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Commissioner, Social Security Administration
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Comments in Response to Social Security Administration's Advance Notice of Proposed Rulemaking on Criteria for Evaluating Mental Disorders

As Requested in the Federal Register, March 17, 2003

These comments are submitted in response to the notice of March 17, 2003 regarding SSA's intention to revise the criteria for evaluating mental impairments under federal disability programs.

They are submitted from the perspective of the care givers to those suffering from brain disorders who make up the membership of our organization – NAMI, the National Alliance for the Mentally Ill. Despite the fact that the family members and those with the brain disorders are tested veterans of the battles with mental illness their contribution to public policy formation or regulatory development is neither sought nor desired. Speaking for one NAMI affiliate, I am taking this opportunity to add the perspective of our point of view in responding to your request.

The current mental impairment Listings criteria work well. While there are important updates and refinements that should be included in the Listings for adults and/or for children, a major overhaul of the mental disorder Listing is not necessary. However, certain other SSA rules explain aspects of the Listings more fully and it would be most helpful to include that very useful information in the Listings in the Introductory section, as suggested below.

I. Introduction to Mental Disorders Listings: Section 12.00

This section of the Listings provides detailed guidance for all disability adjudicators and plays an important role in the decision-making process for individuals with mental impairments, including those whose impairments do not meet a specific Listing. The Introduction should be expanded to include SSA policy pronouncements from other sources and well as being updated through several policy changes. Following are specific suggestions to accomplish this.

1. Assessment of severity

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. SSA should add language to the adult Listings that an impairment meets the "B" criteria if

there is an "extreme" limitation in one of the four "B" criteria, in addition to the current language requiring "marked" limitations" in two of the "B" criteria.

2. Better definition of "marked" and "extreme"

The regulatory definition of "marked" in the childhood Listings should be included in the adult Listings. That definition requires "standardized testing with scores that are at least two, but less than three, standard deviations below the mean." 20 C.F.R. § 416. The definition of "extreme" functional limitation should also adopt the childhood definition, 20 C.F.R. § 416.

3. Evidence issues

A. The importance of recognizing evidence from all medical sources

SSA should provide clear guidance to adjudicators in the Introduction section of the Listings and in separate regulations regarding the importance of evidence from all health care professionals and care givers in assessing the limitations imposed by mental impairments.

The fact that SSA has established a distinction between "medical" and "non-medical" evidence allows adjudicators to consider non-physician 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 key information needed to establish the individual's functional limitations. This is especially true with respect to the care givers who have the greatest amount of detailed information.

Evidence from an "acceptable medical source" is necessary to establish the existence of a "medically determinable impairment" under the Social Security Act. However, 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. These "other sources" include many of the primary sources of health care treatment for individuals with mental impairments, e.g., nurse practitioners and physicians' assistants, therapists, psychiatric social workers, and educational personnel. Evidence from other sources regarding the severity of the impairment should not be treated differently when provided by licensed health professionals than when given by a psychiatrist or psychologist. The evidence from part and full time care givers who witness the functioning and behavior of the individual is given little credence, if accepted at all, denying adjudicators the most knowledgeable source of information, despite the fact that these care givers are likely to be the best experts regarding the specific mental condition of the individual.

The organization of community mental health programs is such that an individual may see the psychiatrist rarely, and only to evaluate medications during a very brief visit. 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 do not treat evidence from such sources 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. Often the adjudicator of the claim will give more weight to consultative examiners who

see the individual only once or to non-examining state agency physicians who only review the file.

SSA should 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 merely because they cannot afford treatment in a setting where most of the work is done by physicians.

4. Consideration of drug use as symptom of another mental impairment

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.

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 Listings language. SSA should clarify that drug use may be a symptom of another mental impairment and that a determination is required as to whether drug addiction or alcoholism is a contributing factor material to the determination of disability.

5. Effects of Medication

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 the Listed disorder) but nonetheless meet the B criteria regarding function. The Introduction should clarify that when an individual meets the B criteria and they have the diagnosis cited in the A criteria they qualify, just as do others whose overt symptoms are not controlled with medication. This is especially important since there is no cure for those afflicted with brain disorders even though medication helps restore various degrees of functioning. As an analogy, a one-legged person does not become a two-legged person with a prosthesis.

6. Medical equivalence

The Introduction should make clear that individuals with medically determinable impairments who cannot exactly meet any specific A criteria but who satisfy either the paragraph B or C criteria, are disabled. This establishes a "medical equivalence" standard for such persons. This approach focuses on the impact of functional limitations, which are assessed under the B or C criteria.

7. Documentation

A discussion about school attendance and vocational training should be added to the Introduction to provide guidance for evaluating cases of young adults for whom such evidence is particularly relevant.

II. "A" Criteria Listings Issues

"Marked" as a factor in the "A" criteria

The "A" criteria should only deal with the diagnosis, primarily to satisfy the statutory requirement that a person suffer from 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. However, for a number of diagnoses, there are functional requirements that have crept into the A criteria. Since this is not universal, it gives the impression that the criteria for certain mental illness diagnoses have a higher threshold of disability whereas the level of dysfunction that leads to a finding of disability should not vary from one diagnosis to another. These A criteria also often use the term "marked" to describe the diagnostic symptoms that are required, adding an additional layer of confusion.

For example in 12.06A.3/112.06A.5: "Recurrent *severe* panic attacks manifested by a sudden unpredictable onset of *intense* apprehension ... occurring on the average of *at least once a week*." Other examples are in 12.06 A.4/112.06A.6, requiring "recurrent obsessions or compulsions which are a source of *marked* distress" and in 10.08 which requires "a significant impairment in social or occupational functioning or subjective distress" for personality disorders.

For children, see 12.10/112.10: The definition of an Autistic Disorder requires a "*markedly* restricted repertoire of activities and interests," a phrase repeated in A.1.c; 112.03, the children's schizophrenia Listing, that requires a "*marked* disturbance of thinking feeling and behavior"; 112.04, the children's mood disorder Listing which requires "*markedly* diminished interest or pleasure" at two separate places, and at 112.11, the ADHD Listing that requires *marked* inattention, impulsiveness, hyperactivity and then refers the adjudicator to the B criteria to make further findings of two more *marked* functional limitations.

The language in all Listings should be reviewed and revised to eliminate measures of functioning or references to "marked" limitations.

III. "B" Criteria Listings Issues

1. Clarifying Language for B Criteria

The four current "B" criteria that measure functional impairment also need revision. The following suggestions are based upon existing SSA material (either taken from the current Introduction to the Listings or from other documents relating to the RFC assessment) and would expand the explanation of each factor, thus providing further helpful guidance for adjudicators:

A. Activities of Daily Living

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.

B. Social Functioning

Additional material should be added to this section to explain that social functioning includes the ability to interact independently, appropriately, effectively and on a sustained basis with other individuals in a social or work related environment, including the ability to remember people, incidents and facts and to engage successfully in problem solving around tasks or social interactions.

C. Concentration, persistence or pace.

Additional material should be added to explain that concentration, persistence and pace in work situations may involve the ability on a sustained basis to carry out short, simple instructions or more detailed instructions, to maintain attention and concentration for extended periods, perform activities within a schedule, be punctual, sustain a routine without special supervision, work in proximity to others, make simple work decisions and complete a normal workday and workweek, and perform at a consistent pace without an unreasonable number or length of rest periods.

D. Episodes of Decompensation.

The phrase "highly structured and directing household"should be changed to "highly structured and supportive" settings to make it consistent with other language in the Introduction defining "highly structured and supportive" settings. (This language is also similar to that used in the SSI childhood disability listing 112.00.F.)

2. Supported Work

When a claimant is engaged in supportive work, adjudicators often concluded that he/she can have no significant limitations in social functioning or in concentration, persistence and pace. The Listings should clarify that supported employment should not be improperly interpreted to mean that the claimant is not disabled. Generally, the need for such a setting for a claimant with a mental impairment is evidence of disability and the need for services to compensate for that disability before the individual can engage in any work activity. Without the supports and services furnished through supported employment, these individuals could not engage in competitive employment.

IV. "C" Criteria Listings Issues

Section 12.00 should be amended to create a subsection that discusses the "C" criteria in order to provide greater clarity. SSA should incorporate language from current §12.00A, 12.00E, and the "C" criteria in specific listings so as to describe six concepts relevant to "C" criteria (but also relevant at all steps of the sequential evaluation):

1. Effects of structured settings. (This should refer to the effect of living in a structured or supportive setting, including living at home with supports that may help to control signs and symptoms. SSA should consider the amount of help needed to maintain functioning, adjustments made to the environment and how the individual might function without the structured or supportive setting being available.)

2. Stress and mental illness. (This section should incorporate language currently found in Social Security Ruling (SSR) 85-15, including the discussion of how good mental health services may enable individuals to function adequately in the community by lowering pressures, by medication and through services of outpatient or day programs.

Mental illness is characterized by adverse responses to stress, and individuals may b unable to face the demands of getting to work regularly, having their performance supervised and remaining all day. These and other factors cited in the Ruling should be considered in determining eligibility under the Part C criteria.)

3. Extra help. This section should include the language in the similar section in the SSI childhood disability regulations that requires adjudicators to consider how independent the individual is and how much they need supervision, direction or cuing or whether they need special equipment, devices or medications to perform daily activities.

4. Unusual settings. This section should include the more expansive language from the SSI childhood disability regulations that discusses how an individual may appear less impaired in a single examination than indicated by information covering a longer period.

5. Effects of medication. This section should be modeled on the SSI childhood disability regulations and also incorporate language from the current section 12.00G in order to ensure that adjudicators give proper attention to the effects of medication on symptoms, signs and ability to function as well as to side effects of medications.

6. Effects of treatment. This section should reflect the current 12.00H that discusses the impact of treatment on signs, symptoms and function. Treatment may, or may not, assist in the achievement of a level of adaptation adequate to perform sustained Substantial Gainful Activity.

IV. 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.

V. New listings needed

Several new listings should be added because of the prevalence of these disorders.

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

PTSD, a condition found in adults who have been members of the armed forces and other victims of terrorism, violence, or traumatic events, including children exposed to violence in the home or community. Currently it is buried in section 12.06 of the Adult Listings, where it is hard to find, in part because it is never named.

A separate Listing for PTSD should be included in both the Adult and the Children's Listings.

2. Attention Disorders (ADHD, ADD) for adults

This new listing should be similar to the children's ADHD Listing, § 112.11, recognizing that ADHD/ADD continues into adulthood.

3. Alzheimer's Disease and Senile or Pre-Senile Dementia

Alzheimer's Disease and other dementias should be added to the mental impairment Listings.

VIII. GAO's Recommendations Regarding "Corrected Conditions"

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. 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.

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. Loss of SSI often means loss of the very drugs that might make the person employable and therefore less needy of cash assistance. 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. 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.

IX. Other Listing Issues

1. Functional Equivalence for Adults

An effective method is needed 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. This recommendation has special significance for young 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 look at the impact of impairment across the domains of function critical for an adult to function in competitive employment.

2. Use of regulations

SSA should 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

SSA should 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. In particular, SSA should emphasize the use of vocational CEs for people who have no real employment history, and encourage the use of clinical

social workers as CEs to collect evidence on medical and social history from individuals, care givers, and families.

X. 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. 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 better case development at earlier levels. Unfortunately, very often the files of denied claimants show that inadequate development was done at the initial and reconsideration levels. 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.

2. Administrative Process

The SSDI and SSI application processes can be both lengthy and complex. Often, persons with mental impairments have difficulty even applying for benefits at a crowded SSA field office, unless they are provided with assistance. And, if a mentally ill individual does file an application, they frequently have 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 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.

Because these problems severely impact SSDI and SSI applicants with mental impairments, we offer the following recommendations to help improve the process.

- SSA should institutionalize SSDI/SSI outreach to low income persons with mental disabilities, particularly those populations with a high incidence of mental impairments, such as homeless persons or children.

- 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 can be sufficient to demonstrate good cause for failure to file a timely appeal or other SSA document.
- SSA should refer all children's SSI applicants not already receiving Medicaid coverage to state Medicaid and CHIP enrollment offices, so that those who are eligible can receive these critical health care benefits.
- 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.
- SSA should require state DDS agencies to have specialized adjudicators to handle children's SSI claims. SSA and DDS's generally make every adjudicator a generalist. The 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.

3. Psychotherapy treatment records need to be accessed and obtained by SSA

SSA currently uses its general client signed release form to obtain medical and clinical records, but under the Health Insurance Portability and Accountability Act regulations, which require specific informed release for psychotherapy notes and records, mental health providers do not send these records in. SSA needs to immediately address this by amending form SSA 827 to specifically and explicitly cite psychotherapy records as covered by the release.

4. Third Party Evidence

It is not uncommon for some individuals with mental impairments to underestimate the impact of their impairments on their functioning. Under such circumstances, third-party input from persons who live or interact routinely with the claimant is essential. When a claimant is unable or reluctant 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 or reluctant to describe her limitations, as well as whenever the self-reported functioning surpasses what would be expected from the medical evidence of record.

Our NAMI members believe they are the best source of third party evidence and thus in fairness should be heard. Those of us who've dealt with the SSA "system" for decades have few positive experiences to cite, but remain hopeful that our expertise will be

heard, evaluated, and utilized to provide the most effective support to those with mental disorders with the goal of enabling them to exploit their abilities to the maximum while reducing the overall cost to society.

Thank you for your attention.

Sincerely,

JAMES W.R. ADAMS
President, NAMI South King County