DOI: 10.1111/dmcn.15865

#### ORIGINAL ARTICLE

## Assessment of functioning in ADHD according to World Health Organization standards: First revision of the International Classification of Functioning, Disability and Health Core Sets

Sven Bölte <sup>1,2,3</sup>	Lovisa Alehagen <sup>1</sup>   Melissa H. Black <sup>1</sup>   John Hasslinger <sup>1,2</sup>
Elina Wessman <sup>1,2</sup>	Karl Lundin Remnélius <sup>1</sup>   Peter B. Marschik <sup>1,4,5</sup> 💿   Emily D'arcy <sup>3</sup> 💿
Andreas Seidel <sup>6</sup>	Sonya Girdler <sup>1,3</sup>   Eric Zander <sup>1</sup>

<sup>1</sup>Center of Neurodevelopmental Disorders, Department of Women's and Children's Health, Centre for Psychiatry Research, Karolinska Institutet & Region Stockholm, Stockholm, Sweden

<sup>2</sup>Child and Adolescent Psychiatry, Stockholm Health Care Services, Region Stockholm, Stockholm, Sweden

<sup>3</sup>Curtin Autism Research Group, Curtin School of Allied Health, Curtin University, Perth, Western Australia, Australia

<sup>4</sup>Department of Child and Adolescent Psychiatry and Psychotherapy, University Medical Center Göttingen and Leibniz Science Campus Primate Cognition, Göttingen, Germany

<sup>5</sup>Interdisciplinary Developmental Neuroscience, Division of Phoniatrics, Medical University of Graz, Austria

<sup>6</sup>Department of Economics and Social Sciences, University of Applied Sciences Nordhausen, Nordhausen, Germany

#### Correspondence

Sven Bölte, Center for Neurodevelopmental Disorders at Karolinska Institutet, Center for Psychiatry Research, Department of Women's and Children's Health, Child and Adolescent Psychiatry Stockholm, Gävlegatan 22 (Entré B), Floor 8, SE-11330 Stockholm, Sweden. Email: sven.bolte@ki.se

#### **Funding information**

Trygg-Hansas Forskningsstiftelse; Forskningsrådet om Hälsa, Arbetsliv och Välfärd; Stiftelsen Sunnerdahls Handikappfond; Stiftelsen Clas Groschinskys Minnesfond; Stiftelsen Promobilia

#### Abstract

**Aim:** To conduct the first revision of the World Health Organization International Classification of Functioning, Disability and Health (ICF) Core Sets for attention-deficit/hyperactivity disorder (ADHD).

**Method:** A Delphi-like method was used, integrating evidence from stakeholder feedback and developing and piloting the ADHD ICF Core Set platform to inform revisions to the ADHD Core Sets.

**Results:** A total of 27 second-level ICF codes were added to the comprehensive ADHD Core Set: body functions of temperament and personality, and basic sensory functions; activities and participation in terms of learning to read and write, spoken communication, community life, religion and spirituality, education, economy, and human rights; environmental factors for domestic animals; and several societal services. The revised comprehensive Core Set contains 98 ICF codes: 18 body function codes; 47 activities and participation codes; and 33 environmental factor codes. Extensive changes were also made to the age-appropriate brief Core Sets to allow their independent use in research and clinical practice.

**Interpretation:** Although substantially expanded, the revised ICF Core Sets better reflect the lived experience of individuals with ADHD and clinical implementation preferences than the initial sets. We recommend further feasibility and validation studies of these Core Sets with the goal of optimizing their acceptance and practicability, and strengthening their evidence base.

 ${\bf Abbreviations:} ICF, International Classification of Functioning, Disability and Health; WHO, World Health Organization.$ 

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made. © 2024 The Authors. *Developmental Medicine & Child Neurology* published by John Wiley & Sons Ltd on behalf of Mac Keith Press.

Check for updates

Attention-deficit/hyperactivity disorder (ADHD) is a common neurodevelopmental condition caused by multiple genetic and environmental factors that accumulate in several combinations.<sup>1</sup> Despite its defining symptoms of inattention, impulsivity, and hyperactivity, among other diagnostic criteria, individuals with ADHD vary widely in their functioning profiles, that is, how their activities and participation unfold from an interplay between their individual characteristics and their environment. The biopsychosocial framework of the International Classification of Functioning, Disability and Health (ICF) by the World Health Organization (WHO) and the ICF Children and Youth version (ICF-CY)<sup>2,3</sup> offers a standardized system to bridge the gap between a condition (diagnosis) and how a person is living with it (functioning). The ICF conceptual framework and classification system can be used across a broad range of disciplines and sectors (e.g. health and social services, education) to support the functioning of individuals with ADHD. In clinical settings, it provides a basis for tools that holistically measure, describe, and document functioning; in research, it can be used for data collection, compilation, and analysis. Use of the ICF is also beneficial at a societal level where it can guide social policy and legislation.<sup>2,4,5</sup>

The ICF-CY contains codes for both childhood and adulthood, operationalizing functioning using 1685 codes organized hierarchically across four levels to evaluate an individual's body structures (n = 329) and functions (n = 531)(somatic and psychological prerequisites and potential), activities (what a person is doing or not doing in their life) and participation (n=552) (the person's social and societal involvement), and environment (n = 273) (the person's physical and social milieu). Use of the ICF framework is underpinned by ethical guidelines, which emphasize collaboration with individuals, valuing their lived experiences, and respecting autonomy.<sup>2,3,6</sup> Importantly, the ICF framework and its guiding ethical principles closely align with the notions of the neurodiversity paradigm and neuro-affirmative action.<sup>7</sup> However, the ICF has also been criticized for being laborious and unwieldy, failing to align with the demands of clinical practice in terms of feasibility and diagnostic fit, which hinders its implementation. In addressing these limitations, a rigorous protocol for developing ICF Core Sets for specific conditions was defined by the WHO and the ICF Research Branch.<sup>8</sup> Core Sets are shortlists of all ICF codes, mostly held on the second level of ICF code detail, seeking to enhance practicability and diagnostic compatibility for ICF use in clinical practice and research.<sup>8,9</sup> To date, official ICF Core Set development, monitored and approved by the WHO, has been concluded for about 30 diagnoses, including neurodevelopmental conditions such as cerebral palsy<sup>10</sup> and autism.<sup>11</sup>

The official initial ICF Core Sets for ADHD were adopted in 2016 and published in 2018,<sup>12</sup> after completion of the WHO and ICF Research Branch protocol, consisting of a systematic literature review, an international expert survey, a qualitative and clinical study, and a consensus conference.<sup>13–16</sup> A comprehensive, a common brief, and three age-appropriate brief ICF ADHD Core Sets were developed.

#### What this paper adds

- The revised Core Sets integrate feedback from stakeholders and the lived experience of individuals with attention-deficit/hyperactivity disorder (ADHD).
- Body function, activity and participation, and environmental codes better reflect the functioning of individuals with ADHD.
- Age-appropriate brief Core Sets were modified to enable their independent use in research and clinical practice.

A comprehensive Core Set should include all codes necessary to describe the functioning of individuals with specific conditions across their entire lifespan, containing as few codes as possible to do so. A common brief Core Set is a shorter selection of ICF codes derived from the comprehensive ICF Core Set, containing only the most significant codes for the condition. Three age-appropriate brief Core Sets (preschool, 0-5 years; school-age, 6-16 years; older adolescent and adult, ≥17 years) were also viewed as essential to maximize accessibility and the utility of the ICF ADHD Core Sets for given paediatric, adolescent, and adult settings. Use of the 17 years or older age range was a consensus decision made by the international Core Set development Steering Committee composed of representatives from all WHO regions in order to better comply with worldwide practice. While 18 years or older might be a standard age in the Global North, it is not in the Global South, and even in the Global North adolescent ages are characterized by increasing societal rights and duties. The development yielded 72 ICF codes in the comprehensive Core Set for ADHD: eight body functions; 35 activities and participation; and 29 environmental factors. The common brief Core Set consisted of 38 codes, while the age-appropriate Core Sets included 47 codes in the preschool version, 55 in the school-age version, and 52 in the older adolescent and adult version.

The WHO and ICF Research Branch protocol for initial Core Set development requires that Core Sets be scientifically validated in clinical practice and continuous implementation of user experiences.<sup>17,18</sup> This is an ongoing and prospective process where empirical studies, shifts in diagnostic concepts, and stakeholder feedback will probably indicate the necessary revisions. Regarding the ADHD Core Sets, there has been rapid development in research and clinical practice related to individuals with ADHD. While previously conceptualized exclusively from biological perspectives, neurodevelopmental conditions are now increasingly also viewed through a lens of neurodiversity, recognizing environmental influences on functioning and disability, and the importance of lived experiences. Given these rapid conceptual shifts, revision of the ICF Core Sets was deemed necessary. Compared to the initial Core Set development, there is no

criterion standard for optimizing and updating this continuous iterative phase of the ICF Core Sets. In this article, we present the necessary changes to and provide the first revision of the initial ICF Core Sets for individuals with ADHD for clinical and research purposes.

## METHOD

#### Design

Ethical approval was obtained from the Swedish Ethical Review Authority. Because the WHO and ICF Research Branch provide limited guidance on the procedure for updating Core Sets, evidence from stakeholder feedback and a pilot study of the ADHD ICF Core Set platform was integrated using a Delphi-like method to generate the first revision of the initial ICF ADHD Core Sets. These sources provided qualitative and quantitative information on potentially missing or superfluous ICF codes in the initial Core Sets as perceived by individuals with ADHD, their caregivers and other community members.

The Delphi method is a structured but flexible iterative communication technique that relies on the opinions and feedback of a group of experts to achieve scientific decisionmaking.<sup>19</sup> Our study's prerequisites had limited degrees of freedom for a typical classical Delphi process in terms of voting procedure and expert group member composition. This was owing to the a priori restricted number of possibly qualified Delphi-group members, and the focus on a particular task, where specified novel evidence was used to update a given set of items (ICF codes in the initial ADHD Core Sets). Thus, our design is more adequately described as Delphi-like using 'bricolage'.<sup>20</sup> Herein, different, mostly qualitative, analytical moves are combined as plausible and as aligning with the study objective. Such a strategy aligns with recommendations for expedient Delphi method modifications.<sup>21</sup> The Delphi-like expert panel for this study had 10 members (all authors) who were selected based on their combined experience in ADHD or the ICF, their involvement in ongoing studies applying the ADHD Core Sets, and their experience in implementing the ICF. Experts were men (n = 5) and women (n = 5) from two WHO regions (European and Western Pacific), and four high-income countries (Australia, Austria, Germany, and Sweden), representing four professions (physician, psychologist, occupational therapist, linguist). The professional experience of group members varied. Experts had between 2 and 27 years of experience in ADHD research or 2 and 27 years in clinical practice, and 1 to 15 years of experience with the ICF. Over a 4-year period (May 2019-April 2023), an open iterative process was undertaken, whereby the first author (SB) facilitated discussions within subgroups of the expert panel. The Delphi-like method was guided and driven by evidence from stakeholder feedback, and qualitative data from the development and pilot studies of the ADHD ICF Core Sets platform. Five experts (SB, EZ, EW, LA, JH) who

had been more extensively involved in the revision process for a longer period engaged in consensus discussions to make final decisions about adding or removing ICF codes from the initial ADHD Core Sets. Within consensus discussions, experts considered the new evidence from the stakeholder feedback and ADHD Core Set platform pilot study in relation to the previous four preparatory studies<sup>13-16</sup> and relevant ADHD research. Deliberations focused on (1) determining whether the content identified for inclusion belonged to the ICF universe (i.e. whether it could be assigned an ICF code), (2) if an existing code already encompassed content, and (3) the consequences of adding and removing codes. At the conclusion of this open iterative process, agreement regarding the inclusion and exclusion of codes was unanimous (100%).

## Stakeholder feedback

While the initial version of the ICF Core Sets for ADHD were based on preparatory studies that sought to capture the perspectives of individuals with ADHD and their families, community stakeholders had limited opportunity to input directly into the final selection of codes in the initial Core Sets. After the publication of the initial Core Sets, community stakeholders, including individuals with ADHD, their families, and interested organizations, provided comprehensive feedback on the content of Core Sets to members of the expert group, especially the lead author. Feedback was received via personal communication, social media comments (X [formerly Twitter], Facebook), through faceto-face discussions at scientific meetings and community events (especially after presentations of the Core Sets), via e-mail, and during scheduled meetings with stakeholders in different contexts. This informal process of collecting feedback ensured that there was a low threshold for contributing, where all forms of feedback were considered valuable. It also enabled feedback to be provided through multiple contemporary channels through which community members commonly make their voices heard (e.g. social media). All stakeholder feedback received by the expert group was recorded and integrated into the Delphi-like process, where expert group members discussed the feedback and considered its appropriateness and significance in informing possible ICF code revisions.

#### Development and pilot studies of the ADHD ICF Core Set platform

To enhance the application of the initial Core Sets for ADHD in practice, Core Sets were operationalized and implemented on a cloud-based Internet platform (https:// icfcoresets.se/). Within this platform, ICF codes are operationalized into items designed to capture both selfreport and informant report ratings of functioning. Operationalization involved developing as few items as

3

possible, but as many as necessary to capture the meaning of the code. Once all items are rated, a summary report detailing a brief functioning profile is automatically generated in real time. The English, German, and Swedish versions of the platform are currently standardized and validated using the revised Core Sets presented in this article. The phase of operationalization of ICF codes to platform items (questions for self-report and informant report) and translation of the initial Core Sets from Swedish into English and German generated multiple, sustained, and in-depth discussions about the appropriateness of existing codes. Both lack of coverage of functioning areas by the codes but particularly their fit in the age-appropriate Core Sets were evaluated. The conclusions from these discussions were integrated into the Delphi-like process. Between 2021 and 2023, using the initial Core Sets, the platform was also piloted in Sweden using a qualitative design to explore user-friendliness, the appropriateness of the operationalization of ICF codes to items, and the clarity of item wording. Moreover, quantitative data were collected to preliminary validate the Core Sets in a casecontrol design. The pilot study consisted of 208 children, adolescents, and adults, as well as 367 participants from the general population (self-report and informant report) in Sweden. Results from the pilot study of the platform are reported elsewhere in detail.<sup>22</sup> Information relevant to the revisions of the initial ICF Core Sets for ADHD was extracted from this pilot study and considered by the expert group in the Delphi-like process.

## RESULTS

#### Stakeholder feedback

Table 1 provides an overview of new and removed codes in the revised ICF Core Sets for ADHD derived from stakeholder feedback. We received comments from Australia, China, Germany, Sweden, Switzerland, the Netherlands, the UK, the USA, and Turkey. A total of 29 comments and queries of various types, and of differing comprehensiveness and depth, were recorded. They came predominantly from adults with ADHD, parents of children and adolescents with ADHD, and researchers. The feedback concerned a multitude of indications of missing codes for body functions, activities and participation, and environmental factors in the initial comprehensive ADHD Core Set, as well as missing codes in the age-appropriate brief Core Sets. If deemed adequate by the expert panel in terms of being consistent with and applicable to the ICF framework, the feedback was translated into ICF codes and included in the revised comprehensive Core Set. ICF codes for the following areas were added: (1) body functions of temperament and personality, and basic sensory functions (taste, smell, touch, pain, other sensory functions); (2) activities and participation in terms of learning to read and write, spoken communication, community life, religion and spirituality, and human rights; (3)

environmental factors for domestic animals; and (4) several societal services (e.g. housing, communication, media). Many of the ICF codes added to the comprehensive Core Set for ADHD were also added to the age-appropriate brief Core Sets, particularly to the school-age (6-16 years) and older adolescent and adult (≥17 years) Core Sets. Moreover, stakeholder feedback led to ICF codes being added to the age-appropriate Core Sets across ages that had already been part of the initial comprehensive Core Set, although not of the brief age-appropriate Core Sets. These concerned several activities and participation codes (e.g. driving, self-care) and environmental factor codes (e.g. healthcare professionals, attitudes, services, policies, systems). Stakeholder feedback also indicated removing codes, but only from the preschool set (0-5 years), for example, activity and participation codes for informal social relationships and family relationships.

#### Development and pilot studies of the ICF Core Set platform for ADHD

Table 1 summarizes the codes added or removed from the initial ICF ADHD Core Sets using evidence from the development and pilot of the ICF ADHD Core Set platform. Many discussions emerged among the researchers and clinicians involved during the operationalization of the ICF codes in the comprehensive and brief age-appropriate initial ICF ADHD Core Sets into items for self-report and informant rating. Discussions concerned the wording to exactly reflect the intended function in a broadly comprehensible way. Furthermore, the necessary number of items, logical order of the presentation of items, and the best translation of items from Swedish into English and German were debated. Several of these discussions were of relevance for the revision of the initial Core Sets for ADHD. First, there was agreement that body functions of temperament and personality, memory functions, and a range of sensory processing, as well as motor control, should be added to all age-appropriate Core Sets and thus even to the comprehensive Core Set. There was also agreement that a range of activities and participation codes for learning (reading/writing), cognition (thinking), communication, self-care, involvement in community life, human rights, and religion and spirituality should be added. Finally, platform development identified domestic animals as an important environmental functional code to be added. Second, researchers and clinicians agreed that the Core Sets would most likely be applied in clinical practice and research examining current, rather than lifetime, functioning. Thus, the age-appropriate Core Sets, specific to age and development, may hold greater clinical utility than the comprehensive Core Set. The expert group agreed that the significance of the age-appropriate Core Sets should be stressed and their contents should be elaborated. It was agreed that (1) most of the new ICF codes added to the comprehensive Core Set should also be added to the age-appropriate ones, (2) some activities and participation

TABLE 1 Overview of ICF candidate codes from each source of evidence and decision for the first ICF Core Sets for ADHD revision.

ICF candidate codes	Stakeholder feedback	Development and pilot studies of the ICF platform	Core Set versions: code added according to the Delphi-like method	Core Set versions: code removed according to the Delphi-like method
b126 Temperament and personality functions	Х	Х	C, 0–5, 6–16, ≥17	
b144 Memory functions	Х	Х	C, 0–5, 6–16, ≥17	
b164 Higher-level cognitive functions		Х		0-5
b210 Seeing functions		Х	C, 0–5, 6–16, ≥17	
b230 Hearing functions		Х	C, 0–5, 6–16, ≥17	
b250 Taste function	Х	Х	C, 0–5, 6–16, ≥17	
b255 Smell functions	Х	Х	C, 0–5, 6–16, ≥17	
b265 Touch functions	Х	Х	C, 0−5, 6−16, ≥17	
b270 Sensory functions related to temperature and other stimuli	Х		C, 0–5, 6–16, ≥17	
b280 Sensation of pain	Х	Х	C, 0−5, 6−16, ≥17	
b298 Other sensory functions	Х	Х	C, 0−5, 6−16, ≥17	
b760 Control of voluntary movement functions		Х	≥17	
d140 Learning to read	Х	Х	C, 6–16	
d145 Learning to write	Х	Х	С, 6–16	
d163 Thinking		Х	С, 6–16	
d166 Reading	Х	Х	≥17	
d175 Solving problems		Х		0-5
d177 Making decisions		Х		0-5
d220 Undertaking multiple tasks		Х		0-5
d310 Communicating with-receiving spoken messages		Х	C, 0–5, 6–16, ≥17	
d475 Driving	Х	Х	6–16	
d520 Caring for body parts	Х	Х	≥17	
d550 Eating	Х	Х	C, 0-5, 6-16	
d570 Looking after one's health	Х	Х	0-5	
d620 Acquisition of goods/services	Х	Х	≥17	
d630 Preparing meals	Х	Х	≥17	
d650 Caring for household objects	Х	Х	C,≥17	
d660 Assisting others		Х	C, 6–16, ≥17	
d750 Informal social relationships	Х	Х	≥17	0-5
d760 Family relationships	Х	Х		0-5
d815 Preschool education		Х	С, 0-5	
d860 Basic economic transactions		Х	C, ≥17	
d910 Community life	Х	Х	C, ≥17	
d930 Religion and spirituality	Х	Х	C, 6–16, ≥17	
d940 Human rights	Х	Х	C, ≥17	
e130 Products and technology for education	Х	Х	≥17	
e240 Light	Х	Х	0−5, ≥17	
e250 Sound	Х	Х	≥17	
e325 Acquaintances, peers, colleagues, neighbours, and community members	Х	Х	0−5, ≥17	
e340 Personal care providers and personal assistants		Х	6–16, ≥17	
e350 Domestic animals	Х	Х	C, 6–16, ≥17	
e360 Other professionals	Х	Х	0-5	
e420 Individual attitudes of friends		Х		0-5

#### **TABLE 1** (Continued)

ICF candidate codes	Stakeholder feedback	Development and pilot studies of the ICF platform	Core Set versions: code added according to the Delphi-like method	Core Set versions: code removed according to the Delphi-like method
e425 Individual attitudes of acquaintances, peers, colleagues, neighbours, and community members		Х	0-5, 6-16	
e440 Individual attitudes of personal care providers and personal assistants	Х	Х	6–16, ≥17	
e455 Individual attitudes of other professionals	Х	Х	0–5, 6–16, ≥17	
e525 Housing services, systems, and policies	Х	Х	C, ≥17	
e535 Communication services, systems, and policies	Х	Х	C, 6–16, ≥17	
e550 Legal services, systems, and policies	Х	Х	C, 0−5, 6−16, ≥17	
e560 Media services, systems, and policies		Х	C, 6–16, ≥17	

0-5, early childhood; 6-16, school-age; ≥17, adulthood; C, comprehensive Core Set.

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; ICF, International Classification of Functioning, Disability and Health.

codes needed to be removed from the age-appropriate sets for ages 0 to 5 years to match age, and (3) that many codes from the comprehensive Core Set needed to be added to the age-appropriate Core Sets to enable them to be used on their own (without also needing the comprehensive Core Set). Suggestions were foremost to add several activities and participation, and environment, codes to all three age-appropriate Core Sets, but particularly to the 6 to 16 years and 17 years or older Core Sets.

Evidence from stakeholders and the development of the ICF Core Set platform were corroborated by the pilot study of the ICF Core Set platform described elsewhere in detail.<sup>22</sup> The pilot study supported the addition of bodily sensory functions related to taste, smell, pain, and touch, as well as other activities and participation codes for learning to read and write, eating, household maintenance, community life, religion and spirituality, human rights, and the environmental factor of domestic animals. Pilot study participants broadly agreed with the potential usefulness of the assessment and found it feasible to complete. Caregivers completing the operationalized ageappropriate Core Sets commented on areas of functioning that they believed were missing in the Core Set, or that were included but were unnecessary to capture. In the 0 to 5 years Core Set, participants identified items for activities and participation that were deemed unnecessary and thus recommended their removal (e.g. activity and participation: family and informal and social relationships). For the adolescent and adult Core Set, adult, adolescent, and caregiver participants commented on areas of functioning that were included in the comprehensive Core Set, which they believed were important to also include in the age-appropriate Core Sets, for example, reading, driving (6-16 years), daily living codes (e.g. preparing meals, ≥17 years) for activities and participation, and many environmental factors (e.g. light, sound, immediate family, peers/neighbors/colleagues, personal care providers, healthcare professionals [all for  $\geq$ 17 years, and some for 0-5 years and 6-16 years]).

# Added and removed ICF codes after the Delphi-like procedure

Table 1 shows which ICF codes were added to or removed from the comprehensive and the age-appropriate brief ICF Core Sets for ADHD. A total of 27 ICF codes were added to the comprehensive Core Sets: 10 body functions (b126, b144, b210, b230, b250, b255, b265, b270, b280, b298), 12 activity and participation codes (d140, d145, d163, d310, d550, d650, d660, d815, d860, d910, d930, d940), and five environmental factors (e350, e525, e535, e550, e560). One environmental factor was removed (e360) because it was not deemed particularly valuable for any age group. Twenty codes were added to the 0 to 5 years Core Sets: 10 body functions (b126, b144, b210, b230, b250, b255, b265, b270, b280, b298), four activities and participation (d310, d550, d570, d815), and six environmental factors (e240, e325, e420, e425, e455, e550). We removed one body function (b164) and five activities and participation items from the 0 to 5 years Core Sets (d175, d177, d220, d750, d760). Twenty-six codes were added to the 6 to 16 years Core Set: 10 body functions (b126, b144, b210, b230, b250, b255, b265, b270, b280, b298), eight activities and participation (d140, d145, d163, d310, d475, d550, d660, d930), and eight environmental factors (e340, e350, e425, e440, e455, e535, e550, e560). Thirty-five codes were added to the 17 years or older Core Set: 11 body functions (b126, b144, b210, b230, b250, b255, b265, b270, b280, b298, b760), 12 activities and participation (d166, d310, d520, d620, d630, d650, d660, d750, d860, d910, d930, d940), and 12 environmental factors (e130, e240, e250, e325, e340, e350, e440, e455, e525, e535, e550, e560). Importantly, the common brief ICF Core Set for ADHD was not revised for the reasons discussed in the following section.

#### The revised ICF Core Sets for ADHD

The updated revised comprehensive ICF Core Set for ADHD, and the three corresponding age-appropriate Core Sets (0–5, 6–16, and  $\geq$  17 years) are shown in Tables 2 to 5. The revised

4698749, 0, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/dmcn.15865, Wiley Online Library on [07/042024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

**TABLE 2** Second-level ICF codes included in the comprehensive ICF Core Set for ADHD (*n*=98).

Code number and description	
b125 Dispositions and intrapersonal functions	d750 Informal social relationships
b126 Temperament and personality functions	d760 Family relationships
b130 Energy and drive functions	d770 Intimate relationships
b134 Sleep functions	d815 Preschool education
b140 Attention functions	d820 School education
b144 Memory functions	d825 Vocational training
b147 Psychomotor functions	d830 Higher education
b152 Emotional functions	d845 Acquiring, keeping, and terminating a job
b164 Higher-level cognitive functions	d850 Remunerative employment
b210 Seeing functions	d860 Basic economic transactions
b230 Hearing functions	d870 Economic self-sufficiency
b250 Taste function	d880 Engagement in play
b255 Smell functions	d910 Community life
b265 Touch functions	d920 Recreation and leisure
b270 Sensory functions related to temperature and other stimuli	d930 Religion and spirituality
b280 Sensation of pain	d940 Human rights
b298 Other sensory functions	e110 Products or substances for personal consumption
b760 Control of voluntary movement functions	e115 Products and technology for personal use in daily living
d140 Learning to read	e125 Products and technology for communication
d145 Learning to write	e130 Products and technology for education
d160 Focusing attention	e240 Light
d161 Directing attention	e250 Sound
d163 Thinking	e310 Immediate family
d166 Reading	e315 Extended family
d170 Writing	e320 Friends
d172 Calculating	e325 Acquaintances, peers, colleagues, neighbours, and community members
d175 Solving problems	e330 People in positions of authority
d177 Making decisions	e340 Personal care providers and personal assistants
d210 Undertaking a single task	e350 Domestic animals
d220 Undertaking multiple tasks	e355 Health professionals
d230 Carrying out daily routine	e410 Individual attitudes of immediate family members
d240 Handling stress and other psychological demands	e415 Individual attitudes of extended family members
d250 Managing one's own behaviour	e420 Individual attitudes of friends
d310 Communicating with-receiving-spoken message	e425 Individual attitudes of acquaintances, peers, colleagues, neighbours, and community members
d350 Conversation	e430 Individual attitudes of people in positions of authority
d440 Fine hand use	e440 Individual attitudes of personal care providers and personal assistants
d475 Driving	e450 Individual attitudes of health professionals
d520 Caring for body parts	e455 Individual attitudes of other professionals
d550 Eating	e460 Societal attitudes
d570 Looking after one's health	e465 Social norms, practices, and ideologies
d571 Looking after one's safety	e525 Housing services, systems, and policies
d620 Acquisition of goods and services	e535 Communication services, systems, and policies
d630 Preparing meals	e550 Legal services, systems, and policies
d640 Doing housework	e560 Media services, systems, and policies

7

(Continues)

#### TABLE 2 (Continued)

Code number and description	
d650 Caring for household objects	e570 Social security services, systems, and policies
d660 Assisting others	e575 General social support services, systems, and policies
d710 Basic interpersonal interactions	e580 Health services, systems, and policies
d720 Complex interpersonal interactions	e585 Education and training services, systems, and policies
d740 Formal relationships	e590 Labour and employment services, systems, and policies

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; ICF, International Classification of Functioning, Disability and Health.

**TABLE 3** Second-level ICF codes included in the age-appropriate ICF Core Set for ADHD (0–5 years) (*n*=61).

Code number and description	
b125 Dispositions and intrapersonal functions	d815 Preschool education
b126 Temperament and personality functions	d820 School education
b130 Energy and drive functions	d880 Engagement in play
b134 Sleep functions	d920 Recreation and leisure
b140 Attention functions	e110 Products or substances for personal consumption
b144 Memory functions	e115 Products and technology for personal use in daily living
b147 Psychomotor functions	e240 Light
b152 Emotional functions	e250 Sound
b210 Seeing functions	e310 Immediate family
b230 Hearing functions	e315 Extended family
b250 Taste function	e320 Friends
b255 Smell functions	e325 Acquaintances, peers, colleagues, neighbours, and community members
b265 Touch functions	e330 People in positions of authority
b270 Sensory functions related to temperature and other stimuli	e340 Personal care providers and personal assistants
b280 Sensation of pain	e355 Health professionals
b298 Other sensory functions	e410 Individual attitudes of immediate family members
b760 Control of voluntary movement functions	e415 Individual attitudes of extended family members
d160 Focusing attention	e420 Individual attitudes of friends
d161 Directing attention	e425 Individual attitudes of acquaintances, peers, colleagues, neighbours, and community members
d210 Undertaking a single task	e430 Individual attitudes of people in positions of authority
d230 Carrying out daily routine	e440 Individual attitudes of personal care providers and personal assistants
d240 Handling stress and other psychological demands	e450 Individual attitudes of health professionals
d250 Managing one's own behaviour	e455 Individual attitudes of other professionals
d310 Communicating with-receiving-spoken message	e460 Societal attitudes
d350 Conversation	e465 Social norms, practices, and ideologies
d440 Fine hand use	e550 Legal services, systems, and policies
d550 Eating	e570 Social security services, systems, and policies
d570 Looking after one's health	e575 General social support services, systems, and policies
d571 Looking after one's safety	e580 Health services, systems, and policies
d710 Basic interpersonal interactions	e585 Education and training services, systems, and policies
d720 Complex interpersonal interactions	

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; ICF, International Classification of Functioning, Disability and Health.

comprehensive Core Set now contains 98 second-level ICF-CY codes (5.8% of all ICF-CY codes), that is, 18 body functions, 47 activities and participation, and 33 environmental factors.

The revised 0 to 5 years age-appropriate Core Sets contain 61 ICF codes: 17 body functions, 18 activities and participations, and 26 environmental factors. The revised 6 to 16 years Core

TABLE 4 Second-level ICF codes included in the age-appropriate ICF Core Set for ADHD (6–16 years) (n=81).

Code number and description	
b125 Dispositions and intrapersonal functions	d710 Basic interpersonal interactions
b126 Temperament and personality functions	d720 Complex interpersonal interactions
b130 Energy and drive functions	d740 Formal relationships
b134 Sleep functions	d750 Informal social relationships
b140 Attention functions	d760 Family relationships
b144 Memory functions	d820 School education
b147 Psychomotor functions	d880 Engagement in play
b152 Emotional functions	d920 Recreation and leisure
b164 Higher-level cognitive functions	d930 Religion and spirituality
b210 Seeing functions	e110 Products or substances for personal consumption
b230 Hearing functions	e115 Products and technology for personal use in daily living
b250 Taste functions	e125 Products and technology for communication
b255 Smell functions	e130 Products and technology for education
b265 Touch functions	e240 Light
b270 Sensory functions related to temperature and other stimuli	e250 Sound
b280 Sensation of pain	e310 Immediate family
b298 Other sensory functions	e315 Extended family
b760 Control of voluntary movement functions	e320 Friends
d140 Learning to read	e325 Acquaintances, peers, colleagues, neighbours, and community members
d145 Learning to write	e330 People in positions of authority
d160 Focusing attention	e340 Personal care providers and personal assistants
d161 Directing attention	e350 Domestic animals
d163 Thinking	e355 Health professionals
d166 Reading	e410 Individual attitudes of immediate family members
d170 Writing	e415 Individual attitudes of extended family members
d172 Calculating	e420 Individual attitudes of friends
d175 Solving problems	e425 Individual attitudes of acquaintances, peers, colleagues, neighbours, and community members
d177 Making decisions	e430 Individual attitudes of people in positions of authority
d210 Undertaking a single task	e440 Individual attitudes of personal care providers and personal assistants
d220 Undertaking multiple tasks	e450 Individual attitudes of health professionals
d230 Carrying out daily routine	e455 Individual attitudes of other professionals
d240 Handling stress and other psychological demands	e460 Societal attitudes
d250 Managing one's own behaviour	e465 Social norms, practices, and ideologies
d310 Communicating with-receiving-spoken messages	e535 Communication services, systems, and policies
d350 Conversation	e550 Legal services, systems, and policies
d475 Driving	e560 Media services, systems, and policies
d520 Caring for body parts	e570 Social security services, systems, and policies
d550 Eating	e575 General social support services, systems, and policies
d570 Looking after one's health	e580 Health services, systems, and policies
d571 Looking after one's safety	e585 Education and training services, systems, and policies
d660 Assisting others	

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; ICF, International Classification of Functioning, Disability and Health.

Sets now include 81 ICF codes: 18 body functions, 32 activities and participation, and 31 environmental factors. Finally, the older adolescent and adult Core Sets (≥17 years), after revision,

contains 87 ICF codes, that is, 18 from body functions, 36 from activities and participation, and 33 from environmental factors.

9

**TABLE 5** Second-level ICF codes included in the age-appropriate ICF Core Set for ADHD ( $\ge$ 17 years) (*n*=87).

Code number and description	
b125 Dispositions and intrapersonal functions	d825 Vocational training
b126 Temperament and personality functions	d830 Higher education
b130 Energy and drive functions	d845 Acquiring, keeping, and terminating a job
b134 Sleep functions	d850 Remunerative employment
b140 Attention functions	d860 Basic economic transactions
b144 Memory functions	d870 Economic self-sufficiency
b147 Psychomotor functions	d910 Community life
b152 Emotional functions	d920 Recreation and leisure
b164 Higher-level cognitive functions	d930 Religion and spirituality
b210 Seeing functions	d940 Human rights
b230 Hearing functions	e110 Products or substances for personal consumption
b250 Taste function	e115 Products and technology for personal use in daily living
b255 Smell functions	e125 Products and technology for communication
b265 Touch functions	e130 Products and technology for education
b270 Sensory functions related to temperature and other stimuli	e240 Light
b280 Sensation of pain	e250 Sound
b298 Other sensory functions	e310 Immediate family
b760 Control of voluntary movement functions	e315 Extended family
d160 Focusing attention	e320 Friends
d161 Directing attention	e325 Acquaintances, peers, colleagues, neighbours, and community members
d166 Reading	e330 People in positions of authority
d175 Solving problems	e340 Personal care providers and personal assistants
d177 Making decisions	e350 Domestic animals
d220 Undertaking multiple tasks	e355 Health professionals
d230 Carrying out daily routine	e410 Individual attitudes of immediate family members
d240 Handling stress and other psychological demands	e415 Individual attitudes of extended family members
d250 Managing one's own behaviour	e420 Individual attitudes of friends
d310 Communicating with-receiving-spoken messages	e425 Individual attitudes of acquaintances, peers, colleagues, neighbours, and community members
d475 Driving	e430 Individual attitudes of people in positions of authority
d520 Caring for body parts	e440 Individual attitudes of personal care providers and personal assistants
d570 Looking after one's health	e450 Individual attitudes of health professionals
d571 Looking after one's safety	e455 Individual attitudes of other professionals
d620 Acquisition of goods and services	e460 Societal attitudes
d630 Preparing meals	e465 Social norms, practices, and ideologies
d640 Doing housework	e525 Housing services, systems, and policies
d650 Caring for household objects	e535 Communication services, systems, and policies
d660 Assisting others	e550 Legal services, systems, and policies
d710 Basic interpersonal interactions	e560 Media services, systems, and policies
d720 Complex interpersonal interactions	e570 Social security services, systems, and policies
d740 Formal relationships	e575 General social support services, systems, and policies
d750 Informal social relationships	e580 Health services, systems, and policies
d760 Family relationships	e585 Education and training services, systems, and polies
d770 Intimate relationships	e590 Labour and employment services, systems, and policies
d820 School education	

Abbreviations: ADHD, attention-deficit/hyperactivity disorder; ICF, International Classification of Functioning, Disability and Health.

## DISCUSSION

We present the first revision of the initial ICF Core Sets for ADHD published in 2018. The fields of neurodevelopmental conditions in general, and ADHD in particular, have seen considerable change and development, not only regarding research and clinical practice, but also in how ADHD and neurodevelopment are conceptualized. Given these developments, and in light of new evidence that we collected on the adequacy of the initial Core Sets, we believe that an update was necessary and appropriate. We used a Delphi-like method to evaluate and integrate data on the initial ICF Core Set for ADHD collected between 2019 and 2023. Feedback from stakeholders, experiences from the operationalization and implementation of the Core Sets on an online assessment platform, and data and feedback through piloting the platform among individuals with ADHD and their families were used to inform revisions. The comprehensive and the three age-appropriate Core Sets for ADHD were substantially revised, foremost by widening them, including additional body functions, activities and participation, and environmental factor codes; only one code was removed from the comprehensive Core Set and a few codes were removed from the 0 to 5 years brief age-appropriate Core Set.

The most prominent change to the comprehensive and the three age-appropriate Core Sets is probably the inclusion of different body functions for sensory functioning. These were strongly endorsed by stakeholder feedback, experiences from the Core Set operationalization and platform development, and platform users during piloting. Therefore, we added the ICF body function codes for sight, hearing, taste, smell, touch, temperature, pain, and other sensory functions to the comprehensive Core Set and the age-appropriate Core Sets. Several of these were also previously indicated in one or more of the preparatory studies of the initial ICF Core Sets for ADHD,<sup>13-16</sup> although not included after the consensus conference.<sup>12</sup> Because the development of the initial ICF Core Sets did not sufficiently involve the voices and primary perspectives of individuals with ADHD, the expert group of this study deemed it a priority to consider their feedback in the revision; sensory functioning was an area of functioning particularly highlighted by stakeholders. Indeed, there is now robust evidence from different study designs indicating that hypersensitivity and hyposensitivity are frequent in ADHD<sup>23</sup> and do not differ in their intensity when compared to autism; in fact, they may exceed the sensory alterations observed in autism.<sup>24,25</sup> Two other body functions added are temperament and personality, as well as memory functions. Both functions were suggested by stakeholders, and the development of the ICF platform and pilot, as well as being indicated by all preparatory studies of the initial sets,<sup>13-16</sup> and current ADHD preclinical and clinical research.<sup>26–28</sup>

Most ICF codes added to the comprehensive Core Set for ADHD in the activities and participation domain were

consistently endorsed by all sources evaluated in this study; they had been indicated in one or more of the preparatory studies for the initial comprehensive Core Set.<sup>13–16</sup> Still, some were only indicated in the development and pilot of the ICF platform (e.g. thinking) or had not emerged in any of the preparatory studies (e.g. religion and spirituality, human rights). This perhaps reflects more recent insights or developments in ADHD. Thinking was included because it covers aspects of flow, hyperfocus, or divergent thinking, which have been reported as possible functional strengths in some individuals with ADHD.<sup>29,30</sup> Religious and spiritual activities impact ADHD symptoms both positively and negatively,<sup>31,32</sup> while human rights engagement, especially in the neurodiversity movement, is vital for many individuals with ADHD.<sup>33</sup>

Five new environmental factor codes were included in the comprehensive ADHD Core Set; their significance was strongly endorsed by our data, although they were hardly indicated in the preparatory studies. This may, at least in part, be related to the fact that previously ADHD and functioning in ADHD have primarily been viewed from a biological standpoint. Four newly identified environmental factors pertain to generic and systemic factors regarding housing, communication, legal and media services, systems, and policies to highlight the decisive nature of access to accommodation, information exchange, and Internet for functioning in ADHD. There has been increasing awareness in recent years that ADHD is not only associated with negative social outcomes<sup>34</sup> but also how societal structures and social mediators and moderators shape outcomes in ADHD.<sup>35–37</sup> The implementation of national programs for ADHD and guideline implementation are avenues to comply with increasing societal responsibility taking in ADHD.<sup>38,39</sup> The fifth new environmental ICF code added was domestic animals. Although the evidence for the significance of human-animal interactions in ADHD functioning is still emerging,<sup>40</sup> feedback from stakeholders both to the authors directly and during the pilot of the ICF platform was indicative of motivating, calming, and prosocial effects. Thus, it was included to value lived experience in addition to science, which is a core principle of the ICF.

The Delphi-like process revealed that the ageappropriate Core Sets probably hold greater utility in research and clinical practice compared to the comprehensive Core Set. Researchers and practitioners are typically more concerned with current rather than lifetime functioning and tend to work within particular age groups (pediatric, adolescent, and adulthood groups). Additionally, because the comprehensive Core Set is designed to capture functional information across the lifespan, it is likely to contain superfluous and irrelevant codes when applied to individuals from specific age groups. The age-appropriate Core Sets specific to developmental periods (early childhood, childhood and adolescence, adulthood) align with the age groups seen in clinical practice, increasing the relevance of captured functional information and reducing the likelihood that individuals or caregivers are exposed to

codes irrelevant to their situation and context. Given the significance of the age-appropriate brief Core Sets, considerable modifications were made to (1) transfer the new ICF codes from the revised comprehensive Core Set to the relevant age-appropriate brief Core Sets, (2) make the ageappropriate brief Core Sets more useful for research and practice, and (3) enable them to be used as stand-alone and independent from the comprehensive Core Set without loss of important functional information. Another consequence of prioritizing the age-appropriate Core Sets is that the revised comprehensive Core Set for ADHD only includes ICF codes that appear in any of the age-appropriate sets; this is different from the initial comprehensive Core Set that also had unique additional codes. The common brief ICF Core Set, which includes only the most significant codes across the lifespan, was discussed as lacking much functional content deemed essential by stakeholders. For this reason, we did not update the common brief ICF ADHD Core Set and do not recommend its future use. Instead, we recommend applying the comprehensive and age-appropriate brief Core Sets for ADHD. Importantly, our recommendation is based on feedback from professionals in the context of ADHD. However, common brief Core Sets may still be meaningful in other contexts or for other conditions, such as cerebral palsy, for which Core Sets exist.<sup>10</sup> Limitations with generating age-appropriate selections of ICF codes were encountered when revising the age-appropriate Core Sets for ADHD. For example, the age ranges for the age-appropriate brief Core Sets contain several developmentally intense age groups (e.g. infancy and early childhood) and age groups that include environment-related transitions (e.g. from education to employment). Developing age-appropriate Core Sets capturing the nuances of these broad developmental periods is difficult. For example, the 0 to 5 years brief ADHD Core Set contains several codes important to assess children aged 4 or 5 years, such as verbal communication or basic self-care, which may not apply (yet) to younger individuals. The 17 years or older Core Set contains codes that are not likely to apply to all individuals below the age of 20 years, especially in high-income countries, such as those related to employment or independent living. The options to streamline the age-appropriate brief ICF Core Sets for ADHD further are limited; however, we removed five activities and participation codes, and one body function code, codes reflecting higher-order cognitive processes from the 0 to 5 years set (e.g. thinking, problem-solving, undertaking multiple tasks) deemed expendable in early childhood. Overall, the revision of the Core Sets involved adding, not removing, ICF codes from the Core Sets. The inclusion of additional codes may impact the feasibility of implementing Core Sets in practice where time is a limited resource. However, we deemed it necessary to prioritize the feedback of professionals over considerations of implementation feasibility in the current revisions. Future iterations may benefit from exploring other ways in which the feasibility of implementing Core Sets may be improved.

In this article, we present one of the first ever conducted ICF Core Set revisions. Although updating ICF Core Sets is a necessary phase of Core Set development, no criterion standard procedural guidelines for revisions exist. For the moment, we chose the most efficient and constructive approach, a Delphi-like process, to sort and condense aggregated data from different sources on the initial Core Sets for ADHD<sup>12</sup> to date. There are certainly methodological limitations, mostly concerning limited international data availability and subjectivity in certain parts of the data collection and decision-making. For instance, most of the evidence used originated from high-income countries, while no researchers in neurodivergence were part of the expert panel. In addition, our collection of stakeholder feedback was largely through informal processes; while conferring several advantages, such as a lower threshold for contribution, we were not able to collect demographic data to profile those providing feedback. These aspects must be kept in mind and improved when designing the methods for future revisions of the ICF Core Sets. Moreover, we prioritized the sensitivity and enlargement of the Core Sets, particularly for the age-appropriate brief Core Sets over brevity and specificity. Even though we believe there is good justification to do so as outlined earlier, this deviates from the original official Core Set development process. We have also highlighted the significance of the age-appropriate Core Sets over the comprehensive and common brief Core Sets. A comparable process regarding revisions of the ICF Core Sets for autism has been conducted in parallel;<sup>11,41</sup> here the evidence base for the revisions was richer because several naturalistic validation and linking studies of these Core Sets in several clinical, educational, and community settings had been published since the launch of the initial Core Sets. Such validation studies were not available for ADHD at the time of writing but are needed to further validate the Core Sets in clinical practice. Although Core Set development involved multiple countries across WHO regions, most countries were high-income countries; thus, in keeping with the ICF Core Set development methodology, validations should be conducted at a global level to ensure that revisions are culturally sensitive and reflective of the experiences of individuals with ADHD globally. Despite these shortcomings, we believe that the revisions are based on sufficiently consistent and solid evidence and decision-making; they improve the initial version's validity and acceptability, hence adding value to the ADHD ICF Core Sets used in research and practice. The comprehensive Core Set now includes 98 ICF codes (27 added, one removed), the 0 to 5 years Core Set includes 61 codes (20 added, six removed), the 6 to 16 years Core Set includes 81 codes (26 added), and the 17 years or older Core Set includes 87 codes (35 added).

#### FUNDING INFORMATION

This work received funding from the Swedish Research Council for Health Working Life and Welfare, Trygg Hansa, the Promobilia Foundation, the Sunnerdahl's Disability Fund, and Clas Groschinskys Memorial Fund Foundation.

#### CONFLICT OF INTEREST STATEMENT

In the last 3 years, Sven Bölte has acted as an author, consultant, or lecturer for Medice and Linus Bio. He has received royalties for textbooks and diagnostic tools from Hogrefe, Liber, Ernst Reinhardt, Kohlhammer, and UTB. He is a partner in NeuroSupportSolutions. Peter B Marschik has received royalties for textbooks from Thieme, Elsevier, Mac Keith Press, and Springer. Eric Zander has received royalties for diagnostic tools from Hogrefe.

## DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

#### ORCID

*Sven Bölte* https://orcid.org/0000-0002-4579-4970 *Peter B. Marschik* https://orcid.org/0000-0001-8932-0980 *Emily D'arcy* https://orcid.org/0000-0001-7978-0123

#### REFERENCES

- Faraone SV, Banaschewski T, Coghill D, Zheng Y, Biederman J, Bellgrove MA, et al. The World Federation of ADHD International Consensus Statement: 208 Evidence-based conclusions about the disorder. Neurosci Biobehav Rev. 2021 Sep;128:789–818.
- World Health Organization (WHO). International Classification of Functioning, Disability and Health. Geneva: WHO, 2001.
- 3. World Health Organization (WHO). International Classification of Functioning, Disability and Health: Child and Youth Version. Geneva: WHO, 2007.
- 4. Bölte S, Lawson WB, Marschik PB, Girdler S. Reconciling the seemingly irreconcilable: The WHO's ICF system integrates biological and psychosocial environmental determinants of autism and ADHD: The International Classification of Functioning (ICF) allows to model opposed biomedical and neurodiverse views of autism and ADHD within one framework. Bioessays. 2021 Sep;43(9):e2000254.
- 5. Bölte S. A more holistic approach to autism using the International Classification of Functioning: The why, what, and how of functioning. Autism. 2023 Jan;27(1):3–6.
- Bickenbach J. Ethics, disability and the International Classification of Functioning, Disability and Health. Am J Phys Med Rehabil. 2012 Feb;91(13 Suppl 1):S163-7.
- Fletcher-Watson S, Adams J, Brook K, Charman T, Crane L, Cusack J, Leekam S, Milton D, Parr JR, Pellicano E. Making the future together: Shaping autism research through meaningful participation. Autism. 2019 May;23(4):943–53.
- Selb M, Escorpizo R, Kostanjsek N, Stucki G, Üstün B, Cieza A. A guide on how to develop an International Classification of Functioning, Disability and Health Core Set. Eur J Phys Rehabil Med. 2015 Feb;51(1):105–17.
- Tofani M, Mustari M, Tiozzo E, Dall'Oglio I, Morelli D, Gawronski O, Salata M, Cantonetti L, Castelli E, Di Lallo D, Raponi M. The development of the International Classification of Functioning, Disability and Health for Child and Youth (ICF-CY) Core Sets: a systematic review. Disabil Rehabil. 2022 Oct 22:1–10.
- Schiariti V, Selb M, Cieza A, O'Donnell M. International Classification of Functioning, Disability and Health Core Sets for children and youth with cerebral palsy: a consensus meeting. Dev Med Child Neurol. 2015 Feb;57(2):149–58.
- 11. Bölte S, Mahdi S, de Vries PJ, Granlund M, Robison JE, Shulman C, Swedo S, Tonge B, Wong V, Zwaigenbaum L, Segerer W, Selb M. The Gestalt of functioning in autism spectrum disorder: Results of the international conference to develop final consensus International

Classification of Functioning, Disability and Health core sets. Autism. 2019 Feb;23(2):449-67.

- Bölte S, Mahdi S, Coghill D, Gau SS, Granlund M, Holtmann M, Karande S, Levy F, Rohde LA, Segerer W, de Vries PJ, Selb M. Standardised assessment of functioning in ADHD: consensus on the ICF Core Sets for ADHD. Eur Child Adolesc Psychiatry. 2018 Oct;27(10):1261–81.
- de Schipper E, Mahdi S, Coghill D, de Vries PJ, Gau SS, Granlund M, Holtmann M, Karande S, Levy F, Almodayfer O, Rohde L, Tannock R, Bölte S. Towards an ICF core set for ADHD: a worldwide expert survey on ability and disability. Eur Child Adolesc Psychiatry. 2015 Dec;24(12):1509–21.
- 14. de Schipper E, Lundequist A, Wilteus AL, Coghill D, de Vries PJ, Granlund M, Holtmann M, Jonsson U, Karande S, Levy F, Al-Modayfer O, Rohde L, Tannock R, Tonge B, Bölte S. A comprehensive scoping review of ability and disability in ADHD using the International Classification of Functioning, Disability and Health-Children and Youth Version (ICF-CY). Eur Child Adolesc Psychiatry. 2015 Aug;24(8):859–72.
- 15. Mahdi S, Ronzano N, Knüppel A, Dias JC, Albdah A, Chien-Ho L, Almodayfer O, Bluschke A, Karande S, Huang HL, Christiansen H, Granlund M, de Vries PJ, Coghill D, Tannock R, Rohde L, Bölte S. An international clinical study of ability and disability in ADHD using the WHO-ICF framework. Eur Child Adolesc Psychiatry. 2018 Oct;27(10):1305–19.
- Mahdi S, Viljoen M, Massuti R, Selb M, Almodayfer O, Karande S, de Vries PJ, Rohde L, Bölte S. An international qualitative study of ability and disability in ADHD using the WHO-ICF framework. Eur Child Adolesc Psychiatry. 2017 Oct;26(10):1219–31.
- Cieza A, Ewert T, Ustün TB, Chatterji S, Kostanjsek N, Stucki G. Development of ICF Core Sets for patients with chronic conditions. J Rehabil Med. 2004 Jul;(44 Suppl):9–11.
- Grill E, Stucki G. Criteria for validating comprehensive ICF Core Sets and developing brief ICF Core Set versions. J Rehabil Med. 2011 Jan;43(2):87–91.
- Dalkey NC, Helmer O. An experimental application of the Delphi method to the use of experts. Managerial Sci. 1963; 9, 458–67.
- Pratt MG, Sonenshein S, Feldman MS. Moving Beyond Templates: A Bricolage Approach to Conducting Trustworthy Qualitative Research. Org Res Methods. 2022; 25, 211–38.
- Keeney S, Hasson F, McKenna H. Consulting the oracle: ten lessons from using the Delphi technique in nursing research. J Adv Nurs. 2006 Jan;53(2):205–12.
- 22. Alehagen L, Hasslinger J, Wessman E, Black M, Lundin Remnelius K, Bölte S. ICF Core Sets for autism implementation development, qualitative and quantitative piloting of an online assessment tool. In preparation. 2023.
- Rani I, Agarwal V, Arya A, Mahour P. Sensory Processing in Children and Adolescents with Attention Deficit Hyperactivity Disorder. J Atten Disord. 2023 Jan;27(2):145–51.
- Neufeld J, Taylor MJ, Lundin Remnélius K, Isaksson J, Lichtenstein P, Bölte S. A co-twin-control study of altered sensory processing in autism. Autism. 2021 Jul;25(5):1422–32.
- 25. Dellapiazza F, Michelon C, Vernhet C, Muratori F, Blanc N, Picot MC, Baghdadli A; for ELENA study group. Sensory processing related to attention in children with ASD, ADHD, or typical development: results from the ELENA cohort. Eur Child Adolesc Psychiatry. 2021 Feb;30(2):283–91.
- Pinzone V, De Rossi P, Trabucchi G, Lester D, Girardi P, Pompili M. Temperament correlates in adult ADHD: A systematic review J Affect Disord. 2019 Jun 1;252:394–403.
- He JA, Antshel KM, Biederman J, Faraone SV. Do Personality Traits Predict Functional Impairment and Quality of Life in Adult ADHD? A Controlled Study. J Atten Disord. 2019 Jan;23(1):12–21.
- Ramos AA, Hamdan AC, Machado L. A meta-analysis on verbal working memory in children and adolescents with ADHD. Clin Neuropsychol. 2020 Jul;34(5):873–98.

- Hupfeld KE, Abagis TR, Shah P. Living "in the zone": hyperfocus in adult ADHD. Atten Defic Hyperact Disord. 2019 Jun;11(2):191–208. Epub 2018 Sep 28. Erratum in: Atten Defic Hyperact Disord. 2019 Mar 8;.
- Sedgwick JA, Merwood A, Asherson P. The positive aspects of attention deficit hyperactivity disorder: a qualitative investigation of successful adults with ADHD. Atten Defic Hyperact Disord. 2019 Sep;11(3):241–53.
- Dew RE, Kollins SH, Koenig HG. ADHD, Religiosity, and Psychiatric Comorbidity in Adolescence and Adulthood. J Atten Disord. 2022 Jan;26(2):307–18.
- 32. Novis-Deutsch N, Dayan H, Pollak Y, Khoury-Kassabri M. Religiosity as a moderator of ADHD-related antisocial behaviour and emotional distress among secular, religious and Ultra-Orthodox Jews in Israel. Int J Soc Psychiatry. 2022 Jun;68(4):773–82.
- Chapman R, Botha M. Neurodivergence-informed therapy. Dev Med Child Neurol. 2023 Mar;65(3):310–7.
- Riglin L, Todd A, Blakey R, Shakeshaft A, Stergiakouli E, Davey Smith G, Tilling K, Thapar A. Young-Adult Social Outcomes of Attention-Deficit/Hyperactivity Disorder. J Clin Psychiatry. 2023 Jan 25;84(2):22m14379.
- Christoffersen MN. Overcoming the Odds: Does Social Support Make a Difference for Young People With ADHD Symptoms? J Atten Disord. 2023 Jul 20:10870547231188348.
- Østergaard SD, Larsen JT, Dalsgaard S, Wilens TE, Mortensen PB, Agerbo E, Mors O, Petersen L. Predicting ADHD by Assessment of Rutter's Indicators of Adversity in Infancy. PLoS One. 2016 Jun 29;11(6):e0157352.
- Keilow M, Wu C, Obel C. Cumulative social disadvantage and risk of attention deficit hyperactivity disorder: Results from a nationwide cohort study. SSM Popul Health. 2020 Jan 31;10:100548.

- 38. May T, Birch E, Chaves K, Cranswick N, Culnane E, Delaney J, Derrick M, Eapen V, Edlington C, Efron D, Ewais T, Garner I, Gathercole M, Jagadheesan K, Jobson L, Kramer J, Mack M, Misso M, Murrup-Stewart C, Savage E, Sciberras E, Singh B, Testa R, Vale L, Weirman A, Petch E, Williams K, Bellgrove M. The Australian evidence-based clinical practice guideline for attention deficit hyperactivity disorder. Aust N Z J Psychiatry. 2023 Aug;57(8):1101–16.
- Swedish Regions and Municipalities. National care and support program for ADHD: https://www.vardochinsats.se/adhd/, 2022.
- Schuck SE, Emmerson NA, Fine AH, Lakes KD. Canine-assisted therapy for children with ADHD: preliminary findings from the positive assertive cooperative kids study. J Atten Disord. 2015 Feb;19(2):125–37.
- 41. Bölte S, Alehagen L, Black MH, Hasslinger J, Wessman E, Lundin Remnélius K, Marschik PB, D'Arcy E, Crowson S, Freeth M, Seidel A, Girdler S, Zander E. The Gestalt of Functioning in Autism Revisited – First Revision of the International Classification of Functioning, Disability and Health Core Sets. 2023 (under review).

How to cite this article: Bölte S, Alehagen L, Black MH, Hasslinger J, Wessman E, Remnélius KL, et al. Assessment of functioning in ADHD according to World Health Organization standards: First revision of the International Classification of Functioning, Disability and Health Core Sets. Dev Med Child Neurol. 2024;00:1–14. <u>https://doi.org/10.1111/</u> <u>dmcn.15865</u>