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Statewide Parent Advocacy Network, Inc.

Empowered Families: Educated, Engaged, Effective!

**Family Voices-NJ Comments on the Revised Medical Criteria for Evaluating
Mental Disorders; Proposed Rule
Submitted November 16, 2010**

Thank you for the opportunity to comment on the revised medical criteria for evaluation of mental disorders under the proposed rule of the Social Security Administration. Family Voices is a national network that advocates on behalf of children with special healthcare needs and works to “keep families at the center of children’s healthcare”. Our NJ State Affiliate is housed at the Statewide Parent Advocacy Network (SPAN), NJ’s federally designated Parent Training and Information Center, Family-to-Family Health Information Center, and chapter of the Federation of Families for Children's Mental Health. The Family Voices Coordinator also serves as a volunteer and board member of the local chapter of the National Alliance on Mental Illness.

SPAN’s foremost commitment is to children with the greatest need due to disability; poverty; discrimination based on race, sex, or language; geographic location; or other special circumstances. It is from these perspectives, the perspectives of the many families we assist, and our own experiences as parents of children with special needs, that we are sharing these comments. Personally, as the Family Voices Coordinator for New Jersey, I am the parent of a child with multiple disabilities, including autism.

Why are we proposing to revise the listings for mental disorders? We understand that the 12.00 listings for mental disorders for adults have not been revised since 1985 and that the last published final rules for mental disorders in children appeared in 1990 and agree that it is important and timely to revise them now.

How did we develop these proposed rules? We understand and appreciate that historically this involved the NRC (National Research Council) report in 2000, scientific basis regarding intelligence and adaptive behavior, differential diagnosis, and an ANPRM (advance notice of proposed rulemaking) in 2003 which was followed by a policy conference in Washington DC.

How are the current mental disorders listings structured, and what do they require? We understand that currently the first part is an introductory paragraph. The second part contains “paragraph A” criteria on symptoms, signs, and laboratory findings. The third part is the “paragraph B” criteria for adults on functional limitations

and ability to work. We are concerned with this new requirement as it will disqualify many applicants who are unable to work and our specific comments appear below. Some mental disorders include a fourth part which is “paragraph C” criteria as an alternative to paragraph B, which establishes the severity of certain mental disorders and ability to work. Again, besides references to ability to work in paragraph B criteria, we have the same concerns for paragraph C criteria and our specific comments follow.

What major revisions are we proposing? We understand that the proposed changes include eliminating the introductory paragraph and paragraph A criteria. A mental disorder can be demonstrated under “one of the ten listing categories” and “except for certain listings under 12.05, results in marked limitations of two or extreme limitation of one of four paragraph B ‘mental abilities’ or satisfies paragraph C criteria”.

We understand that the proposed changes would broaden categories and include more disorders, add listings, revise paragraph B criteria, revise paragraph C criteria to included all disorders (except 12.05 and 112.05), and clarify the definitions of “marked” and “extreme”.

We understand that not all disorders from the current DSM (Diagnostic and Statistical Manual of Mental Disorders) are going be listed because they may not result in functional limitations or meet duration requirements. We understand that criteria for work-related terms will be clarified and that for children beginning at age 3 the terms must be “appropriate to childhood functioning”. We understand that criteria will be clarified for “marked” or “extreme” limitation and that there are already criteria from birth to age three but not for older children or adults. For children, we agree that the definitions should concur with the SSI (Supplemental Security Income) childhood disability regulations.

We agree with revising paragraph C criteria for a 2 year history of medical documentation to align with the 1 year duration requirement in the definition of a disability. We also agree with replacing “decompensation” to “deterioration” as the former is not always applicable.

We support the recommendation to recognize that non-physicians such as therapists and social workers can also serve as professional sources.

What other significant revisions are we proposing? We understand that the proposal includes removing 404.152 and 416.920, revising introductory text, changing terminology on mental retardation, removing substance abuse, changing the title from only ADHD (Attention Deficit Hyperactivity Disorder) to comprehensive childhood disorders, adding eating disorders for children, and changing the title to Developmental Disorders (eliminating Emotional) up to age 3. We will discuss our thoughts on each in the sections below.

Proposed 12.00 - Introductory Text to the Adult Mental Disorders Listings

We understand that the following are proposed changes to the introductory text.

Proposed 12.00A – What are the mental disorders listings, and what do they require? *Proposed 12.00A1* We understand that there will be changes to the names to more accurately reflect the current DSM, one listing will be removed, and there will be two added listings. Our comments on these changes will appear in each listing category below.

Proposed 12.00A2 We understand that while “marked” limitations remains the same, that the new standard of “extreme” limitations will be added. We are concerned with this new requirement on scores and our comments appear in 12.00D3 under the definition of “extreme”.

Proposed 12.00A3 We understand that in this section, it is explained how “ID/MR” meets the proposed listing 12.05 and our comments appear in that section.

Proposed 12.00B – How do we describe the mental disorders listing categories? We understand that “the sections of proposed 12.00B do not require explanation, except for proposed 12.00B1 and 12.00B4”.

Proposed 12.00B1 – Dementia and Amnestic and Other Cognitive Disorders We will not comment on this section as it is not applicable to the children we serve.

Proposed 12.00B1 – Intellectual Disability/ Mental Retardation This is currently section 12.05 and our comments appear below.

Proposed Name Change We agree with the name change to “intellectual disability”. We completely *disagree* with not removing “mental retardation” from the listing. The reasons given for keeping this terminology is that it is “familiar”, included in the DSM-IV, appears in medical reports, and state/federal benefits programs. The term is familiar but outdated and stigmatizing. The proposed DSM-5 will remove this term. Federal programs will also remove this terminology. On 10/5/10 President Obama signed Rosa’s Law to replace “mental retardation” terminology with “intellectual disability”.

Proposal to Require “Significant” Deficits in Adaptive Functioning To Demonstrate ID/MR We understand that the current 12.05 does not describe level of severity. Proposed 12.00B4a would require “significant” deficits of adaptive functioning. We understand that this was the result of several sources. The most recent edition of the American Association on Intellectual and Developmental Disabilities requires “2 standard deviations below the mean of either (a) one of the following three types of adaptive behavior: conceptual, social or practical, or (b) overall score on a standardized measure of conceptual, social, and practical skills.” The APA (American Psychological Association) Manual of Diagnosis and Professional Practice in Mental Retardation also requires two or more standard deviations below the mean for adaptive behavior. The DSM-IV requires “significant limitations...in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety (Criterion B).” However we are concerned that for people with mental illness, there is

no scientific basis for the use of standardized testing. This would affect thousands of people who cannot work and would be ineligible under the proposed rule.

Proposed Clarification of Our Rule on the Developmental Period for ID/MR We understand that the condition had to be manifested before age 22. We strongly agree with the addition in 12.00B4c that if there is no evidence, there would still be the finding “if current evidence and the history of the impairment are consistent with the diagnosis...” We also agree that there should be acceptance of the lowest IQ score for tests that provide more than one score (e.g. verbal, full scale, etc.) We agree that this will help “confirm the validity of test results with other evidence, especially of a person’s day to day functioning.” We understand that the person must have “‘significant’ deficits in adaptive functioning.” We also understand that listing 12.05C would not consider impairments that are not severe, even if they affect work, and that “other physical or mental impairment must be separate from the limitations caused by ID/MR” and will address this under that section.

Proposed 12.00C – What are the paragraph B criteria? We understand that this refers to abilities of adults as related to work. However, there are many people with serious mental illness who will now not be eligible under the new rules. Namely these are the ability to “understand, remember, and apply information; interact with others; concentrate, persist, and maintain pace; and manage oneself”. We agree with using “an approach for evaluation limitation similar to the approach....in determining functional equivalence for children under SSI.”

Proposed 12.00C1 – Understand, Remember, and Apply Information It is noted that the proposal to remove paragraph B1 criterion will be explained “later in this preamble” so our comments will be in that section.

Proposed 12.00C2 – Interact With Others We understand that this would replace the current paragraph B2 criterion, removing social functioning, and instead focusing on “mental abilities needed to work...for example, cooperating with co-workers or accepting criticism from a supervisor”. We again are concerned with the focus on abilities needed to work and the inappropriate use of standardized testing for people with mental illness. We also understand that information on social functioning will be removed from 12.00C2, revised, and moved to 12.00D and our comments appear there.

Proposed 12.00C3 – Concentrate, Persist, and Maintain Pace We understand that there will be a slight change from “or” to “and” maintain pace, and that guidance on medical/nonmedical evidence will be moved to 12.00G; our comments appear there.

Proposed 12.00C4 – Manage Oneself We understand that the proposed change will include “ability to respond to demands and changes in the workplace” as an indicator of the importance of self-management and independence. Again, we feel that self-management and skills for independence encompass more than the workplace and this should not be the requirement.

Proposal to Remove the Current Paragraphs B1 and B4 Criteria We understand that ADLs (activities of daily living) will be removed because they are the result of any or all of the four proposed areas of mental abilities and are across domains.

Proposed 12.00D – How do we use the paragraph B mental abilities to evaluate your mental disorder? We understand rather than rating severity in sections in the current listing 12.00C1, C2, and C3, that the guidance will be moved to 12.00D1. Please note that although previous section 12.00C2 mentioned social functioning will be moved to this section, we did not see it addressed here.

Proposed 12.00D1 We agree that “marked” or “extreme” limitations indicate the degree to which the mental disorder affects the individual’s abilities. We strongly support that “no single piece of information (including test scores) can establish whether a person has marked or extreme limitation” as a safeguard. We also strongly support consideration of the “kind or extent of supports a person receives” in determination of their ability to function.

Proposed 12.00D2 – What We Mean By “Marked” Limitation We understand that this is similar to the childhood disability rules and applies to adults as well. We agree “that ‘marked’ is the equivalent of functioning...on standardized testing with scores that are at least two, but less than three, standard deviations below the mean.” We agree that this would be defined on the scale “no limitation, slight limitation, moderate limitation, marked limitation, and extreme limitation”.

Proposed 12.00D3 – What We Mean by “Extreme” Limitation We agree that “extreme” could be demonstrated in a score “at least three standard deviations below the mean” and would appear in the range scale above. However, we are concerned that many of those with mental illness would not be eligible because they would need low scores to qualify, and feel that standardized testing is not scientifically based for this population.

Proposed 12.00D4 – How We Consider Your Test Results We strongly agree that while IQ scores can be considered that it must be noted if the score is “valid and consistent with the developmental history and functional limitation.”

Proposed 12.00E – What are the paragraph C criteria and how do we use them to evaluate your mental disorder? We agree with simplification of the current criteria rather than counting episodes of decompensation, to now include: “‘serious and persistent’ mental disorder and ...marginal adjustment”, and broadening of the definition of marginal adjustment to reflect “minimal capacity to adapt to changes in the environment”. We agree that “serious and persistent” is more accurate as some disorders may not “have a ‘chronic’ specifier” (e.g., duration varies such as in cases of post traumatic stress disorder). We agree that “serious and persistent” disorders would be defined as those requiring “continuing treatment, have psychosocial supports, or be in a highly structured setting.” We strongly agree that adjudicators can use “paragraph C criteria without first considering whether the mental disorder satisfies the paragraph B criteria” to expedite the process.

Proposed 12.00F – How do we consider psychosocial supports, highly structured settings, and treatment when we evaluate your functioning? We support the use of the “expanded list of examples” which would take into consideration that “controlling...symptoms with medications and community supports does not eliminate the underlying mental disorder and that ...should not interpret...active involvement in a supported work setting...to mean that the person is not disabled.”

Proposed 12.00G – What evidence do we need to evaluate your mental disorder? We understand that the current 12.00B or 12.00D on medical evidence are not included as they appear in other provisions of the proposed rules.

Proposed 12.00G1 – General We understand that this section is regarding medical evidence and “ability to function in a work setting”. However as stated earlier, there does not appear to be a scientific basis for standardized measurement for those with serious mental illness and this new restriction would cause thousands who cannot work to still be ineligible for disability benefits. We support that the current 12.00D4 will be revised so “it applies to all evidence, not just mental status examinations”.

Proposed 12.00G2 – Evidence From Medical Sources We strongly support the revision of current 12.00D1c to expand consideration of evidence to other sources “who are not ‘acceptable medical sources’ such as therapists and licensed clinical social workers.” We also support expansion of the list of evidence to include “cultural background and sensory, motor, and speaking abnormalities that may affect our evaluation of a person’s mental disorder.” We agree with removing the current 12.00D4 which discusses the mental status examination in detail. We also agree with removing 12.00D11 regarding documentation for anxiety disorders as “it does not require anything that we would not ordinarily require to evaluate other mental disorders.” This will allow both flexibility and increase simplification of the evaluation process.

Proposed 12.00G3 – Evidence From You and Persons Who Know You We agree with keeping information from current 12.00D1b and 12.00D1c, but simplifying the language to streamline the process.

Proposed 12.00G4- Evidence From School, Vocational Training, Work, and Work-Related Programs We strongly agree with adding information from school or work evidence.

Proposed 12.00G5 – Evidence From Psychological and Psychiatric Measures We agree with removing the current 12.00D5-D9 on psychological testing as “most of this information is educational and procedural, and tests are constantly being revised...”

Proposed 12.00G6 – Need for Longitudinal Evidence We agree with keeping the language from current 12.00D2 but expanding to including functioning over time. We agree that in addition to medical history, new section 12.00G6c will allow for evidence from family or employers on functioning over time. We also strongly support the addition of 12.00G6d to include consideration of the affects of stress.

Proposed 12.00H – How do we evaluate substance use disorders? We understand that this new section will replace 12.09 substance addiction disorders.

12.001 – How do we evaluate mental disorders that do not meet one of the mental disorders listings? We agree with the addition of this new section which is “similar to guidance we provide on other body systems.” This will allow for increased flexibility in the determination process.

12.01 Category of Impairment, Mental Disorders

Proposal to Remove the Introductory Paragraphs and Paragraph A Criteria We appreciate that the current listings are seen as “too prescriptive” and that the list will be more comprehensive to include “mental disorders that we often see on disability claims.” We agree by having adjudicators not have to find “evidence demonstrating specific paragraph A criteria” will simplify the process.

Proposed Changes to Specific Listings in This Body System Proposed Listing 12.05 We agree with the changes in 12.05 changing the current listing from two of the following “activities of daily living...or social functioning...or maintaining concentration, persistence or pace,...or episodes of decompensation” to marked limitation in two of the following “understand, remember and apply information,... ability to interact, ...ability to concentrate, persist, and maintain pace... ability to manage oneself”.

Proposal to Remove Current Listing 12.09 Again, we agree with removing Substance Addiction Disorders (and remove 12.00A because it explains 12.09 structure) because it is a reference listing which refers “to criteria in other listings”. Claimants would still “qualify under the listings to which they cross-refer” so this should simplify the determination process. We agree with proposed 12.00H which will consider “whether a substance abuse disorder is a contributing factor material to disability.” This emphasizes the recognition that dual diagnosis of mental health/substance abuse is a common occurrence.

Proposed Listings 12.11 and 12.13 We strongly support the proposed listing of “other Disorders Usually First Diagnosed in Childhood or Adolescence” and that it will “correct some omissions in our current listings.” We agree also that 12.13 on eating disorders should also provide a listing for adults.

Proposed 112.00 – Introductory Text to the Childhood Mental Disorders Listings We agree that the introductory language of 12.00 for adults can also apply to children. We also agree since the previous provisions are explanatory that there is no need to duplicate in this section the references of children vs. adults, age appropriate vs. work, etc. because there only needs to be information on “provisions that are unique to the childhood rules.” Thus the only changes in this section would remove current 112.00A on “certain diagnostic categories applicable only to children” and “why we do not include separate paragraph C criteria...because we are now proposing to include the same paragraph C criteria in the childhood listings that we propose for the adult rules” and these are both covered in the proposed 12.00A and B.

Proposed 112.001 We somewhat agree with using the “same kinds of information for infants and toddlers as we do for older children.” We agree with using criteria for marked and extreme limitations. We also agree with including several “unrelated” disorders together such as pervasive developmental disorders, developmental coordination disorder, and developmental delay. However, we are deeply concerned with section 112.0016 regarding “deferring a determination for infants” and obtaining a “longitudinal history”. There should be certain presumptive eligibility categories such as Down Syndrome, Fragile X, etc. that would result in determination regardless of the age of the child as these are not merely developmental delays, but lifelong developmental disorders. Further, current 112.00D2 provides for determination at 3 months for full term and undetermined for premature infants. Proposed changes will increase this to 6 months for full term infants and adjusted age for preterm infants. Again, we strongly disagree as some disorders are evidenced at birth and there is no reason to delay determination. In fact the NJ Early Intervention System proposed to remove adjusted age for premature infants because they were most at risk and were not being identified for services early enough despite research that sooner treatment resulted in better health outcomes. We appreciate that under 112.0016c there is an explanation that “we will not always defer adjudication” but this section still requires determination based on functionality and again we feel there should be presumptive eligibility for certain conditions.

112.01 Category of Impairment, Mental Disorders We agree that the proposed childhood listing is similar to adult disorders but strongly support the addition of proposed 112.14 for children from birth to age three.

Proposed Listing 112.05 We agree that under proposed 112.05B a child with an “IQ of 59 or less would have an impairment that meets the listing without reference to paragraph B functional criteria” and that under 112.05D a child with and “IQ of 60 to 70 and ‘marked’ limitations in two of the proposed paragraph B criteria would have an impairment that meets that listing”.

Proposal to Remove Listing 112.09 We agree with removing substance abuse from this section because “children with substance abuse disorders must satisfy the same requirement that applies to...adults; that is, if we find that a child is disabled, we must also determine whether the child’s substance use disorder is a contributing factor material to our determination of disability”.

Proposed Listing 112.14 – Developmental Disorders of Infants and Toddlers
We agree that the new listing will “evaluate these disorders in children from birth to ...age 3” and that there is no need to “have separate criteria for children from age 1 to...age 3 in other...listings because we would evaluate all mental disorders for children in that age group under proposed listing 112.14”.

How We Evaluate Children From Birth to Age 3 Under the Current Listings

Currently there are four areas for rating severity in “cognitive/communicative functioning; motor development; apathy, over-excitability, or fearfulness; and social interaction” using measurements of marked or extreme limitations.

Proposed Listing 112.14 The new listing for paragraph B criteria would include: “ability to plan and control motor movement...ability to learn and remember...ability to interact...ability to regulated physiological functions, attention, emotion, and behavior”. For children, we agree that birth to age 3 “is better viewed as a continuum rather than two distinct age groups” and to evaluate infants and toddlers as a single age grouping. We disagree however with using “developmental disorders” instead of “emotional and developmental disorders” because “specialists prefer to wait until a child is age 3 or older before making a definitive diagnosis”. Many disorders are apparent prior to age three, some are evident at birth, and early intervention is key. Further, mental health disorders are distinct from developmental disorders and eliminating emotional disorders will delay determination of eligibility for certain children for years.

Why are we proposing to remove 404.1520a and 416.920a, Evaluation of Mental Impairments? We understand that the removal of the PRT (Psychiatric Review Technique form) is because “most pages of the PRTF restate the paragraph A diagnostic criteria” and is duplicative.

Other Proposed Changes We agree with the “nonsubstantive editorial changes to update medical terminology.” We understand that for children, immune disorders include “criteria that cross-refer to the functional criteria” and that a small number of children would also still “qualify under functional equivalence data”. The section would remain for adults because it does not cross-refer to mental disorders but includes “specific functional criteria within each of the adult listings”. We agree with eliminating the “outdated term ‘mental deficiency’” and terminology about “unable to attend any school”. Rather than school attendance, the new requirement would be “complete inability to independently perform basic self-care activities” starting at age 4. We agree with lowering the presumptive disability (without medical evidence) from age 7 to 4, but would suggest that some conditions should qualify for presumptive eligibility at birth.

What other projects are we doing to determine the requirements of work? We understand that these rules include criteria regarding the requirements of work. There will be two forthcoming projects related to this: Occupational Information System and possibly using the International Classification of Functioning domains in predicting disability.

What is our authority to make rules and set procedures for determining whether a person is disabled under the statutory definition? We understand that the Social Security Administration has “full power and authority to make rules and regulations, and to establish necessary and appropriate procedures to carry out such provisions”.

How long would these proposed rules be effective? We understand that these rules, once final, will be in effect for 5 years.

Clarity of These Proposed Rules Our comments regarding clarity would be to avoid duplication in sections and we appreciate the chart of current vs. proposed listing categories. Perhaps a flow chart of Paragraph B and C criteria could be developed.

When will we start to use these rules? We understand these rules will only go into effect after evaluation of public comment and final rules will be published in the Federal Register. Until that time, current rules will continue to be in effect.

Regulatory Procedures

Executive Order 12866

We agree that these rules “meet the requirements for a significant regulatory action”.

Regulatory Flexibility Act

We also agree that “these proposed rules would not have a significant economic impact on a substantial number of small entities because they would affect only individuals”.

Paperwork Reduction Act

We agree that “these rules do not create any new, or affect any existing collections and, therefore, do not require Office of Management and Budget approval under the Paperwork Reduction Act”.

In summary, we support the majority of the proposed revisions with the critical exceptions noted above. Thank you again for the opportunity to comment on the proposed revisions for SSA medical criteria pertaining to evaluation of mental disorders.

Sincerely,

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Our Mission: To empower families and inform and involve professionals and other individuals interested in the healthy development and educational rights of children, to enable all children to become fully participating and contributing members of our communities and society.