



Standardised assessment of functioning in ADHD: consensus on the ICF Core Sets for ADHD

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Abstract

Attention-deficit/hyperactivity disorder (ADHD) is associated with significant impairments in social, educational, and occupational functioning, as well as specific strengths. Currently, there is no internationally accepted standard to assess the functioning of individuals with ADHD. WHO's International Classification of Functioning, Disability and Health—child and youth version (ICF) can serve as a conceptual basis for such a standard. The objective of this study is to develop a comprehensive, a common brief, and three age-appropriate brief ICF Core Sets for ADHD. Using a standardised methodology, four international preparatory studies generated 132 second-level ICF candidate categories that served as the basis for developing ADHD Core Sets. Using these categories and following an iterative consensus process, 20 ADHD experts from nine professional disciplines and representing all six WHO regions selected the most relevant categories to constitute the ADHD Core Sets. The consensus process resulted in 72 second-level ICF categories forming the comprehensive ICF Core Set—these represented 8 body functions, 35 activities and participation, and 29 environmental categories. A Common Brief Core Set that included 38 categories was also defined. Age-specific brief Core Sets included a 47 category preschool version for 0–5 years old, a 55 category school-age version for 6–16 years old, and a 52 category version for older adolescents and adults 17 years old and above. The ICF Core Sets for ADHD mark a milestone toward an internationally standardised functional assessment of ADHD across the lifespan, and across educational, administrative, clinical, and research settings.

Keywords ADHD · Functioning · Assessment · Psychiatry · ICD · DSM · Consensus conference · ICF Core Sets

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Background

With a worldwide estimated prevalence of between 3 and 7% [1–4], attention-deficit/hyperactivity disorder (ADHD) is a common neurodevelopmental condition defined by persistent age-inappropriate patterns of inattention, hyperactivity, and impulsivity [5]. ADHD is associated with challenges to functioning in daily life, including academic and vocational difficulties [6, 7], social exclusion [8], and delinquency [9, 10]. Co-existing psychiatric issues are also common [11, 12]. Moreover, the overall quality of life is lower [13, 14] for those with ADHD and the risk for premature mortality is higher than in the non-ADHD population [15]. However, there is substantial variability in individual abilities, disability, and functional outcomes. For example, limited research suggests specific strengths related to ADHD, including sense of entrepreneurship [16] and innovative thinking [17]. The interindividual differences in functioning can be influenced by personal factors (e.g., self-esteem and self-efficacy) [18], participation in skill training programs [19], pharmacological treatments [20], and degree of family support [21], among others. While ADHD is predominantly operationalised in terms of its symptoms, research clearly suggests that ADHD should be viewed from a wider perspective, taking into account personal, social, and environmental factors, and functioning.

Such a bio-psycho-social perspective is promoted by the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF), offering a comprehensive, integrative framework of functioning, and disability [22]. The ICF complements the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5) [5] and the International Classification of Diseases—Tenth Revision (ICD-10) [23], both of which focus on biomedical elements of ADHD. The holistic underpinning of the ICF is reflected in its classification structure [22]. The ICF comprises of two parts—(1) functioning and disability and (2) contextual factors. Functioning and disability include body functions (i.e., physiological and mental functions of the body system), body structures (i.e., anatomical parts of the body), activities (i.e., execution of tasks), and participation (i.e., involvement in life situations). Contextual factors consist of environmental factors (i.e., factors not inherent to the individual, e.g., family, work, recreational opportunity, government agencies, laws, and societal attitudes) as well as personal factors (i.e., personal experience, race, gender, age, educational level, and coping styles). Even though personal factors are part of the ICF framework, these are currently not classified given their extensive cultural and social diversity [22]. All other components of the ICF are

divided into “chapters” that have hierarchically organised “categories” with up to three levels of increasing detail. This hierarchy is illustrated in Fig. 1 with an example from the activities and participation component.

In 2007, a Child and Youth version of the ICF, the ICF-CY, was published [24]. The ICF-CY encompasses all the categories of the reference version of the ICF plus additional ones that capture the functional characteristics and environments of developing individuals. Altogether, it comprises 1685 categories: 531 in the body functions component; 329 in body structures; 552 in activities and participation; and 273 environmental factors. For the development of the ICF Core Sets for ADHD described here, we decided to use the more comprehensive ICF-CY (but referred to as “ICF” from now on).

The use of the ICF in managing ADHD supports emphasis on individual abilities, disabilities, and the impact of the specific context on individual functioning. This take on the impact of ADHD is meaningful for many reasons [25, 26]. First, functioning is often perceived as less stigmatising than diagnosis or psychopathology; the ICF offers a framework that can be used to assess strengths in addition to impairments. Furthermore, functional problems are often the reason for the initial referral to services and an important focus for interventions. Given this, these functional aspects are likely to be more tangible and meaningful to individuals with ADHD, their families and society as a whole than diagnosis and psychopathology. Describing an individual's functioning can also be useful in identifying real-life challenges, guiding treatment planning [27], and enhancing communication between individuals with ADHD and their environment and with professionals. Moreover, clarifying

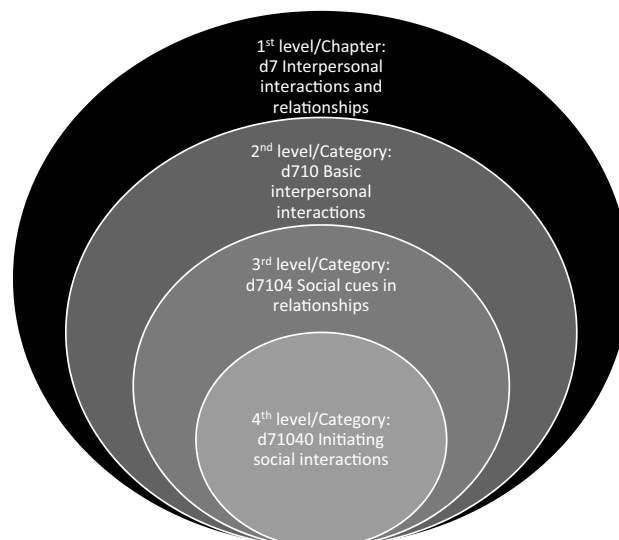


Fig. 1 Example of the hierarchically organised category structure of the ICF

the functioning of individuals or a group of individuals has potential for improving the calculation of health-related service costs [28, 29]. Finally, the ICF highlights the possible influence of the environment—positive and/or negative—on an individual's outcome. Understanding this modifying role of environmental factors provides the basis for possible adaptation of specific factors to improve outcome.

In spite of all these positive aspects, applying the ICF in day-to-day settings can be challenging. For one, compared to ICD and DSM, the ICF is much less well known and has not yet been widely accepted by professionals and researchers in the ADHD community. Moreover, its exhaustive comprehensiveness can make its use in daily practice difficult and time-consuming. In practice, only a fraction of the ICF categories are needed when evaluating functioning of individuals with specific health conditions. To address these issues, shortlists of ICF categories relevant for specific health conditions, so-called 'ICF Core Sets', have been developed [30].

The development of ICF Core Sets involves a rigorous scientific procedure aimed at reducing the number of ICF categories to those that are most significant for a given condition. This procedure comprises of four international, multiperspective preparatory studies—a comprehensive scoping review, an expert survey, a qualitative study and a clinical study, and a multidisciplinary and expertise-based decision-making and consensus (conference) process [30].

ICF Core Sets have been developed for diagnoses such as cerebral palsy [31], depression [32], and bipolar disorder [33], but not yet for any DSM-5 defined neurodevelopmental disorder. For this reason, the Karolinska Institutet Center of Neurodevelopmental Disorders (KIND), in collaboration with the ICF Research Branch, a cooperation partner within the WHO Collaboration Centre for the Family of International Classifications in Germany (at DIMDI), and the European Network for Hyperkinetic Disorders (EUNETHYDIS), initiated the development of ICF Core Sets for ADHD [34]. The objective of this paper is to provide a summary of the international consensus conference, where the ICF Core Sets for ADHD were created.

Method

Overall process

The ICF Core Sets for ADHD were generated at a specially convened consensus conference, by a multidisciplinary and international group of experts. This group based their decision-making on evidence generated in the four preparatory studies, i.e., comprehensive scoping review, expert survey, qualitative study and clinical study, and on their own knowledge and experience with persons living with ADHD. Each preparatory study resulted in a set of candidate categories,

i.e., a selection of ICF categories that represented the different perspectives captured in each of the studies. Throughout the decision-making and consensus conference, the participants were reminded to consider the preparatory studies results in their discussions and voting.

Preparatory studies

The study designs and methodologies were different in each of the preparatory studies, but candidate categories for ICF Core Sets for ADHD were identified similarly. After extracting functioning concepts from the respective data sets collected in each preparatory study, concepts were linked to the ICF using established linking rules [35] and a frequency analysis was conducted. The most frequently reported categories in each study were included in the list of candidate categories for that study. The preparatory studies included:

1. A scoping review of functioning data gathered by 80 ADHD-related outcome studies that were identified through a comprehensive search using scientific databases (e.g., Medline, PubMed, and Cinahl) [36].
2. An international survey of ADHD experts which collected the views and opinions of 174 experts across 11 professional disciplines from 45 countries and all WHO world regions [37].
3. A qualitative study that involved focus group discussions and semi-structured interviews of individuals with ADHD, family members, and professional caregivers from 16 stakeholder groups in 5 countries from 5 WHO world regions [38].
4. A clinical cross-sectional study [39] which, unlike the other preparatory studies, derived candidate categories from the extended ICF checklist that clinicians and clinical researchers used to assess 112 individuals with ADHD recruited at 9 clinical sites in 8 countries in 4 different WHO world regions. Since each ICF checklist item already indicated a corresponding ICF category, ICF linking was not conducted here.

A detailed description of each study can be found in separate scientific publications [36–39].

Consensus conference

Participants

To generate the first ICF Core Sets for ADHD, international experts were invited to participate in a three-day iterative decision-making and consensus conference that took place at the KIND center in Stockholm (Sweden) in September 2016. Experts had to meet the following inclusion criteria to be eligible for conference participation: (1) a professional

background in childhood disability, which included psychiatry, psychology, psychotherapy, social work, special education, speech-language pathology, nursing, occupational therapy, paediatrics, and physiotherapy, (2) at least 5 years of working experience with children, adolescents, or adults with ADHD, and (3) fluency in English. The nomination of experts was predominantly made by the Project Steering Committee, a group of key opinion leaders in the field of ADHD or experts in ICF. The Steering Committee included clinicians, educators, researchers, and self-advocates from all six WHO regions (see acknowledgement and authors DC, SFG, MG, MH, SK, FL, LR, PdV). To achieve a broad representation of professional backgrounds and WHO world regions, the Steering Committee members were asked to nominate experts who matched their own professional field and WHO world region. Altogether, invitations to participate in the consensus conference were sent to 30 international ADHD experts.

Procedure

The consensus conference followed a standardised iterative decision-making and consensus (voting) process established for ICF Core Set development. In accordance with the previous ICF Core Set projects, comprehensive and Brief (Common) ICF Core Sets were developed [31, 32]. In addition, based on a decision made by the Steering Committee, three age-specific Brief Sets were also developed: a preschool set (ages 0–5 years), a school-age set (ages 6–16), and an older adolescent and adult set for individuals 17 years and older (Fig. 2) [30]. Throughout the voting process, a specialized data analysis program in MS Office Access was employed. This data program displayed the category descriptions and corresponding frequencies of the candidate categories from each preparatory study, tracked the expert votes, and generated summary results that informed the subsequent steps of the voting procedure. A condensed ICF workshop was also held prior to starting the formalized voting process to familiarize the participating ADHD experts with the ICF and prepare them for the iterative decision-making and consensus (voting) process. The voting process comprised two stages—stage 1 to generate the Comprehensive ICF Core Set for ADHD and stage 2 to generate the brief versions. Stage 1 was completed by alternating discussions and voting in working group (Votes A and B) and plenary sessions (Votes C to E). Stage 2 involved a two-round ranking and cut-off exercise for each brief set.

Stage 1

For the working group (WG) discussions and voting of Votes A and B, the ADHD experts were divided into three groups of 6 or 7 participants. Participants remained in the

same WG throughout stage 1. In determining the composition of the WGs, efforts were made to ensure a balanced representation of professional disciplines, WHO world regions, and gender. A WG leader was appointed for each group to moderate the WG discussions and voting procedure. To support the WG leader, two assistants were assigned to each WG to present the results from the preparatory studies for each candidate category, make notes of the discussion, and enter the votes into the data analysis program. The WG leader called for arguments for and against including the individual candidate categories, and encouraged the experts to consider the preparatory study results, their own expertise in ADHD, as well as relevant issues relating to country and cultural applicability. Since the WG leaders were allowed to vote, they were instructed to communicate objectively and ensure that each WG participant had the opportunity to express an opinion before voting. To avoid leader bias, the WG leaders were also instructed to give their own feedback only until after several other group members had already provided their comments. Voting was conducted through a show of hands.

As in the previous ICF Core Set projects [31, 33], for a specific category to be automatically included in the Comprehensive Core Set for ADHD in Votes A and B, at least 75% of the experts had to vote in favour of including that category. Categories that received 40% positive votes or less were automatically excluded from the comprehensive set. Individual candidate categories were considered “ambiguous” if more than 40% but less than 75% of the experts voted to include that category. Ambiguous categories were carried over to the next session for re-discussion and a new voting round occurred. Between the WG sessions in Votes A and B, a plenary session took place to review Vote A results and to enable the participants to again present pros and cons for including each of the ambiguous categories. Ambiguous categories that remained after Vote B were re-discussed in the subsequent plenary session, during which Vote C took place. In Vote C, the majority (> 50%) of the participants had to agree to include the ambiguous category for it to be part of the Comprehensive Core Set.

Up to this point, the categories that were already included in the Comprehensive Core Set for ADHD were at second-level. In Vote D, the experts were asked to decide whether these second-level categories were specific enough to describe the functioning of individuals with ADHD or “dive deeper”, i.e., continue to Vote E, during which they had the opportunity to consider replacing the second-level category with more specific third- or fourth-level categories. As only 40% of the experts voted for diving deeper, the categories all remained at the second level. At this point, Stage 1 was considered complete and the Comprehensive ICF Core Set for ADHD was finalized.

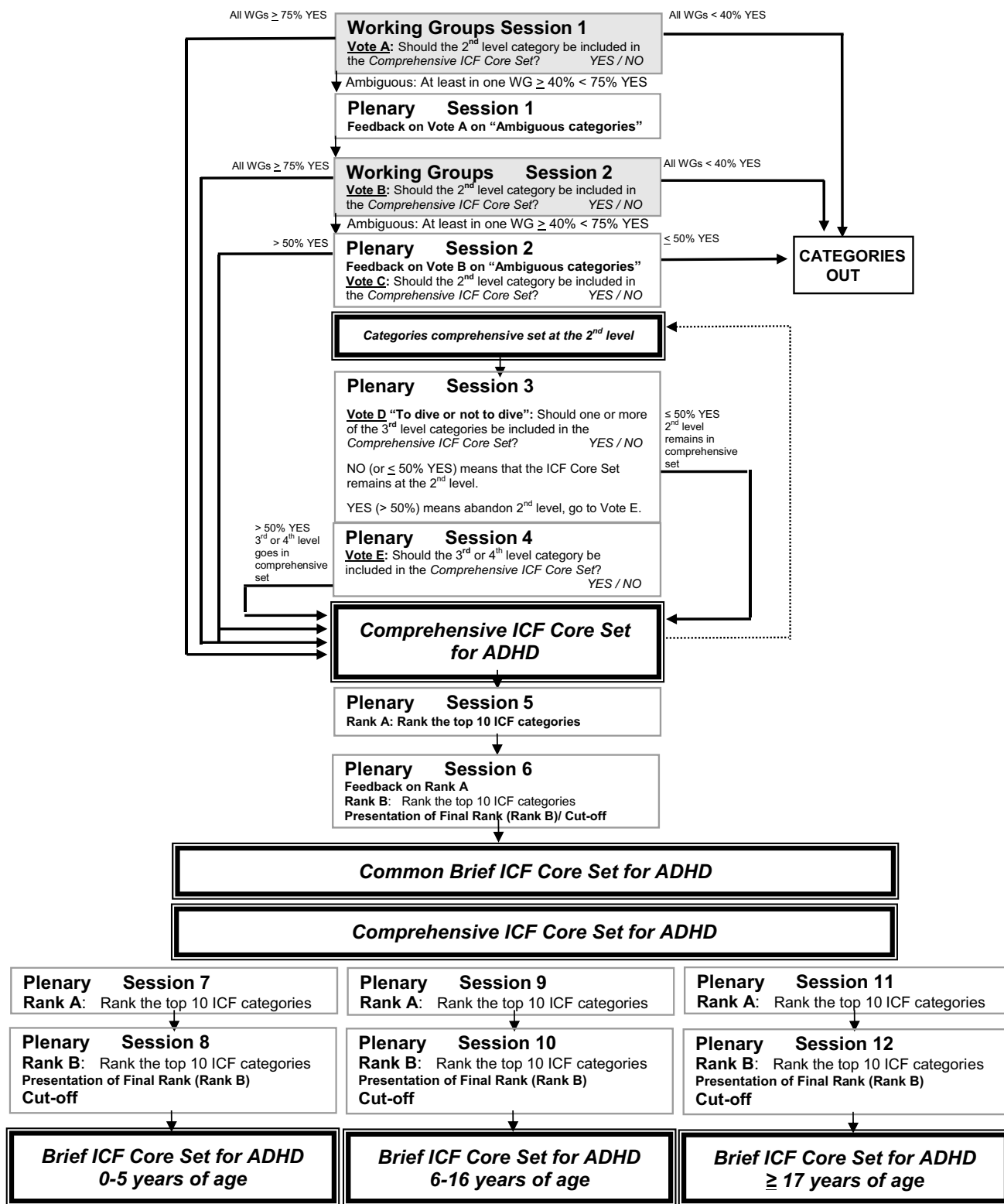


Fig. 2 Iterative decision-making process at the consensus meeting

Stage 2

In stage 2, the brief common set and the three age-specific Brief Sets were developed by conducting a two-round ranking and cut-off exercise for each set. In deciding on the ranking and cut-off, the experts were reminded that the Brief Sets should comprise the fewest number of categories possible while still capturing the most essential.

In the first ranking round to develop the Common Brief Set, each expert received a handout with all the categories from the Comprehensive Core Set for ADHD organised according to ICF component, and were instructed to rank the top 10 most essential categories for each ICF component from 1 to 10, with “1” being most essential. The ranking results of each expert were analysed using descriptive statistics and combined to generate a common ranking. The common ranking was then presented and the participating experts were given the opportunity to discuss reasons for their ranking decision and arguments for including selected categories. Subsequently, the second ranking round began following the same procedure. After conclusion of the second ranking round, the experts were asked to choose a cutoff, i.e., the number of categories per ICF component that would be crucial to include in the brief common set. The same ranking and cut-off procedure was repeated for each of the age-specific brief sets. However, the starting list of categories did not include the categories of the Common Brief Set, since these were automatically included in each of the age-specific brief sets. Categories that were included in all the three age-specific brief sets were integrated retrospectively in the Common Brief Set.

Results

The scoping review identified 50 [36], the international expert survey 53 [37], the qualitative study 82 [38], and the clinical cross-sectional study 109 second-level candidate categories [39]. Taken together, the four preparatory studies identified 132 unique second-level ICF candidate categories. The majority of the categories came from the activities and participation component ($k = 55$, 42%), followed by body functions ($k = 37$, 28%), environmental factors ($k = 36$, 27%), and body structures ($k = 4$, 3%). Table 1 summarizes the second-level candidate ICF categories that were identified across the four preparatory studies.

Consensus conference experts

Of the 30 experts who were invited to participate in the international consensus conference, 8 declined due to other commitments and 2 did not respond to the invitation. In total, 20 experts (14 females and 6 males) from 12 countries

(Australia, Czech Republic, Germany, India, Mexico, Portugal, Puerto Rico, Saudi Arabia, South Africa, Sweden, United Kingdom, and United States), representing all six WHO world regions, participated in the consensus conference (see acknowledgement). Table 2 summarizes the participating experts by WG, gender, professional background, country, and WHO world region.

Comprehensive ICF Core Set for individuals with ADHD

Table 3 shows the categories included in the Comprehensive ICF Core Set for ADHD, along with the percentage of agreement for each category that was included. Of the 132 second-level candidate categories that were identified in the preparatory studies, 72 (55%) were included in the Comprehensive Core Set. A large majority of the included categories were from the activities and participation component ($k = 35$, 49%), followed by environmental factors ($k = 29$, 40%) and body functions ($k = 8$, 11%). No body structures were included. All nine chapters from the activities and participation component and all five chapters of the environmental factors were represented in the Comprehensive Core Set. All body functions categories, except from b760 Control of voluntary movement functions, were mental functions. The most frequently covered chapters were e4 Attitudes ($k = 10$, 14%) and e3 Support and relationships ($k = 8$, 11%) from the environmental factor component.

Common Brief ICF Core Set for individuals with ADHD

Table 4 lists the 38 second-level ICF categories included in the Common Brief set for ADHD, along with their final rank order. It comprises the 31 categories that were included following the initial ranking and cut-off process and additional 7 categories that were found to be common to all of the age-specific brief sets. The Common Brief Set categories came from the environmental factors component ($k = 17$, 45%), activities and participation ($k = 14$, 37%), and body functions ($k = 7$, 18%). The most frequently covered chapters were b1 Mental functions ($k = 7$, 18%), e4 Attitudes ($k = 6$, 16%), and e3 Support and relationships ($k = 5$, 13%).

Brief ICF Core Set for preschool-age children (0–5 years old)

Table 5 summarizes the categories included in the Brief Set for the preschool-age group of 0–5 years old, along with their final rank order. This specific Brief Set consisted of 47 second-level ICF categories across three different components: environmental factors ($k = 20$, 43%), activities and participation ($k = 19$, 40%), and body functions

Table 1 Candidate ICF categories from each respective preparatory study

Second-level ICF category	Scoping review	Expert survey	Qualitative study	Clinical study
Body function				
b110 Consciousness functions	X			
b114 Orientation functions	X		X	X
b117 Intellectual functions		X	X	
b122 Global psychosocial functions			X	X
b125 Dispositions and intra-personal functions	X	X	X	X
b126 Temperament and personality functions	X	X	X	X
b130 Energy and drive functions	X	X	X	X
b134 Sleep functions	X	X	X	X
b140 Attention functions	X	X	X	X
b144 Memory functions	X	X	X	X
b147 Psychomotor functions	X	X	X	X
b152 Emotional functions	X	X	X	X
b156 Perceptual functions	X	X	X	X
b160 Thought functions	X		X	X
b163 Basic cognitive functions	X			X
b164 Higher level cognitive functions	X	X	X	X
b167 Mental functions of language	X		X	X
b172 Calculation functions	X			
b180 Experience of self and time functions		X	X	X
b220 Sensations associated with the eye and adjoining structures	X			
b235 Vestibular functions		X		X
b240 Sensations associated with hearing and vestibular function	X			
b265 Touch function				X
b280 Sensation of pain	X		X	X
b330 Fluency and rhythm of speech functions				X
b410 Heart functions			X	
b455 Exercise tolerance functions			X	
b510 Ingestion functions	X			
b525 Defecation functions	X			
b530 Weight maintenance functions	X		X	X
b535 Sensations associated with the digestive system	X		X	X
b640 Sexual functions				X
b710 Mobility of joint functions				X
b735 Muscle tone functions		X		X
b760 Control of voluntary movement functions		X	X	X
b765 Involuntary movement functions			X	X
b840 Sensation related to the skin	X			
Body structures				
s110 Structure of brain		X	X	
s710 Structure of head and neck region			X	
s730 Structure of upper extremity		X		
s750 Structure of lower extremity		X		
Activities and participation				
d110 Watching				X
d115 Listening		X		X
d140 Learning to read	X			X
d145 Learning to write	X			X

Table 1 (continued)

Second-level ICF category	Scoping review	Expert survey	Qualitative study	Clinical study
d150 Learning to calculate	X			X
d160 Focusing attention	X	X	X	X
d161 Directing attention		X	X	X
d166 Reading	X			X
d170 Writing	X	X		X
d172 Calculating	X		X	X
d175 Solving problems			X	X
d177 Making decisions			X	X
d210 Undertaking a single task	X	X	X	X
d220 Undertaking multiple tasks	X	X	X	X
d230 Carrying out daily routine		X	X	X
d240 Handling stress and other psychological demands	X	X	X	X
d250 Managing one's own behaviour	X	X	X	X
d310 Communicating with—receiving—spoken messages			X	X
d315 Communicating with—receiving—nonverbal messages				X
d330 Speaking				X
d335 Producing nonverbal messages				X
d350 Conversation				X
d440 Fine hand use		X	X	X
d446 Fine foot use		X		X
d455 Moving around			X	
d470 Using transportation			X	X
d475 Driving				X
d510 Washing oneself			X	X
d520 Caring for body parts			X	X
d530 Toileting	X		X	X
d540 Dressing			X	X
d550 Eating				X
d570 Looking after one's health	X	X	X	X
d571 Looking after one's safety	X	X	X	X
d620 Acquisition of goods and services				X
d630 Preparing meals			X	X
d640 Doing housework			X	X
d650 Caring for household objects			X	
d660 Assisting others			X	X
d710 Basic interpersonal interactions			X	X
d720 Complex interpersonal interactions	X	X	X	X
d730 Relating with strangers				X
d740 Formal relationships	X	X	X	X
d750 Informal social relationships	X	X	X	X
d760 Family relationships	X	X	X	X
d770 Intimate relationships	X			X
d820 School education	X	X	X	X
d825 Vocational training		X		X
d830 higher education		X		
d845 Acquiring, keeping, and terminating a job	X			
d850 Remunerative employment		X		X
d870 Economic self-sufficiency				X

Table 1 (continued)

Second-level ICF category	Scoping review	Expert survey	Qualitative study	Clinical study
d880 Engagement in play			X	X
d910 Community life	X			X
d920 Recreation and leisure	X	X	X	X
Environmental factors				
e110 Products or substances for personal consumption	X	X	X	X
e115 Products and technology for personal use in daily living		X	X	X
e120 Products and technology for personal indoor and outdoor mobility and transportation				X
e125 Products and technology for communication			X	X
e130 Products and technology for education			X	X
e140 Products and technology for culture, recreation and sport			X	
e165 Assets				X
e225 Climate				X
e240 Light				X
e250 Sound		X	X	X
e310 Immediate family		X	X	X
e315 Extended family			X	X
e320 Friends			X	X
e325 Acquaintances, peers, colleagues, neighbours and community members		X	X	X
e330 People in positions of authority			X	X
e340 Personal care providers and personal assistants		X	X	X
e355 Health professionals				X
e360 Other professionals		X	X	X
e410 Individual attitudes of immediate family members		X	X	X
e415 Individual attitudes of extended family members			X	
e420 Individual attitudes of friends			X	X
e425 Individual attitudes of acquaintances, peers, colleagues, neighbours, and community members	X	X	X	X
e430 Individual attitudes of people in positions of authority			X	
e440 Individual attitudes of personal care providers and personal assistants			X	X
e450 Individual attitudes of health professionals				X
e455 Individual attitudes of other professionals		X	X	X
e460 Societal attitudes		X	X	X
e465 Social norms, practices, and ideologies				X
e535 Communication services, systems, and policies				X
e550 Legal services, systems, and policies				X
e570 Social security services, systems, and policies				X
e575 General social support services, systems, and policies				X
e580 Health services, systems, and policies		X	X	X
e585 Education and training services, systems, and policies	X	X	X	X
e590 Labour and employment services, systems, and policies			X	X
e595 Political services, systems, and policies			X	

Table 2 Composition of the Working Groups

WG 1	WG 2	WG 3	Gender	Profession	Country	WHO region
		1	Male	Nurse	Portugal	EURO
1			Female	OT	South Africa	AFRO
1			Female	OT	United Kingdom	EURO
	1		Female	OT	Sweden	EURO
		1	Female	OT	Sweden	EURO
	1		Female	PedMD	Sweden	EURO
1			Male	PT	Germany	EURO
	1		Male	PsychMed	South Africa	AFRO
		1	Male	PsychMed	Australia	WPRO
1			Male	PsychMed	Mexico	AMRO
1			Female	Psychol.	Sweden	EURO
	1		Female	Psychol.	Sweden	EURO
		1	Female	Psychol.	Sweden	EURO
		1	Female	Psychol.	Saudi Arabia	EMRO
	1		Female	Psychol.	India	SEARO
	1		Male	SW	Puerto Rico	AMRO
		1	Female	SW	United States	AMRO
1			Female	Special Ed.	India	SEARO
	1		Female	Special Ed.	Czech Republic	EURO
1			Female	SLP	Sweden	EURO

WG 1 working group 1, WG 2 working group 2, WG 3 working group 3, OT occupational therapist, PT physiotherapist, PedMed paediatrician, PsychMed psychiatrist, Psychol. psychologist, SW social worker, Special Ed special educator, SLP speech-language pathologist, AFRO Africa, EMRO Eastern Mediterranean, EURO Europe, SEARO South East Asia, AMRO The Americas, WPRO Western Pacific

($k = 8$, 17%). All five chapters of the environmental factors component were represented in the Brief Set, and 8 out of the 9 activities and participation chapters were covered; no categories of d6 domestic life were included. The three most frequently represented chapters were b1 Mental functions ($k = 7$, 15%), e4 Attitudes ($k = 7$, 15%), and e3 Support and relationships ($k = 6$, 13%).

Brief ICF Core Set for school-age children and adolescents (6–16 years old)

Table 6 displays the categories were included in the Brief Set for school-age individuals (6–16 years old), along with their final rank order. It contains 55 second-level ICF categories (including the 47 Brief Common Set categories), with the categories distributed across the activities and participation component ($k = 24$, 44%), environmental factors ($k = 23$, 42%), and body functions ($k = 8$, 14%). All five environmental factor chapters were represented. Except for d4 Mobility and d6 Domestic life, all the activities and participation chapters were also covered. The three most represented chapters were b1 Mental functions ($k = 7$, 13%), d1 Learning and applying knowledge ($k = 7$, 13%), and e4 Attitudes ($k = 7$, 13%).

Brief ICF Core Set for older adolescents and adults (≥ 17 years old)

Table 7 shows the categories that were included in the Brief ICF Core Set for older adolescents and adults (≥ 17 years old), along with their final rank order. The experts voted to include 52 second-level ICF categories for this set. Categories were mostly from the activities and participation component ($k = 24$, 46%), followed by environmental factors ($k = 21$, 40%) and body functions ($k = 7$, 14%). Contrary to the Brief Core Sets for pre-schoolers and school-age children, not all five environmental factor chapters were represented in this set; e2 Natural environment and human-made changes were not covered. In addition, b760 Control of voluntary movement functions was not included in this set. The three most covered chapters were e4 Attitudes ($k = 8$, 15%), b1 Mental functions ($k = 7$, 13%), and d8 Major life areas ($k = 6$, 12%).

Discussion

The aim of the international consensus conference described in this paper was to develop Comprehensive and Brief ICF Core Sets for ADHD based on the evidence collected

Table 3 Second-level ICF categories included in the Comprehensive ICF Core Set for ADHD across the lifespan, along with the percentage of agreement for each category that was included

Second-level ICF category	% Agreement (Vote round)
b125 Dispositions and intra-personal functions	100% (Vote B)
b130 Energy and drive functions	85% (Vote A)
b134 Sleep functions	95% (Vote A)
b140 Attention functions	100% (Vote A)
b147 Psychomotor functions	100% (Vote A)
b152 Emotional functions	85% (Vote A)
b164 Higher level cognitive functions	95% (Vote A)
b760 Control of voluntary movement functions	100% (Vote B)
d160 Focusing attention	100% (Vote A)
d161 Directing attention	90% (Vote A)
d166 Reading	100% (Vote B)
d170 Writing	100% (Vote B)
d172 Calculating	100% (Vote B)
d175 Solving problems	95% (Vote A)
d177 Making decisions	100% (Vote B)
d210 Undertaking a single task	100% (Vote A)
d220 Undertaking multiple tasks	95% (Vote A)
d230 Carrying out daily routine	95% (Vote A)
d240 Handling stress and other psychological demands	100% (Vote A)
d250 Managing one's own behaviour	95% (Vote A)
d350 Conversation	100% (Vote B)
d440 Fine hand use	65% (Vote C)
d475 Driving	95% (Vote B)
d520 Caring for body parts	100% (Vote B)
d570 Looking after one's health	100% (Vote A)
d571 Looking after one's safety	95% (Vote A)
d620 Acquisition of goods and services	100% (Vote B)
d630 Preparing meals	100% (Vote B)
d640 Doing housework	100% (Vote B)
d710 Basic interpersonal interactions	90% (Vote A)
d720 Complex interpersonal interactions	100% (Vote A)
d740 Formal relationships	95% (Vote A)
d750 Informal social relationships	95% (Vote A)
d760 Family relationships	90% (Vote A)
d770 Intimate relationships	90% (Vote A)
d820 School education	100% (Vote A)
d825 Vocational training	80% (Vote A)
d830 Higher education	100% (Vote A)
d845 Acquiring, keeping, and terminating a job	95% (Vote A)
d850 Remunerative employment	95% (Vote A)
d870 Economic self-sufficiency	90% (Vote A)
d880 Engagement in play	100% (Vote B)
d920 Recreation and leisure	95% (Vote A)
e110 Products or substances for personal consumption	100% (Vote A)
e115 Products and technology for personal use in daily living	95% (Vote A)
e125 Products and technology for communication	90% (Vote C)
e130 Products and technology for education	95% (Vote A)
e240 Light	75% (Vote C)
e250 Sound	90% (Vote A)
e310 Immediate family	95% (Vote A)
e315 Extended family	90% (Vote A)

Table 3 (continued)

Second-level ICF category	% Agreement (Vote round)
e320 Friends	100% (Vote A)
e325 Acquaintances, peers, colleagues, neighbours, and community members	100% (Vote A)
e330 People in positions of authority	100% (Vote A)
e340 Personal care providers and personal assistants	60% (Vote C)
e355 Health professionals	95% (Vote A)
e360 Other professionals	85% (Vote A)
e410 Individual attitudes of immediate family members	100% (Vote A)
e415 Individual attitudes of extended family members	85% (Vote A)
e420 Individual attitudes of friends	95% (Vote A)
e425 Individual attitudes of acquaintances, peers, colleagues, neighbours, and community members	90% (Vote A)
e430 Individual attitudes of people in positions of authority	80% (Vote A)
e440 Individual attitudes of personal care providers and personal assistants	55% (Vote C)
e450 Individual attitudes of health professionals	95% (Vote A)
e455 Individual attitudes of other professionals	100% (Vote C)
e460 Societal attitudes	95% (Vote A)
e465 Social norms, practices, and ideologies	95% (Vote A)
e570 Social security services, systems, and policies	100% (Vote B)
e575 General social support services, systems, and policies	85% (Vote A)
e580 Health services, systems, and policies	95% (Vote A)
e585 Education and training services, systems, and policies	90% (Vote A)
e590 Labour and employment services, systems, and policies	95% (Vote A)

through four international preparatory studies, i.e., a scoping review [36], an expert survey [37], a qualitative study [38], and a clinical cross-sectional study [39]. This aim was fulfilled by an international multiprofessional group of experts. The expert group decided to include categories in the Comprehensive Core Set for ADHD that highlight activities of daily living and functioning in various environments, while putting less emphasis on body functions and none on structures. The Brief Core Sets followed the same pattern, including categories taken predominantly from the activities and participation component and environmental factors. The activities and participation categories that were identified as characteristic of living with ADHD were diverse. They range from challenges with social relationships and interactions [8, 40] to academic achievement [6, 7], occupational functioning [7], and self-care [41]. Contrary to activities and participation, the body function categories were less heterogeneous, consisting mainly of b1 mental function categories. Nevertheless, physical aspects of the body, such as motor coordination, were included in the Comprehensive Core Set. This reflects the previous findings that suggest that the impact of ADHD extends beyond mental functions into other body processes, including voluntary movement functions [42].

Interestingly, during the consensus conference, the experts were generally less favourable to including body function categories in the ADHD Core Sets compared to

activities and participation categories and environmental factors. One possible explanation might be that, since the conceptualisation of ADHD has historically been rooted in a biomedical framework, with its biomedical features already described in ICD-10 [23] and DSM-5 [5], the participating experts may have perceived the development of ICF Core Sets for ADHD as a chance to incorporate personal, social, and environmental aspects of the individual in a more holistic perspective of ADHD [25, 43]. Still, however, mental functions were covered in all age-specific brief sets, supporting the notion that ADHD is a persistent neurodevelopmental condition associated with cognitive challenges [44, 45]. Notably, motor coordination was included in all core sets, except for the older adolescent and adult version. The previous research findings on ADHD have shown motor coordination issues to persist into adulthood [46]. The absence of motor coordination may be related to greater emphasis adults with ADHD and their environment place on social/relationship problems and subsequent effect on self-image and self-esteem than on the physical issues being present [47, 48]. Another explanation may be that motor coordination issues generally receive less attention in clinical practice compared to cognitive impairments [49].

In this bio-psycho-social perspective of ADHD, environmental factors seem to play an important role, as evidenced by the composition of the 5 core sets, i.e., each of the core sets is composed of at least 40% environmental

Table 4 Second-level ICF categories included in the Common Brief ICF Core Set for ADHD across the lifespan, along with their final rank order per ICF component

Second-level ICF category	Final rank order (1 = most essential)
b125 Dispositions and intra-personal functions	(6)
b130 Energy and drive functions	(2)
b134 Sleep functions	(5)
b140 Attention functions	(1)
b147 Psychomotor functions	(7)
b152 Emotional functions	(4)
b164 Higher level cognitive functions	(3)
d160 focusing attention	(1)
d161 Directing attention	(2)
d175 Solving problems	(12)
d177 Making decisions	(9)
d220 Undertaking multiple tasks	(10)
d230 Carrying out daily routine	(6)
d240 Handling stress and other psychological demands	(8)
d250 Managing one's own behaviour	(7)
d571 Looking after one's safety	(11)
d710 Basic interpersonal interactions	(13)
d720 Complex interpersonal interactions	(4)
d760 Family relationships	(3)
d820 School education	(5)
d920 Recreation and leisure	(14)
e110 Products or substances for personal consumption	(4)
e115 Products and technology for personal use in daily living	(9)
e310 Immediate family	(1)
e315 Extended family	(8)
e320 Friends	(5)
e330 People in positions of authority	(13)
e355 Health professionals	(10)
e410 Individual attitudes of immediate family members	(6)
e415 Individual attitudes of extended family members	(17)
e430 Individual attitudes of people in positions of authority	(15)
e450 Individual attitudes of health professionals	(16)
e460 Societal attitudes	(3)
e465 Social norms, practices, and ideologies	(11)
e570 Social security services, systems, and policies	(12)
e575 General social support services, systems, and policies	(14)
e580 Health services, systems, and policies	(7)
e585 Education and training services, systems, and policies	(2)

factors and 4 out of the 5 core sets cover all the environmental factor chapters. This is consistent with research that highlight selected environmental factors relevant in ADHD [17–19], argue for a better understanding of the environment factors that influence functional outcomes in ADHD [50, 51], and promote interventions that help individuals with ADHD to more optimally perform in key environmental contexts [52], such as education [53], vocation [54], and community participation [9].

There were some commonalities and differences with regard to environmental factor representation in the different age-specific sets. Common in all age-specific brief sets is category e575 General social support services, systems, and policies, which demonstrates the importance of access to support services for the functioning of individuals with ADHD across the lifespan [50]. Principally, support services, systems, and policies, including social security, health, and education, were deemed important, as evidenced

Table 5 Second-level ICF categories included in the Brief ICF Core Set for preschool aged children (0–5 years old), along with their final rank order per ICF component

Second-level ICF category	Final rank order (1 = most essential) ^a
b125 Dispositions and intra-personal functions	
b130 Energy and drive functions	
b134 Sleep functions	
b140 Attention functions	
b147 Psychomotor functions	(1)
b152 Emotional functions	
b164 Higher level cognitive functions	
b760 Control of voluntary movement functions	(2)
d160 Focusing attention	
d161 Directing attention	
d175 Solving problems	
d177 Making decisions	
d210 Undertaking a single task	(3)
d220 Undertaking multiple tasks	
d230 Carrying out daily routine	
d240 Handling stress and other psychological demands	
d250 Managing one's own behaviour	
d350 Conversation	(6)
d440 Fine hand use	(5)
d571 Looking after one's safety	
d710 Basic interpersonal interactions	(1)
d720 Complex interpersonal interactions	
d750 Informal social relationships	(4)
d760 Family relationships	
d820 School education	
d880 Engagement in play	(2)
d920 Recreation and leisure	(7)
e110 Products or substances for personal consumption	
e115 Products and technology for personal use in daily living	
e250 Sound	(5)
e310 Immediate family	
e315 Extended family	
e320 Friends	
e330 People in positions of authority	
e340 Personal care providers and personal assistants	(6)
e355 Health professionals	
e410 Individual attitudes of immediate family members	
e415 Individual attitudes of extended family members	(1)
e430 Individual attitudes of people in positions of authority	(3)
e440 Individual attitudes of personal care providers and personal assistants	(7)
e450 Individual attitudes of health professionals	(4)
e460 Societal attitudes	
e465 Social norms, practices, and Ideologies	
e570 Social security services, systems, and policies	
e575 General social support services, systems, and policies	(2)
e580 Health services, systems, and policies	
e585 Education and training services, systems, and policies	

^aThe rank order here does not comprise the categories that were included in the Brief Common Set

Table 6 Second-level ICF categories included in the Brief ICF Core Set for school-aged children and adolescents of 6–16 years old, along with their final rank order per ICF component

Second-level ICF category	Final rank order (1 = most essential) ^a
b125 Dispositions and intra-personal functions	
b130 Energy and drive functions	
b134 Sleep functions	
b140 Attention functions	
b147 Psychomotor functions	(1)
b152 Emotional functions	
b164 Higher level cognitive functions	
b760 Control of voluntary movement functions	(2)
d160 Focusing attention	
d161 Directing attention	
d166 Reading	(3)
d170 Writing	(4)
d172 Calculating	(8)
d175 Solving problems	
d177 Making decisions	
d210 Undertaking a single task	(2)
d220 Undertaking multiple tasks	
d230 Carrying out daily routine	
d240 Handling stress and other psychological demands	
d250 Managing one's own behaviour	
d350 Conversation	(7)
d520 Caring for body parts	(12)
d570 Looking after one's health	(11)
d571 Looking after one's safety	
d710 Basic interpersonal interactions	(1)
d720 Complex interpersonal interactions	
d740 Formal relationships	(9)
d750 Informal social relationships	(5)
d760 Family relationships	
d820 School education	
d880 Engagement in play	(10)
d920 Recreation and leisure	(6)
e110 Products or substances for personal consumption	
e115 Products and technology for personal use in daily living	
e125 Products and technology for communication	(7)
e130 Products and technology for education	(1)
e240 Light	(10)
e250 Sound	(9)
e310 Immediate family	
e315 Extended family	
e320 Friends	
e325 Acquaintances, peers, colleagues, neighbours, and community members	(8)
e330 People in positions of authority	
e355 Health professionals	
e410 Individual attitudes of immediate family members	
e415 Individual attitudes of extended family members	(3)
e420 Individual attitudes of friends	(2)
e430 Individual attitudes of people in positions of authority	(4)
e450 Individual attitudes of health professionals	(6)

Table 6 (continued)

Second-level ICF category	Final rank order (1 = most essential) ^a
e460 Societal attitudes	
e465 Social norms, practices, and ideologies	
e570 Social security services, systems, and policies	
e575 General social support services, systems, and policies	(5)
e580 Health services, systems, and policies	
e585 Education and training services, systems, and policies	

^aThe rank order here does not comprise the categories that were included in the brief common set

by the inclusion of corresponding categories in the Common Brief Set. This is especially relevant when considering the transition of adolescents with ADHD to adulthood, as health care and intervention programs appropriate for individuals with ADHD undergoing this period of transition are limited [55, 56]. Another common representation is the environmental factor chapter e4 Attitudes that was covered in each respective age-specific set. This may reflect the notion that ADHD is still not fully accepted as a legitimate medical condition by affected families and a large portion of society [57–59]. A key difference that was found between the different age-specific brief sets was the lack of categories from the e2 Natural environment and human-made changes to environment chapter (i.e., sound, light) in the older adolescent and adult version. This is supported by literature which indicates that older adolescents and adults with ADHD seem to develop over time certain coping strategies that help them to become less susceptible to loud noises or bright lights [60]. To understand the complex interplay between abilities and disabilities with age as a modifier better, further research is needed.

The environmental factors included in the ADHD Core Sets can be useful in describing possible facilitators and barriers of functioning in various environments. However, they may not be comprehensive or detailed enough for optimal applicability in interventions. For example, e310 Immediate family, e315 Extended family, and e330 People in positions of authority are insufficiently detailed for an accurate assessment of an individual's social supports [61]. Despite this, the ADHD Core Sets can facilitate awareness raising about the value of environmental factors, especially in encouraging the ADHD community to explore existing attitudes and social beliefs [62, 63]. This is especially relevant when considering cultural differences. Although symptoms of neurodevelopmental disorders may be similar across cultures, the way that symptoms are perceived, interpreted, or accepted is not [64]. Taking this into account, as well as WHO's push for internationality, efforts were made to ensure that cultural and attitudinal differences were considered in developing the ICF Core Sets for ADHD. Equipping stakeholders with

useful tools that can also be applied in exploring the attitudinal environment of individuals with ADHD may enable them to more effectively identify and address environmental barriers, such as social stigma, with knowledge transfer and other interventions.

Despite the numerous advantages of recognizing environmental factors, these have been neglected by the common standardised process of diagnosing ADHD. For example, the two major diagnostic systems, ICD-10 [21] and DSM-5 [5], do not take environmental factors into account. Interestingly, individuals diagnosed with ADHD and their caregivers seem to emphasize the importance of environmental factors more than other stakeholders as shown by the comparison of the qualitative study results [38] with the results of the scoping review [36] and expert survey [37].

Study limitations

There were some challenges faced in developing the ADHD Core Sets that deserve attention, most of which have also been discussed in the publications on the preparatory studies [36–39]. First, although all six WHO world regions were represented in the preparatory studies and in the international consensus conference, parts of the world were not equally represented, potentially causing a risk that culture-sensitive categories were overlooked. For example, there was considerable difficulty to identify and recruit ADHD experts from different parts of the world, e.g., Africa other than South Africa, to participate in the consensus conference. To address this issue, the conference participants were regularly reminded to discuss country and culture-specific aspects that may impact the applicability of the ICF Core Sets for ADHD and consider these aspects in their voting decisions.

Second, despite efforts to achieve a broad representation of disciplines, some professional groups were underrepresented. For instance, few speech-language pathologists and nurses participated in the consensus conference. Perhaps, the reason for the relatively low number of categories related to language development or gastrointestinal functions.

Table 7 Second-level ICF categories included in the Brief ICF Core Set for older adolescents and adults (≥ 17 years old), along with their final rank order per ICF component

Second-level ICF category	Final rank order (1 = most essential) ^a
b125 Dispositions and intra-personal functions	
b130 Energy and drive functions	
b134 Sleep functions	
b140 Attention functions	
b147 Psychomotor functions	(1)
b152 Emotional functions	
b164 Higher level cognitive functions	
d160 Focusing attention	
d161 Directing attention	
d175 Solving problems	
d177 Making decisions	
d220 Undertaking multiple tasks	
d230 Carrying out daily routine	
d240 Handling stress and other psychological demands	
d250 Managing one's own behaviour	
d475 Driving	(10)
d570 Looking after one's health	(2)
d571 Looking after one's safety	
d640 Doing housework	(11)
d710 Basic interpersonal interactions	(5)
d720 Complex interpersonal interactions	
d740 Formal relationships	(6)
d760 Family relationships	
d770 Intimate relationships	(1)
d820 School education	
d825 Vocational training	(9)
d830 Higher education	(7)
d845 Acquiring, keeping and terminating a job	(3)
d850 Remunerative employment	(12)
d870 Economic self-sufficiency	(4)
d920 Recreation and leisure	(8)
e110 Products or substances for personal consumption	
e115 Products and technology for personal use in daily living	
e125 Products and technology for communication	(4)
e310 Immediate family	
e315 Extended family	
e320 Friends	
e330 People in positions of authority	
e355 Health professionals	
e410 Individual attitudes of immediate family members	
e415 Individual attitudes of extended family members	(8)
e420 Individual attitudes of friends	(2)
e425 Individual attitudes of acquaintances, peers, colleagues, neighbours, and community members	(7)
e430 Individual attitudes of people in positions of authority	(6)
e450 Individual attitudes of health professionals	(5)
e460 Societal attitudes	
e465 Social norms, practices, and ideologies	
e570 Social security services, systems, and policies	

Table 7 (continued)

Second-level ICF category	Final rank order (1 = most essential) ^a
e575 General social support services, systems, and policies	(1)
e580 Health services, systems, and policies	
e585 Education and training services, systems, and policies	
e590 Labour and employment services, systems, and policies	(3)

^aThe rank order here does not comprise the categories that were included in the brief common set

Finally, while individuals with ADHD and family members were involved in the preparatory studies to capture their unique views and experiences, they were not expressly recruited to be part of the consensus conference. Since shared decision-making between researchers and stakeholders in neurodevelopmental disorders is desirable, future research should actively recruit the input of individuals with ADHD and family [65, 66].

Applications of the ICF Core Sets for ADHD

A novel and integral part of the diagnostic procedures and criteria recommended for ADHD in the upcoming ICD-11 is the use of ICF categories to describe the impact of a health condition on individual functioning [25]. The ICF Core Sets for ADHD may potentially guide the selection of categories used in the ICD-11, hereby marking a paradigm shift in the diagnostic assessment of ADHD. If realised, the international operationalisation of ADHD will not only disorder-based, but also contain functioning-related health information that can be used to reflect the unique situation of the patient. The ICF Core Sets for ADHD can enrich diagnostic decision-making and treatment planning with a broad range of information that considers relevant environmental factors and the specific needs of the individual.

Another area of application may be resource allocation. With the ICF, and the Core Sets derived from it, it is possible to describe an individual's strengths and ADHD-associated functioning problems in a comprehensive and individualised manner. With this in mind, the ICF and ICF Core Sets can serve as a guide to more individualised rather than a solely diagnosis-based resource allocation and reimbursement in health care and in education [29, 67, 68].

To increase the utility of the ADHD Core Sets in these and other application areas, it would be advisable to develop standardised user-friendly ICF Core Set-based tools, such as a questionnaire with a scale that apply established measurement standards, or observation schedules and interviews. Comparable with scales derived from ICD-10 or DSM-5 diagnostic criteria, practitioners may find using the ADHD Core Sets easier and more practical in a form that they are familiar with, such as a questionnaire or interview

instrument. An example of an ICF Core Set-based instrument is the ASAS Health Index for spondyloarthritis [69]. Another clinical and research application of the ICF Core Sets is the toolbox of psychometrically sound measures that cover the content of the ICF Core Sets for children and youth with cerebral palsy. This toolbox lays the groundwork for standardising the measurement and reporting of functioning information in cerebral palsy and for facilitating the comparison of study results from all over the world [70]. Beyond developing tangible tools for clinical use and research, we envision the ICF Core Sets for ADHD as a driver of service quality improvement and functioning, informed policy-making at the local, regional, and national levels.

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