TO: Commissioners of Social Services

DATE: September 13, 1991

SUBJECT: Sullivan v. Zebley -- Change of Disability Standards for Children Under Age 18

SUGGESTED DISTRIBUTION:
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ATTACHMENTS:
See Attachment I

FILING REFERENCES

90 ADM-42 |90 LCM-150 |360-5 |20 CFR |Disability |90 LCM-150
|360-4 |416.924 |Manual |GIS 90MA036
|20 CFR |MARG pg. 9
|416.926a
|20 CFR
|416.994a

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I. PURPOSE

This release advises social services districts of the final regulations for the evaluation of childhood disability cases. These regulations replace the Interim Standard, which was sent to the districts on September 19, 1990 by means of 90 LCM-150.

II. BACKGROUND

On February 20, 1990, the Supreme Court of the United States held (Sullivan v. Zebley, et al., 110 S.Ct. 885) that the Social Security Administration (SSA) regulations used to determine whether or not a child under 18 years of age was disabled were inconsistent with the statutory standard of "comparable severity" for determining disability in adults. The court found that a medical "listings only" approach was used in evaluating childhood disability claims, with no provision for the additional medical-vocational evaluation steps that were required for adults. As a result, SSA introduced the requirement of an individualized functional assessment (IFA) for children whose impairments did not meet or equal the severity of listed medical impairments. On July 13, 1990, GIS 90MA036 was issued to alert districts to the Zebley case. On September 19, 1990, 90 LCM-150 was issued to provide districts with the substance of the SSA Interim Standard for use by all disability review teams pending promulgation of final federal regulations.

III. PROGRAM IMPLICATIONS

As with the Interim Standard, the major provision of the final federal regulations (20 CFR 416.924) is a mandate that, for cases that do not meet or equal a listing, disability reviewers must consider fully a child's functional limitations when evaluating the severity of an impairment. In addition to medical documentation, recognition must be given to the importance of observations made by parents, caregivers, teachers, and others regarding limitations of the child in determining whether a child is functionally disabled. The child's ability to perform a full range of activities of daily living and to behave in an age-appropriate manner must be individually assessed in a manner comparable to the way residual functional capacity is evaluated in adults.

The new regulations require that a child's functioning be assessed at two steps in the evaluation process. First, they provide a new policy for considering functioning at the listings equivalence step. Second, they include a process for evaluating childhood disability that is not based solely on listing-level severity at a step beyond the listings. At that additional step, children with severe impairments that do not meet or equal (medically or functionally) a listing may be determined disabled based on an assessment of their functioning (IFA) that demonstrates that they have impairments of "comparable severity" to impairments that would disable adults.
Children who are determined disabled under the new disability criteria will be entitled to have their financial eligibility re-evaluated using the Supplemental Security Income (SSI)-related budgeting methodology.

IV. REQUIRED ACTION

A. General

Effective February 11, 1991, both State and county Medical Assistance Disability Review Teams must evaluate children's disability cases based on the final federal regulations. These regulations are explained and summarized below.

Determinations based on the final federal regulations should reference 20 CFR 416.924 as a regulatory basis on the DSS-639, "Disability Review Team Certificate".

Children who are determined disabled under the new disability criteria are entitled to have their financial eligibility redetermined using the SSI-related budgeting methodology. If the child is both SSI-related and Aid to Dependent Children (ADC)-related, the choice of category must be offered. Expanded eligibility for children up to age six in accordance with 90 ADM-42 may be more beneficial than the SSI-related category for some children.

B. Definitions

1. Disability for Children

A child is considered disabled if he or she has any medically determinable physical or mental impairment(s) "of comparable severity" to that which would disable an adult, and which meets the duration requirement.

2. Comparable Severity

The term "comparable severity" means that a child's physical or mental impairment(s) so limits the child's ability to function independently, appropriately, and effectively in an age-appropriate manner that the impairment(s) and its consequent limitations are comparable to those that would disable an adult. This means that a child's impairment(s) must substantially reduce or, in the case of infants from birth to age one, be expected to substantially reduce the ability to grow, develop, or mature in an age-appropriate manner.

C. Sequential Evaluation

As is the case for adults, the sequential evaluation process must be followed.
The steps of the sequential evaluation process for children's cases include:

- determining if the child is engaged in substantial gainful activity;
- determining if the child has a severe impairment(s);
- determining if the child's impairment(s) meets or equals a listing and meets the duration requirement; and,
- determining if the child's impairment(s) is of comparable severity to that which would disable an adult and meets the duration requirement.

The sections which follow (IV.C.1-4) fully describe these sequential steps, and Attachment VI is a flow chart which graphically outlines this procedure.

1. Substantial Gainful Activity

Is the child engaging in substantial gainful activity?

Inasmuch as the basic statutory definition of disability requires an inability to engage in substantial gainful activity, no individual, including a child, may be found disabled if he or she is actually working at this level. A child's impairments will not be considered, no matter how severe they are, if the child is engaging in substantial gainful activity. The same rules for determining whether an adult is engaging in substantial gainful activity, which provide for consideration of such things as subsidies, impairment-related work expenses, and other special considerations in determining the level of earnings, also apply to children (please refer to the Medical Assistance Disability Manual). Except for some older children who may be employed, most children will not be engaged in substantial gainful activity, and it will be necessary to continue with the sequential process.

If a child is engaging in substantial gainful activity, the child will be determined not disabled. If not, the reviewer will proceed to the next step in the sequence.

2. Severity of Impairment

Does the child have a "severe" impairment or combination of impairments?

If the child is found to have no more than a minimal limitation in the ability to function, the child will be determined not disabled. A determination of not disabled may be made at this step only if the child has no abnormalities
or only slight abnormalities that do not significantly affect the child’s ability to function independently, appropriately and effectively in an age-appropriate manner. If a child has an impairment or combination of impairments that cause more than a minimal limitation in the ability to function, the reviewer will find that the child has a severe impairment(s) and go on to the next step in the process.

3. Meeting or Equaling the Listings

Does the child have a medically determinable impairment(s) that meets a listing? If so, the child will be determined disabled. If not, does the child have an impairment or combination of impairments that is equivalent in severity to any impairment in the Listing of Impairments, either medically or functionally?

While all possible impairments or combinations of impairments are not described in the listings, the listings are a standard and a set of examples against which every impairment or set of impairments can be judged.

NOTE: To determine a child disabled at the "meets or equals" step, the duration requirement must be met.

a. Medical Equivalence

(1) With a listed impairment. Medical equivalence is established when the child has a listed impairment, but:

(a) not all the specified medical findings are present, or not all are as severe as specified; and,

(b) there are other medical findings related to the impairment that are at least of equal medical significance.

(2) With an unlisted impairment. Medical equivalence is established when the child has an unlisted impairment or combination of impairments, no one of which meets or is equivalent to a listing, but:

(a) the medical findings can be compared to a closely analogous listed impairment; and,

(b) the findings associated with the impairment(s) are at least of equal medical significance to those of the analogous listed impairment.
b. Functional Equivalence

If medical equivalence cannot be established as above, the child must then be evaluated for functional equivalence, i.e., the child's functional limitation(s) which results from the impairment(s) must be compared with the functional consequences of any listed impairment which includes the same functional limitations. If the functional limitation(s) resulting from the impairment(s) is the same as the disabling functional consequences of a listed impairment, the child's impairment(s) will be found equivalent to the listed impairment. The child's impairment does not need to be medically related to the listing used for comparison. The primary focus is on the disabling consequences of the impairment, as long as there is a direct, medically determinable cause for these consequences.

(1) Examples of impairments of children that are functionally equivalent to the listings. The following are some examples of consequences of impairments that are functionally equivalent to listed impairments, and in such cases the child may be determined disabled based on this functional equivalence. The consequences of each child's impairments must be assessed to determine whether they are functionally equivalent to those of a listed impairment and should not be limited to the examples below. Examples of appropriate listings to which the examples of impairments may be found equivalent are also indicated.

NOTE: This is not an all inclusive list.

(a) Documented need for major organ transplant (e.g., heart, liver). Cases of equivalence should be referenced to a listing for the appropriate body system. For example, liver transplant would be equivalent to Listing 105.05, Chronic Liver Disease.

(b) Any condition that is disabling at the time of onset, requiring a series of staged surgical procedures within 12 months after onset as a life-saving measure or for salvage or restoration of major function, and such major function is not restored or is not expected to be restored within 12 months after onset of the condition. Cases of equivalence should be referenced to a listing for the appropriate body system. For example, a musculoskeletal impairment such as
that described is equivalent to the adult Listing 1.13, Soft Tissue Injuries of an Upper or Lower Extremity.

(c) Daily need for a life-sustaining device (e.g., mechanical ventilation), at home or elsewhere, lasting or expected to last 12 months. For some medical conditions, this may be equivalent to Listing 110.08A, Catastrophic Congenital Abnormalities or Disease. There are medical reasons for this impairment for which a different listing may be more analogous and therefore more appropriate.

(d) Complete inability to stand and walk. For some medical conditions, this may be equivalent to Listing 111.06B, Motor Dysfunction (due to any neurological disorder). There are medical reasons for this impairment for which a different listing may be more analogous and therefore more appropriate.

(e) Marked inability to stand and walk, e.g., ambulation possible only with obligatory bilateral upper limb assistance. For some medical conditions, this may be equivalent to Listing 101.03B, Deficit of Musculoskeletal Function. There are medical reasons for this impairment for which a different listing may be more analogous and therefore more appropriate.

(f) Complete inability to perform self-care skills. For some medical conditions, this may be equivalent to Listing 101.03C, Deficit of Musculoskeletal Function. There are medical reasons for this impairment for which a different listing may be more analogous and therefore more appropriate.

(g) Marked restriction of age-appropriate activities of daily living and marked difficulties in maintaining age-appropriate social functioning. For some medical conditions, this may be equivalent to Listing 112.02B, the paragraph B criteria for the Children's Mental Listings. For others, there may be medical reasons for this impairment for which a different listing may be more analogous and therefore more appropriate.
(h) Impairment causing complete inability to function independently outside the area of one's home within age-appropriate norms. For some medical conditions, this may be equivalent to the adult Listing 12.06C, Anxiety Related Disorders. There are medical reasons for this impairment for which a different listing may be more analogous and therefore more appropriate.

(i) Requirement for 24-hour a day supervision for medical or behavioral reasons, lasting or expected to last 12 months. For some medical conditions, this may be equivalent to Listing 103.03A, Bronchial Asthma. There are medical reasons for this impairment for which a different listing may be more analogous and therefore more appropriate.

(j) Premature infants (i.e., 37 weeks or less) weighing less than 1200 grams at birth, until one year of age. Generally this is equivalent to Listing 100.02, Growth Impairment.

(k) Premature infants weighing at least 1200 but less than 2000 grams at birth and who are at least four weeks small for gestational age, until one year of age. Generally this is equivalent to Listing 100.02, Growth Impairment.

(l) In an infant who is not yet one year old, any physical disorder that satisfies the requirements of Listing 112.12. Generally this is equivalent to Listing 112.12, Developmental and Emotional Disorders of Newborn and Younger Infants (Birth to Age One).

(m) Major congenital organ dysfunction (e.g., congenital heart disease) which could be expected to result in death within the first year of life without surgical correction, until attainment of one year of age. Cases of equivalence should be referenced to a listing for the appropriate body system. For example, an impairment due to congenital heart disease such as that described is equivalent to Listing 104.02, Chronic Congestive Failure.
(n) Tracheostomy in a child who is not yet age three. Generally this is equivalent to Listing 103.03, Bronchial Asthma.

(o) Gross microcephaly of greater than three standard deviations. Generally this is equivalent to Listing 110.08, Catastrophic Congenital Abnormalities or Disease.

If the child has an impairment or combination of impairments that meets or equals a listing, and also meets the duration requirement, the child will be determined disabled. If not, the reviewer will proceed to the final step in the sequence.

4. Individualized Functional Assessment or IFA

Does the child have an impairment or combination of impairments that so limits the child's physical or mental abilities to function independently, appropriately, and effectively in an age-appropriate manner that the limitations are comparable in severity to those which would disable an adult?

a. General

The information that follows is arranged such that the first five sections (IV.C.4.b-f) set the parameters within which an individualized functional assessment is made. The next section (IV.C.4.g) describes the manner in which the reviewer makes a disability determination within these parameters.

It must be kept in mind that these guidelines are not intended to be applied mechanically in a rigid manner, and that the examples given are not the only instances in which a child may be found to have comparable severity.

NOTE: To determine a child disabled at the "individualized functional assessment" step, it is necessary that the duration requirement be met.

b. Documentation

In order to determine whether or not comparable severity exists, the reviewer will do an individualized functional assessment, considering all information in the case record which documents the impact of the child's impairment on functioning. This information may be obtained from both medical sources (please refer to the Medical Assistance Disability Manual for discussion of acceptable medical sources and consultative examinations) and non-medical sources.
Non-medical sources include school records, parents, caregivers, teachers, and others who know the child and can provide evidence that can help in assessing the child's functioning on a longitudinal basis (i.e., over time).

NOTE: Federal regulations now recognize the report of an interdisciplinary team that contains the evaluation and signature of an acceptable medical source as acceptable medical evidence.

Forms have been developed to assist the reviewer in obtaining this information (please refer to 90 LCM-150, Zebley v. Sullivan: Interim Standard, attachments 2, 3, and 4). One form is to be completed by the physician, a second by the child's caregiver, and a third by the child's school, if appropriate. All of these forms address the child's ability to function independently, appropriately, and effectively in an age-appropriate manner. While these forms are not required for the case record, they should be helpful in obtaining the necessary evidence of the child's functioning.

When conflicts in evidence must be resolved, the case record should be documented to show how they were resolved and the basis for any conclusions reached.

c. Terms Used to Describe Functioning

Terms used to describe functioning are as follows:

(1) Age-appropriate activities. The term "age-appropriate activities" is a comprehensive term that refers to what a child is expected to be able to do given the child's age. A child's activities may be described in terms of the achievement of "developmental milestones", "activities of daily living", or other such terms. Information about a child's activities creates a profile of how the child is functioning, i.e., what a child does, and thus what he or she is able to do. This makes possible a comparison between the child's profile and the activities that are age-appropriate for that child.

(2) Developmental milestones. The term "developmental milestones" refers to a child's expected principal developmental achievements at particular points in time. Ordinarily, failures to achieve developmental milestones are the most important indicators of impaired functioning from birth until the attainment of age six, although they may be used to evaluate older children, especially school-age children.
(3) Activities of daily living. The term "activities of daily living" refers to those activities of children that involve continuity of purpose and action, and goal or task orientation; that is, the practical implementation of skills mastered at earlier ages. Ordinarily, activities of daily living are the most important indicators of functional limitations in children aged six to 18, although they may be used to evaluate younger children, especially preschool-age children.

(4) Domains and behaviors. The terms "developmental domains" and "functional domains" refer to broad areas of development or functioning that can be identified in infancy and traced throughout a child's growth and maturation into adulthood. They describe the child's major spheres of activity, i.e., physical, cognitive, communicative, social/emotional, and personal/behavioral. The term "developmental domains" is generally used when discussing younger children, i.e., from birth to age six; the term "functional domains" is generally used when discussing older children and young adolescents, i.e., from age six to age 16.

The term "behaviors" refers to:

(a) an infant's physical and emotional responses to stimuli.

(b) manifestations of cognitive, psychological, and affective states involved in a child's concentration, persistence, and pace, after the child has reached the age of three.

d. Age Categories

When assessing whether the child is functioning independently, appropriately, and effectively in an age-appropriate manner, the reviewer will consider age in the following categories; however, these age categories will not be applied mechanically in borderline situations.

(1) Newborn and young infants (birth to age one).

NOTE: Guidelines for evaluating premature and low birthweight infants are found in section IV.C.4.g.(3).

(2) Older infants and toddlers (age one to age three).
(3) Children (age three to age 18). These are considered according to the following subcategories:

(a) Preschool children (age three to age six);

(b) School-age children (age six to age 12);

(c) Young adolescents (age 12 to age 16); and,

(d) Older adolescents (age 16 to age 18).

In general, the younger the child, the greater the reviewer will consider the impact of the child's impairment(s) on the ability to grow and develop. Although various kinds of growth and development occur throughout childhood and adolescence, the earliest years, from birth to approximately age six, are characterized by complex and rapid changes; for example, learning to walk, talk, and care for basic physical and emotional needs. The development of fundamental skills both within and across functional domains is a cumulative process founded upon skills acquired at each stage of a child's life. A child's ability to acquire or perform these skills ultimately determines the ability to master learning tasks in school and more complex physical activities and, eventually, affects the ability to work. Therefore, deficits of function resulting from impairments that occur before the age of six may have a potentially greater, more limiting effect on a child's overall growth and development than impairments that occur later in life, and such deficits are increasingly significant the younger the child is when the deficits occur.

Furthermore, the mastery of skills in early childhood is a highly interactive and interdependent process for a child. This interdependence is especially true of development in certain areas; e.g., cognitive skill deficits may affect communications, and social and emotional deficits may affect cognitive and communicative development. This interdependent process also requires proper functioning in areas that may not be obviously relevant to the acquisition of the skill. For example, physical mobility is affected by how well a child sees; therefore, visual impairment, especially in a young child, can affect the way a child acquires certain motor skills even though the child does not have a specific motor impairment. Similarly, emotional bonding to parents can be affected by how well a child hears. Therefore, the impact of such seemingly isolated impairments can have implications for the overall development of the youngest children.
The potentially greater impact of physical or mental impairments on the youngest children is analogous to the consideration of age in the rules for determining whether an adult has the ability to make an adjustment to other work. Whereas the older an adult is, the more significant the impact of a physical or mental impairment on the ability to adjust to other work, the reverse is generally true in a child. As a child approaches the age of 18, he or she is generally (though not always) comparable to a young adult (i.e., those age 18 to 45) in physical and mental makeup and potential.

This guidance must not be applied mechanically, since there are situations in which an impairment(s) acquired by an older child would have an equal or greater impact than the same impairment(s) would in a younger child. Each case must be evaluated on its own merits, regardless of the child's age.

e. Domains and Behaviors

(1) Listing of Domains and Behaviors. The following are the domains of development or functioning that may be addressed in an individualized functional assessment:

(a) Cognition;
(b) Communication;
(c) Motor abilities;
(d) Social abilities;
(e) Personal/behavioral patterns (in children from age one to age 18);

The following are specific behaviors that may be addressed in an individualized functional assessment:

(f) Responsiveness to stimuli (in children from birth to age one);

(g) Concentration, persistence, and pace in task completion (in children from age three to age 18).

(2) Description of domains and behaviors for newborns and young infants (birth to age one). Children in this age group are evaluated in an individualized functional assessment in terms of four
developmental domains and an area of behavior important to newborns and young infants.

(a) Cognitive development, e.g., the ability to begin to organize and regulate how the child feels and the ways he or she reacts to the environment;

(b) Communicative development (includes speech and language), e.g., the ability to communicate with intention through visual, motor, and vocal exchanges;

(c) Motor development (includes gross and fine motor skills), e.g., the ability to explore the environment by moving the body, and the ability of the child to manipulate the environment by using the hands;

(d) Social development, e.g., the ability to form and maintain relationships with primary caregivers;

(e) Responsiveness to stimuli, e.g., the ability to respond appropriately to visual, auditory, or tactile stimulation.

(3) Description of domains for older infants and toddlers (age one to age three). Children in this age group are evaluated in an individualized functional assessment in terms of five developmental domains.

(a) Cognitive development, e.g., the ability to understand by responding to increasingly complex requests, instructions or questions, by the child's ability to self-refer, and to refer to things around the child by pointing and eventually by naming, and by copying things or imitating actions shown to the child by others;

(b) Communicative development (includes speech and language), e.g., the ability to communicate by understanding, imitating, and using an increasing number of intelligible words and eventually forming two to four word sentences;

(c) Motor development (includes gross and fine motor skills), e.g., the ability to move in the environment by use of the body with steadily increasing dexterity and
(4) Description of domains and behaviors for preschool children (age three to age six). Children in this age group are evaluated in an individualized functional assessment in terms of five developmental domains and an area of behavior important to preschool children.

(a) Cognitive development, e.g., the ability to understand, to reason and to solve problems, and to use acquired knowledge and concepts;

(b) Communicative development (includes speech and language), e.g., the ability to communicate by telling, requesting, predicting, and relating information, by following and giving directions, by describing actions and functions, and by expressing needs, feelings, and preferences in an increasingly intelligible manner;

(c) Motor development (includes gross and fine motor skills), e.g., the ability of the child to move and use the arms and legs in increasingly more intricate and coordinated activity, or the ability of the child to use the hands with increasing coordination to manipulate small objects during play;

(d) Social development, e.g., the ability to respond to the social environment through appropriate self-control and increasingly complex interpersonal behaviors, such as sharing, cooperating, helping, and relating to a group;

(e) Personal/behavioral development, e.g., the ability of the child to help in taking care
of personal needs or to cooperate with others in taking care of these needs, in adapting to the environment, and in learning new skills;

(f) Concentration, persistence, and pace, e.g., the ability to engage in an activity, such as dressing or playing, and to sustain the activity for a period of time and at a pace appropriate to the child's age.

(5) Description of domains and behaviors for school-age children (age six to age 12). Children in this age group are evaluated in an individualized functional assessment in terms of five functional domains and an area of behavior important to school-age children.

(a) Cognitive function, e.g., the ability to progress in learning the skills involved in reading, writing and mathematics;

(b) Communicative function (includes speech and language), e.g., the ability to communicate pragmatically (i.e., to meet the child's needs) or conversationally (i.e., to exchange information or ideas in the classroom, with peers, or family);

(c) Motor function (includes gross and fine motor skills), e.g., the ability to engage in the physical activities involved in play, physical education, and self-care appropriate to the child's age;

(d) Social function, e.g., the ability to play alone, or with another child, or in a group; to develop friendships, and to relate to siblings and parents or caregivers;

(e) Personal/behavioral function, e.g., the ability of the child to help in taking care of personal needs or to cooperate with others in taking care of these needs and safety; to understand authority relationships and school rules; to develop a sense of responsibility and of respect for others; and to learn new skills;

(f) Concentration, persistence, and pace, e.g., the ability to engage in an activity, such as playing or reading, and to sustain the activity for a period of time and at a pace appropriate to the child's age.
(6) Description of domains and behaviors for young adolescents (age 12 to age 16). Children in this age group are evaluated in an individualized functional assessment in terms of five functional domains and an area of behavior important to young adolescents.

(a) Cognitive function, e.g., the ability to progress in applying the skills involved in reading, writing, mathematics and conceptual growth, and in reasoning and problem-solving abilities;

(b) Communicative function (includes speech and language), e.g., the ability to communicate pragmatically (i.e., to meet the child's needs) or conversationally (i.e., to exchange information or ideas in school classes, with peers, or family);

(c) Motor function (includes gross and fine motor skills), e.g., the ability to engage in the physical activities involved in physical education, sports, social events, and self-care appropriate to the child's age;

(d) Social function, e.g., the ability to develop friendships, to relate to peer groups, and to reconcile conflicts between the child and peers or family members;

(e) Personal/behavioral function, e.g., the ability of the child to help in taking care of personal needs and safety; to respond appropriately to authority and school rules; and to learn new skills;

(f) Concentration, persistence, and pace, e.g., the ability to engage in an activity, such as studying or practicing a sport, and to sustain the activity for a period of time and at a pace appropriate to the child's age.

(7) Description of domains and behaviors for older adolescents (age 16 to age 18).

(a) Descriptive information about the child's activities of daily living will indicate the nature and age-appropriateness of these activities with respect to cognitive functioning, communicative functioning, motor functioning, social functioning, personal/behavioral functioning and
concentration, persistence and pace in school or work-related activities.

(b) As the child approaches adulthood (i.e., beginning at about age 16) some school activities may be considered as evidence of the ability to function in a job setting. For example, the ability to understand, carry out, and remember short instructions and work like procedures in the classroom will be considered as evidence of the child's ability to do these things in a job. The reviewer will consider the child's ability to maintain attention for extended periods of time and to sustain an ordinary daily routine without special supervision as evidence of ability to do these things in a job. The reviewer will consider ability to interact with authority figures and to follow directions in school, responding appropriately to correction or criticism, as an indication of ability to deal with supervision on a job. The reviewer will consider ability to regulate mood and behavior in various school settings as some indication of the ability to deal with change in a work setting. The reviewer will consider ability to engage in physical activities both in and out of school as it relates to the ability to perform the physical demands of work. The reviewer will also consider whether any skills have been acquired from specific vocational education and whether any part-time or stay-in-school employment has been pursued.

(c) If the child is working or has worked, the reviewer will evaluate such things as the physical activities in which the child is engaged on the job; the regularity and punctuality of attendance; the ability to follow directions and interact with supervisors; and the ability to work independently and to deal with others in the workplace.

f. Other Factors to be Considered in the Individualized Functional Assessment

When an individualized functional assessment is done, all factors that are relevant to the evaluation of the effects of the child's impairment(s) in regard to functioning will be considered, such as the effects of medications, the setting in which the child lives, the
need for assistive devices, and how the child functions in school. Therefore, when assessing the effect of the child's impairment(s) on functioning, all evidence will be considered from both medical and nonmedical sources. Some of the factors to be considered include but are not limited to the following:

1) Chronic illness. If repeated hospitalizations or frequent outpatient care with supportive therapy is required for a chronic impairment(s), this need for treatment will be considered as a factor in the determination of the child's overall ability to function. If the child's hospitalizations are so long or so frequent that they interfere with overall functioning on a longitudinal basis or outpatient care significantly interferes with daily activities (either because of its frequency, its effects on functioning, or both), the child may be determined disabled because of the need for, or the level of, treatment for the child's chronic illness.

2) Effects of medication. The effects of medication on the child's symptoms, signs, and laboratory findings will be considered, including the ability of the child to function. Although medications may control the most obvious manifestations of the child's condition(s), they may or may not affect the functional limitations imposed by these impairment(s). If symptoms or signs are reduced by medications, the reviewer will consider whether the child has any functional limitations which may nevertheless persist, even if there is apparent improvement from the medications. The reviewer will also consider whether these medications create any side effects which cause or contribute to the child's functional limitations.

3) Effects of structured or highly supportive settings. Children with severe impairments may spend much of their time in structured or highly supportive settings. A structured or highly supportive setting may be the child's own home, in which family members make extraordinary adjustments to accommodate the child's impairments; or the classroom at school whether a regular class in which the child is accommodated, or a special classroom for children with similar needs; or a residential facility or school where the child lives for a period of time. Children with chronic impairments also commonly have their lives structured in such a way as to minimize stress, and reduce their symptoms or signs, and therefore some may be relatively free of obvious
symptoms or signs of impairment. Others may continue to have persistent pain, fatigue, decreased energy, or other symptoms or signs, though at a lesser level of severity. Such children may be more impaired in their overall ability to function in an age-appropriate manner than their symptoms and signs would indicate. Therefore, if symptoms or signs are controlled or reduced by the environment in which the child lives, the reviewer will consider ability to function independently, appropriately, and effectively in an age-appropriate manner outside of this highly structured setting.

(4) Adaptations. The reviewer will consider the nature and extent of any other adaptations that are made for the child in order to enable the child to function. Such adaptations may include assistive devices, appliances, or technology. Some adaptive devices are relatively unobtrusive and may increase or restore functioning: examples of such devices may include eyeglasses, hearing aids, ankle-foot orthoses, and hand or foot splints. Others may be less effective or may impose additional limitations that interfere with performance of age-appropriate activities: examples of such devices may include specially adapted or custom-made tools, utensils, or support for self-care activities such as bathing, feeding, toileting, dressing, and sleeping. When evaluating the child's overall ability to function independently, appropriately, and effectively in an age-appropriate manner with an adaptive device or other adaptation, the reviewer will consider such things as the degree to which the adaptation enables the child to function and any additional limitations caused by the adaptation.

(5) Multidisciplinary therapy. The child may need frequent and on-going therapy from more than one kind of health care professional in order to maintain or improve function. This is considered to be multidisciplinary therapy, and may include occupational, physical or speech and language therapy, special nursing services, psychotherapy or psychosocial counseling. Frequent and continuous therapy, although intended to improve functioning, may also interfere significantly in the child's opportunities to engage in and sustain age-appropriate activities. If the child receives such therapy at school during a normal school day, it may or may not interfere significantly with age-appropriate activities. If the child must
frequently interrupt activities at school or at home in order to go for therapy, these interruptions may interfere with development and age-appropriate functioning. When a determination is made as to whether a child has an impairment(s) of comparable severity to an impairment(s) that would disable an adult, the reviewer will consider the frequency of any multidisciplinary therapy that the child must have, how long the child has needed the therapy or will need the therapy, and the extent to which it interferes with age-appropriate functioning.

(6) School attendance.

(a) School records and information from people at school who know or have examined the child such as teachers, school psychologists, psychiatrists, or therapists, may be important sources of information about the child's impairment(s) and its effect on ability to function. If the child attends school, this evidence will be considered.

(b) The fact that the child is able to attend school will not in itself be an indication that he or she is not disabled. Consideration should be given to the circumstances of school attendance, such as the child's ability to function independently in a classroom setting in an age-appropriate manner. Likewise, the fact that he or she is in a special education classroom setting, or that he or she is not in such a setting will not in itself establish the child's actual limitations or abilities. The reviewer will consider the fact of such placement or lack of placement in the context of the remainder of the evidence in the case record.

(c) However, if the child is unable to attend school on a regular basis because of an impairment(s), the reviewer will consider this when determining whether the child is able to function in an age-appropriate manner.

(7) Treatment and intervention, in general. With adequate treatment or intervention, some children not only have their symptoms and signs reduced, but also return to or achieve a level of functioning that is consistent with the norms of their age. However, there are also cases in which
the child's actual level of impairment may be masked by the treatment or intervention. Therefore, the effects of the child's treatment or intervention will be evaluated to determine the actual outcome of the treatment or intervention in each particular case.

g. Guidelines for Determining Disability using the Individualized Functional Assessment.

(1) General. The guidelines in this section are provided as a framework for deciding whether a child who has a severe impairment(s) that does not meet or equal the listings nevertheless has an impairment(s) that is of comparable severity to one that would disable an adult, and is, therefore, disabled. The examples in this section are only guidelines to illustrate severity and are not all-inclusive rules.

Forms have been developed to assist the reviewer in completing the individualized functional assessment. (See Attachments II-V.) While these forms are not required for the case record, they should be helpful in making a determination based on an individualized functional assessment.

(2) How functional limitations are described. The terms used in this section to describe functional severity of both physical and mental impairments employ as a frame of reference the terminology and definitions found in the new childhood mental listings in 112.00 of the Listing of Impairments, December 1990 page replacements to the Medical Assistance Disability Manual. Hence, the examples of "moderate" and other impairments are derived from comparison with the "marked" levels of functional limitations in the listings. As in those listings, "marked" and "moderate" are not the number of activities or functions which are restricted, but the overall degree of restriction or combination of restrictions. A marked or moderate limitation may arise when several activities or functions are impaired, or even when only one is impaired.

A description of the terms "marked" and "moderate" is made within the context of describing their use for each of the different age categories. As the child gets older, these terms become less quantified, and in the discussion of older adolescents, an approach closely resembling the medical-vocational considerations as used in adult disability determinations is introduced.
(3) Evaluating premature and low birth weight infants. Chronological age (that is, a child's age based on birth date) is generally used when deciding whether, and the extent to which, a physical or mental impairment(s) affects a child's ability to function independently, appropriately, and effectively in an age-appropriate manner. However, if the child was born prematurely, he or she may be considered to be younger than the actual chronological age. An infant born at less than 37 weeks' gestation is considered to be "premature-by-date". Prematurity is considered as follows:

(a) Children born prematurely who satisfy the weight guidelines for establishing functional equivalence as discussed in IV.C.3.b.(1)(j) above (i.e., weight of less than 1200 grams at birth) will be found disabled at least until the age of 12 months. The number of weeks of prematurity will not be a factor in the determination of disability.

(b) Children born prematurely who satisfy the weight and size guidelines for establishing functional equivalence as discussed in IV.C.3.b.(1)(k) above (i.e., weight of at least 1200 grams but less than 2000 grams at birth and at least four weeks "small for gestational age") will be found disabled at least until the age of 12 months. When deciding the extent to which a child was "small for gestational age" at birth, the reviewer will consider the child's actual gestational age, as shown by appropriate medical evidence.

(c) The claims of other children who were born prematurely will be evaluated in the same way that the claims of infants who were not premature are evaluated, applying the following principles:

   (i) If evaluating an impairment of development, a "corrected" chronological age will be used, that is, the chronological age adjusted by the period of gestational prematurity. The corrected chronological age is computed by subtracting the number of weeks of prematurity from the chronological age. This corrected age is used when evaluating developmental delay in
premature children until it is no longer
a significant factor; generally, at
about age two.

(ii) When evaluating an impairment of linear
growth, such as under the listing in
100.00, I Appendix 75 of the Medical
Assistance Disability Manual, neonatal
growth charts which have been developed
to evaluate growth in premature-by-date infants are referenced. Because these
growth charts already take prematurity
into account, a corrected age is not
computed in such cases.

(4) Evaluating young children (birth to age three).
If the child is a newborn or young infant (birth
to age one), the severity of the impairment(s) is
evaluated with respect to four developmental
domains (cognitive, communicative, motor, and
social development) and responsiveness to
stimuli. (See IV.C.4.e(2) for descriptions of the
domains and behaviors appropriate to this age
group.) If the child is an older infant or
toddler (age one to age three), the severity of
the impairment(s) is evaluated with respect to
five developmental domains (cognitive,
communicative, motor, social, and
personal/behavioral development. See IV.C.4.e(3)
for descriptions of the domains appropriate to
this age group).

For children in these age groups, the child's
functional limitations will generally be described
in terms of developmental delay, or the fraction
or percentage of the child's chronological age
that represents the level of the child's
functioning. Failure to achieve development of no
more than one-half of the child's chronological
age in a single domain, or of no more than two-
thirds of the child's chronological age in two
domains represents listing level severity, and
therefore represents functional/medical equival-
ence.

If the child is functioning in one of the domains
or behaviors noted at more than one-half, but not
more than two-thirds, of the child's chronological
age, he or she is said to have a marked
impairment. If the child is functioning in one of
the domains or behaviors at more than two-thirds
but not more than three-fourths of the child's
chronological age, he or she is said to have a
moderate impairment. These guidelines, and those that follow, are not to be applied in a rigid or mechanical manner. Each case must be evaluated on its own merits.

Examples of when comparable severity will generally be found and thus, a determination of disabled made, include the following:

(a) The child is functioning at a marked level in one domain (e.g., motor development) and functioning at a moderate level in another domain (e.g., communicative);

(b) The child is functioning at a moderate level in three domains (e.g., cognitive, motor, and social development).

(5) Evaluating older children and young adolescents (age three to age 16). If the child is in this age group the severity of the impairment(s) is evaluated with respect to five functional domains (cognitive, communicative, motor, social, and personal/behavioral function), and the child's concentration, persistence, and pace in the completion of age-appropriate tasks. (See IV.C.4.e(4)-(6) for descriptions of the domains and behaviors appropriate to each age group).

The terms "marked" and "moderate" are defined for this age group in a more qualitative fashion than for younger children. "Marked" is defined as more than "moderate" but less than "extreme", and "moderate" means more than "mild" but less than "marked". An impairment may be considered "marked" when standardized tests are used as a measure of a child's functional ability and the child has a valid score that is two standard deviations below the norm (e.g., an IQ score of 70 on the WISC-R). An impairment may be considered "moderate" when the child has a valid score that is between approximately one and one-half and two standard deviations below the norm, (e.g., an IQ score on the WISC-R ranging from 71 through 77).

In the case of preschoolers (age three to age six), it may be appropriate to evaluate the level of severity in terms of developmental age, as in younger children. Although it is sometimes appropriate to evaluate severity in this age group in the same terms as those used for evaluating young children as in IV.C.4.g(4) (e.g., describing "moderate" as more than two-thirds but not more than three-fourths of the child's chronological
The older a child becomes, the less precise are the means of determining the level of severity.

Examples of when comparable severity will generally be found and, thus, a determination of disabled made, include the following:

(a) The child is functioning at the marked level in one domain (e.g., in the domain of social functioning, the child is generally unable to maintain age-appropriate relationships with peers and adults, with frequent serious conflicts with family, classmates, and teachers) and is functioning at the moderate level in another domain (e.g., in the domain of personal/behavioral functioning he or she is frequently unable adequately to perform major age-appropriate activities of daily living); or

(b) The child is functioning at the moderate level in three domains (e.g., in cognitive functioning, the child has a valid full scale IQ of 74; in social functioning, he or she has limited age-appropriate relationships with peers and adults, with occasional serious conflicts with family, classmates, teachers and others; and with respect to concentration, persistence and pace, the child is frequently unable to complete age-appropriate complex tasks, and occasionally unable to perform simple age-appropriate tasks adequately).

(6) Evaluating older adolescents (age 16 to age 18).

(a) Children aged 16 to 18 are closely approaching adulthood and can be evaluated in terms that are the same as, or similar to, those used for the evaluation of the youngest adults. Children in this age range who do not have impairment-related limitations are ordinarily expected to be able to do the kinds of physical and mental activities expected of individuals who are at least 18 years old.

The discussions in this section are predicated on the foregoing principles. They describe limitations of physical and mental functions that are associated with, or related to, functions in the workplace, as demonstrated by a child's performance of age-
appropriate activities in age-appropriate contexts, such as school, part-time or full-time work, vocational programs and organized activities. Information concerning the child's functioning in five functional domains (cognitive, communicative, motor, social, and personal/behavior) and in concentration, persistence, and pace, is also used to establish the child's ability, or potential ability, to perform physical and mental functions in the workplace. (See IV.C.4.e(7)).

As in the examples for younger children, the guidance for evaluating older adolescents is not intended to be all-inclusive or a standard by which all cases must be judged. Each case must be evaluated on its own merits using the principles and guidelines of all of the regulations addressing childhood disability.

(b) The reviewer will consider the child's mental capacity to perform on a sustained basis (i.e., eight hours a day, five days a week) the general kinds of mental activities that are evaluated for adults, in order to determine if there is a substantial loss or deficit in the child's ability to meet any one of the basic mental demands of unskilled work. The reviewer will consider such things as the ability to understand, carry out, and remember simple instructions; to maintain attention for extended periods of time; to use judgment; to make simple decisions; to take necessary safety precautions; to respond appropriately to supervision and peers (e.g., by being able to accept instructions and criticism, by not requiring special supervision, and by not being unduly distracted by peers or unduly distracting to them in a school or work setting); and dealing with changes in the routine of the school or work setting.

(c) The reviewer will consider the child's physical capacity to perform on a sustained basis (i.e., eight hours a day, five days a week) the types and ranges of exertional and nonexertional activities that are evaluated for adults, e.g., sitting, standing, walking, lifting, carrying, pushing, pulling, reaching, handling, manipulating, seeing,
hearing and speaking. The reviewer will consider these and any other relevant factors to determine if there is a substantial loss or deficit in the child's ability to meet any one of the basic physical demands of sedentary work.

(d) If an individualized functional assessment shows that the child experiences a substantial loss or deficit of capacity to perform the age-appropriate mental or physical activities described, the impairment(s) will be found to seriously interfere with the child's ability to function independently, appropriately, and effectively in an age-appropriate manner, and that it has substantially reduced the child's ability to acquire the skills needed to assume roles reasonably expected of adults.

Therefore, the child will be found to have an impairment(s) that is comparable in severity to an impairment that would disable an adult, and the child will be determined disabled.

D. Continuing Disability Review

1. General

All disability cases with an expiration date require a continuing disability review prior to that date to determine if the child continues to be disabled.

Because the rules for finding a child disabled are no longer based on a listings only test, policies for finding that a child's disability continues or has ended have been revised, since these were also formerly based on a listings-only test. The provisions of the adult rules for determining continuing disability have generally been adopted for the new childhood rules, inasmuch as the new childhood disability process is now comparable to the adult process. However, substantial gainful activity is not considered in children's continuing disability review.

Continuing disability review determinations which are approved based on lack of medical improvement as described below should refer to 20 CFR 416.994a as a regulatory basis on the DSS-639, "Disability Review Team Certificate".

2. Process

The steps of the sequential evaluation process for children's continuing disability review cases include:
o determining if the child meets or equals (medically or functionally) a listing;

o determining if there has been medical improvement;

o determining if medical improvement is related to the ability to work;

o determining if the child's impairment(s) is currently severe; and,

o determining if the child's impairment(s) is comparable to that which would disable an adult.

a. Meeting or Equaling the Listings

Does the child have an impairment or combination of impairments that meets or equals a listing?

If the child has an impairment that meets a current listing, or an impairment or combination of impairments that is of equivalent severity to a current listing, the child's disability will be found to continue. If not, the reviewer will proceed to the next step in the sequence.

b. Medical Improvement

Has there been medical improvement in the child's condition?

(1) General. Medical improvement is defined as any decrease in the medical severity of the child's impairment(s) which was present at the time of the most recent favorable decision that he or she was disabled or continued to be disabled. A determination that there has been a decrease in medical severity must be based on changes (improvement) in the symptoms, signs, or laboratory findings associated with the child's impairment(s).

(2) The most recent favorable decision. The most recent favorable decision is the latest final determination or decision involving a consideration of the medical evidence and whether the child was disabled or continued to be disabled.

(3) Temporary remissions. Some impairments are subject to temporary remissions, which can give the appearance of medical improvement when in fact there has been none. If the child has the kind of
impairment that is subject to temporary remissions, the reviewer will be careful to consider the longitudinal history of the impairment, including the occurrence of prior remissions and prospects for future worsenings, when deciding whether there has been medical improvement. Improvements that are only temporary will not warrant a finding of medical improvement.

(4) Evaluation. If the reviewer finds that there has been improvement in the child's symptoms, signs, or laboratory findings, medical improvement will be found to have occurred. A determination of medical improvement does not necessarily mean that the reviewer will find that the child's disability has ended. If the reviewer determines that medical improvement has not occurred, the reviewer will determine whether an exception applies. (Please refer to the Medical Assistance Disability Manual for definition/discussion of exceptions. Please note that the exception which pertains to an individual who is engaging in substantial gainful activity does not apply to children's cases.) If a group I exception applies, the reviewer will proceed to the next step. If a group II exception applies, the reviewer will determine that disability has ended. If no exception applies, the child will continue to be found disabled. If medical improvement is found to have occurred, the reviewer will proceed to the next step.

(5) Prior file cannot be located. If the prior file cannot be located, the reviewer will first determine whether the child is currently disabled under the sequence set forth in section C. In this way, the child's disability may be determined to continue without reconstructing prior evidence. If the child is determined disabled in this manner, the child's disability will continue unless one of the second group of exceptions applies. If not, the reviewer will follow the policies set forth under section II.G.2.i.(2) of the Medical Assistance Disability Manual.

c. Medical Improvement as Related to the Ability to Work

Is medical improvement related to the ability to work?

For a child, medical improvement is related to the ability to work when there has been an increase in the ability to function independently, appropriately, and
effectively in an age-appropriate manner. Hence, if the child's impairment(s) has medically improved as defined above, but the ability to function in an age-appropriate manner has not increased, the child's medical improvement will be found not related to the ability to work. The reviewer will determine whether medical improvement is related to the ability to work as follows:

(1) Previous decision made on the basis of meeting/equaling a listing.

(a) If the most recent favorable decision was based on a finding that the child's impairment(s) met or equaled a listing that is in the current Listing of Impairments, and the impairment(s) no longer meets or equals that listing, the reviewer will determine at this step that medical improvement was related to the ability to work.

(b) If the most recent favorable decision was based on a finding that the child's impairment(s) met or equaled a listing that is no longer in the Listing of Impairments or that has since been revised, the reviewer will consider whether the child's impairment(s) continues to meet or equal that prior listing at this step. If the child's impairment continues to meet or equal the prior listing, the reviewer will find that the child's disability continues (provided that no exception applies), even though the impairment(s) does not meet or equal any current listing. If the impairment(s) no longer meets or equals the prior listing, the reviewer will determine at this step that medical improvement was related to the ability to work.

(2) Previous decision made on the basis of an individualized functional assessment. If the most recent favorable decision was based on an individualized functional assessment, the reviewer will do a new individualized functional assessment based on the previously existing impairment(s). However, the new individualized functional assessment will be based on those functions which are appropriate to the child's current age.

(a) The reviewer will use this assessment to determine whether there has been an increase
in the child's ability to function in an age-appropriate manner since the most recent favorable decision by comparing the current assessment with the assessment made at the time of the most recent favorable decision.

(b) The reviewer will not generally do a new individualized functional assessment for the time of the most recent favorable decision. The assessment made at the time of the last decision will be used. However, if the reviewer does not have the assessment made at the time of the most recent favorable decision (e.g., because it is missing from the child's file), the reviewer will have to reconstruct the assessment. This will be done by assuming that the child had the maximum functional abilities consistent with a decision of allowance or continuance at the time of the most recent favorable decision.

(c) If there has been improvement in the child's age-appropriate functioning, the reviewer will find that the child's medical improvement is related to the ability to work.

If the reviewer finds that the medical improvement is not related to the ability to work, the reviewer will determine whether an exception applies. If no exception applies, the child will continue to be found disabled. If a group I exception applies, the reviewer will continue to the next step. If a group II exception applies, the reviewer will find that the child's disability has ended. If medical improvement is determined to be related to the ability to work, the reviewer will go on to the next step.

d. Severity of Impairment(s)

The reviewer will determine if the child has a severe impairment, as discussed in previous sections. If it is determined that a severe impairment no longer exists, the child's disability will be found to have ended. If the child is determined to have a severe impairment(s), which has lasted, or is expected to last, at least 12 months or to result in death, the reviewer will proceed to the next step.
e. Individualized Functional Assessment

The reviewer will do an individualized functional assessment on the child. If the child is determined disabled on this basis, the child's disability will be found to continue. If the child is found to be not disabled, disability will be found to have ended.

E. Automatic Rereview of Children's Cases Disapproved since February 1, 1990/ Potential for Rereview in Event of Revisions to Final Regulations

As indicated in 90 LCM-150, any children's cases which were disapproved under the Interim Standard now need to be reviewed again in accordance with the final regulations as set forth in this Directive. Since the final regulations are subject to a period of public comment, it is possible that further revisions of these regulations may occur. Therefore, any children's cases which are disapproved under the current final regulations will be retained by the Disability Review Team to be reviewed again, should the final regulations be further revised.

1. Notice to Clients

For those children's cases which are disapproved, the following notice to the client of this automatic re-review must be included with the DSS-4141, "Notice of Medical Assistance Disability Determination".

DISAPPROVAL NOTICE LANGUAGE

As a result of the Supreme Court decision in the case of Zebley v. Sullivan, the Social Security Administration (SSA) has been required to change the rules governing childhood disability and to consider the child's daily living activities in deciding these cases. Final regulations have been issued and are being used to decide these cases; however, these final regulations are subject to further revision following a period of public comment. In the event that the regulations are further revised, your case will automatically be reviewed again using these revised regulations, and you will receive another notice informing you of the decision.
F. Tracking and Reporting

In 90 LCM-150, districts were advised that children's cases evaluated since February 1, 1990 under the Interim Standard were to be tracked with the following information noted: name, date of birth, CIN #, disposition of the case (approved, disapproved, or no action), and the date of disposition.

At this time, in order to evaluate the fiscal and programmatic impact of the Zebley decision, districts should note that a report will be due no later than November 1, 1991 on all the children's disability cases reviewed between February 1, 1990 and February 11, 1991. This report must contain the following data from districts:

- number of cases reviewed
- number of cases approved

This report is required of those districts which have their own Disability Review Team. The State Disability Review Team will prepare this report for those districts which submit cases to it for review.

This report must be submitted to Sharon Stein, New York State Department of Social Services, Division of Medical Assistance, 40 North Pearl Street, Albany NY 12243 no later than November 1, 1991.

One additional report will be due no later than July 1, 1992 on all the children's disability cases reviewed between February 12, 1991 and February 1, 1992. The report must again contain the number of cases reviewed and number of cases approved.

V. EFFECTIVE DATE

This ADM is effective September 15, 1991, retroactive to February 11, 1991.

Jo-Ann A. Costantino
Deputy Commissioner
Division of Medical Assistance
**Listing of Attachments**

**Attachment I**  
Listing of Attachments (available on-line)

**Attachment II**  
Individualized Functional Assessment for A Child from Birth to Age One (not available on-line)

**Attachment III**  
Individualized Functional Assessment for A Child from Age One to Age Three (not available on-line)

**Attachment IV**  
Individualized Functional Assessment for A Child from Age Three to Age 16 (not available on-line)

**Attachment V**  
Individualized Functional Assessment for A Child from Age 16 to Age 18 (not available on-line)

**Attachment VI**  
Sequential Evaluation Flow Chart For Children's Cases (not available on-line)