

# Measurement Informed Care in Attention-Deficit/Hyperactivity Disorder (ADHD)



Margaret Danielle Weiss, MD PhD<sup>a,\*</sup>, Mark A. Stein, PhD<sup>b</sup>

## KEYWORDS

- ADHD • Measurement • Outcome • Scales • Symptoms • Function • Improvement • Remission

## KEY POINTS

- Best practice in management of ADHD requires measurement informed care with standardized rating scales.
- Outcome in ADHD must capture core ADHD symptoms, comorbid conditions, and associated impairments.
- An evaluation of functional impairment is essential to establish targeted interventions and to identify continued difficulty despite ADHD symptom response.
- Optimal treatment goes beyond improvement to remission of both symptoms and symptom-driven functional impairment.
- Outcome in ADHD is dynamic and fluctuates with the patient's current challenges. Repeated use of a systematic assessment battery over time identifies those environmental challenges and patient strengths that may be critical to long-term outcome.

## INTRODUCTION

A landmark in this history of our understanding of optimizing outcome in ADHD was the MTA finding that expert medication management was superior to community-based care. The take-home message of this finding was that systematic evaluation, gathering of collateral information, individualized and systematic titration, and careful follow-up were critical to optimizing drug outcome. Measurement informed care (MIC) is now a cornerstone of both shared decision-making and evidence-based practice. This article reviews current best practice in use of diagnostic interviews and rating scales in assessment and follow-up evaluation. This includes MIC for diagnostic evaluation, broad-based symptom screening, diagnosis-specific symptom screening, and

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<sup>a</sup> Department of Child Psychiatry, Cambridge Health Alliance, 1493 Cambridge Street, Cambridge, MA 02139, USA; <sup>b</sup> Departments of Psychiatry and Behavioral Sciences, and Pediatrics, University of Washington School of Medicine, 1959 NE Pacific Street, Box 356560, Seattle, WA 98195-6560, USA

\* Corresponding author.

E-mail address: [Margaret.weiss@icloud.com](mailto:Margaret.weiss@icloud.com)

Child Adolesc Psychiatr Clin N Am 31 (2022) 363–372

<https://doi.org/10.1016/j.chc.2022.03.010>

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assessment of health quality outcomes such as functional impairment. MIS is also always personalized to address-specific, patient-targeted challenges such as executive function or emotional dysregulation.

## ADHD INTERVIEWS

The cornerstone of assessment is the clinical interview. Several structured interview tools specific to ADHD have been developed to assist clinicians in conducting and documenting a diagnostic evaluation. These interviews provide clinicians with a structured format to assure that they cover the most salient aspects of a psychiatric interview in general, as well screening for issues specific to an ADHD evaluation of comorbid conditions, the developmental history and family history, the severity of symptoms, and patient examples and screening for the presence of symptoms in childhood or earlier in life.

The first such diagnostic interview to come to prominent attention was the Conners' Adult ADHD Diagnostic Interview for DSM-IV (<https://storefront.mhs.com/collections/caadid>).

The Diagnostic Interview for ADHD in Adults (DIVA) ([www.divacenter.eu](http://www.divacenter.eu)) has now been translated into more than 25 languages and has greatly facilitated clinician acceptance and comfort with diagnostic assessment for ADHD.<sup>1</sup> DIVA-5<sup>2</sup> asks about the presence of ADHD symptoms in adulthood as well as childhood, the chronicity of these symptoms, and significant lifetime impairments due to these symptoms. DIVA-5 has been adjusted for children age 5 to 17 (Young DIVA-5) and for people with intellectual disability (DIVA-5-ID). The DIVA can be downloaded for a fee to offset the cost of development. The interview can be scored for DSM-5 diagnoses.

The ADHD Child Evaluation (ACE) and the adult version (ACE +) are comprehensive interviews in the public domain (<https://www.psychology-services.uk.com/ACE-and-ACE-plus/>). These interviews have been translated into 22 languages, and online training is available to support their use. The interviews include a guide to scoring per DSM-5 and ICD-10.

The ACE rating scales are preassessment tools that can be completed in advance of the ACE clinical interview, with either self-report or informant report. The scales differ from other rating scales because the rater is asked to provide specific examples of how each endorsed symptom impacts on the person's behavior when they were (a) a child (by the age of 12 years old) and/or (b) in the last 6 months (the self-report version only enquires about behavior over the last 6 months). With the addition of this qualitative information, the scales are useful tools to gain preassessment and follow-up information on the person's functioning across settings.

## BROAD-BASED SYMPTOM SCREENING

Most patients with ADHD present with comorbid diagnoses that may drive outcome as much as the core symptoms of ADHD. This is particularly true in tertiary referral settings. An evaluation of symptoms requires systematic empirical assessment for multiple conditions to establish the most prominent or treatable disorder, the comorbid diagnoses, and differential diagnosis before establishing targeted treatment for one condition.

Although this seems self-evident, broad based symptom screening is not always routine practice. This is most evident in looking at some key Web sites, which provide clinicians with assessment tools such as the AACAP Toolbox for Clinical Practice and Outcomes ([https://www.aacap.org/AACAP/Member\\_Resources/AACAP\\_Toolbox\\_for\\_Clinical\\_Practice\\_and\\_Outcomes/Home.aspx](https://www.aacap.org/AACAP/Member_Resources/AACAP_Toolbox_for_Clinical_Practice_and_Outcomes/Home.aspx)) or the NIH Toolbox (<https://www>.

[healthmeasures.net/explore-measurement-systems/nih-toolbox/obtain-and-administer-measures](https://healthmeasures.net/explore-measurement-systems/nih-toolbox/obtain-and-administer-measures)), neither of which include a broad-based diagnostic symptom screen. The systematic clinical use of a broad based symptom measure to augment the assessment interview would significantly improve the identification of disorders that would otherwise be missed, assist in differential diagnosis and a primary diagnosis.

The Strengths and Difficulties Questionnaire (SDQ) ([www.sdqinfo.org](http://www.sdqinfo.org)) is the most widely used broad-based screening tool. The SDQ is remarkable in its scope and design. The advantages of the SDQ include:

- Validation and widespread use in clinical, population, and research settings.
- Extensive population norms from different geographic regions that include age and gender norms.
- Availability of comparative forms for self-report and collateral including parents and teachers.
- An ‘impact’ module to look at the impact of symptoms.
- Translation into more than 75 languages.
- Use in more than 5000 publications and more than 100 countries in a wide range of studies.
- Short, easy to use and patient friendly.
- Five key domain outcomes of clinical interest are emotional problems, conduct problems, hyperactivity, peer problems, and a positive prosocial scale. The hyperactive domain consists of two attention items, two hyperactive items, and one impulsive item.
- Electronic or paper scoring.

There are several, commercially available broad-based scales that provide both dimensional ratings of various domains and DSM-5 screening. These are also age and gender normed and available in paper and pencil format and electronically, with online assessment able to provide both scoring and a report. Different forms for these measures have also been developed for different ages and informants. Some of the best known such measures are the Behavior Assessment System for Children (up to age 21 years),<sup>3</sup> the Achenbach (<https://aseba.org>), and the Conners (<https://mhs.com/info/conners3>).

The American Psychiatric Association now offers ‘emerging’ measures designed to address the need for broad-based DSM-5 screening (<https://www.psychiatry.org/psychiatrists/practice/dsm/educational-resources/assessment-measures>): one for children (The DSM-5 Parent/Guardian-Rated Level 1 Cross-Cutting Symptom Measure—Child Age 6–17) and another for adults (DSM-5 Self-Rated Level 1 Cross-Cutting Symptom Measure—Adult). These tools screen for depression, anger, irritability, mania, anxiety, somatic symptoms, inattention, suicidal ideation/attempt, psychosis, sleep disturbance, repetitive thoughts and behaviors, and substance use. These scales are limited by the absence of large psychometric validation studies, age and gender norms, translations, and difficulty of scoring and interpretation. Similar limitations apply to the Weiss Symptom Record–II (WSR-II) developed in Canada over the last 15 years (<https://www.caddra.ca/wp-content/uploads/WSR-II.pdf>). The WSR-II group items by diagnostic domain with a built in calculator are simplifying the clinicians’ ability to immediately compare and contrast the severity of different disorders.

A revolution in broad-based assessment occurred with the development of computerized adaptive testing (CAT). It may be said that one of the reasons for the sluggish growth of broad-based screening is that to cover every possible condition for every individual, measures were both lengthy and contained an excess of

items that were irrelevant. Adaptive testing is the personalized medicine of rating scales.

CAT uses artificial intelligence, so that as the subject answers questions, the test selects from a large data bank of questions those items that are most relevant to that patient. As a result, a full assessment for a wide variety of conditions can be completed in minutes with a much higher level of detail and accuracy for the areas that relevant for that individual. Increasing the relevance of items also increases the subject's interest, motivation, and completion.<sup>4</sup>

Since CAT responses can be stored electronically, it becomes possible to collect a large amount of information that can contribute to population norming, validation and evaluation of sensitivity, and specificity of outcomes against clinical diagnostic assessment. Limitations of adaptive testing may be cost and need for a digital interface. Several private adaptive testing companies such as Adaptive Testing Technologies (<https://adaptivetestingtechnologies.com/team>) and Assessment Systems Corporation (<https://assess.com/about-assessment-systems>) continue to pioneer these methods globally and in many large behavioral health systems.

The Patient-Reported Outcomes Measurement Information Systems (PROMIS) program has evolved over the last 10 years to generate a well-organized and effective assessment system in clinical research in a wide variety of chronic diseases. The second phase of PROMIS studies (PROMIS II), funded from 2009 to 2014, incorporated novel features that included longitudinal analyses and more sociodemographically diverse samples. PROMIS includes broad-based, quality of life, and targeted assessments as well as adaptive testing.

Whether a clinician elects to use an older and simpler broad-based screening tool such as the SDQ, an electronic measure or to invest in adaptive testing, an initial broad-based screening improves the accuracy and efficiency of an initial assessment.

## TARGETED ADHD SYMPTOM ASSESSMENT

The broad-based screening tools described above will include some type of assessment of attention and disruptive behavior, but once this has been identified as a target of intervention a measure specific to ADHD with or without disruptive behavior is needed to assess severity and to allow easy, sequential administration to track change over time. ADHD outcome measures exist in the public domain, for purchase with age and gender norms, on paper, and electronically.

ADHD diagnosis in adults presents the unique challenge of demonstrating the presence of ADHD in childhood. The Wender Utah Rating Scale (WURS) has demonstrated good sensitivity and specificity as a measure that can increase the reliability of a retrospective childhood diagnosis<sup>5,6</sup> Notably, the WURS expands on DSM symptom lists and includes broader symptom clusters.

Ideally, a targeted follow-up outcome measure should include the ability to generate a comparison with pretreatment baseline. Treatment outcome measures should be evaluated to determine a psychometrically validated standard for the minimally important clinical difference (MICD). There are various ways to do this, such as patient report of a visible difference or a psychometric standard of  $\frac{1}{2}$  SD.<sup>7</sup>

The MICD can be used to define the percent of patients who have 'improved.' Improvement is an evaluation of change. Equally important is determining whether the patient is 'well' or in 'remission' at end point. A patient who is severely ill may improve significantly and still be severely ill. By contrast, for a patient who has mild difficulties only slight degree of improvement may result in an end score that meets the criteria for remission.

For many disorders such as depression,<sup>8</sup> remission is predictive of a better outcome. For ADHD, this is more complex, and a status of 'remission' may change over time as the balance between symptom control and shifts in environmental supports and demands.<sup>9</sup> The classical definition of remission in ADHD is a mean score of 1 or less on any measure based on a 4-point Likert-type scale of the 18 items of ADHD.<sup>10</sup> Improvement in functioning can also be defined as meeting the threshold for a 40% decrease in functional impairment or a change consistent with the MICD. Alternatively, functional remission can be understood as any patient who falls below the receiver operating characteristic (ROC) cutoff that distinguishes the clinical population from the normative population.<sup>11</sup>

Two of the earliest and most commonly used ADHD symptom outcome measures are the Swanson, Nolan and Pelham (SNAP) and the National Institute for Children's Health Quality Vanderbilt forms (<https://www.aap.org/en/publications/caring-for-children-with-adhd-2nd-ed/adhd2/>). These measures were developed for children and youth. The advantage of these measures is that they are free, short, and the SNAP is one of the few measures in the public domain that has norms.<sup>12</sup> This is particularly important in ADHD where there are such wide discrepancies between age and genders: a level of hyperactive behavior that is appropriate for a male toddler would be a clinical concern in a female adolescent. One of the important and often unrecognized limitations in how these measures are used in clinical practice is that they are scored categorically, with ratings or often or very often for more than 6/9 items being considered 'diagnostic.' The wide disparity in the cutoff between what is normative or at risk when one evaluates age and gender norms means that categorical use of scales as positive or negative for 6/9 items or either domain will lead systematic over and under identification of ADHD.

Like the SDQ, the SNAP has been translated into many languages and used in many studies. Both SNAP and Vanderbilt also attempt to capture to a limited degree the most common and concerning aspects of comorbidity, such as opposition or conduct externalizing symptoms (SNAP) and depressive or anxiety internalizing symptoms (Vanderbilt). These forms are widely available as PDF files for printing or online self-scoring electronic platforms. Electronic, self-scoring measures in the public domain are particularly useful in telehealth settings where there is no direct access to giving the patient a form. The clinician can send the link to such a scale in the virtual chat and then 'share screen' to review the results in a future meeting.

In 2012, Swanson and colleagues recognized that using statistical cutoffs in a population in which scores are highly skewed toward pathology was problematic. He created the Strengths and Weaknesses of ADHD Symptoms and Normal Behavior Rating Scale (SWAN), so that the measure might be informative of both skills and deficits. The SWAN consists of 30 items measuring the full range of behavior, instead of only the pathologic signs and symptoms of ADHD. The psychometric properties of the scale have been demonstrated to be excellent.<sup>13,14</sup> The paradigm shift from the SNAP, which is pathology oriented to the dimensional approach of the SWAN, supports the clinician who wishes to take a strength-based approach to treatment.

The World Health Organization developed, normed, and validated a measure of ADHD in adults, the Adult Self-Report Rating Scale (ASRS) for use in the National Comorbidity Survey. This is available free of charge in more than 20 languages (<https://www.hcp.med.harvard.edu/ncs/asrs.php>). This work has had a major impact in improving access and care for ADHD in adults and providing an international standard for measurement of severity and population screening. The ASRS consists of 6 quick screening questions, which are also used to establish the sensitivity/specificity of the scoring paradigm. The other core symptoms of ADHD are included in Part B for clinical reference. The format

of the ASRS does not group symptoms by inattentive/hyperactive-impulsive domains making it somewhat more cumbersome to easily identify/visualize domain-specific scores.

There are several ADHD-specific scales available for purchase either electronically or in paper and pencil format. These are popular and widely used despite the cost because they offer age and gender norms, age-specific formats, informant-specific formats and provide considerably more information regarding where the individual is in the normal range, at clinical risk or above 1.5 SD from the norm. The electronic version of such measures may generate a report, which is very useful as a tool to provide students with support for a 504 or an Individual Education Plan. The Conners 3<sup>15</sup> includes a short and a long form for this purpose and is currently under revision for a fourth edition. The Conners 4 will be released Fall 2021.

## FUNCTIONAL OUTCOME

Diagnostic evaluation is a reflection of the clinician perspective: “What disorder(s) am I treating?” The patient perspective is typically based on functional impairment: “I have a problem with...”. For example, a parent comes in complaining that her son has no friends, an adolescent girl complains her parents nag her, or a college student complains that he has partied away the semester and is now going to ‘flunk out.’ A 2012 study compared measured outcome in ADHD studies and found that 95% of studies included symptom outcomes and less than half of studies looked at quality outcomes such as functional impairment.<sup>16</sup> This is changing with growing appreciation for the importance of looking beyond core symptoms.<sup>17,18</sup>

In most of the cases, there is a strong overlap and a moderate correlation between symptoms and functioning, but the clinician is particularly interested in the way in which identified symptoms of emotional or behavior problems are driving the patient’s perceived functional impairment. From a clinical perspective, it is those instances in which symptoms and function are *not* correlated that may be of interest. If treatment leads to symptom improvement and remission but the patient-identified target or functioning has not changed, additional intervention is needed. For example, a parent may present complaining that her daughter is not doing as well in school as expected and the clinician successfully treats the child for attention deficits, but there is no improvement in academic outcome. Further assessment identifies a learning disability, which responds to an individualized education program. Without an evaluation of both symptoms and functional impairment, the patient’s difficulty would not have been addressed.

The converse is also possible. Some patients may describe significant symptoms, without complaints of functional impairment. Screening may identify that a young woman describes herself as a disruptive child and still describes residual difficulty with ADHD symptoms. However, she notes that this does not cause her any distress, impact her relationships, academic or social functioning, or cause any other difficulty that might be a concern. Her perception is that she has ‘channeled her ADHD into being more productive at work.’ Symptoms in the absence of impairment do not necessarily warrant treatment.

Early global assessment measures such as the Children’s Global Assessment Scale<sup>19</sup> have been used as a marker of severity to complement any diagnosis and included items relevant to functioning. The Brief Impairment Scale<sup>20</sup> and the Impairment Rating Scale (IRS)<sup>21</sup> have been widely used in ADHD populations as short, reliable measures of function sensitive to change with treatment. The IRS is one of the few ADHD function scales that offers a version specifically for teachers. The scale has limitations as a measure of domain-specific impairment since there are a small number of items in each domain and the scale loads as a single factor.

The Barkley Functional Impairment Scale<sup>22</sup> is an age- and gender-normed measure of function in ADHD populations. The measure provides an opportunity for standardized and systematic evaluation of how an individual is functioning as compared with peers. The BFIS looks at functioning over the last 6 months, independent of whether impairment is secondary to mental health, so that it is an excellent measure of function as a trait in ADHD populations rather than a state sensitive to brief changes driven by improvement in symptoms.

The Weiss Functional Impairment Rating Scale (WFIRS) is a parent (WFIRS-P) or self-report (WFIRS-S) survey of impairment in several distinct domains: school (learning and behavior) or work, self-concept, social, life skills, family, and high-risk activities. Identification of domain-specific scores allows the clinician to identify functional strengths and weaknesses to assist with developing targeted treatment plans for specific areas of impairment. The measure is individualized in that only items relevant to the patient are scored. Population norms for ADHD and clinical controls generated T scores, which provide estimations of clinical concern (1–1.5 SD) or ROC cutoff scores (>1.5 SD) for each domain and the total score. The WFIRS measures functional impairment *secondary* to symptoms and is highly sensitive to change, making it particularly useful as an outcome in ADHD treatment trials. The WFIRS is translated in more than 20 languages and validated in research, population, and clinical populations in 7 different countries with robust cross setting, cross informant, and cross-cultural validity.<sup>23</sup>

## MEASUREMENT INFORMED CARE WITH ADHD-RELATED DIMENSIONS OF OUTCOME

Other domains of outcome have been found to be closely related to ADHD and patient outcomes, including executive function, emotional regulation, sluggish cognitive tempo, and mind-wandering. Specific measures to evaluate these outcomes include the Behavior Rating Inventory of Executive Function,<sup>24</sup> the Barkley Deficits in Executive Function Scale,<sup>25</sup> the Sluggish Cognitive Tempo Scale,<sup>26</sup> and the Mind Wandering Scale.<sup>27</sup> These scales are clinically relevant in providing a personalized assessment where these concerns are central in the patient's presentation and have also enabled research into the relationship between each of these domains and ADHD as a diagnosis.

Two ADHD symptom scales are particularly popular in that they give greater prominence to some of these important areas of disability critical to understanding the ADHD patient. The Wender Rheimherr<sup>28,29</sup> is a broad-based symptom rating scale that reflects the important role Paul Wender originally placed on emotional dysregulation as a core construct in ADHD. Tom Brown has conceptualized a model of ADHD with six domains: activation, focus, effort, emotion, memory, and action, which are in turn captured in the Brown scales for measurement of ADHD.<sup>30</sup> Historically, these were some of the earliest broad-based measures for clinical assessment of ADHD, which have now taken on new interest as the field has embraced moving beyond the core 18 symptoms to embrace the breadth of difficulties experienced by patients with ADHD.

## SUMMARY

MIC is an essential component of best practice. This includes use of appropriate diagnostic interviews and rating scales in

- Evaluation
- Establishing a childhood history in adults

- Differential diagnosis and identification of comorbid conditions
- Obtaining collateral information from different informants and settings
- Improvement and remission of ADHD symptoms
- Improvement and remission of functional impairment secondary to symptoms
- Identification of strengths and weakness in particular domains of functional impairment
- Identification of deficits in associated domains such as executive function, emotional dysregulation, sluggish cognitive tempo, and mind-wandering

In all these areas, MIC is critical to the therapeutic alliance, patient education, efficiency and accuracy of evaluation, documentation of results, and establishment of treatment response. This review has identified some of the strengths and weakness of the tools available to assist ADHD clinicians in each of these areas. Clinicians have access to psychometrically validated, user-friendly tools to assist with all aspects of ADHD care. This has been a remarkable clinical and research achievement, which has historically done a great deal to establish confidence in the diagnosis and global access to the best standard of care.

### CLINICS CARE POINTS

- ADHD-specific assessment with a child or adult begins with a diagnostic interview.
- Baseline assessment should include screening for a broad range of comorbid conditions, in addition to targeted diagnosis-specific symptom severity scales.
- Measurement of functional impairment is critical; typically, this is the chief complaint.
- MIC is the key to patient understanding of the diagnosis, shared decision-making, psychoeducation, and global initiatives to establish core global standards for clinical care, training, and research.
- Outcome measures allows the clinician to push beyond improvement in core symptoms to achieving optimal functioning and symptom remission.
- Evaluations are needed pre and post treatment, following major life changes, and at least annually to assure continued response and need for additional interventions.
- Clinicians are now able to access associated deficits such as emotional regulation and executive function, which has enriched the depth of our understanding of the patient experience and our ability to establish personalized care for their unique challenges.

### DISCLOSURE

M.D. Weiss has received consulting fees/honoraria from Tris, Purdue, Adlon, Takeda, Huron, Mundipharma, MHS Assessment, Rhodes, CBPartners and Idorsia; support for travel to meetings, manuscript preparation, or other purposes from World Federation of ADHD, Eunethydis, Canadian Attention Deficit Disorder Resource Alliance (CADDRA), Children and Adults with Attention Deficit Disorder (CHADD), American Professional Society for ADHD and Related Disorders (APSARD), Israeli Federation of ADHD, Purdue CA, Purdue US, Rhodes Pharmaceutical, Akili. Takeda, Global Medical Education, and Boston Children's Hospital; payment for lectures from Global Medical Education, Center for ADHD Awareness Canada (CADDAC), and CADDRA; and has received royalties from Multi Health Systems, Johns Hopkins University Press.



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