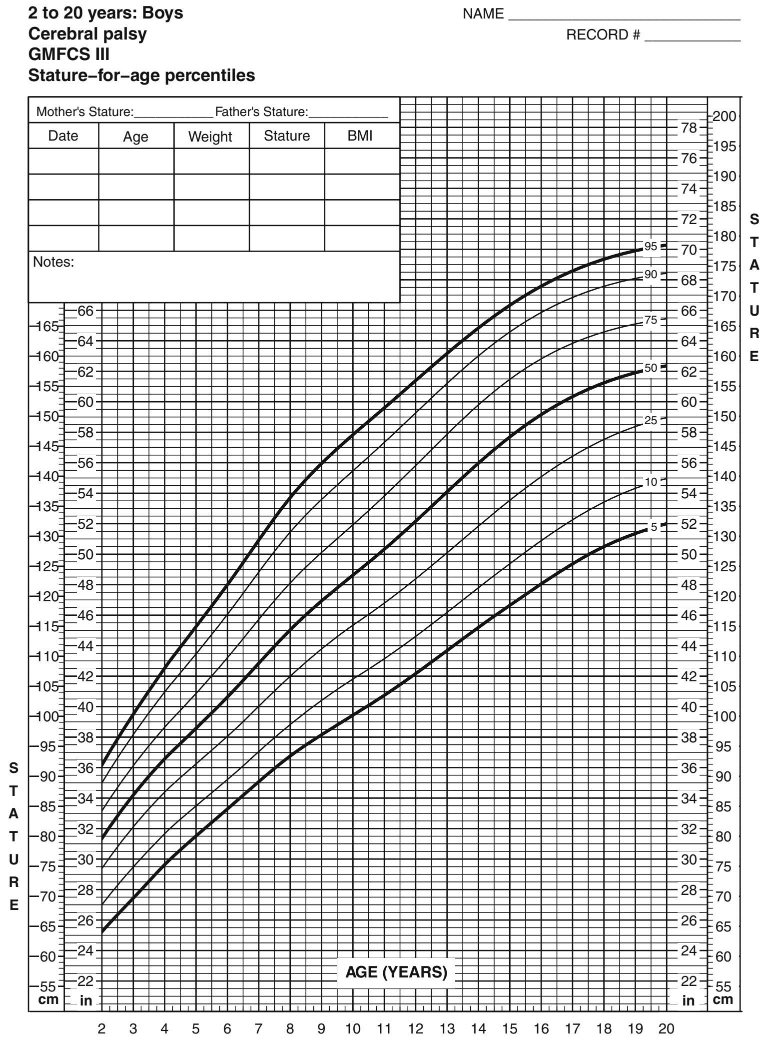

Fig. 101.15 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Boys GMFCS III stature-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

children with CP. Evidence linking BMI with poor health in the CP population is lacking. This is true even among ambulatory children with CP, though general population evidence is presumably more pertinent to these groups.

The difficulty in measuring height accurately for children with CP is a challenge that will have to be addressed before a given percentile of BMI can be used as a cutoff for obesity in this population. Preliminary investigations revealed a mixed association of high BMI with mortality or presence of chronic major medical conditions.

In the general population many health complications associated with obesity, including increased mortality risk, do not manifest until well into adulthood. Further research is needed before obesity in CP can be meaningfully linked with the growth charts presented here (or any growth charts) or with health outcomes in CP generally.

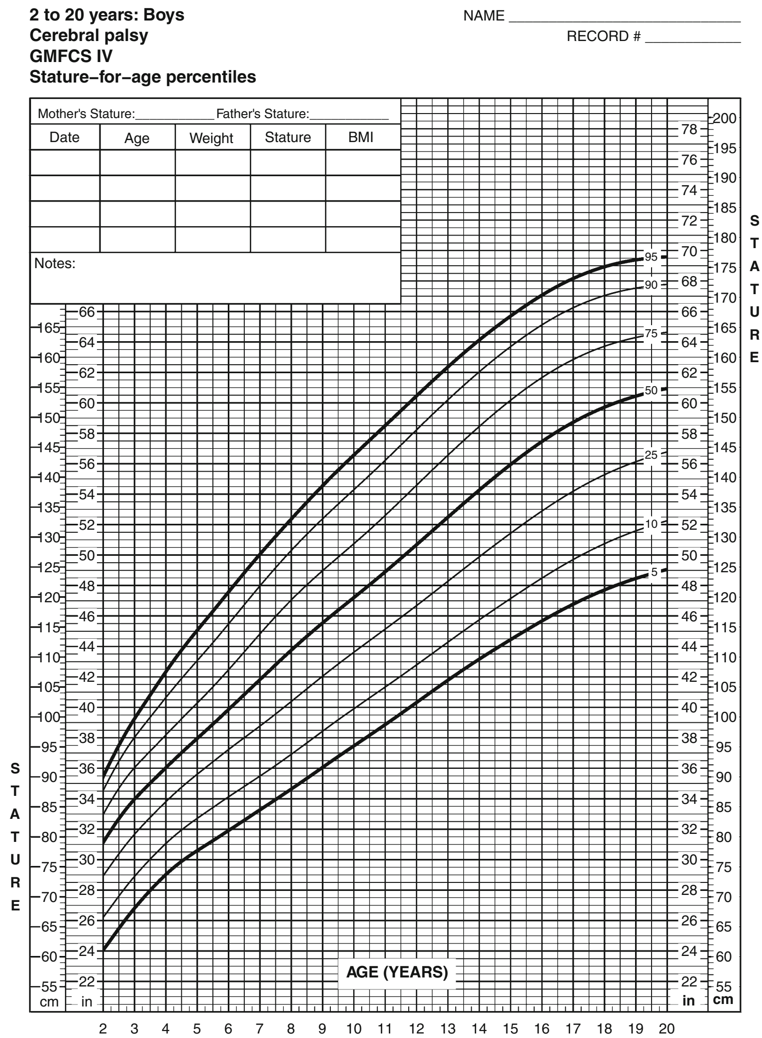

Fig. 101.16 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Boys GMFCS IV stature-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

101.9 Should the New Growth Charts for CP Be Considered References or Standards?

In a discussion of the general principles of growth charts, the CDC observes:

> The distinction between a growth reference and a growth standard is relevant to the development and application of growth charts. The WHO working groups have defined a reference as a tool for providing a common basis for purposes of comparison, and a standard as embodying a concept of a norm or target, that is, a value judgment. In simple terms, a reference describes ''what is,'' whereas a standard prescribes ''what should be.'' In practice, however, reference values are often used as a standard. Growth references are intended to be used to screen and monitor growth in individuals and populations. They are not intended to be the sole independent diagnostic instruments upon which clinical decisions are made (Kuczmarski et al., 2002).

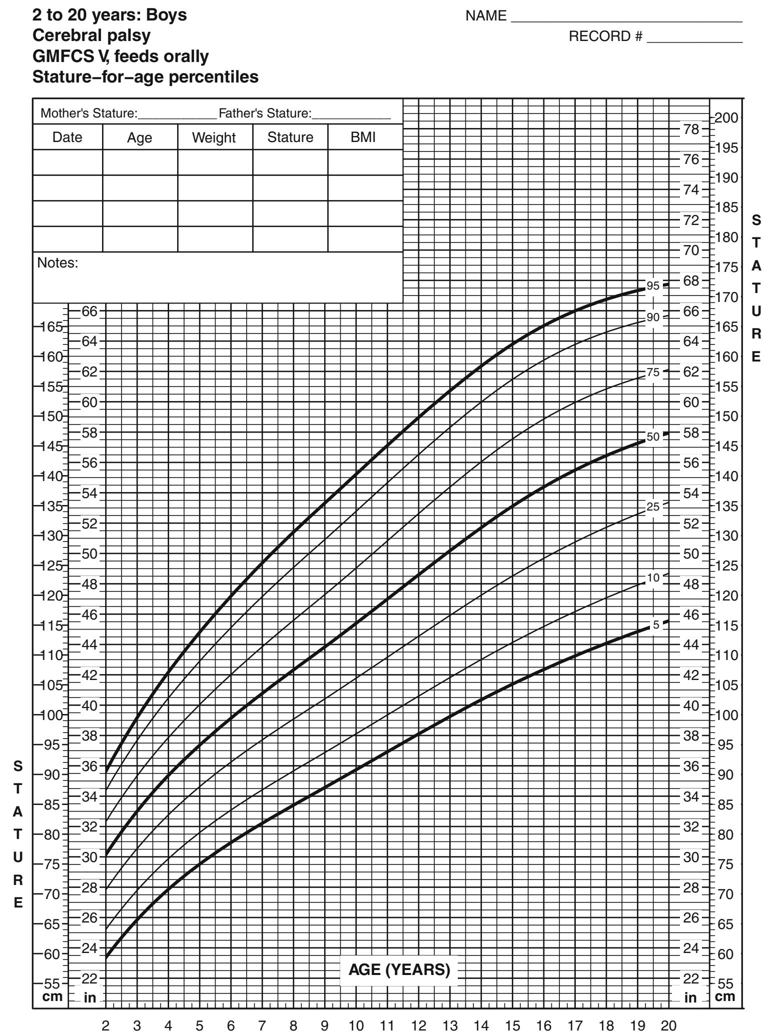

Fig. 101.17 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Boys GMFCS V, feeds orally stature-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

In the sense described, the new growth charts for CP presented in this chapter must be viewed as references rather than standards. Though the low weight zones shown in the charts offer some guidance on weights that are too low, thus describing what in some sense *should not be*, overall the charts describe *what is* for a large population of children with CP in California during the years 1988–2002. As such the charts provide a valuable basis for comparison, but leave value judgments to the clinicians who might use them. With some common sense and caution (see the next section), the charts will provide guidance useful for screening and monitoring growth in individuals with CP.

It has been suggested that charts for healthy children with CP, similar to the WHO charts for healthy children in the general population, might be created by identifying a group of children with CP in "good health" and describing their growth (Kuperminc and Stevenson, 2008). This would

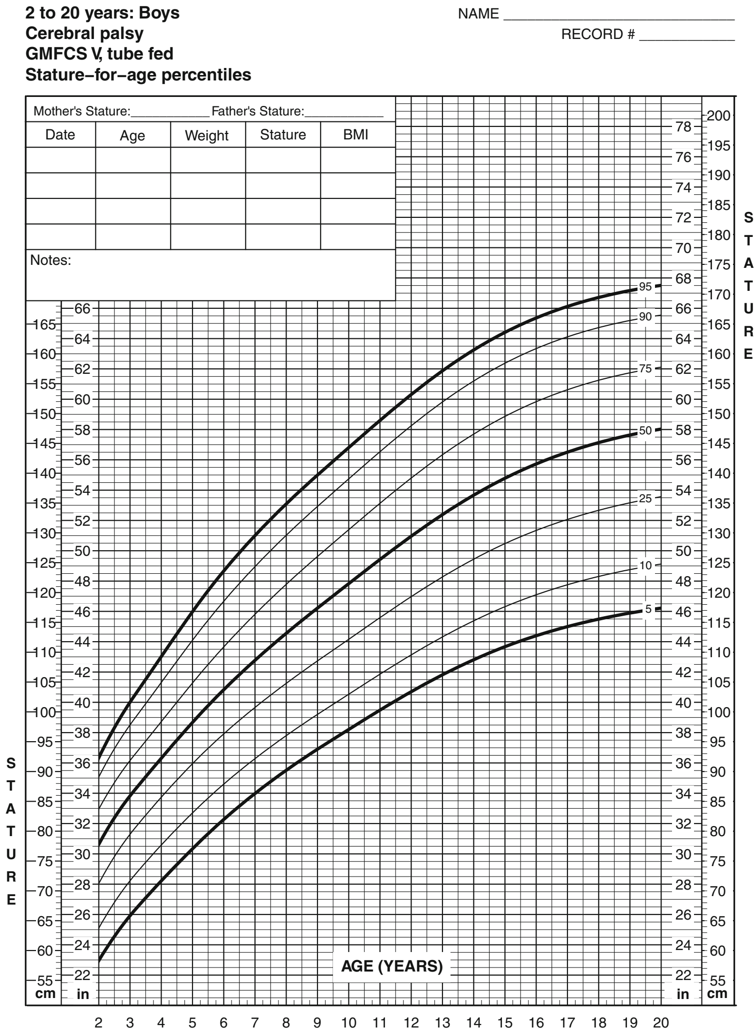

Fig. 101.18 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Boys GMFCS V, tube fed stature-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

undoubtedly be a worthy endeavor. What is meant by "good health" in CP, especially for children at GMFCS levels IV or V, will require considerable deliberation.

101.10 Using the Growth Charts

The format of the weight-for-age charts in Figs. 101.1–101.12 and stature-for-age charts in Figs. 101.13–101.24 should be familiar to most clinicians and many parents or guardians, and their use will likely need no explanation. Nevertheless, some cautionary notes are in order.

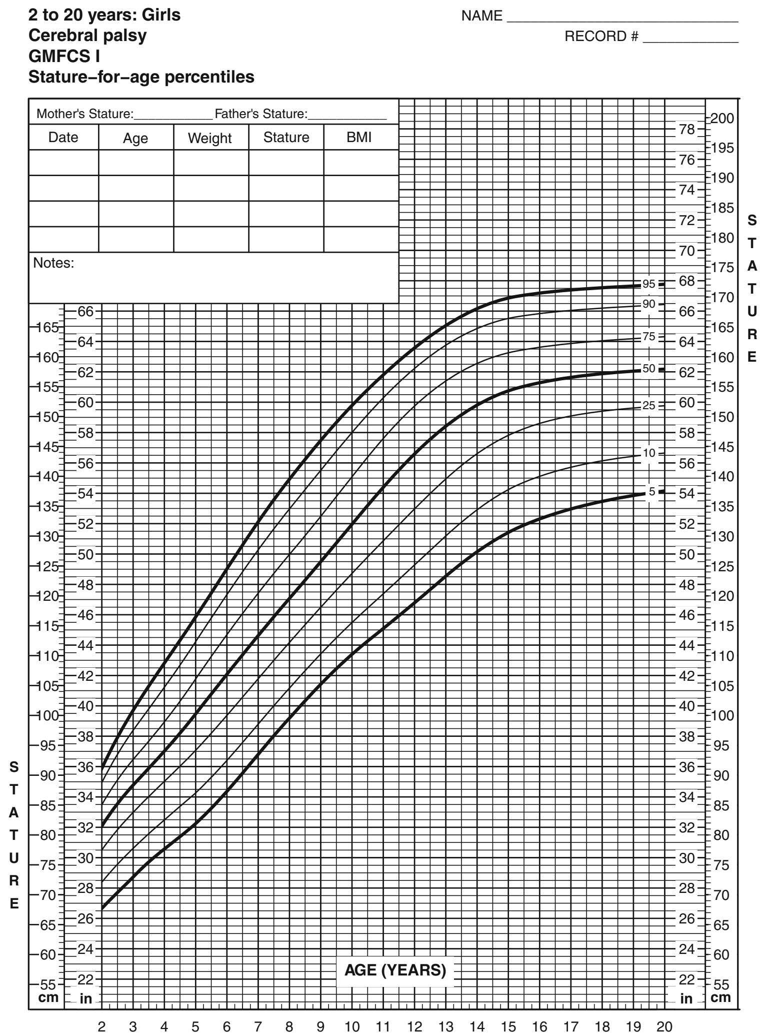

Fig. 101.19 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Girls GMFCS I stature-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

1. The charts are based on a cross-validated measurement of weight and an unvalidated measurement of height of children receiving services from the California Department of Developmental Services from 1988 to 2002. As such, these charts are representative of the CP client base of the DDS during this period. With a total of 25,545 persons with cerebral palsy aged 2–20 years living in their own homes, small group homes, or in the larger developmental centers, this client base is likely very representative of the CP population in California. It has been suggested that persons with the highest level of functioning may voluntarily withdraw from the system. If this were the case, the growth charts for GMFCS level I would perhaps underestimate percentiles of weight and height for the overall GMFCS level I CP population in California.
2. It should be borne in mind that growth may vary depending on care setting. For example, Henderson et al. reported that after controlling for age, GMFCS level, and use of a feeding tube,

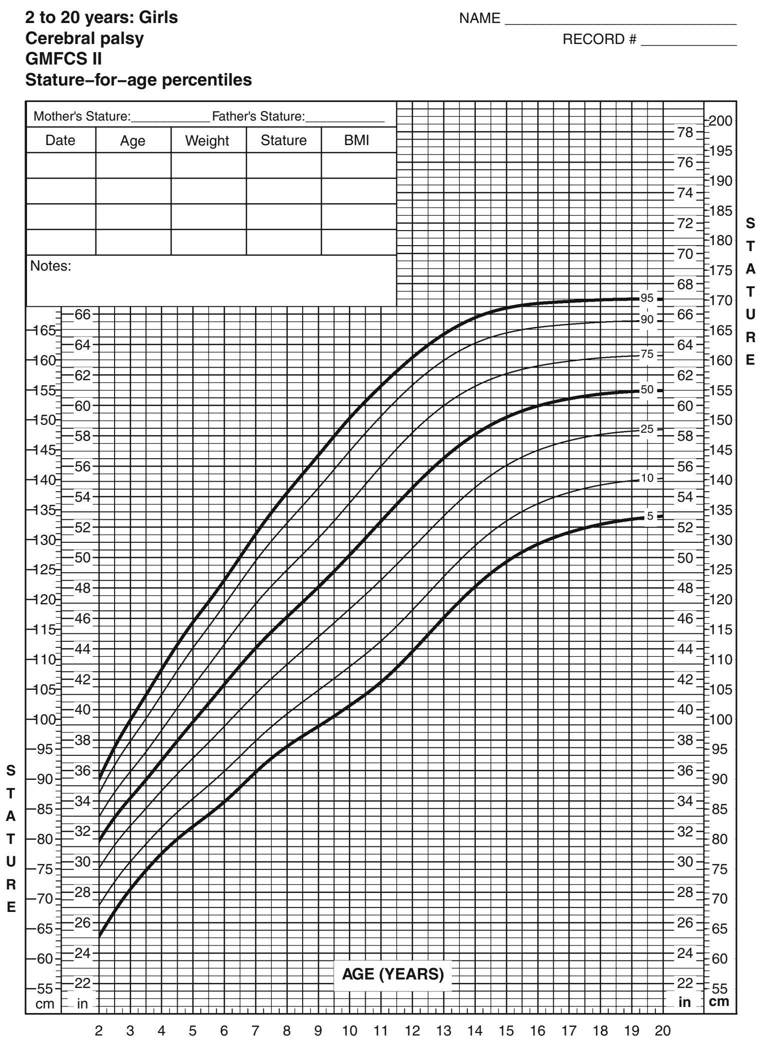

Fig. 101.20 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Girls GMFCS II stature-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

persons with CP living in residential care centers had significantly greater weight, height, skinfold thickness, and mid-arm muscle area *Z*-scores than persons living in their own homes (Henderson et al., 2007). They conjectured that for persons with particularly complex health-care needs, the close proximity of physician, nursing, physical therapy, respiratory therapy, and nutrition services in the residential care centers may be of a quantity and quality that are difficult to obtain in a personal home setting. A majority of the children contributing to the data used to produce the charts presented here were living in their own homes or in small group homes. The percentage varies according to GMFCS level, with a higher percentage of GMFCS level V children being cared for in the larger developmental centers. How the charts might differ if we used only data on children who were living in California developmental centers is not known at present, but the Henderson et al. results would suggest that percentiles for both weight and height may be somewhat higher.

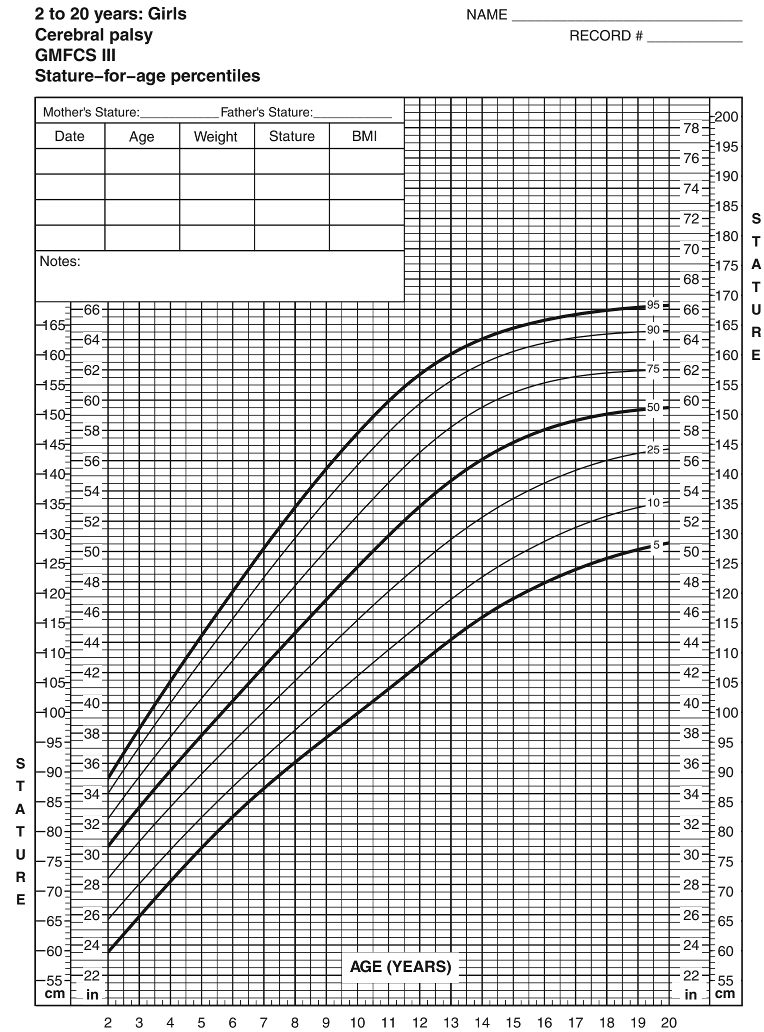

Fig. 101.21 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Girls GMFCS III stature-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

3. The low weight zones on the charts of weight-for-age (Figs. 101.1–101.12) provide some indication of potentially poor growth. However, if a child's weight is classified as 'low' on the charts, caution must be exercised in interpreting this and in relaying it to the individual or to family members. A number of factors must be considered for an individual child before one comes to any definitive conclusions. For one thing there may be a benign reason for such a low weight. For example, the child may be recovering from an illness or from major surgery or the child's parents may be especially small.
4. The marked "low weight" zones should not be viewed as an indicator of a specific condition that is likely to lead to early death. Rather they make the point that impaired nutritional status is a non-specific risk factor that requires further investigation. For children in GMFCS levels III–V, weight below the 20th percentile was associated with a 1.5-fold increase in mortality risk. For

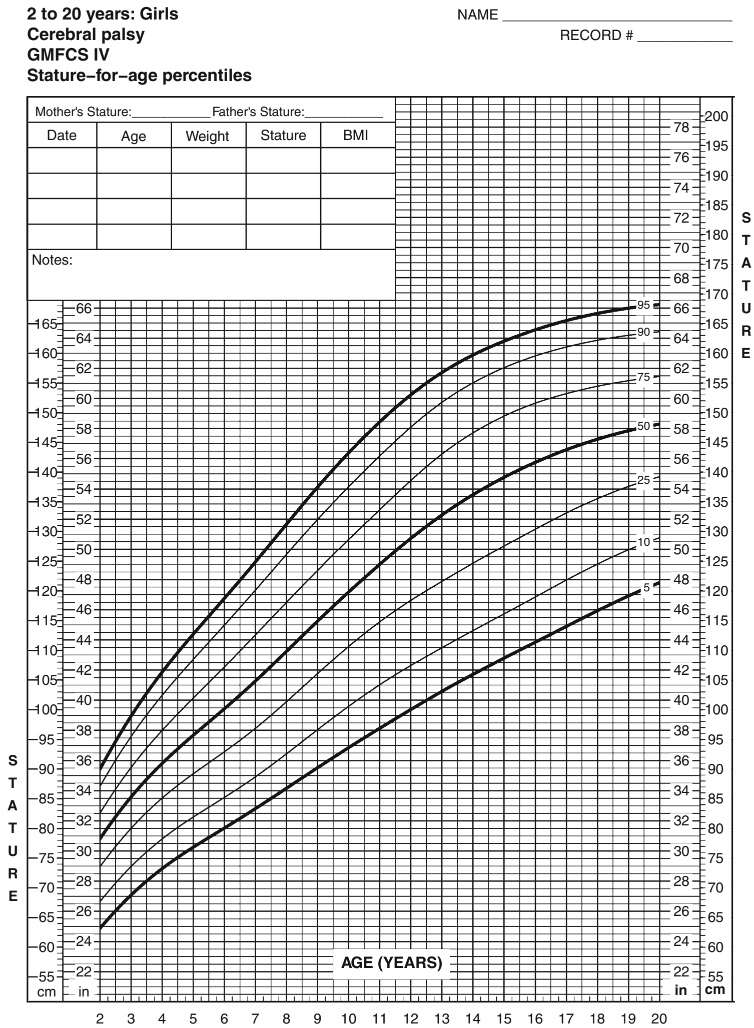

Fig. 101.22 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Girls GMFCS IV stature-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

children in GMFCS levels I and II, weight below the 5th percentile was associated with a 2.2-fold increase mortality risk. As the absolute mortality rates varied from roughly 1.5 deaths per thousand person-years for GMFCS I to 50 deaths per thousand for GMFCS V with feeding tube, the increase in mortality associated with the shaded low weight zone ranges from roughly 1 to 25 extra deaths per thousand person-years. Though these numbers represent significant increases in mortality risk, they do not result in anything that could be called terminal.

5. As mentioned previously, charts of height-for-age are based on measurements of height that have not been validated and as such should be used with some caution. Height is notoriously difficult to measure in more severe CP (GMFCS levels III–V). Similarly, caution must be exercised in interpreting the BMI charts (not presented here, but available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml) as BMI is calculated using these same measurements of height.

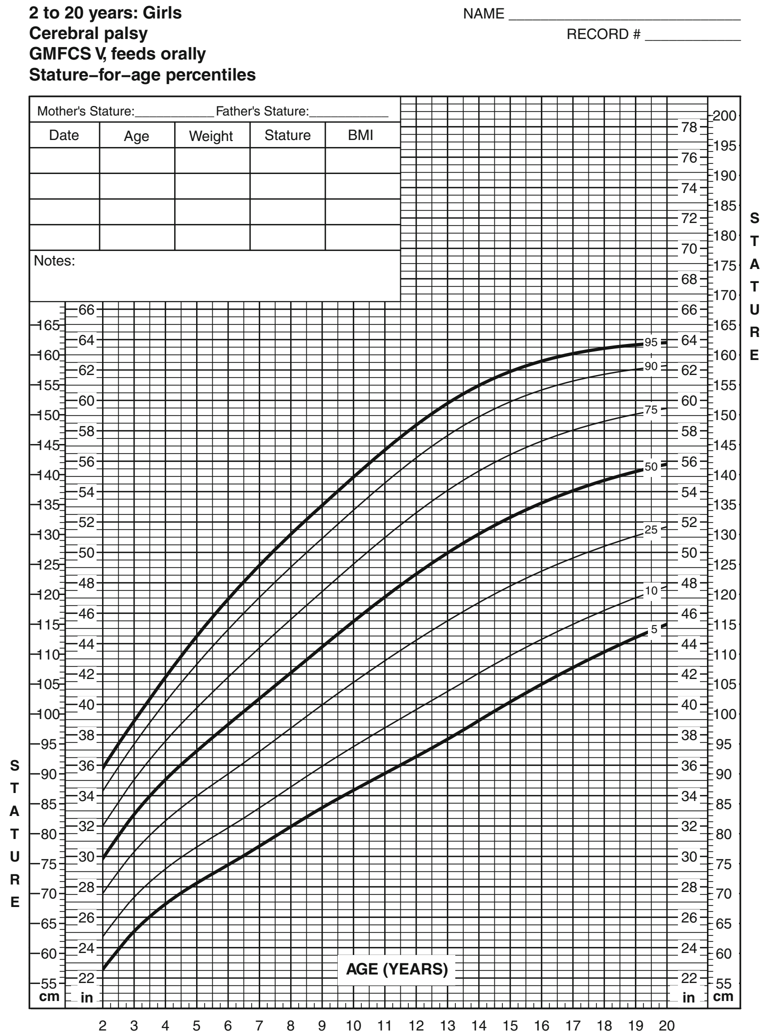

Fig. 101.23 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Girls GMFCS V, feeds orally stature-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

101.11 Applications to Other Areas of Health and Disease

The growth charts presented in this chapter are unlikely to apply to children with conditions other than CP. Children with progressive brain lesions, for example, may well have growth patterns very different from those represented in these charts. On the other hand, the basic concepts employed in producing the growth charts for CP may have wider application.

Growth charts have been developed for a number of other special populations of infants and children. These have included Down syndrome (Al Husain, 2003; Cremers et al., 1996; Cronk et al., 1988; Cronk, 1978; Myrelid et al., 2002; Piro et al., 1990; Toledo et al., 1999), neurofibromatosis

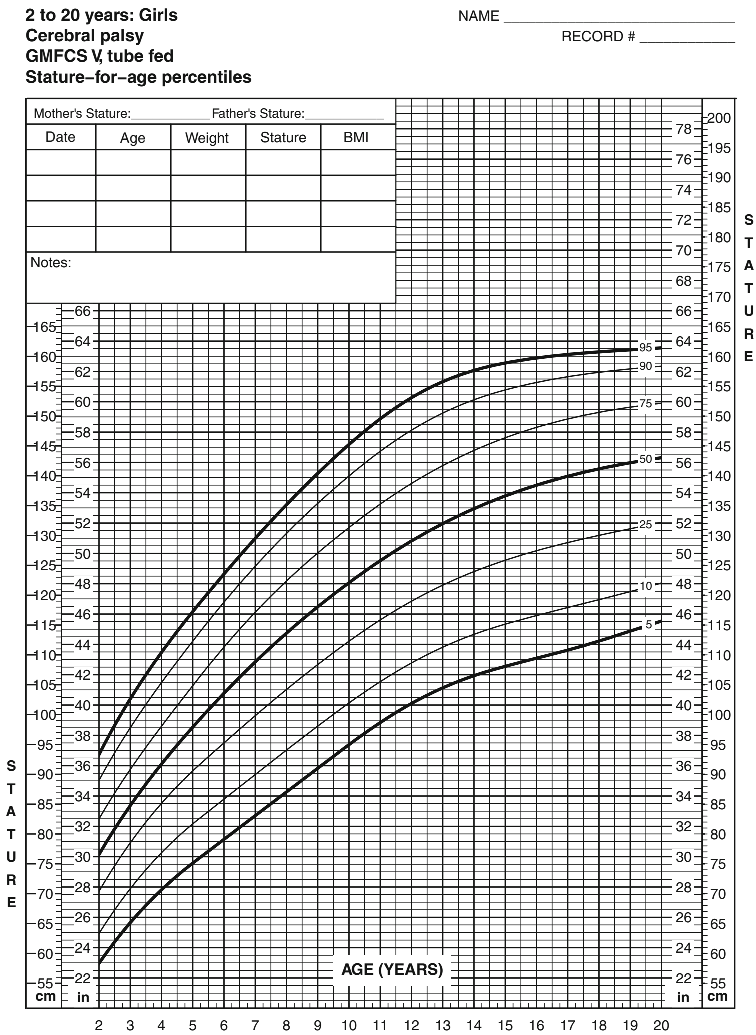

Fig. 101.24 CP growth chart 5th, 10th, 25th, 50th, 75th, 90th, 95th percentiles, 2–20 years: Girls GMFCS V, tube fed stature-for-age. Source: Developed by the Life Expectancy Project (2011). Based on data from the California Department of Developmental Services. Available at http://www.LifeExpectancy.org/Articles/NewGrowthCharts.shtml

type 1 (Szudek et al., 2000), Ullrich-Turner syndrome (Isojima et al., 2009; Sempe et al., 1996), pediatric liver transplant recipients (Saito et al., 2007), Laron syndrome (Laron et al., 1993), Noonan syndrome (Witt et al., 1986), and achondroplasia (Horton et al., 1978).

In the future, if measurements tracked in such charts can be linked to health outcomes (e.g., mortality) the charts will be more valuable to clinicians. Stratification of growth charts according to condition-specific variables that may be associated with growth would also be valuable. Stratification according to level of gross motor function as we have done for CP may be helpful for some other chronic and static conditions originating in the perinatal period or early childhood. On the other hand, in cases of disabling disorders that are progressive, such as multiple sclerosis, such stratification may be unhelpful. For developmental disabilities in which gross motor functioning is not as significantly

Table 101.3 Number of persons[a] contributing data by age, gender, and GMFCS level

	GMFCS				
Gender/Age (years)	I	II	III	IV	V
Female					
2–5	1,331	882	337	1,400	1,192
5–10	376	2,312	844	1,405	1,049
10–15	574	1,698	816	1,192	823
15–20	650	1,548	710	1,063	723
Male					
2–5	1,985	1,190	541	1,842	1,547
5–10	641	3,108	1,067	1,867	1,287
10–15	921	2,101	989	1,603	900
15–20	1,004	1,823	743	1,348	750

[a]Note that persons may contribute to more than one group as they grow older and their functional abilities change. Thus, row and column totals for each sex exceed the study population totals of 11,142 females and 14,403 males

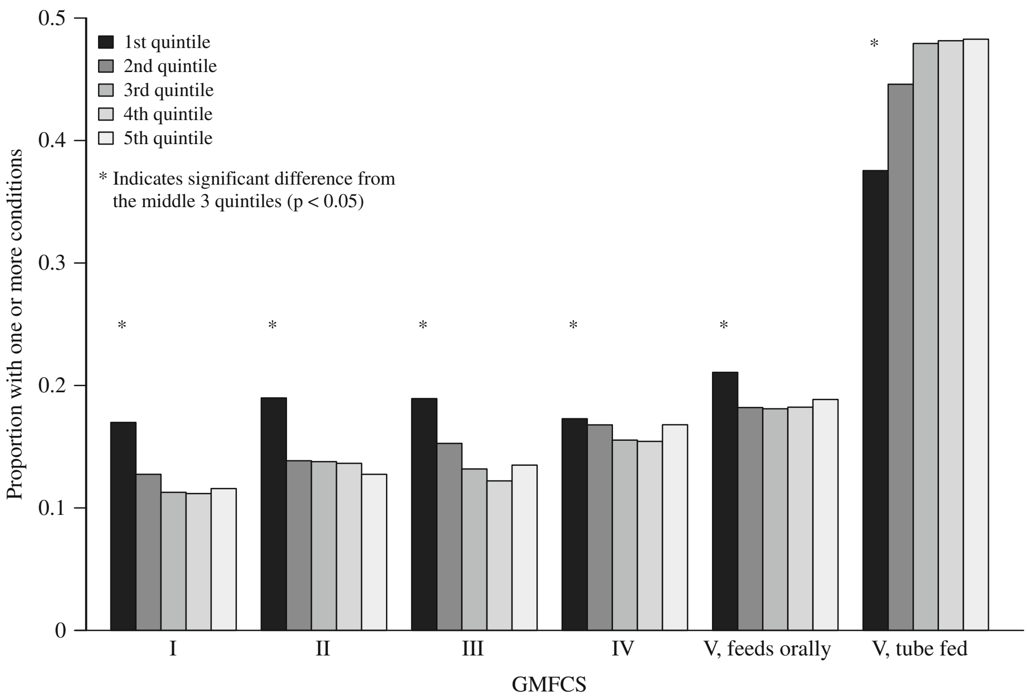

Fig. 101.25 Proportion of CDER observations with one or more major medical conditions by weight-for-age percentiles. Statistical tests comparing proportions for the lowest (L) and highest (H) quintiles with middle three quintiles (M) as reference resulted as follows: GMFCS I: L, $p < 0.0001$; H, not significant; GMFCS II: L, $p < 0.0001$; H, not significant; GMFCS III: L, $p < 0.0001$; H, not significant; GMFCS IV: L, $p < 0.05$; H, not significant; GMFCS V without feeding tube: L, $p < 0.005$; H, not significant; GMFCS V with feeding tube: L, $p < 0.0001$; H, not significant

impaired as in CP, stratification by more subtle levels of ambulatory ability or by levels of cognitive disability, fine motor skills, or feeding ability may be more appropriate.

In Down syndrome, for example, most children are typically able to walk independently by age 5, but their eventual level of fine motor functioning, self-feeding abilities, and cognitive functioning varies more widely (Day et al., 2005). Growth charts that have been developed for children with

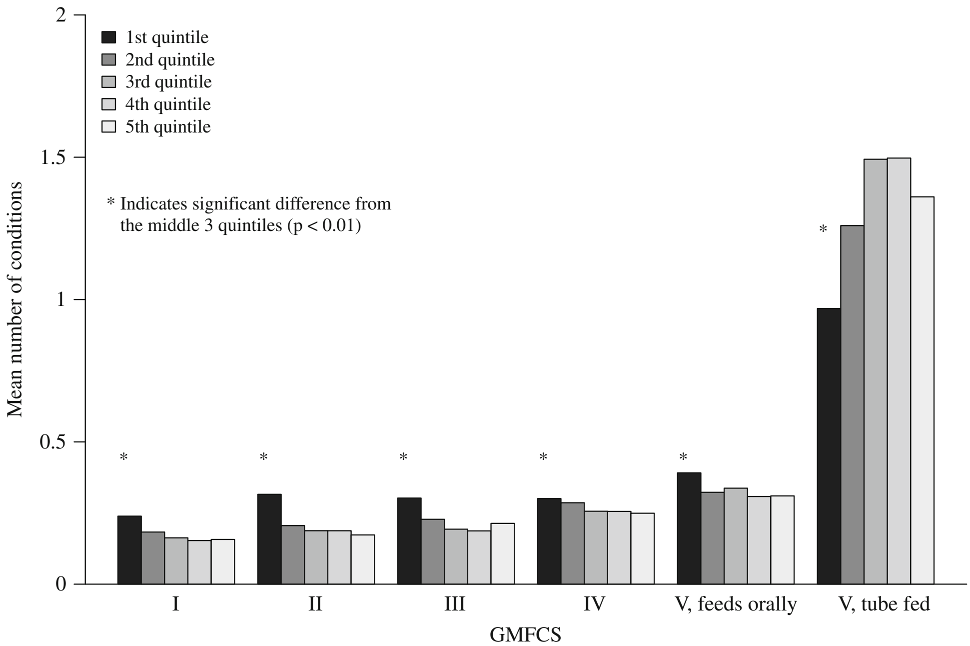

Fig. 101.26 Mean number of major medical conditions by weight-for-age percentiles. Statistical tests (*t*-tests) comparing mean numbers of major medical conditions for lowest quintiles (L) with those of the middle three quintiles (M) as reference, and comparing same for highest quintiles (H) with those of middle three quintiles (M) gave the following results. GMFCS levels I–V: L > M, $p < 0.01$; H and M not significantly different ($p > 0.05$)

Down syndrome are not stratified by level of disability (Al Husain, 2003; Cremers et al., 1996; Cronk et al., 1988; Cronk, 1978; Myrelid et al., 2002; Piro et al., 1990; Toledo et al., 1999). It has been reported that nutritional status varies according to level of IQ in children with mental retardation (Sanchez-Lastres et al., 2003). Developing charts for DS according to specific levels of IQ or according to more subtle differences in gross motor functioning than the GMFCS affords may be valuable. Linking various levels of low or high weight in DS with health outcomes will be important.

101.12 Conclusions

Growth charts can be useful tools for clinicians. Their value is greatly enhanced when the percentiles or *z*-scores of anthropometric measurements tracked are linked to important health outcomes. For some special populations of children, including those with cerebral palsy, patterns of growth deviate significantly from those illustrated in standard charts from the CDC, the WHO, or others. The charts presented here, based on weight and height measurements of children with CP and stratified by gender and level of GMFCS, are undoubtedly more valuable for tracking growth in CP. Indications on the weight-for-age charts of percentiles below which mortality risk is increased provide a valuable link between the charts and one broad measure of health. We hope these charts might spur further research that will link other health outcomes to growth parameters in CP.

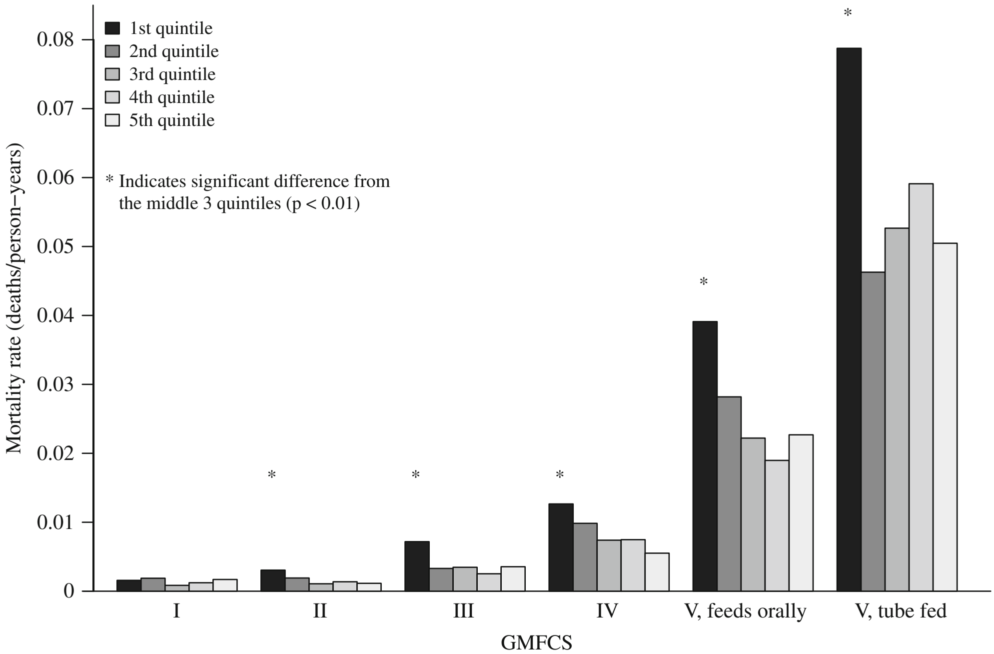

Fig. 101.27 Crude annual mortality rates by GMFCS level and weight-for-age percentiles. *Note*: Mortality rates for GMFCS levels II–V (level V with or without feeding tubes) were significantly higher for the lowest quintile of weight than for the middle three quintiles (test for proportions, $p < 0.01$). For GMFCS level I, there was no significant difference in mortality rates. Comparisons of mortality rates for the highest quintile of weight to the middle three quintiles yielded no significant difference for any GMFCS level

Summary Points

- Weight and stature in CP often track below 5th percentiles on CDC or other general population reference charts, making such charts of little value for CP.
- Percentiles of weight or stature in CP vary substantially with level of independent gross motor functioning.
- New weight-for-age, height-for-age, and BMI-for-age charts for CP are presented.
- Separate charts are presented for boys and girls, and for each GMFCS level I–V, with level V being further divided according to presence of feeding tube.
- For the highest functioning children (GMFCS I), percentiles of weight and height are modestly below those of the CDC reference charts.
- For GMFCS levels II through V, percentiles of weight and height are progressively lower.
- Among children at GMFCS level V, percentiles of weight and height are higher for those who have a feeding tube.
- Very low weight, below the 20th percentile for GMFCS III–V or below the 5th percentile for GMFCS I and II, is associated with significantly increased mortality risk.

Acknowledgments Provision of data from the California Department of Developmental Services and Bureau of Vital Statistics is gratefully acknowledged.

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