



NAMI-NEW YORK STATE

National Alliance for the Mentally Ill - New York State

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J. David Seay, JD

June 12, 2003

Commissioner of Social Security
P.O. Box 17703
Baltimore, MD 21235-7703

Dear Commissioner:

On behalf of the National Alliance for the Mentally Ill of New York State (NAMI-NYS), I am pleased to submit a response to the Social Security Administration's Advance Notice of Proposed Rulemaking concerning Revised Medical Criteria for Evaluating Mental disorders (68 *Federal Register* 12639, March 17, 2003.).

With 5,000 members and 58 affiliates throughout New York State, NAMI-NYS is a grass-roots organization whose mission is to provide support, education, and advocacy for New Yorkers with mental illness and their families. As "New York's Voice on Mental Illness," our goal is to find a cure for the brain diseases referred to as mental illness, and until then, to improve the lives of all those affected by these no-fault, neurobiological disorders.

We at NAMI-NYS are well aware of the vital role played by the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs in the lives of individuals with severe and persistent mental illness. These programs are a social safety net for those who, due to the nature and severity of their illness, are either temporarily or permanently incapable of supporting themselves through substantial gainful employment.

We are grateful to the Social Security Administration for its invitation to comment on revising the medical criteria for evaluating mental disorders. We believe that any change in criteria for determining mental impairment - hence eligibility for SSDI and/or SSI - must: a) be based on the most up-to-date scientific evidence and methods; b) take into account the uniquely disabling nature of mental illness, from its diverse manifestations and symptoms to its impact on the ability to perform tasks necessary for functioning in a competitive economy.

NAMI-NYS fully endorses the recommendations offered by the Consortium for Citizens with Disabilities (CCD), a coalition of over 100 national disability organizations, including the National Alliance for the Mentally Ill. A listing of their recommendations is submitted for your review.



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In addition to the recommendations of the CCD, NAMI-NYS recommends that under the *Activities for Daily Living* section of the “B” criteria listings, additional material should be added to this section to explain that relevant ADLs include the ability to engage, independent of supervision or direction, appropriately, effectively and in a sustained manner in activities such as ability to pay bills, carry out simple instructions, maintain personal appearance and health, travel in unfamiliar places, set realistic goals, manage and maintain a work or home environment and cope with routine stresses of daily life.

On behalf of NAMI-NYS, I again thank you for giving our organization the opportunity to comment on this critical issue.

Sincerely,

A handwritten signature in black ink, appearing to read 'J. David Seay', written over a horizontal line.

J. David Seay, J.D.
Executive Director
NAMI-NYS

**CCD COMMENTS TO ADVANCE NOTICE OF PROPOSED
RULEMAKING ON REVISED MEDICAL CRITERIA
FOR EVALUATING MENTAL DISORDERS**

68 Fed. Reg. 12639 (Mar. 17, 2003)

I. Introduction to Comments

The Consortium for Citizens with Disabilities Task Forces on Social Security and Work Incentives Implementation (hereinafter “CCD”) appreciate the opportunity to comment on the Advance Notice of Proposed Rulemaking regarding revised medical criteria for evaluating mental disorders.

CCD is a working coalition of national consumer, advocacy, provider, and professional organizations working together with and on behalf of the 54 million children and adults with disabilities and their families living in the United States. The CCD Social Security and Work Incentives Implementation Task Forces focus on disability policy issues in the Title XVI Supplemental Security Income program and the Title II disability programs.

In general, CCD believes that the structure and design of the mental impairment listing works for the purpose of assessing children and adults with mental disorders. The basic structure and approach to the listings were developed by an expert panel appointed by the Social Security Administration prior to the publication of the adult listing in 1985. Based on the adult listing and with significant input from childhood disability experts, SSA published the children’s listing in 1990. In fact, many of our member organizations worked extensively with members of the expert panel on recommendations regarding provisions currently in the listings. The structure and approach have stood the test of time and still prove to be practical and workable for the evaluation of adults and children.

CCD believes that there are important updates and refinements that should be included in the listings for adults and children and we make specific recommendations below. These recommendations are for refinements within the current structure of the listing. We do not believe that major overhaul of the mental disorder listing is necessary. However, if SSA contemplates major overhaul of the listing, we urge that SSA formally adopt an expert panel process similar to that used prior to the publication of the adult listing in 1985, to ensure careful consideration of all recommendations for and ramifications of change.

II. Introduction to Mental Disorders Listings: Section 12.00

The Introduction to the Mental Disorders Listings, Section 12.00, provides detailed guidance for all disability adjudicators. As a result, it plays an important role in the decision-making process for individuals with mental impairments, including those whose impairments do not meet a listing. Our comments, as described below, address: (1) inclusion of important SSA policies in the Introduction; and (2) recommendations for policy changes.

We have included proposed language amending section 12.00, which is attached as Appendix A to our comments.

1. Assessment of severity

- **Add “extreme” for measuring degree of limitation**

In SSI childhood disability claims, SSA looks at six different domains to determine functional equivalence to a listed impairment. A child is considered disabled if he or she has “marked” limitations in two domains or an “extreme” limitation in one domain. We recommend that SSA add explicit language that an impairment meets the “B” criteria if there is an “extreme” limitation in one of four “B” criteria, in addition to the current language requiring “marked” limitations” in two of the “B” criteria. See App. A.

- **Better definition of “marked” and “extreme”**

For “marked,” we have added language from the SSI childhood disability regulations that include “standardized testing with scores that are at least two, but less than three, standard deviations below the mean.” 20 C.F.R. § 416.926a(e)(2). See App. A. It is important to stress that “marked” represents a serious, but less than extreme level of functional limitation. “Marked” should not be interpreted as requiring little or no function, such as being unable to feed and clothe oneself without assistance, or being limited to social interaction with only a few friends or family members.

For “extreme,” we have used the definition in the SSI childhood disability regulations. 20 C.F.R. § 416.926a(e)(2). See App. A.

We also recommend that the Introduction mention that other measures of function, including the Global Assessment of Functioning (GAF), frequently found in the diagnostic portion of mental health records, can provide useful evidence of overall, serious functional deficits when adequately documented and can be used as evidence to measure the severity of functional limitations. However, since it is a “global” assessment of function, an overall score that appears above the level of marked may in fact hide deficits in particular areas that meet the requirements of the listings.

2. Evidence issues

- **The importance of recognizing and properly weighing evidence from all treating sources**

We recommend that SSA provide clear guidance to adjudicators in the Introduction section of the listings and in separate regulations regarding the importance of evidence from all treating nonphysician professionals in assessing the limitations imposed by mental impairments.

The fact that SSA has established a distinction between “medical” and “nonmedical” evidence allows adjudicators to consider nonphysician evidence, even though provided by licensed health professionals, to be less important. As a result, they give it less weight than it deserves, despite the fact that it is the key information needed to establish the individual’s functional limitations.

We agree that evidence from an “acceptable medical source” is necessary to establish the existence of a “medically determinable impairment” as required by the Social Security Act. See 20 C.F.R. §§ 404.1513(a) and 416.913(a). However, where the regulations go on to say that once a “medically determinable impairment” is established, evidence from “other sources” is obtained to show the severity of the impairment and the limitations it imposes. This creates an artificial distinction between evidence elicited from a particular source. 20 C.F.R. §§ 404.1513(d) and 416.913(d). Evidence from treating sources who are licensed health professionals working under the supervision of a physician should not be treated differently than that given by a psychiatrist or psychologist.

These “other sources” include many of the primary sources of treatment for individuals with mental impairments, e.g., nurse practitioners and physicians’ assistants, therapists, psychiatric social workers, and educational personnel. Many individuals with mental illness are seen infrequently by physicians and usually only for a review of medications. Other nonphysician professionals are entrusted with their day to day care and are qualified and trained to recognize, treat, and evaluate mental illness.

Often, adjudicators over-rely on physician evidence. Based on our experience, the non-physician professional sources often are disregarded or given less weight because they are not physicians, when, in fact, they are the most important source of evidence about individuals with mental impairments.

SSA has recognized that evidence from these “other sources” is crucial to establishing the severity of mental impairments and the limitations they impose. For instance, similar concerns were raised in comments regarding the final rule on mental disorders, 65 Fed. Reg. 50746 (Aug. 21, 2000). In response, SSA noted that, while these non-physician medical sources are not “acceptable medical sources,” “[s]uch sources can, however, provide very valuable information about the severity of an impairment(s) once [a medically determinable impairment] has been established.” 65 Fed. Reg. at 50761. However, in creating this dichotomy, SSA has relegated the evidence of such professionals to a catch-all status that is easily dismissed.

Another comment noted that many individuals with mental impairments have no history of being treated for their disorders and that SSA’s emphasis on “medical” evidence “tends to reward those who can afford treatment while penalizing poorer individuals.” 65 Fed. Reg. at 50763. In sharing these concerns, SSA responded that “we consider all evidence in the case record that is relevant to our assessment of the individual’s ability to function. This includes information from both medical and nonmedical sources.” *Id.* at 50764. In fact, such evidence is often ignored and individuals are denied because they have not adequately documented their limitations with “medical evidence.”

The same concerns were raised in the final rule on SSI childhood disability, 65 Fed. Reg. 54747 (Sept. 11, 2000), where such evidence receives more serious attention. One commenter urged SSA to consider evidence from social workers, clinical psychologists, and nurse specialists as “valid and appropriate documentation of disability.” *Id.* at 54765. Recognizing the importance of these medical sources, SSA responded that “[e]vidence from these other health care professionals helps us understand how a child’s impairments affect ability to function.” *Id.* They should be treated no differently than other medical sources.

- **Role of nonphysicians and multi-disciplinary concept in treatment**

A recurring problem concerning evaluation of persons who have mental impairments is the treatment of evidence from therapists and other professionals who have the most contact with patients. The organization of and division of labor in community mental health centers is such that an individual patient may see the psychiatrist only once a month to evaluate medications, often for a very brief visit. On the other hand, the people most familiar with the case and the individual claimant’s functional limitations are

therapists or psychiatric social workers who see the individual on a daily or weekly basis. Current regulations treat evidence from such individuals merely as “other evidence,” which creates several problems.

Such evidence is not treated as “medical evidence of record,” even though it is prepared by a professional, included in the psychiatric case file and an integral part of a physician supervised treatment team. Indeed, if a psychiatrist were to find the time to write a report for Social Security he or she would certainly rely upon the day-to-day description found in the case file prepared by these professionals. We urge the Social Security Administration to alter its position and treat such information as medical evidence when it comes from a licensed clinic or is part of a medically supervised treatment plan. To do otherwise is to treat low-income claimants unfairly, since it denigrates the evidence of the people who know the patient best, merely because they cannot afford treatment in a setting where most of the work is done by physicians. We are not arguing for special treatment – obviously there will be situations in which the evidence provided is not credited for a variety of reasons, just as evidence from treating psychiatrists is not always given controlling weight. We are only urging treatment that affords such evidence its proper weight. Similar treatment has been afforded in the past to evidence from members of multi-disciplinary team members, even if they were not physicians, as long as the evaluations were part of the team’s treatment plan.

Considering such evidence will have several effects. For instance, it will allow the opinions of those who know claimants best to discuss whether the claimant meets the C criteria. See discussion of “C” criteria below in § V.

Second, a similar problem is the failure to afford any special weight to the opinion of therapists and others as to claimant function. Oftentimes, the adjudicator will give more weight to consultative examiners who see the claimant only once, and even worse, to non-examining state agency physicians who only review the file. Indeed, the regulations and other SSA policies seem to reinforce this result. Considering the evidence of a mental health center and all its personnel as medical evidence of a treating source would do much to resolve this unfairness, while still giving SSA the flexibility to make decisions based on the totality of the evidence.

Many of the troubling problems SSA encounters with differential approval rates from state to state and by race may be attributable to the inadvertent bias that has crept into the evaluation process as a result of the failure of the regulations to take into account the different treatment options available to low income people, especially in states and cities where public health facilities are hard pressed and strapped for resources. Recognition of the value of opinions from nonphysicians would help rectify this problem and make for a fairer climate of adjudication.

- **Third-party evidence**

It is not uncommon for some individuals with mental impairments to underestimate the impact of their impairments on their functioning. Sometimes an individual with a mental impairment will discount significant limitations in order to make herself appear more like other people, or to improve how other people relate to her. Under such circumstances, third-party input from persons who live or interact routinely with the claimant is essential.

We recommend that SSA explain in Section 12.00D.1.b that under some circumstances it would be beneficial to obtain a third-party assessment of an adult claimant’s functioning. Especially for impairments impacting cognitive abilities, such as traumatic brain injury (TBI) and mental retardation, the claimant may be unable to describe his or her actual limitations; and for some impairments, like personality disorders or obsessive compulsive disorder, the claimant may be averse to revealing any functional limitations. For some claimants with TBI and mental retardation in particular, it may be necessary that SSA examiners interview a reliable third party to gain independent knowledge of the claimant’s impairments prior to making a disability determination.

When a claimant is unable to describe functional limitations, or when the medical evidence suggests more serious functional limitations than are self-reported, it is necessary to make every effort to obtain a description of the claimant's typical functioning from a person who interacts routinely with the claimant to supplement any self-report of functioning. We recommend that SSA make every effort to obtain third-party descriptions of functioning whenever a claimant is unable to describe her limitations, as well as whenever the self-reported functioning surpasses what would be expected from the medical evidence of record.

- **Work and work attempts: Supported work**

We have proposed changes to Section 12.00 regarding supported work settings. Some adjudicators conclude that attendance in a supported work setting means that a claimant with a mental impairment can have no significant limitations in social functioning or in concentration, persistence, and pace merely because the claimant is engaged in work-like activities. Furthermore, when a claimant with autism or one of the autistic spectrum disorders is engaged in supportive work, some adjudicators conclude that the claimant has no "qualitative deficits in reciprocal social interaction" and no "qualitative deficits in verbal and nonverbal communication" merely because the claimant participates in a supported work program. This especially is problematic for redeterminations of 18 year olds who may have been disabled since infancy.

Because there is no vocational assessment involved in the decision making at the initial and reconsideration levels (and only vocational expert testimony is available at the administrative law judge hearing level), it is apparent that supported work employment may be improperly interpreted to mean that the claimant is not disabled without a full appreciation for the realities of supportive work settings. Generally, the need for such a setting for a claimant with a mental impairment would preclude gainful activity in competitive employment. Moreover, should the claimant's impairment not meet or equal listings-level severity, a thorough vocational assessment should lead to a finding of disabled under Step 5 because a claimant in supportive work settings usually would be unable to learn to do unskilled work within 30 days.

3. Consideration of drug use as a symptom of another mental impairment

Drug use may be a symptom of another mental impairment. Further, many individuals diagnosed with mental illness also have substance abuse problems. SSA's rules should provide clear guidance to adjudicators that the mere fact of substance abuse is not grounds for denying a claim and that they must distinguish between cause and effect.

The current Introduction does not fully discuss how drug addiction and alcoholism (DAA) is to be evaluated under the Listings. Although the DAA provisions were last changed in 1996, SSA has not changed the listing language, either listing 12.09, which is structured as a reference listing, or to reference the "materiality" regulations, 20 C.F.R. §§ 404.1535 and 416.935. We have proposed language that cross-references SSA's existing rules which require a determination whether drug addiction or alcoholism is a contributing factor material to the determination of disability.

The listing language should reflect the DAA regulations because most medical advisors at ALJ hearings do not have access to the entire set of regulations but instead rely on the SSA publication, "Disability Evaluation Under Social Security," which includes only the listings.

4. Treatment affecting signs and symptoms

For many individuals with mental illness, medication will treat the overt signs and symptoms (such as hallucinations) but not the resulting functional deficits (often termed negative symptoms). This means that some individuals on medication may no longer meet the A criteria regarding signs and symptoms, even though they have a diagnosis of a listed disorder, but nonetheless they meet the B criteria regarding function.

Section 12.00 should clarify that when an individual meets the B criteria with a diagnosis cited in the A criteria, he or she will qualify, just as others do whose overt symptoms are not controlled with medication.

5. Documentation

A discussion about school attendance and vocational training has been added to the Documentation section to provide needed guidance for evaluating cases of young adults for whom such evidence is particularly relevant.

6. Medical equivalence

For persons who cannot exactly meet any specific A criteria, but who meet the B or C criteria, we have expanded discussion of the “B” and “C” criteria generally to make clear that individuals with medically determinable impairments who satisfy either Paragraph B or C criteria are disabled. This establishes a “medical equivalence” standard and such an approach, like the focal point of the mental disorders listings, focuses on the impact of the functional limitations, which are assessed under the B or C criteria.

III. “A” Criteria Issues Regarding Specific Listings

1. “Marked” as a factor in the “A” criteria

We begin with the assumption that the “A” criteria should only deal with the diagnosis, primarily to satisfy the statutory requirement that a person be diagnosed with a physical or mental impairment. The extent to which a particular diagnosed impairment is or is not disabling is largely a function of the B and C criteria. This seems to be the operating assumption SSA has used in constructing the Listings. However, for a number of diagnoses, there are functional requirements that have crept in to the A criteria. Since this is not universal, it gives the impression that the criteria for certain mental impairment diagnoses have a higher threshold of disability, when, as we understand it, the level of dysfunction that leads to a finding of disability should not vary from one diagnosis to another. To make matters worse, these A criteria often use the term “marked” to describe the diagnostic symptoms that are required, adding an additional layer of confusion. Does that mean the same thing as “marked” in the B criteria, and, if so, what does it mean to have a “marked” in the A criteria? Does that mean one needs three marked for particular diagnoses, or does it mean that one already has a “marked” impairment of function that obviates the need to meet two others? Examples of this include:

- 12.06A.3/12.06A.5: “Recurrent *severe* panic attacks manifested by a sudden unpredictable onset of *intense* apprehension ... occurring on the average of *at least once a week*.” With symptoms of this magnitude how could anyone not have “marked” impairments in function? Even panic attacks of less frequency might leave a person with a “marked” inability to perform activities of daily living (ADLs).
- 12.06 A.4/12.06A.6: “Recurrent obsessions or compulsions which are a source of *marked* distress” and 12.06A.5/12.06A.7. “Recurrent and intrusive recollections of a traumatic experience, which are a source of *marked* distress.” Both these requirements of “marked” distress confuse the issue and make one wonder if the definition is the same for “marked” in the B criteria. Is it possible to have marked distress and not meet the B criteria for marked in ADLs and social function?
- 12.07/12.07: “Somatoform disorders: Physical symptoms for which there are no demonstrable organic findings or known physiological mechanisms.” Requiring *no* organic findings is inconsistent with the DSM and unrealistic since many who suffer from this disorder have slight organic findings to which they attach inappropriate significance. In fact the capsule definition is inconsistent with the criteria in 12.07A.3, which only requires “unrealistic *interpretation* of physical signs.”
- 12.07.A.1: “A history of multiple physical symptoms of several years duration, beginning before age 30, that have caused the individual to take medicine frequently, see a physician often and *alter life patterns significantly*.” This one subsection contains several problems. First, it is clear in the DSM

that not all such disorders require onset before age 30. (Compare 300.81, Somatization Disorder, requiring onset by age 30, with 300.82, Somatoform Disorder, which has no diagnostic onset date.) Second, of course, it is unclear how life patterns could be altered significantly without that having a marked effect on activities of daily living. Third, not all such individuals will take medicine frequently, since their physicians may refuse to prescribe it. Finally, requiring symptoms of several years duration is inconsistent with the Act, if individuals are not allowed to provide evidence that such symptoms are projected to persist for several years. While duration of symptoms may be clinically significant (and even the DSM does not require symptoms to last “several years”), the law simply does not require such a long duration, especially given how vague “several years” is as a standard.

- 12.08: The capsule definition reads: “Personality disorders: A personality disorder exists when personality traits are inflexible and maladaptive and cause either *significant* impairment in social or occupational functioning or subjective distress.” This is certainly a higher functional hurdle than for other impairments, since in addition to meeting these capsule requirements, the claimant must also meet the same B criteria as other individuals. In addition, the requirement that “characteristic features are typical of long term functioning and are not limited to discrete episodes of illness” seems inconsistent with B.4 “repeated episodes of decompensation.”
- 12.10/112.10: The capsule definition of an Autistic Disorder requires a “*markedly* restricted repertoire of activities and interests,” a phrase repeated in A.1.c. Would this not also satisfy a marked restriction in social function? How would this be different than a qualitative deficit in reciprocal social interaction, another A criteria, specifically, 12.09A.2.a?
- 112.03: The children’s schizophrenia listing requires a “*marked* disturbance of thinking, feeling, and behavior.”
- 112.04: The children’s mood disorder listing requires “*markedly* diminished interest or pleasure” at two separate places, the capsule definition and at 112.04 A.1.b.
- 112.11: The children’s ADHD listing requires *marked* inattention, impulsiveness, hyperactivity and then refers the adjudicator to the B criteria to make further findings of two more *marked* functional limitations.
- 12.05/112.05: As we discuss more fully in the section dealing with mental retardation, see below, the requirement in the capsule section of “deficits in adaptive function,” 12.05/112.05, can impose a standard of disability that is unrealistically high, in that it requires not only a very significant cognitive deficit, but also requires an adaptive deficit that is currently ill defined and, we fear, may be set too high when the draft listings are promulgated. Cognitive deficits such that a person tests at 2 or more standard deviations below the norm, are highly predictive of disability and should not require a significant additional hurdle to clear.

2. Traumatic Brain Injury (TBI)

- Extend the time frame to twelve months in Section 11.00F for deferring adjudication

In Section 11.00F, we recommend that SSA extend the time frame of “6 months” to “12 months” for deferring adjudication if a finding of disability is not possible within 3 months post-injury. SSA must also avoid unnecessarily delaying claims that can be favorably decided within the earlier timeframe.

It is clear in the general neurological medical literature that late onset impairments often occur post-injury, including seizure activity, spasticity and cognitive deficits. Twelve months is a reasonable time frame within which neurologists and neuropsychologists will have a more accurate picture of a patient's deficits, whether the TBI is mild, moderate or severe. Twelve months is also a reasonable time period to allow a TBI patient to undergo more completely a spontaneous recovery.

However, to avoid erroneously denying claims, SSA must be sensitive to the fact that the true picture of long-term functional limitations resulting from TBI may not be fully developed within 2 to 6 months post-injury. The 6-month time period could lead to an erroneous conclusion of improvement in a patient's health status. For example, a person with a TBI may be in a coma for one month with severe cognitive impairments and resulting poor neurological and neuropsychological testing scores. Within one month, the patient may be out of his or her coma and may undergo testing. Within another month (now 3 months post-injury), the same patient may be tested again. Finally, the patient is tested at 6 months post-injury. When the three-month test scores are compared to the 6-month test scores, the results could reflect a significant improvement in health status/scores that could erroneously reflect a dramatic recovery. Further, a person coming out of a coma may not be physically stable enough to undergo a battery of neurological testing at 6 months post-injury because he or she likely may have motor and attention difficulties or severe agitation. The 12-month time frame allows a reasonable period for spontaneous recovery and accurate test results. Twelve months certainly is a reasonable time frame when one considers the fact that the "healing" period for persons with TBI could be several years -- or never.

On the other hand, SSA must also avoid unnecessarily delaying claims that can be favorably decided earlier in the process, particularly in light of the lengthy administrative appeals process. People who experience TBI often face great disruption in their lives, including the inability to financially support themselves during the recovery process. Access to disability benefits can be crucial during this time. Thus, we recommend that SSA provide clear instructions and criteria to disability adjudicators on the factors needed to determine which TBI claims can be favorably decided and which must be deferred.

- **SSA should add more "A" criteria to Section 12.02, Organic Mental Disorders**

The regulations indicate that TBI cases should be evaluated under 12.02, Organic Mental Disorders, if applicable. However, this listing is sorely inadequate in describing the vast range of mental impairments often experienced by TBI patients. The functional sections or lobes of the brain are divided into the "right" and "left" sides. Each side of the brain is responsible for different functions. Impairments and general dysfunction will vary depending upon the site of injury.

We recommend that SSA add the following requirements in addition to those listed in section "A" or to any other appropriate section in the Listings:

- o Muscle movement and coordination impairments (including left neglect or inattention to the left side of the body and decreased control over left-sided body movements)
- o Hearing, vision, taste, smell and touch impairments (including visual-spatial impairment and visual memory deficits)
- o Sleep disturbance
- o Personality changes
- o Evidence of a loss of intellectual functioning, apart from evidence from formal IQ testing
- o Language impairments (including receptive and expressive language difficulties or understanding language and speaking output)
- o Sequencing difficulties
- o Sexual dysfunction or inappropriate sexual behavior
- o Deficit awareness impairments (see discussion below)

Further, we recommend that SSA add “deficit awareness impairments” to section 12.02 “A” or to any other appropriate section. Deficit awareness impairment is a condition of a brain injury that prohibits a person from using cues from the environment and from peers to change strategies in an attempt to be successful at a work task. Further, deficit awareness impairments do not allow a person with a brain injury to strategize an improvement plan.

It is not uncommon for a person with a brain injury to have difficulty comprehending their deficits and how those deficits affect them day to day and in the workplace. This lack of deficit awareness is significant during the recovery process – extensive rehabilitation may not result in patient improvements because of deficit awareness or because of problems in short- and long-term memory.

The lack of awareness in a person with a brain injury stems from the neurological impairment and often is a consequence of a frontal lobe injury. The frontal lobe is the part of the brain that has the ability to “self-monitor” and to assess behaviors and their possible consequences. A person with a TBI might not know to ask for help at work or when presented with a new situation because they are not aware that their deficits will not allow them to be successful performing certain tasks. In fact, if you ask a person with a deficit awareness impairment how they may perform a task, the person may greatly overstate or overestimate their success. The result is an employee returning to work post-injury who does not ask for assistance or accommodation because he or she simply is not aware of the impairment.

—Others (Chris/APA)

IV. “B” Criteria

- **Revisions to the current criteria**

We have proposed revisions to section 12.00 (see Appendix A) that would create a separate section that discusses the “B” criteria. Currently, they are discussed in the

Assessment of Severity section. By creating a separate section, it allows addition of a section immediately following it that discusses the “C” criteria. While keeping the four current “B” criteria intact, we have recommended language that expands the explanation of each factor, thus providing further guidance for adjudicators:

1. Activities of daily living. An additional sentence lists ADLs that are relevant in work activities. These have been incorporated from activities listed in the Mental Residual Functional Assessment form that is currently used by some state DDSs.

2. Social functioning. A sentence has been added that references to specific activities of social functioning that are relevant in work settings, also found in the Mental Residual Functional Assessment form that is currently used by some state DDSs. Another sentence has been added that incorporates social functioning activities in the SSI childhood disability regulations.

3. Concentration, persistence or pace. A sentence has been added that incorporates activities of concentration, persistence, or pace that are found in the Mental Residual Functional Assessment form that is currently used by some state DDSs.

4. Episodes of Decompensation. While we are supportive of the retention of this B criteria, we urge SSA to avoid the use of the sole word “decompensation” in that such a phrase, as used by most mental health professionals, means a deterioration so severe as to require hospitalization. A better phrase would be “deterioration in overall function” or “deterioration or decompensation” which would include, but would not be limited to, the more severe notion of decompensation. Certainly, an individual is disabled long before their mental status is such that they must be hospitalized repeatedly for extended periods over the course of a year. While the introductory section reflects a concept of deterioration, the use of the term “decompensation,” without more, in the listing itself, is misleading both for professionals commenting upon a particular case, and for adjudicators looking through records for instances of “decompensation.”

In Section 12.00, we also have changed the phrase “highly structured and directing household” to “intensive supports” to make it consistent with other language in the introduction defining “highly structured and supportive” settings. The language is similar to that used in the SSI childhood disability listing 112.00.F.

- **Add a new “B” criteria: Communication**

We also urge the adoption of a fifth B criteria, based on the ability to communicate. In reviewing the DSM-IV, it is apparent that the ability or inability to communicate efficiently and effectively is an important measure of the severity of a particular mental illness. While elements of communication are certainly implicit in assessing social function and ADLs, they do not get the importance they deserve when mixed with these important overarching concepts. Instead, the ability to communicate is often ignored, despite its pivotal importance in obtaining and retaining substantial gainful activity. Just as the childhood listings recognize the importance of communication, and afford it its own domain or area, so too, should the adult listings have a separate B criteria for communication.

More needed??

Communication??

V. “C” Criteria

We have proposed language that amends section 12.00 to create a section that discusses the “C” criteria which allows for greater clarity. See App. A.

As discussed in Section II.2, we urge SSA to provide clear guidance to adjudicators regarding the need to properly recognize and weigh evidence from nonphysician professional sources. The current “C” criteria call for a medically documented history of a particular disorder with periods of decompensation. See, e.g., Listing 12.02 C. Especially during periods of remission, mental health clinics are unlikely to afford patients prolonged exposure to psychiatrists, and, during periods of deterioration or decompensation, such individuals are often not in touch with mental health providers on a regular basis. Much more frequently, the only people who will be able to comment intelligently on a claimant’s longitudinal history will be therapists, social workers and others who maintain regular contact with patients.

The explicit requirement of a “medically documented history” of deterioration both serves to relegate the evidence of nonphysician professionals to second-class status and makes it doubly hard to establish disability under this criteria. By making an explicit distinction between the functional evidence allowed in the determination in part B, and the difference between it and part C, the Listings underline the distinction between the two types of evidence, and draw a distinction where none should exist. At the very least, the requirement of medical documentation should be removed from the part C determination.

VI. Factors Relevant to Disability Determinations

We have proposed a new section called factors relevant to the disability determination. The factors discussed below, taken from concepts in the current introductory language, the childhood disability regulations, and Social Security Ruling 85-15 are, when present, relevant in determining disability at all steps of the disability sequential evaluation.

1. **Effects of structured settings.** This has been moved from the current 12.00.
2. **Stress and mental illness.** This section incorporates language currently found in Social Security Ruling (SSR) 85-15.
3. **Extra help.** This section reflects a similar section in the SSI childhood disability regulations.
4. **Unusual settings.** This section expands on a sentence in current section 12.00E and adds more expansive language from the SSI childhood disability regulations.
5. **Effects of medication.** This section is modeled on the SSI childhood disability regulations. It also incorporates language from the current section 12.00G.
6. **Effects of treatment.** This section is the current 12.00H.

VII. Mental Retardation

Diagnosis

Mental Retardation A and B Criteria – We strongly support the continued use of Sections 12.05 A. and B. criteria and Sections 112.05 B. and C. criteria to determine disability for people with mental retardation. The provisions are practical and provide clear criteria for determining eligibility for people with the most severe levels of mental retardation.

Standard Error of Measurement (SEM) – We urge SSA to give applicants the benefit of the doubt and include as disabled those individuals whose IQ scores place them within the SEM on standardized tests.

The use of hard and fast IQ scores may appear to make the process simpler, but it actually raises the risk of erroneous exclusion and the resulting failure to assist individuals with severe impairments.

Age of Onset – The current listing uses onset before age 22 as the part of the capsule definition/diagnosis for mental retardation under Sections 12.05 and 112.05. We urge SSA to retain the use of age 22 in establishing the capsule definition for eligibility under the mental retardation listing. This is consistent with the onset age of 22 used in the statute for eligibility for disabled adult child benefits.

Severity

Sections 12.05C. and D. and Section 112.05D. Severity Level – Mental retardation is a significant and severe disability, including for those people whose IQs test in the range of 60 to 70. To meet the capsule definition of mental retardation, the individual has to show an IQ level at least two standard deviations below the mean (≤ 70) along with deficits in adaptive functioning consistent with the measured IQ. We believe that these two requirements meet the general requirements of having “marked” limitations in two areas (cognition and adaptive functioning). Sections 12.05C. and D. require an additional showing of another impairment imposing significant limitations or a showing of marked restrictions in two listed areas of functioning in order to qualify under the listing. The additional requirements in C. and D. seem to require that individuals assessed under these sections must meet a higher standard than marked limitations in two areas. We urge SSA to re-evaluate the requirements in these two sections because they are inconsistent with the legal framework of the listings and set excessively high standards for two of the four groups of individuals who may qualify with mental retardation. At the very least, we urge the continued interpretation of the requirement of a second, “significant” impairment to require only one that imposes some additional restriction on function.

National Research Council (NRC) Recommendations

The National Research Council was commissioned by SSA to evaluate various aspects of coverage for people with mental retardation. The NRC study resulted in a number of recommendations that were presented to SSA in 2002. Here we discuss selected NRC recommendations.

Assessment under other listings – We disagree with the NRC’s recommendation that adjudicators “do not need to determine the presence or absence of mental retardation in individuals who are eligible for SSI due to other neurodevelopmental or psychiatric disabilities.” In fact, we think it is important that adjudicators establish a complete record for individuals who would qualify by meeting the listing for mental retardation. If mental retardation is present, then adjudicators should explore it as the primary diagnosis. As future changes are made to the listings and other relevant regulations, a complete disability determination record is the best protection for people when they are assessed under the medical improvement standard at the time of their continuing disability reviews (CDRs).

Permanent Presumptive Disability – We support the NRC recommendation to remove work disincentives by “considering individuals with mental retardation to be presumptively re-eligible for benefits throughout their lives, if they have previously received benefits, subsequently secured gainful employment, and then lost that employment.” While this may require legislation, especially in the case of people with mental retardation receiving disabled adult child (DAC) benefits, we encourage SSA to propose and to support such legislation. Such a step would remove some major barriers to work for people with the life-long, significant impairment of mental retardation, and ultimately reduce the reliance of many on the SSI and Title II disability programs.

Composite Scores – SSA has a long standing policy that the NRC did not directly address when it took the position to use composite IQ scores, rather than the lowest of the full scale, performance or verbal subtests. We urge SSA to reject the NRC’s recommendation regarding the use of partial or full-scale/composite scores on IQ tests. Composite scores are essentially rough averages that may hide significant information regarding an individual’s disability. As a composite, the score is not a valid descriptor of the individual’s limitations. The low score has significance and should not be lost in the composite when assessing a particular individual. The lower scores, if not explained by other evidence in the file, should prompt

further CE evaluation of the individual's functioning. As is clear from the NRC's note regarding the dissenting view of panel member Keith Widaman, the NRC recommendation is controversial and we oppose its adoption.

Adaptive Behavior Scores – The NRC recommended using 1 standard deviation below the mean in two adaptive behavior areas or 1.5 standard deviations below the mean in one adaptive behavior area as the measure for ascertaining deficits in adaptive behavior that, along with IQ levels 2 standard deviations below the mean, establish listings-level mental retardation. We endorse this NRC recommendation regarding adaptive behavior scores.

Use of Standardized Behavior Assessment – We agree with the NRC's recommendations that SSA should support more research and development of standardized measures of adaptive behaviors. While the use of standardized measures could improve the outcomes of disability determinations for people with mental retardation, we recognize that such measures are not currently available to the degree necessary for SSA to make such testing a requirement. Should SSA decide to require the use of standardized testing for adaptive behaviors, we believe that SSA must be prepared to pay reasonable fees for CEs to conduct such assessments when the information is not available in the record.

Impact of Modifications – The impact of any modifications that SSA makes to the mental retardation listing must be applied only to new applicants, not in continuing disability reviews and not to 18 year olds in SSI. As the result of a suggestion made in the National Research Council's report to SSA, we believe it is important to directly address whether any changes made by SSA would be applicable to continuing disability reviews and to 18 year olds who have been receiving SSI children's disability benefits. Specifically, the NRC believes that its recommended standards for IQ and adaptive behavior should apply also to redeterminations.

While SSA has the ability to use any changes in the listings when redetermining eligibility for benefits in a continuing disability review, should the finding be that the person does not meet the new listing, SSA must apply the old listing to determine if the person will continue to be eligible for benefits. While we urge SSA to limit the changes made to 12.05, it will be essential that any changes to the Listing explain that there will be no impact on current recipients whose conditions have not medically improved and that SSA will rely on the listing in effect at the time the individuals were determined to be eligible. The consequences of not taking this step could be disastrous in the individual lives of many people with mental retardation who depend upon SSI or Social Security benefits for survival and would violate the medical improvement standard included in the statute at 42 U.S.C. § 423(f).

4. Testing

Records of School-Based Testing – When children have Individualized Education Programs (IEPs) in their school files, it is quite likely that the school also has records of testing done to assess the student for the school system. We recommend that SSA routinely request these test results as part of the applicant's file.

Age of Tests – There are several issues regarding old test scores and out-of-date tests that we believe must be addressed.

- We recommend that SSA use only Consultative Examiners for IQ or adaptive behavior tests who use current instruments. Instruments are out-of-date if a newer version or edition, with updated norms, has been published.

- SSA should not discount older scores or scores obtained with out of date instruments in a claimant's file since many claimants do not have access to state of the art testing and evaluation and should not be penalized for their lack of access. The older test should establish valid history and SSA should ensure that a contemporary test is administered, if necessary, to determine current eligibility.
- If a test in a claimant's file was out of date at the time of its administration, SSA should not reject the test entirely; but rather, should make a determination that a new test might be required and order that one be administered at SSA's expense by a consultative examiner

VIII. New Listings Needed

We suggest adding several new listings because of the prevalence of these disorders and the potential to miss them.

1. Post-Traumatic Stress Disorder (PTSD) to 12.06A and 112.06A

PTSD, is a condition found in many members of the armed forces and other victims of and witnesses to violence, terrorism and other traumatic events. Currently it is buried in with 12.06, where it is hard to find, in part because it is never named and only some of the diagnostic criteria of DSM-IV are included.

PTSD is characterized by re-experiencing a specific ordeal in the form of flashback episodes, memories, nightmares, or frightening thoughts, especially when exposed to events or objects reminiscent of the original trauma. Medically documented findings of at least 3 of the following:

- a. emotional numbness
- b. sleep disturbance (e.g., nightmares, insomnia, restless sleep, fear of falling asleep)
- c. hypervigilance
- d. startle response (e.g., startle reaction to sudden noise or flash of light)
- e. easy irritability or outbursts of anger
- f. feelings of intense guilt
- g. avoidance of reminders or thoughts of a traumatic event
- h. flashbacks
- i. problems of memory, thinking, or concentration
- j. substance abuse originating post-trauma and ingested to suppress memories of the traumatic event with intermittent periods of sobriety and increased use at anniversaries or reminders of the traumatic event.

2. Eating Disorders

We strongly suggest the addition of a particular Listing for Eating Disorders, which have been recognized to be a serious problem for many teens and adults.

Add Listings 12.13A & 112.13A:

Eating Disorders (Anorexia Nervosa, Bulimia, Other Types). *Anorexia nervosa* includes two subtypes that describe distinct patterns: 1) Restricting Type maintains low body weight by restricting food intake and increasing activity (i.e. compulsive exercise); and 2) Binge-Eating/Purging Type restricts food intake but also regularly engages in binge eating and/or purging behaviors (i.e. self-induced vomiting or abuse of laxatives, diuretics, enemas).

- a. hyper-sensitive about body image
- b. intense fear of weight gain
- c. obsessive dieting or starvation (e.g., hoarding food, concealing food, avoiding others who are eating)
- d. anhedonia (inability to gain pleasure from normally pleasurable experiences)
- e. obsessive exercise, calorie counting
- f. self-induced vomiting or excessive use of laxative, diuretics, and/or diet pills
- g. amenorrhea in women not related to another hormonal imbalance of other etiology
- h. loss of body weight 10% or greater not related to another hormonal imbalance of other etiology

Bulimia Nervosa means recurrent episodes of binge eating, within a discrete period of time (e.g., with a few hours), an amount of food that is greater than most people would consume during a similar period, under similar circumstances; or lack of control over eating (e.g., a feeling that one cannot stop eating or control how much one eats); or recurrent inappropriate compensatory behavior in order to prevent weight gain (e.g., self-induced vomiting, misuse of laxatives, diuretics, enemas, or other medications, fasting, or excessive exercise) occurring at least twice a week for 3 months.

3. Add Attention Disorders (ADHD, ADD) for adults

This new listing, §12.11, would mirror the children's ADHD Listing, § 112.11.

12.11 Attention Deficit Hyperactivity Disorders: Characterized by inappropriate degrees of inattention, impulsiveness and hyperactivity.

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 at least two of the following:
 - 1. Marked inattention; or
 - 2. Marked impulsiveness; or

3. Marked hyperactivity;

AND

B. Resulting in at least two of the following:

1. Marked restriction of activities of daily living; or
2. Marked difficulties in maintaining social functioning; or
3. Marked difficulties in maintaining concentration, persistence, or pace; or
4. Marked difficulties in sustaining gainful employment.

4. Alzheimer's Disease

Alzheimer's disease is the most common cause of dementia, accounting for between 50 to 60% of all cases. Family practitioners, internists or neurologists typically diagnose individuals with Alzheimer's disease. Yet, there is a high prevalence of neuropsychiatric symptoms in dementia and therefore many of these individuals are referred to psychiatrists and other mental health providers for assessment, diagnosis and treatment for these symptoms.

Individuals with Alzheimer's see a variety of practitioners for treatment, including internists, geriatricians, neurologists and psychiatrists, depending on the stage of illness, the presentation of symptoms, the severity of symptoms and secondary complications. There are two different sets of diagnostic codes for Alzheimer's disease and related dementias. In the DSM-IV, the 290 series identifies various dementia codes based on the specific dementia and etiology. In the ICD-9 codes, the 331 series identifies Alzheimer's disease and related dementias as a general medical condition (Axis III). Given that the DSM-IV and ICD-9 codes recognize that these conditions may be both neurological and mental disorders, the listings also should reflect these classifications.

We recommend that Alzheimer's disease be included in 11.15, which is currently reserved, or in 11.17, degenerative disease. These sections should be cross-referenced to 12.02, which should continue to include dementias due to other etiologies. Although all dementias are characterized by development of cognitive deficits and memory impairment, the symptoms and cause vary and should continue to be reflected in the listings. The proposed listing is consistent with the DSM-IV manual and was developed with input from clinicians from Mayo Clinic.

Alzheimer's disease – 11.15 or 11.17

A. The gradual onset with progressive and deteriorating course of multiple cognitive deficits manifested by both:

1. memory impairment, and
2. one or more of the following cognitive disturbances:
 - a. aphasia (loss or impairment of the power to use or comprehend words)
 - b. apraxia (loss of the ability to execute or carry out learned movements)
 - c. agnosia (inability to recognize and identify familiar objects or persons)
 - d. disturbance in executive functioning

AND

B. Resulting in at least one of the following:

1. Marked restriction of activities of daily living, or
2. Marked difficulties in maintaining social functioning, or
3. Marked difficulties in maintaining concentration, persistence, or pace.

5. Autism

There are several types of Pervasive Developmental Delay (“PDD”), only some of which would diagnostically correlate with the A criteria under Listings 12.11 and 112.11. For some children with atypical PDD, or with Asperger’s, for instance, the A criteria requirements are too broad. The preamble to the final rules adding Listings 12.10 and 112.10, published in August 2001, explained that individuals diagnosed with co-morbid autism and mental retardation “can be evaluated under either listing.” 65 Fed. Reg. at 50754.

This directive from the Preamble to the final regulations does not address the issue of the interrelation between other PDDs and mental retardation. Moreover, it is unusual for autism to be diagnosed in very young children, even though the behaviors and functional limitations associated with PDD may be identifiable in infancy. As a result of this apparent confusion, some adjudicators eschew these listings when presented with atypical developmental disorders and inappropriately rely on Listing 12.05 or 112.05 instead. Using Listing 12.05 or 112.05 may be appropriate for many children with autism, but not some with PDDs. Although many with autism have significant limitations in cognitive development at the mental retardation level, some do not, and children with other PDDs may have normal cognitive development, only later regressing.

When the record contains results from intelligence testing but these exceed the requirements of 12.05 and 112.05, the PDD may not be fairly assessed if the claimant is one of those whose PDD has not adversely affected cognitive development. In addition, it is difficult to obtain reliable measures of cognitive development for very young children. Moreover, diagnosing autism (a question of ruling out “other PDD”) is difficult prior to ages 2 or 3, so it is not uncommon for the initial diagnosis of an infant with serious limitations to be PDD that only later is recognized as autism. Similarly, some of manifestations of PDDs begin later than 3 years of age (e.g., disintegration disorder generally manifests between 3 and 10 years of age after somewhat normal development earlier). Adjudicators need to be aware of these considerations related to the claimant’s age and the corresponding difficulties with making accurate diagnoses of autism and the autistic spectrum disorders.

It is imperative that the PDD component of the Listings encapsulates the PDDs more generically. Specifically, the “verbal and nonverbal” descriptor may not apply to some children with Asperger’s or Childhood Disintegrative Disorder, which do not generally affect both domains of communication, and these descriptors may not apply to some children with Rett’s Disorder, which generally affects motor, language, and social skills. We recommend that the descriptor for these listings include the phrase “autistic spectrum disorders” to clarify the relationship of PDDs with autism. For these disorders, we also recommend the use of more general descriptors of qualitative deficits without the specific limitation in verbal and nonverbal skills, and we recommend that there is a disjunctive connection with “imaginative activity” so as to capture the very young child’s limitations prior to any expected development of the other communication skills. And, following parallel recommendations earlier, we recommend striking the modifier “markedly” from the A criteria.

12.10 Autistic Disorder and autistic spectrum disorders (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. Only where evidence of co-morbid mental retardation exists, evaluate under Listing 12.05. Often with autism, there is a restricted repertoire of activities and interests, which frequently are stereotyped and repetitive.

1. 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 reciprocal social interaction; and
- b. Qualitative deficits in verbal and nonverbal communication and/or imaginative activity; and
- c. Restricted repertoire of activities and interests;

OR

2. For other pervasive developmental disorders, both of the following:

- a. Qualitative deficits in reciprocal social interaction; and
- b. Qualitative deficits in communication -or imaginative activity;

AND

B. Resulting in at least two of the following:

- 1. Marked restriction of activities of daily living; or
- 2. Marked difficulties in maintaining social functioning; or
- 3. Marked difficulties in maintaining concentration, persistence, or pace; or
- 4. Repeated episodes of decompensation or deterioration, each of extended duration.

112.10 Autistic Disorder and autistic spectrum disorders (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. Where evidence of co-morbid mental retardation exists, evaluate under Listing 12.05 or 112.05, as applicable. Often with autism, there is a restricted repertoire of activities and interests, which frequently are stereotyped and repetitive.

- 1. 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 reciprocal social interaction; and
- b. Qualitative deficits in verbal and nonverbal communication and/or ~~in~~ imaginative activity; and
- c. Restricted repertoire of activities and interests;

OR

2. For other pervasive developmental disorders, both of the following:

- a. Qualitative deficits in reciprocal social interaction; and
- b. Qualitative deficits in communication or 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.

IX. Recommendations of the General Accounting Office (GAO)

Under no circumstances should SSA incorporate the GAO proposals in these Listings. Many of the pharmaceutical and technological advances upon which GAO bases its recommendations are neither uniformly available nor affordable to people with disabilities across our nation.

In its August 2002 report, *SSA and VA Disability Programs: Re-Examination of Disability Criteria Needed to Help Ensure Program Integrity*, GAO-02-597, the General Accounting Office raises a number of concerns about how disability is determined in both DI and SSI (as well as VA programs, not at issue here). Some of our comments in other sections of this document are relevant to the GAO's recommendations to SSA as well.

For example, GAO notes that "...SSA does not automatically evaluate individuals applying for benefits under corrected conditions. Thus, it is our belief that the programs themselves have not been fully updated to reflect scientific advances, because interventions that could enhance individuals' productive capacities are not, by design, factored into the disability decision-making process." (page 32) While it some day may be possible to fairly make such a determination, as a practical matter, that day can not come until all people with disabilities or other health conditions can secure the health care they need, including ongoing prescription drugs, counseling, and treatment. While it is possible for some people with mental impairments to work while receiving pharmaceutical treatment that is responsive to their medical conditions, it is often eligibility for SSI and therefore Medicaid that makes it possible to secure needed drugs. For some DI recipients, because Medicare does not include a drug benefit, these individuals may not even be able to secure needed treatment while in benefit status. Loss of SSI often means loss of the very drugs that might make the person employable and therefore less needy of cash assistance. We urge SSA to ensure that any proposals that incorporate how SSA will evaluate individuals applying for benefits if they were "under corrected conditions" make clear that such a possibility is fantasy — and could have tragic consequences for people with severe mental impairments — if medical care, including free or very reduced price prescription drugs, is not readily available to that specific individual, whether or not he or she is employed after leaving DI or SSI and for however long as needed to ensure the person can continue to remain independent of DI and SSI.

X. Other Listings Issues

1. Functional Equivalence (FE) for Adults

We urge SSA to replicate and draw from the work of the SSA/AUCD Children's SSI Project over the past five years and develop a functional equivalence step to assess adults who do not meet the particular criteria of specific listings. This recommendation has special significance for younger adults with mental impairments, particularly those who have not worked; Steps 4 and 5 in the disability determination process are inadequate for addressing them. SSA should develop and implement an effective method to assess adults at the listings level when their impairments do not fall within specific listings. This could be done by creating a functional equivalence step for adults, using the concepts developed in assessing functional equivalence for children, or by improving the RFC process to ensure its relevance for younger adults. In either case, SSA should develop an approach, similar to the childhood FE, which looks at the impact of impairment across the domains of function critical for an adult to function in competitive employment.

2. Use of regulations

We urge that SSA construct the children's mental disorder listings so that people do not have to refer back and forth between different listings to find the functional criteria. While this would require repetition of criteria in each of the separate listings, the added clarity for users would be well worth it.

3. Consultative Exams

We urge SSA to make use of Consultative Examiners (CE) on a broader scale than in current practice. Additional information would assist adjudicators in making better decisions in many cases. We urge the following:

- SSA should reinforce the Disability Determination Services' (DDS) responsibility to use consultative exams to acquire additional or "missing" evidence.
- SSA should particularly emphasize the use of vocational CEs for people who have no real employment history. This is of particular importance for younger adults who are finishing their special education, but who have not been tested in the job market.

SSA should encourage the use of clinical social workers as CEs to collect evidence on medical and social history from individuals and families. SSA should treat evidence from appropriately state-certified clinical social workers as "medical evidence," especially where this information helps establish the medical and social history for the individual.

XI. Issues Outside the Listings

1. Improve full development of the record earlier in the process

Developing the record so that relevant evidence from all sources can be considered is fundamental to full and fair adjudication of claims. The decisionmaker needs to review a wide variety of evidence in a typical case, including: medical records of treatment; opinions from medical sources and other treating sources, such as social workers and therapists; records of prescribed medications; statements from former employers; and vocational assessments. The decisionmaker needs these types of information to determine the claimant's residual functional capacity, ability to return to former work, and ability to engage in other work which exists in the national economy in significant numbers. Once an impairment is medically established, SSA's regulations envision that all types of relevant information, both medical and nonmedical, will be considered to determine the extent of the limitations imposed by the impairment(s).

The key to a successful disability determination process is having an adequate documentation base and properly evaluating the documentation that is obtained. Unless claims are better developed at earlier levels, the procedural changes will not improve the disability determination process. Unfortunately, very often the files that denied claimants bring to their representatives show that inadequate development was done at the initial and reconsideration levels. Until this lack of evidentiary development is addressed, the correct decision on the claim cannot be made. Claimants are denied **not** because the evidence establishes that the person is **not disabled**, but because the limited evidence gathered cannot establish that the person is **disabled**.

A properly developed file is usually before the ALJ because the claimant's representative has obtained evidence or because the ALJ has developed it. Not surprisingly, different evidentiary records at different levels can easily produce different results on the issue of disability. To address this, the agency needs to emphasize the full development of the record at the beginning of the claim.

We support full development of the record at the beginning of the claim so that the correct decision can be made at the earliest point possible. Claimants should be encouraged to submit evidence as early as possible. However, the fact that early submission of evidence does not occur more frequently is usually due to reasons beyond the claimant's control.

Our recommendations to improve the development process include the following:

- SSA should explain to the claimant, at the beginning of the process, what evidence is important and necessary.
- DDSs need to obtain necessary and relevant evidence. Representatives often are able to obtain better medical information because they use letters and forms that ask questions relevant to the disability determination process. DDS forms usually ask for general medical information (diagnoses, findings, etc.) without tailoring questions to the Social Security disability standard. The same effort should be made with nonphysician sources (e.g., therapists, social workers) who see the claimant more frequently than the treating doctor and have a more thorough knowledge of the limitations caused by the claimant's impairments.
- Improve treatment source response rates to requests for records, including more appropriate reimbursement rates for medical records and reports.
- Provide better explanations to medical providers, in particular treating sources, about the disability standard and ask for evidence relevant to the standard.

2. Administrative Process

The SSDI and SSI application processes can be both lengthy and complex. Often, persons with mental impairments may have difficulty even applying for benefits at a crowded SSA field office, unless they are provided with assistance. And, if an individual with a mental impairment does file an application, he or she frequently has difficulty in completing the voluminous paperwork – particularly in providing an accurate psychiatric history and a full record of hospitalizations or other medical treatment. Finally, a person with mental illness is likely to struggle in attending appointments – either for CE's or for hearings. Failure to appear at these appointments can result in a claim being dismissed.

Even when a person with a mental impairment is able to pursue their application, claimants are commonly denied at both the initial application and reconsideration levels. These claimants must then file for a hearing before an Administrative Law Judge (ALJ). While a significant percentage of claimants are granted benefits by ALJs, many claimants with mental impairments are unable to file appeals, and thus they never have this additional opportunity to demonstrate their disability. Ironically, the current process results in people whose disabilities make them the least able to file an appeal form being denied benefits, while others who are less impaired, but are still disabled, will be awarded SSDI and/or SSI.

When a person with a mental impairment does receive SSDI or SSI, they are often required to have a representative payee. Many people, particularly those who are homeless or who have lost most social connections, do not have anyone that they can turn to as a reliable payee. Unfortunately, an insufficient number of local service providers are willing to serve as payees. As a result, many low-income persons are taken advantage of by friends or family members who serve as their payees only because nobody else is available.

Because these problems severely impact SSDI and SSI applicants with mental impairments, we offer the following recommendations to help improve the process. It is our belief that implementation of these recommendations would be of great benefit to claimants, while also moving claims through the application process more efficiently.

Pre-Application

- SSA should institutionalize SSDI/SSI outreach to low income persons with mental disabilities. The focus of this outreach should be on specific populations that have a high incidence of mental impairments, such as homeless persons or children in particular areas.

Application Process:

- SSA should expand its use of pre-release agreements, to take more applications before claimants leave public institutions such as hospitals, jails, or prison.
- SSA should provide mentally ill claimants with additional accommodations, including assistance in completing applications and other forms, and flexibility in scheduling appointments for CE's or ALJ hearings.
- SSA should explicitly recognize that assertion of a mental impairment may be sufficient to demonstrate good cause for failure to file a timely appeal or other SSA document. This currently is SSA's policy, as codified in SSR 91-5p; yet, adjudicators often do not follow the policy. According to SSR 91-5p:

When a claimant presents evidence that mental incapacity prevented him or her from timely requesting review of an adverse determination ... at the time of the prior administrative action, SSA will determine whether or not good cause exists for extending the time to request review. If the claimant satisfies the substantive criteria, the time limits in the reopening regulations do not apply; so that, *regardless of how much time has passed since the prior administrative action*, the claimant can establish good cause for extending the deadline to request review of that action. (emphasis added)

Adjudication Process:

- SSA should focus on rapid development of case files, as soon as claims are taken. This should involve building connections with state Mental Health / Mental Retardation agencies, to ensure that providers funded by those agencies are trained on how to quickly submit claimant treatment records to SSA.
- SSA should also focus on expanding the use of presumptive eligibility for persons with mental impairments. Specifically, presumptive eligibility criteria should be revised to indicate that persons with a well-documented history of serious and persistent mental illness can be found presumptively eligible for SSI. And, SSA should seek to expand demonstration programs such as the SSI Advocacy Project in Baltimore, MD. – a former SSA demonstration program that is now independently funded. The SSI Project works with people who are homeless and mentally ill and has received special permission from SSA to submit cases for presumptive eligibility based solely or primarily on mental impairments.

Post-Eligibility

- SSA should make additional efforts to recruit qualified representative payees. In addition, SSA should devote more time to assisting beneficiaries with mental impairments with obtaining reliable representative payees.

3. Drug addiction and alcoholism

We urge SSA to provide guidance in the mental impairment listings Introduction, Section 12.00, on the disability analysis of combinations of substance use disorders and mental impairments. Although the current standard was established by Pub. L. No. 104-121 in 1996, the regulations at 20 C.F.R. §§ 404.1535(b) and 416.935(b) have not been revised and still apply the prior standard. The only complete source of SSA's policy on the analysis of combinations of substance use disorders and mental impairments is contained in subregulatory instructions in EM 96- (8/30/96). The out-of-date regulations and the inaccessibility of the subregulatory materials results in confusion and incorrect determinations. Given the common co-morbidity of substance use disorders and mental impairments, it is critical that SSA include the language we have proposed in Appendix A to help assure fair and correct disability determinations.

4. Specialized adjudicators for childhood mental (and physical) disorders

SSA and DDSs generally labor under the historic legacy of making every adjudicator a generalist who must be as expert in analyzing a 60 year-old man's claim as an infant's claim. The entire medical and health provider world has long stepped away from this approach recognizing the substantial differences and need for specialist expertise in evaluating medical and functional problems of adults and children. It took the SSA central office, almost 20 years after the inception of the SSI program, to establish its Children's Disability bureau within the Office of Disability. Many DDSs have de facto adopted various aspects of specialist attention for children. SSA should encourage DDSs to adopt specialization within its staff for children's cases.

5. Psychotherapy treatment records

SSA currently uses its general client signed release form, SSA 827 (signed in the field office) to obtain medical and clinical records, but under the HIPAA regulations, which require specific informed release for psychotherapy notes and records, mental health providers do not send these records. What is worse, SSA has acquiesced in this situation, and a negative inference against the claimant is often made, discounting this source because of the lack of this underlying documentation.

SSA needs to immediately address this by amending SSA 827 to specifically and explicitly cite psychotherapy records as covered by the release, and to take other steps as necessary, in the period before the form is revised, to achieve this same end.

In the alternative, if SSA has administratively decided to explicitly exclude psychotherapy notes from its general release form, adjudicators should be instructed to make no negative inference from the omission of these documents from the record. Some mental health facilities may uphold a more restrictive rule than HIPAA imposes regarding the release of patient records and claimants should not be adversely affected by these more stringent rules protecting patient privacy.

6. Referral of children to Medicaid and State CHIP Programs

Access to health insurance is essential for all children applying for SSI, both to treat and ameliorate existing health problems causing the disability, and to lessen their time on SSI. The Mississippi pilot of referrals from SSA field offices to the state MA and State Children's Health Insurance Program (CHIP) agency shows the great efficiency and success of this proposal. The total national cost to SSA of this proposal has been determined by SSA to be only \$1 million. Even this cost would be halved in those section 1634 states (more than half in the nation) utilizing the SSA SDX computer tape, shared with the state, which includes SSI child disability applicant children, and their health insurance status.

This reform should be rolled out nationally to ensure that the most vulnerable low income children in the nation, those with disabilities and chronic health problems, receive the health insurance they are already eligible for.

7. Culturally competent assessment tools and process

When considering whether or not an individual meets the definition of “disability”, we recommend that careful consideration be given to the individual’s culture and primary language. In addition, when gathering evidence to make a disability determination, we urge SSA to make sure those assessments, tests and evaluations performed on applicants are done in a manner that is culturally and linguistically relevant.