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Statewide Parent Advocacy Network, Inc.

Empowered Families: Educated, Engaged, Effective!

Family Voices Comments on the Proposed DSM-5

Submitted March 1, 2010

Thank you for the opportunity to comment on the proposed revisions to the DSM-5. Family Voices is a national network that advocates on behalf of children with special healthcare needs and our NJ Chapter is housed at the Statewide Parent Advocacy Network (SPAN), NJ's federally funded Parent Training and Information Center, Family-to-Family Health Information Center, and a chapter of the Federation of Families for Children's Mental Health. The Family Voices Coordinator also serves as a volunteer and is on the board of her local NAMI (National Alliance on Mental Illness). Family Voices receives up to 2000 requests for assistance per month and there has been a tremendous increase in recent years in calls regarding children's mental health. It is from the calls that we receive, as well as my own experience as a parent of a child with both developmental and mental health/behavioral challenges, that I am commenting.

Structural, Cross-Cutting, and General Classification Issues for DSM-5

Diagnoses Proposed by Outside Sources

Fetal Alcohol Syndrome

There is discussion of adding disorders. We would support the addition of Fetal Alcohol Syndrome but the newest terminology is Fetal Alcohol Spectrum Disorders. We agree to include FASD as the National Organization on Fetal Alcohol Syndrome describes part of this as ARND (Alcohol Related Neuro-Developmental Disorder). In addition, according to the Fetal Alcohol Spectrum Disorders Center for Excellence under SAMHSA, "these effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications." This description obviously falls under the auspices of the DSM-5.

Sensory Processing Disorder

However, we would not agree with adding Sensory Processing Disorder. Sensory processing, which is sometimes called Sensory Integration Disorder or Auditory Processing Disorder, is not in and of itself a disorder but rather a symptom of other disorders such as autism, ADHD, etc.

Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence

*Childhood Disorders Not Currently Listed in DSM-IV

Callous and Unemotional Specifier for Conduct Disorder

This disorder doesn't exist in the current DSM-IV. We think it should just be called conduct disorder, plain and simple, without the stigma of "callous and unemotional". We would suggest keeping the information in Attention-Deficit and Disruptive Disorders under *312.8x Conduct Disorder* per the current DSM-IV, and not as a separate disorder.

Learning Disabilities

We agree that this is better terminology than learning "disorder" in the current DSM-IV.

Non-Suicidal Self Injury

Non-Suicidal Self Injury Not Otherwise Specified

Although we support the use of this disorder, we feel there only needs to be one disorder as Non-Suicidal Self Injury. We support this category as an important distinction that distinguishes self injury from suicidal intent, which requires different intervention techniques.

*Childhood Disorders Proposed for Possible Reclassification in Another Diagnostic Category

309.21 Separation Anxiety Disorder

The proposal states that "The work group is still considering the following issues: possible reclassification of this disorder from **Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence** to **Anxiety Disorders**; rewording of the criteria to be suitable for adults as well as children; and the potential problem of overlap with other disorders." We would support this diagnostic category under anxiety but think it fits best with childhood disorders. Further we would strongly urge the work group to retain the category **Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence** as there are disorders specific to children, and even for those that overlap into adulthood, interventions and medications (some of which are contraindicated for pediatric use) are different across the lifespan.

Childhood Disorders Proposed for Possible Removal from DSM (No DSM-5 Criteria Proposed)

299.80 Rett's Disorder

We disagree with the proposal to eliminate Rett's Disorder. This disorder is clearly part of the Pervasive Developmental Disorders. If anything, it should be retained under the category **Autism Spectrum Disorder**.

*Childhood Disorders Proposed to be Subsumed Under Other Diagnoses (No DSM-5 Criteria Proposed)

315.9 Learning Disorder Not Otherwise Specified

We agree with the work group recommendation that this disorder “be subsumed into a new disorder: **learning disability**” for the reasons cited above under

*Childhood Disorders Not Currently Listed in DSM-IV.

299.10 Childhood Disintegrative Disorder

We also agree with the work group recommendation that this disorder “be subsumed into an existing disorder: **Autistic Disorder (Autism Spectrum Disorder)**” as a pervasive developmental disorder.

299.80 Asperger's Disorder

We strongly agree with the work group proposal that this disorder “be subsumed into an existing disorder: **Autistic Disorder (Autism Spectrum Disorder).**” As a parent of a child who was originally diagnosed as Asperger’s and later changed to High Functioning Autism, I have found that even the professionals disagreed if these were separate diagnoses. Further, I found that this distinction caused divisiveness regarding “high” vs. “low” functioning individuals when indeed, both “autism” and “Asperger Syndrome” are pervasive developmental disorders.

299.80 Pervasive Developmental Disorder Not Otherwise Specified

We also agree with the work group recommendation that this disorder “be subsumed into an existing disorder: **Autistic Disorder (Autism Spectrum Disorder).**” This should help eliminate the confusion that PDD and autism are separate disorders when they are actually part of the autism “spectrum” of disorders.

We would further suggest the retention of Rett’s Disorder under **Autism Spectrum Disorder** as a pervasive developmental disorder as mentioned under Childhood Disorders Proposed for Possible Removal from DSM (No DSM-5 Criteria Proposed) above.

Attention-Deficit and Disruptive Disorders

314.0x Attention Deficit/Hyperactivity Disorder

The workgroup was considering “1) Maintain present criteria but without subtypes and with only a single diagnostic code. Provide scales to designate behavior-specific features; or 2) Discontinue predominantly hyperactive/impulsive and predominantly inattentive subtypes.” We disagree with both of these as Attention Deficit can present as inattentive, hyperactive, or combined type and prefer the current DSM-IV definition of the disorder.

Pervasive Developmental Disorders

299.00 Autistic Disorder

Again we agree with listing Autism, Asperger’s, Childhood Disintegrative, PDD under “Autism Spectrum Disorder” and would include Rett’s as mentioned previously.

Mental Retardation

Mental Retardation

319 Mental Retardation, Severity Unspecified

We whole-heartedly support the change in terminology to “Intellectual Disability” throughout this section in keeping with the national movement to eliminate the use of out-dated and stigmatizing terms.

Tic Disorders

Tourette’s Disorder

We read that “The work group is recommending that this disorder remain in Childhood Disorders, if that section is retained, but if that section is not retained then move to Anxiety and Obsessive-Compulsive Disorders.” First of all, we agree that Tourette’s should remain under childhood disorders. Secondly, we would again urge the work group to retain a separate section on childhood disorders per our previous comments under “Childhood Disorders Proposed for Possible Reclassification in Another Diagnostic Category” regarding differences in disorders throughout the lifespan.

Thank you for the opportunity to comment on the proposed revisions to the DSM-5.

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.