DISABILITY POLICY COLLABORATION

A Partnership of The Arc & United Cerebral Palsy

November 17, 2010

Office of Regulations
Social Security Administration
137 Altmeyer Building
6401 Security Boulevard
Baltimore, MD 21235-6401

Submitted on www.regulations.gov

RE: Docket No. SSA-2007-0101

Dear Sir or Madam:

These comments are submitted on behalf of The Arc of the United States and United Cerebral Palsy through the Disability Policy Collaboration in response to the Social Security Administration's (SSA) request for comments [75 Fed. Reg. 51336 (August 19, 2010)] on its Notice of Proposed Rulemaking regarding "Revised Medical Criteria for Evaluating Mental Disorders" ("NPRM").

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities throughout their lifetimes. It provides an array of services and supports of thousands of families and individuals and includes over 140,000 members affiliated through more than 730 state and local chapters across the nation. Along with this network, as well as our individual members, we support their full inclusion and participation in their communities and influence public policy. For more information, please visit www.thearc.org.

United Cerebral Palsy is a leading service provider for adults and children with disabilities. UCP's mission is to advance the independence, productivity and full citizenship of people with disabilities through an affiliate network, and its services reach more than 176,000 adults and children daily through its network of approximately 100 affiliates in the U.S., Canada, Scotland and Australia. For more information, please visit www.ucp.org

As member organizations of the Consortium for Citizens with Disabilities (CCD), we support the comments submitted by the CCD Social Security Task Force.

CCD provided extensive comments to the Advance Notice of Proposed Rulemaking (ANPRM) issued by SSA on March 17, 2003. 68 Fed. Reg. 12639 (Mar. 17, 2003). We are pleased that many of the suggestions provided in those comments were adopted in the NPRM. In general, we believe that the changes proposed in the NPRM will improve the mental impairments listings, providing more clarity for all parties involved in the process and thus leading to better decisions earlier in the process. Following are more detailed comments on each section of the proposed rule, as well as our recommendations for further clarifying the disability review process.

In addition, we want to highlight the following.

1. **Terminology** - We thank SSA for proposing a transition to using the term "intellectual disability" and urge SSA to move forward and drop the use of the term "mental retardation" altogether and include clear instructions that the terms have the same meaning and cover the same people.
2. **Diagnosis of Intellectual Disabilities** - We urge SSA to ensure that decision-makers respect the valid diagnosis of intellectual disability made by professionals and do not allow them to dismiss a valid diagnosis based on their own limited observations. We support SSA's continued use of age 22 as the age prior to which onset for a diagnosis of "Intellectual Disability/Mental Retardation" is appropriate. We also support SSA's continued use of its long-standing policy, which allows use of the lowest of the Full Scale, Performance, or Verbal scores on IQ testing.
3. **Infants and Toddlers** - We support SSA's proposed new listing for Developmental Disorders of Infants and Toddlers to evaluate developmental disorders for children from birth to attainment of age three.
4. **Standardized Tests** - We urge SSA to eliminate the reference to the use of standardized tests for measuring the functional abilities of people with mental impairments, as related to the "paragraph B" criteria of the regulations, until such time as tests have been developed, assessed, and found to truly measure the areas of function that are under consideration.
5. **Categories of Impairments** - The proposed rule divides the "A" criteria into broad categories of impairments, rather than specific diagnoses, and broadens the listings to include more mental disorders, including dementia and other cognitive disorders in listing 12.02; renaming listing 12.05 "Intellectual Disability/Mental Retardation"; specific mention of post-traumatic stress disorder in listing 12.06; describing listing 12.10 as "Autism Spectrum Disorders"; and the addition of "Other Disorders Usually First Diagnosed in Childhood or Adolescence" (listing 12.11) and "Eating Disorders" (listing 12.13). We support these changes. In addition we support the restructuring of the mental disorders listings categories, using brief descriptions, followed by examples of symptoms and signs.
6. **"Extreme" Limitations** - We also support allowing one "extreme" limitation to satisfy the B criteria which may more accurately reflect the reality of a claimant's ability to function in a work setting. To satisfy the paragraph B criteria, an individual's mental disorder, therefore, must result in "marked" limitations of two or "extreme" limitation of one of the mental abilities in paragraph B.

7. **Severity in Functional Assessment** - The use of the terms "mild" or "moderate" in the diagnosis of some disabling conditions should not be assumed to have any meaning or relationship to evaluation of function, since the use of these terms in different fields of discipline and/or diagnosis can have quite different meanings than in descriptions of the individual's ability to function. We urge inclusion of language to clarify that rating of severity in assessing whether an individual meets the paragraph B or C criteria relates to functioning, not to the diagnosis of the mental disorder.
8. **Paragraph B1 and B3 Criteria** - SSA must provide clear and precise guidance to adjudicators that proposed paragraphs B1 and B3 are met if there is a "marked" or "extreme" limitation in any one of the three elements of the paragraph. We recommend that SSA include the language in the preamble (75 Fed. Reg. at 51341) in the section 12.00 Introduction, clarifying for adjudicators SSA's existing policy regarding the overall requirement, i.e., that a "marked" or "extreme" limitation in any one of the three components in paragraphs B1 and B3 will meet the requirements of that particular paragraph.
9. **Rating Scale** - The proposed rule describes "marked" as: while the use of a scale is not required, "marked would be the fourth point on a five-point rating scale consisting of no limitation, slight limitation, moderate limitation, marked limitation, and extreme limitation." Similarly, "extreme" is the fifth point on a five point scale – although it is not intended to mean total limitation. We are concerned that a five-point scale defined by "no" limitation at one end and "extreme" – but not total – limitation at the other is confusing and misleading. To provide more clarification to adjudicators and medical sources, and to avoid confusion, we recommend using a six-point scale: no limitation; slight limitation; moderate limitation; marked limitation; extreme limitation; and total limitation. "Marked" limitation then would be the fourth point on a six-point scale ranging from (1) no impairment to (6) total impairment, while "extreme would be the fifth point on the six-point scale.
10. **Standard Error of Measurement** - The proposed changes do not mention the standard error of measurement (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 include individuals with listing-level severe impairments. SSA should give claimants the benefit of the doubt and include those individuals whose IQ scores place them within the standard error of measurement on standardized tests.
11. **Supports and Structured Settings** - We are pleased that SSA has proposed to consider the kind and extent of supports a claimant receives and the characteristics of any structured setting in which he or she spends time when evaluating the effect of a mental disorder on the claimant's ability to function. Section 12.00F.2 lists examples of "psychosocial supports and highly structured settings." Language should be added to clarify that this is not a complete list and that other types of supports and highly structured settings must be considered, e.g., supported housing with wrap-around services in the home.

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The Arc and United Cerebral Palsy appreciate the opportunity to share our comments with SSA. Thank you for consideration of our comments.

Sincerely,

Paul Marchand
Staff Director