

AUCD Comments to American Psychiatric Association (APA)

Re: Proposed change to diagnostic features text for IDD

Submitted via <https://www.psychiatry.org/psychiatrists/practice/dsm/proposed-changes>

Specialty: AUCD is a national network of university-based interdisciplinary centers and programs in every state and territory that serve as a bridge between the university and the community, bringing together the resources of both to achieve meaningful change for people with disabilities

Summary: AUCD submitted comments to the American Psychiatric Association (APA) strongly opposing a proposed change to the DSM-5 concerning the diagnostic criteria for intellectual disability (ID). In an attempt to clarify the current criteria, the proposed revision creates greater concern around the understanding of intellectual functioning and adaptive behavior. It asserts – incorrectly – that adaptive functioning is a cause of intellectual functioning. We opposed the proposed revision as it could negatively impact peoples' ability to access services and supports.

Comment 1:

The proposed revision to address issues regarding pg. 38 in the Diagnostic Features section of the DSM-5 text on Intellectual Disability is a critical issue that will have ramifications on the identification of people with intellectual disability. AUCD supports the removal of the sentence, "To meet diagnostic criteria for intellectual disability, the deficits in adaptive functioning must be directly related to the intellectual impairments described in Criterion A." Currently, clinicians have to show not only a link between adaptive functioning and intellectual functioning, but that adaptive functioning is caused by the deficits in intellectual functioning. There is no empirical evidence supporting the notion of a measurable, causal (i.e., "consequence of") link between intellectual functioning and adaptive behavior. Research has consistently shown that the correlation between IQ scores and adaptive behavior scores is approximately .50. This means that only 25% of the variance in adaptive behavior can be accounted for on the basis of intelligence, and vice-versa. The remaining 75% of the variance is attributable to other personal characteristics and environmental factors. By adding a phrase implying causation creates a fourth diagnostic criterion that plainly requires clinicians to establish that the deficits in adaptive functioning are a consequence of intellectual deficits. It is impossible for clinicians to scientifically/clinically establish that the deficits in adaptive functioning are directly related to—that is, caused by, a consequence of, or provably linked to—the deficits in intellectual functioning. By deleting this sentence, the DSM-5 will direct clinicians more clearly in the diagnosis of intellectual disability which could positively impact eligibility for supports and services, educational placement and assistance, protection from discrimination, funding for ongoing services and supports, and various legal issues in the criminal and civil justice systems.

Comment 2:

The proposed revision of adding, “Adaptive functioning is understood to be the application of intelligence to functioning in everyday life. Criterion A (deficits in intellectual functions) and Criterion B (deficits in adaptive functions) are related in that the deficits in adaptive functioning are a consequence of intellectual deficits defined in Criterion A and are not the result of a co-occurring DSM-5 mental disorder.” is of concern. AUCD opposes this revision because it assumes adaptive functioning and intellectual functioning are not separate and independent. A deficit in adaptive behavior may not be due to an intellectual functioning deficit. Adaptive functioning is the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives (AAIDD). DSM-5 conceptualization of adaptive functioning as a cognitive construct rather than a behavioral construct is a significant and dramatic departure from previous DSM manuals. It is also in stark contradiction with current clinical and scientific consensus as well as being out of step with other diagnostic systems that define the same condition. This novel conceptualization of adaptive functioning as “adaptive reasoning” is discordant with AAIDD and ICD-11. Maintaining this conceptualization of adaptive functioning would likely result in significant differences in “caseness” between the DSM-5 and the other two diagnostic systems. Currently, AAIDD and ICD-11 are closely aligned with one another. Additionally, we know that research indicates a greater complexity around co-occurring disabilities. By including in the revision that adaptive function deficits are not a result of mental disorder creates confusion around the complex nature of one’s disability and the fluidity of its manifestation. We are concerned that this not only is diagnostically difficult for clinicians to decipher but will also result in stricter intellectual disability (ID) criteria leading to less individuals being identified with ID. This will result in a population of people underdiagnosed, misdiagnosed, or undiagnosed hindering their ability to access services that match their individual needs.

Comment 3:

We know the critical impact of being identified with an intellectual disability. A diagnosis of intellectual disability directly effects service eligibility for individuals. AUCD supports and promotes a national network of university-based interdisciplinary programs playing key roles in every major disability initiative over the past four decades. Many issues, such as early intervention, health care, community-based services, inclusive and meaningful education, transition from school to work, employment, housing, assistive technology, and transportation have been directly benefited by the services, research, and training provided by our centers. It is from this work that we know that without proper identification of an intellectual disability, people will not receive the services and supports that they need. If undiagnosed or misdiagnosed, children will not be eligible for early intervention, educational supports, and transition services from school to work. In order for adults to be eligible for long-term services and supports or home and community-based services through Medicaid waiver systems, people with a diagnosis of intellectual disability are at a greater ability to access necessary services to live independent, inclusive lives in their community. Because of this, we oppose the text

revision as it may result in negatively impacting peoples' ability to access services and supports.

Comment 4:

AUCD proposes the following: Delete the original sentence (“To meet diagnostic criteria for intellectual disability, the deficits in adaptive functioning must be directly related to the intellectual impairments described in Criterion A”) and also the two proposed sentences: “Adaptive functioning is understood to be the application of intelligence to functioning in everyday life. Criterion A (deficits in intellectual functions) and Criterion B (deficits in adaptive functions) are related in that the deficits in adaptive functioning are a consequence of intellectual deficits defined in Criterion A and are not the result of a co-occurring DSM-5 mental disorder.”