The "disability" standards for children with mental illnesses or bio-neurological disorders

In order to qualify for SSI or for Medical Assistance under Category PS 95 (the loophole), the child's mental illness or bio-neurological disorder must be severe enough to meet Social Security's disability standards. [Even though Medical Assistance does not go through Social Security, it uses SSA's disability standards.] Many parents have asked what the disability standards are that their child must meet in order to qualify for Medical Assistance. This section discusses those standards.

IEP not enough
The fact that a child has an IEP and is in special education or early intervention does not, by itself, mean the child meets the disability standards for Medical Assistance or SSI. The eligibility standards for special education and early intervention are completely different from the Social Security and Medical Assistance disability standards. However, the Comprehensive Evaluation Report ("CER") which is usually done prior to an IEP can be an excellent source of documentation of the kinds of factors considered in the Social Security/Medical Assistance disability standard.

Diagnosis not enough
Having a particular diagnosis is not enough to meet the disability standards. There are two parts to the disability standards: diagnosis and functional impairment. The standards contain criteria that specify the characteristics of the various mental illnesses and bio-neurological disorders by general diagnostic category that meet the diagnosis part of the disability standards. However, a child can still meet the diagnosis part of the standards if his or her condition is "equivalent" to one of the disorders listed in the criteria.

Functional impairment is the key
The second part of the disability standards is functional impairment. Documenting a level of functional impairment that meets the disability standards is absolutely essential in order to qualify either for Medical Assistance under the "loophole" or for SSI, regardless of the child's diagnosis.

Four areas of function
The disability standards group areas of functioning into 4 areas. In most cases, the child must have a "marked limitation" in at least 2 of the 4 areas of functioning in order to meet the standards. The 4 areas are:
1) cognitive/communicative functioning
2) social functioning
3) personal functioning and
4) concentration, persistence and pace.
What the 4 areas of functioning mean

1) cognitive/communicative functioning: Cognitive functioning refers to intelligence as measured by standardized intelligence tests. A child with both cognitive limitations and speech or other communicative limitations will still have to have a limitation in another area in order to meet the disability standards.

2) social functioning refers to a child's capacity to form and maintain relationships with parents, other adults, and peers.

3) personal functioning pertains to self-care; i.e., personal needs, health, and safety (feeding, dressing, toileting, bathing, maintaining personal hygiene, proper nutrition, sleep, health habits; adhering to medication or therapy regimens; following safety precautions).

4) concentration, persistence and pace refers to the ability to complete tasks in a timely manner.

What “marked limitation” means

Remember that to meet the Social Security/Medical Assistance disability standards, the child must have “marked limitations” in two of the four areas of functioning listed above. A “marked limitation” is defined in the regulations as: “more than moderate but less than extreme... such as to interfere seriously with the ability to function (based upon age-appropriate expectations) independently, appropriately, effectively, and on a sustained basis. When standardized tests are used as the measure of functional parameters, a valid score that is two standard deviations below the norm for the test will be considered a marked restriction.” Listing 112.00(A) at 20 CFR §404, Subpart P, Appendix 1. In determining whether the limitation is “marked”, Social Security and Medical Assistance will consider the intensity, frequency, and duration of the behaviors or other functional limitations.

Documentation is essential

Some documentation of the child’s diagnosis and the behaviors and functional impairments that were considered in making the diagnosis must come from a physician (most commonly a psychiatrist) or a psychologist. Don’t assume the psychiatrist or psychologist know the disability standards. It is very helpful for the parent/guardian or other person working with the child to remind the psychiatrist, psychologist and/or other treatment professionals of behaviors or other functional limitations that are relevant under one or more of Social Security’s 4 areas of functioning so these behaviors can be noted in the treatment professional’s report. Remember, it is crucial that these reports not only mention behaviors that are relevant to the 4 areas of functioning, but that the reports also include observations as to the intensity, frequency, and duration of the behaviors or other functional limitations. In addition, it is useful to provide records from prior hospitalizations or records from residential placements or outpatient treatment. School records, especially the Comprehensive Evaluation Report (“CER”), can be also useful if they indicate problems relevant to the 4 areas of functioning. Any other individual who has direct knowledge of the child’s behaviors or other functional limitations can supplement the documentation.
Who gets the documentation?
If applying for SSI, Social Security will send out questionnaires to doctors, therapists and teachers. The parent/guardian should strongly encourage the professionals receiving the Social Security disability questionnaires to fill them out completely and promptly. Social Security will often obtain hospital records as well. However, Medical Assistance will not send questionnaires or get hospital records. Obtaining the necessary medical and psychiatric documentation is the responsibility of the parent/guardian when applying for Medical Assistance.

What happens next for Medical Assistance?
For Medical Assistance, the caseworker at the County Assistance Office has authority to immediately find that the child meets the disability standards, pending a final decision, if, based on the documentation provided by the parent/guardian, the child “appears to be disabled”. Medical Assistance Eligibility Handbook §305.26. This is known as “presumptive eligibility” and is very common if good documentation is provided. After that, the caseworker is supposed to transfer the case to the “Disability Advocacy Program Unit” (“DAP Unit”) which usually reviews the documentation, and may request that the parent/guardian get additional documentation or come in for an interview. After that, the DAP Unit is supposed to send the documentation to an agency under contract with Medical Assistance, know as the Medical Review Team (“MRT”) which makes the final decision as to whether the documentation shows that the child meets the disability standards. If the MRT decides that the child’s documented condition does not meet the disability standards, the County Assistance Office will terminate the child’s Medical Assistance unless the child is eligible under another category. However, the parent/guardian can appeal the MRT’s decision and if their appeal is received by the County Assistance Office within 10 days of the termination notice being mailed, the termination cannot go through until after the family has had a hearing and gets a hearing decision. (Of course, if the wins, the termination won’t go through at all.) The termination notice explains how to appeal.

What happens next for SSI?
SSI also has the authority to make an immediate decision that the child meets the disability standards. Social Security calls this “presumptive disability”. Unfortunately however, children with mental illness or bio-neurological disorders other than mental retardation are rarely found presumptively disabled by Social Security. This means the child is not likely to obtain Medical Assistance through SSI for several months (sometimes a year or more) until the full disability determination process is completed. Because of this, it is usually necessary for the parent/guardian to apply separately for Medical Assistance at the County Assistance Office while waiting for a decision on the SSI because the child can usually get Medical Assistance more quickly than SSI. After the SSI application is filed, the case is referred by Social Security to the State Dept. of Labor, Bureau of Disability Determination. They send out questionnaires, obtain hospital records and may even send the child to another psychologist or psychiatrist (at Social Security’s expense) for what is called “a consultative exam”. The Bureau of Disability Determination then makes a recommended decision which Social Security finalizes and sends out. The parent/guardian can appeal that decision if it is unfavorable. If Social Security finds that the child does not meet the disability standards and the child had been receiving Medical Assistance while waiting for the Social Security decision, it is critical that the parent/guardian appeal the Social Security denial, even if the SSI cash benefit is not that important to the family. This is because a finding by Social Security that the child does not meet the disability standards is binding on Medical Assistance.
Therefore, if the child had been receiving Medical Assistance under the loophole or Healthy Horizons, under which the child must meet the disability standards in order to qualify, Social Security’s decision that the child does not meet the disability standards will result in the child losing their Medical Assistance as well.

For more information
Call the PA Health Law Project at 1-800-274-3258 for more information. The full disability standards are available on the internet. The address is: http://www.ssa.gov/OP_Home/cfr20/404/404-ap09.htm. The formal name for the disability standards is the “Listing of Impairments”. The first half of the listings apply to persons 18 and older. The second half apply to children under age 18 and begin with section 100.00. The standards (or “listings”) for children’s “mental disorders” begin at section 112.00.

David Gates
Disability Standard (the "Listing of Impairments") under SSI and Medical Assistance category
PSSS ("loophole") for Children (under 18) with autism spectrum disorders

112.10 Autistic Disorder and Other Pervasive Developmental Disorders:

Characterized by qualitative deficits in the development of reciprocal social interaction, in the development of verbal and nonverbal communication skills, and in imaginative activity. Often, there is a markedly restricted repertoire of activities and interests, which frequently are stereotyped and repetitive.

The required level of severity for these disorders is met when the requirements in both A and B are satisfied.

A. Medically documented findings of the following:
   1. For autistic disorder, all of the following:
      a. Qualitative deficits in the development of reciprocal social interaction;
      b. Qualitative deficits in verbal and nonverbal communication and in imaginative activity;
      c. Markedly restricted repertoire of activities and interests;
   OR
   2. For pervasive developmental disorders, both of the following:
      a. Qualitative deficits in the development of social interaction;
      b. Qualitative deficits in verbal and nonverbal communication and in imaginative activity;
   AND
   B. For older infants and toddlers (age 1 to attainment of age 3), resulting in at least one of the appropriate age-group criteria in paragraph B1 of 112.02; or, for children (age 3 to attainment of age 18), resulting in at least two of the appropriate age-group criteria in paragraphs B2 of 112.02 [see below].

Preschool children (age 3 to attainment of age 6). For the age groups including preschool children through adolescence, the functional areas used to measure severity are:

a. Cognitive/communicative function, (b) social function, (c) personal function, and (d) deficiencies of concentration, persistence, or pace resulting in frequent failure to complete tasks in a timely manner.

After 36 months, motor function is no longer felt to be a primary determinant of mental function, and, of course, any motor abnormalities should be documented and evaluated.

b. Cognitive/communicative function. In the preschool years and beyond, cognitive function can be measured by standardized tests of intelligence, although the appropriate instrument may vary with age. A primary criterion for limited cognitive function is a verifiable performance, or full scale IQ of 70 or less.

The listings also provide alternative criteria, consisting of tests of language development or bizarre speech patterns.

c. Social function. Social functioning refers to a child's capacity to form and maintain relationships with parents, other adults, and peers. Social functioning includes the ability to get along with others (e.g., family members, neighborhood friends, classmates, teachers). Impaired social functioning may be caused by inappropriate externalized actions (e.g., running away, physical aggression— but not self-injurious actions, which are evaluated in the personal area of functioning), or inappropriate internalized actions (e.g., social isolation, avoidance of interpersonal activities, mutism).

The severity must be documented in terms of intensity, frequency, and duration, and shown to be beyond what might be reasonably expected for age. Strength in social functioning may be documented by such things as the child's ability to respond to and initiate social interaction with others, to sustain relationships, and to participate in group activities. Cooperative behaviors, consideration for others, awareness of others' feelings, and social maturity, appropriate to a child's age, also need to be considered. Social functioning in play and school may involve interactions with adults, including responding appropriately to persons in authority (e.g., teachers, coaches) or cooperative behaviors involving other children. Social functioning is observed not only at home but also in preschool programs.

d. Personal function. Personal functioning in preschool children pertains to self-care, i.e., personal needs, health, and safety (feeding, dressing, toileting, bathing, maintaining personal hygiene, proper nutrition, sleep, health habits; adhering to medication or therapy regimens; following safety precautions). Development of self-care skills is measured in terms of the child's increasing ability to help himself/herself and to cooperate with others in taking care of these needs. Impaired ability in this area is manifested by failure to develop such skills, failure to use them, or self-injurious actions.

This function may be documented by a standardized test of adaptive behavior or by a careful description of the full range of self-care activities. These activities are often observed not only at home but also in preschool programs.

e. Concentration, persistence, or pace. This function may be measured through observations of the child in the course of standardized testing and in the course of play.

3. Primary school children (age 6 to attainment of age 12). The measures of function here are similar to those for preschool-age children except that the test instruments may change and the capacity to function in the school setting is supplementing information. Standardized measures of academic achievement, e.g., Wide Range Achievement Test-Revised, Peabody Individual Achievement Test, etc., may be helpful in assessing cognitive impairment. Problems in social functioning, especially in the area of peer relationships, are often observed firsthand by teachers and school nurses. As described in 112.00D, documentation, school records are an excellent source of information concerning function and standardized testing and should always be sought for school-age children.

As it applies to primary school children, the intent of the functional criterion described in paragraph B2d, i.e., deficiencies of concentration, persistence, or pace resulting in failure to complete tasks in a timely manner, is to identify the child who cannot adequately function in primary school because of a mental impairment. Although grades and the need for special education placement are relevant factors which must be considered in reaching a decision under paragraph B2d, they are not conclusive.
There is too much variability from school district to school district in the expected level of grading and in the criteria for special education placement to justify reliance solely on these factors.

4. Adolescents (age 12 to attainment of age 18). Functional criteria parallel to those for primary school children (cognitive/communicative, social, personal, and concentration, persistence, or pace) are the measures of severity for this age group. Testing instruments appropriate to adolescents should be used where indicated. Comparable findings of disruption of social function must consider the capacity to form, appropriate, stable, and lasting relationships. If information is available about cooperative working relationships in school or at part-time or full-time work, or about the ability to work as a member of a group, it should be considered when assessing the child's social functioning.

Markedly impoverished social contact, isolation, withdrawal, and inappropriate or bizarre behavior under the stress of socializing with others also constitute comparable findings. (Note that self-injurious actions are evaluated in the personal area of functioning.)

a. Personal functioning in adolescents pertains to self-care. It is measured in the same terms as for younger children, the focus, however, being on the adolescent's ability to take care of his or her own personal needs, health, and safety without assistance. Impaired ability in this area is manifested by failure to take care of these needs or by self-injurious actions. This function may be documented by a standardized test of adaptive behavior or by careful description of the full range of self-care activities.

b. In adolescents, the intent of the functional criterion described in paragraph 62d is the same as in primary school children. However, other evidence of this functional impairment may also be available, such as from evidence of the child's performance in work or work-like settings.

D. Documentation: The presence of a mental disorder in a child must be documented on the basis of reports from acceptable sources of medical evidence. See §§404.1513 and 416.913. Descriptions of functional limitations may be available from these sources, either in the form of standardized test results or in other medical findings supplied by the sources, or both. (Medical findings consist of symptoms, signs, and laboratory findings.) Whenever possible, a medical source's findings should reflect the medical source's consideration of information from parents or other concerned individuals who are aware of the child's activities of daily living, social functioning, and ability to adapt to different settings and expectations, as well as the medical source's findings and observations on examination, consistent with standard clinical practice. As necessary, information from nonmedical sources, such as parents, should also be used to supplement the record of the child's functioning to establish the consistency of the medical evidence and longitudinality of impairment severity.

E. Effect of Hospitalization or Residential Placement: As with adults, children with mental disorders may be placed in a variety of structured settings outside the home as part of their treatment. Such settings include, but are not limited to, psychiatric hospitals, developmental disabilities facilities, residential treatment centers and schools, community-based group homes, and workshop facilities. The reduced mental demands of such structured settings may attenuate overt symptomatology and superficially make the child's level of adaptive functioning appear better than it is. Therefore, the capacity of the child to function outside highly structured settings must be considered in evaluating impairment severity. This is done by determining the degree to which the child can function (based upon age-appropriate expectations) independently, appropriately, effectively, and on a sustained basis outside the highly structured setting.

On the other hand, there may be a variety of causes for placement of a child in a structured setting which may or may not be directly related to impairment severity and functional ability. Placement in a structured setting in and of itself does not equate with a finding of disability. The severity of the impairment must be compared with the requirements of the appropriate listing.

Where "marked" is used as a standard for measuring the degree of limitation it means more than moderate but less than extreme. A marked limitation may arise when several activities or functions are impaired, or even when only one is impaired, as long as the degree of limitation is such as to interfere seriously with the ability to function (based upon age-appropriate expectations) independently, appropriately, effectively, and on a sustained basis.

When standardized tests are used as the measure of functional parameters, a valid score that is two standard deviations below the norm for the test will be considered a marked restriction.

Need for Medical Evidence: The existence of a medically determinable impairment of the required duration must be established by medical evidence consisting of symptoms, signs, and laboratory findings (including psychological or developmental test findings). Symptoms are complaints presented by the child. Psychiatric signs are medically demonstrable phenomena which indicate specific abnormalities of behavior, affect, thought, memory, orientation, development, and contact with reality, as described by an appropriate medical source. Symptoms and signs generally cluster together to constitute recognizable mental disorders described in paragraph A of the listings. These findings may be intermittent or continuous depending on the nature of the disorder.

C. Assessment of Severity: In childhood cases, as with adults, severity is measured according to the functional limitations imposed by the medically determinable mental impairment. However, the range of functions used to assess impairment severity for children varies at different stages of maturation. The functional areas that we consider are: Motor function; cognitive/communicative function; social function; personal function; and concentration, persistence, or pace. In most functional areas, there are two alternative methods of documenting the required level of severity: (1) Use of standardized tests alone, where appropriate test instruments are available, and (2) use of other medical findings. (See 112.00D for explanation of these documentation requirements.) The use of standardized tests is the preferred method of documentation if such tests are available.