

DOCUMENT SUMMARY

This chapter by Owens, Zalecki, and Hinshaw details the findings from the Berkeley Girls with ADHD Longitudinal Study (BGALS), a landmark prospective study of a large, diverse sample of girls with ADHD followed from childhood into young adulthood. This research is fundamentally important to Enlitens' mission because it provides extensive, multi-method, multi-informant evidence that ADHD in females is a severe and persistent condition with unique developmental pathways and outcomes, particularly an alarming risk for self-harm. The study's findings reveal the inadequacy of relying on self-report for diagnosis and underscore how male-prototyped understandings of ADHD have led to the historical neglect and mischaracterization of the condition in females, making a powerful case for the kind of nuanced, developmentally-informed clinical assessment Enlitens advocates for.

FILENAME

OWENS_ZALECKI_HINSHAW_2017_Berkeley_Girls_with_ADHD_Longitudinal_Study_gender_bias_and_assessment_failures.md

METADATA

- **Primary Category:** ASSESSMENT
- **Document Type:** book_chapter
- **Relevance:** Core
- **Key Topics:** ADHD, gender_bias, assessment_critique, underdiagnosis, longitudinal_study, self-report_unreliability, self-harm, compensatory_strategies, female_presentation
- **Tags:** #ADHD, #assessment_bias, #gender, #females, #underdiagnosis, #longitudinal_study, #self-report, #self-harm, #comorbidity, #developmental_pathways

CRITICAL QUOTES FOR ENLITENS

- "Believed to be a male disorder for much of the 20th century, only recently has recognition been given to the reality of ADHD in girls and women."
- "At that time, the ratio of boys-to-girls with ADHD presenting for services was between 5:1 and 10:1 (American Psychiatric Association, 1994), thus leading to the erroneous assumption that ADHD in girls is rare."
- "The primary take-home message from these BGALS findings is that during childhood, adolescence, and young adulthood, in almost every psychosocial and neuropsychological domain we investigated, females with ADHD show sizable disadvantages and deficits relative to females without ADHD."

- "The sheer range of negative outcomes is noteworthy. Our findings affirm the public health significance of ADHD in girls, given the likelihood of persisting symptoms and (especially) impairment in crucial domains."
- "Impairments among girls and women with ADHD were particularly salient in the BGALS when outcomes were reported by parents or teachers and were less likely when self-reported."
- "Contrary to these expectations, adults with ADHD continued to under-report their symptoms. Parent-reported symptomatology, on the other hand, remained higher than self-reports and correlated well with functional impairments."

CRITIQUE OF CURRENT ASSESSMENT & RESEARCH PRACTICES

Historical Neglect and Sampling Bias

The study was founded on the principle that research on ADHD was fundamentally flawed due to its near-exclusive focus on males.

- "The project was proposed against a backdrop of a long, uphill battle that had been fought (and, indeed, is still being fought) for clinical and research recognition of the presence and impact of ADHD in females."
- "At the time of the initial BGALS grant proposal, exceedingly few girls with ADHD had been investigated via multimethod and multi-informant research protocols, much less followed longitudinally for the purpose of understanding their developmental trajectories."
- "One key reason was that most ADHD researchers typically recruited clinically referred participants. At that time, the ratio of boys-to-girls with ADHD presenting for services was between 5:1 and 10:1... thus leading to the erroneous assumption that ADHD in girls is rare."
- "Additional important features of the BGALS were its ethnic mix (most of the participants with ADHD up to that point had been Caucasian) and its nonreliance on exclusively clinically referred participants."

The Unreliability of Self-Report in Assessment

A consistent finding across the study's multiple follow-ups is the significant under-reporting of symptoms and impairment by girls and women with ADHD themselves, highlighting the danger of relying on self-report questionnaires for diagnosis.

- "Due to the well-established under-reporting of symptoms and impairment by children with ADHD (Owens et al., 2007), the PALS always has included additional informant reports of functioning."
- "Girls with childhood ADHD self-reported lower academic and social competence and higher levels of eating disorder and depressive symptoms at W2, but their self-reported substance use, delinquent behavior, and number of delinquent peers were equivalent to reports from the comparison girls."
- "Relatedly, if we had used youth-report on the DISC-IV to diagnose ADHD during young adulthood, only about one fifth of the girls originally diagnosed with ADHD would have

retained that diagnosis, in comparison with the well over half who did when based primarily on parent-report on the DISC IV."

- "Contrary to these expectations, adults with ADHD continued to under-report their symptoms. Parent-reported symptomatology, on the other hand, remained higher than self-reports and correlated well with functional impairments."
- "This has important implications for clinical decisions such that the under-reporting of symptoms by adults with ADHD must be considered while making diagnostic and treatment decisions. Moreover, there may be a need for additional observer evidence to determine true functioning levels."

METHODOLOGY DESCRIPTIONS (BGALS)

A Multi-Method, Multi-Informant Assessment Protocol

The BGALS study design serves as a model for a comprehensive assessment that goes far beyond simple checklists, aligning with the principles of a thorough clinical evaluation.

- **Longitudinal Design:** Data was collected at Wave 1 (childhood, ages 6-12), Wave 2 (adolescence, ages 11-18), and Wave 3 (young adulthood, ages 17-24).
- **Multi-Gated Screening:** The study used a rigorous process to identify participants, starting with over 1,200 initial callers and using phone screens, parent/teacher rating scales (SNAP-IV, CBCL/TRF), and finally a full diagnostic evaluation with the DISC-IV interview and WISC-III IQ test.
- **Multiple Informants:** Data was collected from parents (primary and secondary caregivers), teachers, peers, observers, and the participants themselves.
- **Naturalistic Observation:** An intensive 5-week summer research program was used at baseline to "allow collection of naturalistic, ecologically valid data from observers and peers regarding the behavioral and social functioning," including peer sociometrics and daily behavior observations. Staff were blind to participants' diagnostic status.
- **Comprehensive Domains:** Assessment covered 11 primary domains: demographics, ADHD diagnosis/symptoms, externalizing problems, internalizing problems, global impairment, neuropsychological performance, school achievement, well-being, peer relations, service utilization, and parenting.

POPULATION-SPECIFIC FINDINGS (FEMALES WITH ADHD)

Persistence of ADHD into Adulthood

- "Overall, of those with childhood ADHD who were followed up during adolescence, 69% continued to meet DSM-IV diagnostic criteria for some form of ADHD."
- Using DSM-IV criteria, 58% of girls with childhood ADHD retained the diagnosis in young adulthood.

- Using updated DSM-5 criteria (requiring 5 symptoms instead of 6), **76.6%** of those with a childhood diagnosis retained the diagnosis during young adulthood.

Severe Impairments Across the Lifespan

- **Childhood (Wave 1):** Girls with ADHD showed significant impairments with medium-to-very-large effect sizes, including psychiatric comorbidities, lower cognitive performance (though still in the average range), and noteworthy peer rejection.
- **Adolescence (Wave 2):** "girls with childhood-diagnosed ADHD continued to show greater psychiatric symptomatology across multiple domains... and larger functional impairments... than did comparison girls".
- **Young Adulthood (Wave 3):** "Across most domains during young adulthood, girls with Wave 1 ADHD diagnoses were significantly more symptomatic and impaired than the comparison group, with effect sizes ranging from medium to very large."

Alarming Rates of Self-Harm and Suicidality

This is a key finding, distinguishing the female ADHD experience and highlighting the life-threatening stakes of under-diagnosis.

- "Significant ADHD-C versus ADHD-I differences at W3 were rarely found, with the important exception of self-injury and suicide attempts, which predominated in the childhood-diagnosed combined type."
- **Suicide Attempts:** Reported by **22%** of girls with childhood ADHD-Combined type, versus 8% of girls with ADHD-Inattentive type and 6% of comparison girls.
- **Nonsuicidal Self-Injury (NSSI):** Over half (**51%**) of the girls with ADHD-Combined type had engaged in moderate to severe levels of NSSI, significantly higher than the ADHD-Inattentive subgroup (29%) or the comparison girls (19%).
- **Mediators:** Adolescent internalizing problems mediated the link between childhood ADHD and later suicide attempts, while adolescent externalizing problems mediated the link to NSSI. Maltreatment was also a major predictor.

ADHD Subtype Differences

While the two ADHD presentations (Combined and Inattentive) were largely similar in outcomes, the Combined type was associated with more severe externalizing issues.

- "Inattentive versus comparison subtype contrasts were not commonly significant."
- Key distinctions for the ADHD-Combined group included "higher rates of previous maltreatment, summer-program peer rejection, and rates and levels of comorbid externalizing problems".
- "The key subtype distinctions were higher rates of externalizing and peer problems during childhood and adolescence, and higher rates of self-harm during young adulthood, among those with ADHD-C compared with those with ADHD-I."