


# 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

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## Abstract

Autism spectrum disorder is associated with diverse social, educational, and occupational challenges. To date, no standardized, internationally accepted tools exist to assess autism spectrum disorder–related functioning. World Health Organization’s International Classification of Functioning, Disability and Health can serve as foundation for developing such tools. This study aimed to identify a comprehensive, a common brief, and three age-appropriate brief autism spectrum disorder Core Sets. Four international preparatory studies yielded in total 164 second-level International Classification of Functioning, Disability and Health candidate categories. Based on this evidence, 20 international autism spectrum disorder experts applied an established iterative decision-making consensus process to select from the candidate categories the most relevant ones to constitute the autism spectrum disorder Core Sets. The consensus process generated 111 second-level International Classification of Functioning, Disability and Health categories in the Comprehensive Core Set for autism spectrum disorder—one body structure, 20 body functions, 59 activities and participation categories, and 31 environmental factors. The Common Brief Core Set comprised 60 categories, while the age-appropriate core sets included 73 categories in the preschool version (0- to 5-year-old children), 81 in the school-age version (6- to 16-year-old children and adolescents), and 79 in the older adolescent and adult version ( $\geq 17$ -year-old individuals). The autism spectrum disorder Core Sets mark a milestone toward the standardized assessment of autism spectrum disorder–related functioning in educational, administrative, clinical, and research settings.

## Keywords

autism spectrum disorder, assessment, consensus conference, disability, functioning, International Classification of Functioning, Disability and Health core sets

## Introduction

Autism spectrum disorder (ASD) is an early onset neurodevelopmental condition characterized by altered social

communication and interaction, alongside restricted and stereotyped behaviors and interests, causing significant

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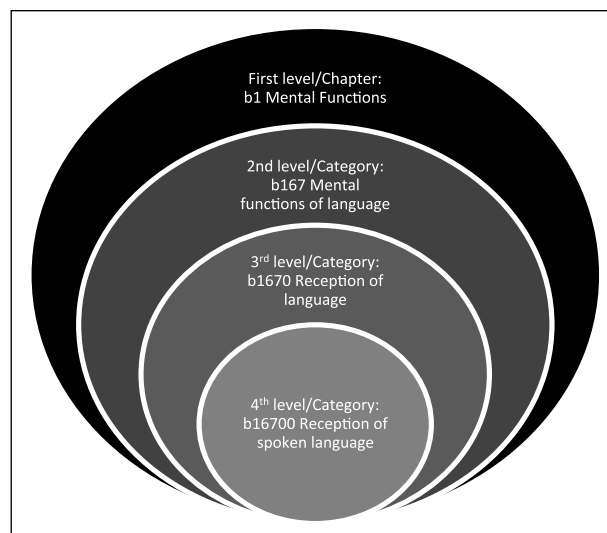
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functional impairment (American Psychiatric Association (APA), 2013). The estimated prevalence of ASD is 1%–2% (Baxter et al., 2015; Centers for Disease Control and Prevention (CDC), 2016; Idring et al., 2015). Individuals with ASD face challenges in education (Levy and Perry, 2011), employment (Howlin et al., 2013), social relationships (Schmidt et al., 2015), self-care (Du et al., 2015), and domestic life (Fortuna et al., 2015). Physical (Cashin et al., 2016) and psychiatric (Joshi et al., 2013; Salazar et al., 2015) comorbidity is also common in ASD, and premature death of individuals with ASD is more likely than in the general population (Hirvikoski et al., 2016). Moreover, life satisfaction is low in many individuals with ASD (Jonsson et al., 2017; Van Heijst and Geurts, 2015). Nevertheless, there is a considerable variation in individual levels of functioning and consequent outcomes. Factors known to contribute to variable outcomes in ASD include intelligence (Kirby et al., 2016), socio-demographic background (Fountain et al., 2012), and accessibility to services such as evidence-based treatments (Dawson et al., 2012; Fein et al., 2017) and family support (Woodman et al., 2015). While ASD has traditionally been viewed predominantly from a phenomenological perspective, research findings endorse the necessity to appraise ASD from a broader perspective than its current behavioral definition, taking into account personal, social, and environmental factors of health-related functioning. The bio-psycho-social model of the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) provides a comprehensive, integrated framework for functional ability and disability to address this need (WHO, 2001). Complementary to the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; APA, 2013) and the International Classification of Diseases–Tenth Revision (ICD-10) (WHO, 1992), both of which classify health conditions and focus on the biomedical elements of disability, the ICF promotes a more holistic perspective of disability by systemizing functioning and factors that influence everyday life outcomes (WHO, 2001). The ICF consists of two parts—(a) functioning and disability and (b) contextual factors. Functioning and disability take into account 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 include environmental factors (i.e. factors not inherent to the individual, for example, family, work, recreational opportunity, government agencies, laws, societal attitudes) as well as personal factors (i.e. personal experience, race, gender, age, educational level, coping styles). Although personal factors are part of the ICF framework, these are currently not classified in the nomenclature given their large cultural and social variability (WHO, 2001). All other components of the ICF are structured into “chapters” that comprise hierarchically



**Figure 1.** Example of the hierarchically organized category structure of the ICF.

organized “categories” with up to three levels of increasing detail. This is demonstrated by an example from the body functions component in Figure 1.

Since 2007, a Child and Youth version of the ICF, the ICF-CY, has been available that additionally captures functional characteristics and environments of developing individuals (WHO, 2007). This version of the ICF encompasses all the categories of the reference version of the ICF plus additional ones for children and youth, comprising 1685 categories: 531 in body functions component, 329 body structures, 552 activities and participation, and 273 environmental factors. For the development of the ICF core sets for ASD described here, we therefore selected to use the more comprehensive child and youth version.

The use of ICF may foster an approach of managing ASD that emphasizes individual abilities, disabilities, and the context that has an impact on the individual’s functioning. This approach is potentially meaningful for several reasons (Bölte, 2009; Escorpizo et al., 2013). First, not only is functioning often perceived as less stigmatizing than psychopathology or diagnosis, but problems in functioning are also often the reason for initial referral to services and focus for interventions rather than psychopathology itself. Given this, aspects of functioning are likely to be more tangible and meaningful than psychopathology/diagnosis to individuals with ASD, their families, and society as a whole. Aspects of functioning are also well suited to describe an individual’s real-life challenges and to guide individual intervention planning (Castro and Pinto, 2013). A functional lens may enable better calculation of health-related service costs (Hopfe et al., 2017; Schraner et al., 2008). Finally, individual descriptions of functional abilities and disabilities may also enhance communication between individuals on the autism spectrum, their environment, and

experts. The ICF highlights the influence of the environment, stressing its positive and negative role in influencing outcome. Recognizing that environmental factors influence an individual's outcome provides an opportunity to change those factors toward outcome improvement. It is also important to note that the ICF offers a framework to assess strengths, rather than just disability.

There are also some challenges to applying the ICF—particularly its continued limited prominence and acceptance by professionals and researchers, and its exhaustive comprehensiveness which makes it difficult and time-consuming for daily use. In practice, only a fraction of the ICF categories is needed when evaluating functioning of individuals with specific health conditions. To address these concerns, the development of ICF Core Sets was initiated (Selb et al., 2015) to generate shortlists of ICF categories pertinent to specific health conditions.

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 four international, multi-perspective preparatory studies: systematic literature review, an expert survey, a qualitative study and a clinical study, and a multidisciplinary and expertise-based decision-making and consensus (conference) process (Selb et al., 2015).

ICF Core Sets have been developed for diagnoses such as cerebral palsy (Schiariti et al., 2015), depression (Cieza et al., 2004), and bipolar disorder (Ayuso-Mateos et al., 2013), but not yet for any DSM-5 defined neurodevelopmental disorders. For this reason, the development of standardized ICF Core Sets for ASD (Bölte et al., 2014) has been initiated. The objective of this article is to provide a summary of the results of the four preparatory studies and the international consensus conference, where the first versions of the ICF Core Sets for ASD were developed.

## Method

### Process

The first version of the ICF Core Sets for ASD was decided at the consensus conference by a multi-professional and international group of participants, who based their decision on their expertise and on evidence generated in four preparatory studies: a systematic literature review, expert survey, qualitative study, and clinical study. Each preparatory study produced a set of candidate categories, that is, a selection of ICF categories that represented the different perspectives captured in each of the studies. Throughout the decision-making and consensus process during the conference, the participants were reminded to consider the preparatory studies results in their discussions and in the final decision.

### Preparatory studies

The study designs and methodologies were different in each of the preparatory studies, but candidate categories were identified similarly. After extracting functioning concepts from the respective datasets collected in each study, concepts were linked to the ICF categories using established ICF linking rules (Cieza et al., 2005) and a frequency analysis was done. The most frequently reported categories in each study were included in the list of candidate categories for that study. In the systematic literature review, functioning data were gathered from 71 ASD-related outcome studies that were identified through systematic searches on scientific databases (e.g. Medline, PubMed, CINAHL) (De Schipper et al., 2015). The international survey of ASD experts collected the views and opinions of 225 experts across 10 professional disciplines from 43 countries and all WHO world regions (De Schipper et al., 2016). The qualitative study involved focus group discussions and semi-structured interviews of individuals with ASD, family members, and professional caregivers from 19 stakeholder groups in five countries from five WHO world regions (Mahdi et al., 2017a). Unlike the other preparatory studies, employing the ICF linking rules was not necessary to identify the candidate categories in the clinical cross-sectional study (Mahdi et al., 2017b). In this study, the extended ICF checklist that clinicians and clinical researchers used to gather data from 122 individuals with ASD recruited at 11 clinical sites in 10 countries in four different WHO world regions already defined an ICF category for each checklist item. A detailed description of each study can be found in separate scientific publications. Ethical approval was obtained for each respective preparatory study and informed consent was acquired (both in written and verbal form) from each participant who took part in the preparatory studies.

### Consensus conference

**Participants.** To generate the first ICF Core Sets for ASD, international experts were invited to participate in a 3-day iterative decision-making process at a consensus conference that took place in Stockholm (Sweden) in September 2016. Experts had to meet the following inclusion criteria to be eligible for conference participation: (a) a professional background in childhood disability, which included psychiatry, psychology, psychotherapy, social work, special education, speech-language pathology, nursing, occupational therapy, pediatrics, and physiotherapy; (b) at least 5 years of working experience with infants, children, adolescents, or adults with ASD; and (c) fluency in English. The nomination of experts was predominately made by the Project Steering Committee, who were a group of key opinion leaders in the field of ASD or experts in the ICF. The Steering Committee included clinicians, educators,

researchers, and self-advocates from all six WHO world regions (see “Acknowledgements” and authors). To achieve a broad representation of professional backgrounds and WHO world regions, Steering Committee members were asked to nominate experts who matched their own professional field and WHO world region. In total, 29 invitations were sent to international ASD experts to participate in the consensus conference.

**Procedure.** The consensus conference followed an iterative standardized decision-making and consensus (voting) process established for ICF Core Set development with an adaptation for age-specific groupings (Figure 2) (Selb et al., 2015) and employed a specialized data analysis program in MS Office Access. This program displayed the candidate categories from each preparatory study, including category descriptions and corresponding frequencies, tracked the expert votes, and generated summary results that informed the subsequent steps of the voting procedure. In accordance with previous ICF Core Set projects, a Comprehensive and a Brief (Common) ICF Core Set were developed (Cieza et al., 2004; Schiariti et al., 2015). In addition, based on a decision made by the Steering Committee, three age-specific brief sets were also developed: a preschool set (aged 0–5 years), a school-age set (aged 6–16 years), and an older adolescent and adult set for individuals 17 years old and older. The iterative voting process comprised two stages which led to the development of the comprehensive version of the ICF Core Set for ASD (Stage 1), and the brief version (Stage 2). Stage 1 was done by alternating discussions and voting in working group (WG) (Votes A and B) and plenary sessions (Votes C to E).

For the WG discussions and voting of Votes A and B, the ASD experts were divided into three groups of six or seven participants. Participants remained in the same WG throughout Stage 1. In the construction 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. Each WG also had two assistants who presented the candidate categories from the preparatory studies, took discussion notes, and entered the voting results in the data analysis program. The WG leader fostered discussion on the pros and cons of including individual candidate categories, and encouraged the experts to consider not only the preparatory study results, their own expertise in ASD, but also country and cultural applicability. Since the WG leader was allowed to vote, he or she was instructed to maintain objectivity and ensure that all opinions were heard before voting. To avoid leader bias, the WG leader was also instructed to wait with giving feedback until after several members have already provided their comments. The voting was conducted openly by a show of hands.

Consistent with previous ICF Core Set projects (Ayuso-Mateos et al., 2013; Schiariti et al., 2015), consensus agreement for automatic inclusion of individual categories in the Comprehensive Core Set for ASD in Votes A and B was set at  $\geq 75\%$ , meaning that at least three-fourths of the experts had to vote in favor of including a category for it to be part of the comprehensive set. Categories that received 40% positive votes or fewer were directly 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. Between the WG sessions (or Votes A and B), a plenary session took place to review Vote A results and to enable the participants to present arguments in favor of or against 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, a majority ( $>50\%$ ) of the participants had to vote 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 ASD were at the 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 ASD or “dive deeper,” that is, consider replacing the second-level category with the respective third- or fourth-level categories for more specificity. The latter would have taken place in Vote E. Fewer than 50% of the experts voted for “dive deeper” ( $n=16$ ; 20%) and Vote E was therefore not used. Completion of Stage 1 consequently led to the Comprehensive ICF Core Set for ASD.

Stage 2 marked the development of the Brief Common Set and the three age-specific brief sets, involving 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 round of developing the Common Brief Set, each expert received a handout with all the categories from the Comprehensive Core Set for ASD organized 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 analyzed using descriptive statistics and combined to generate a common ranking. After each ranking round, the common ranking was presented and the participating experts had the opportunity to discuss reasons for their ranking decision and to argue for the inclusion of selected categories. The latter was important, since they were required after both ranking rounds to choose a cut-off, that is, the number of categories per ICF component that would be crucial to include in the Brief Common Set.

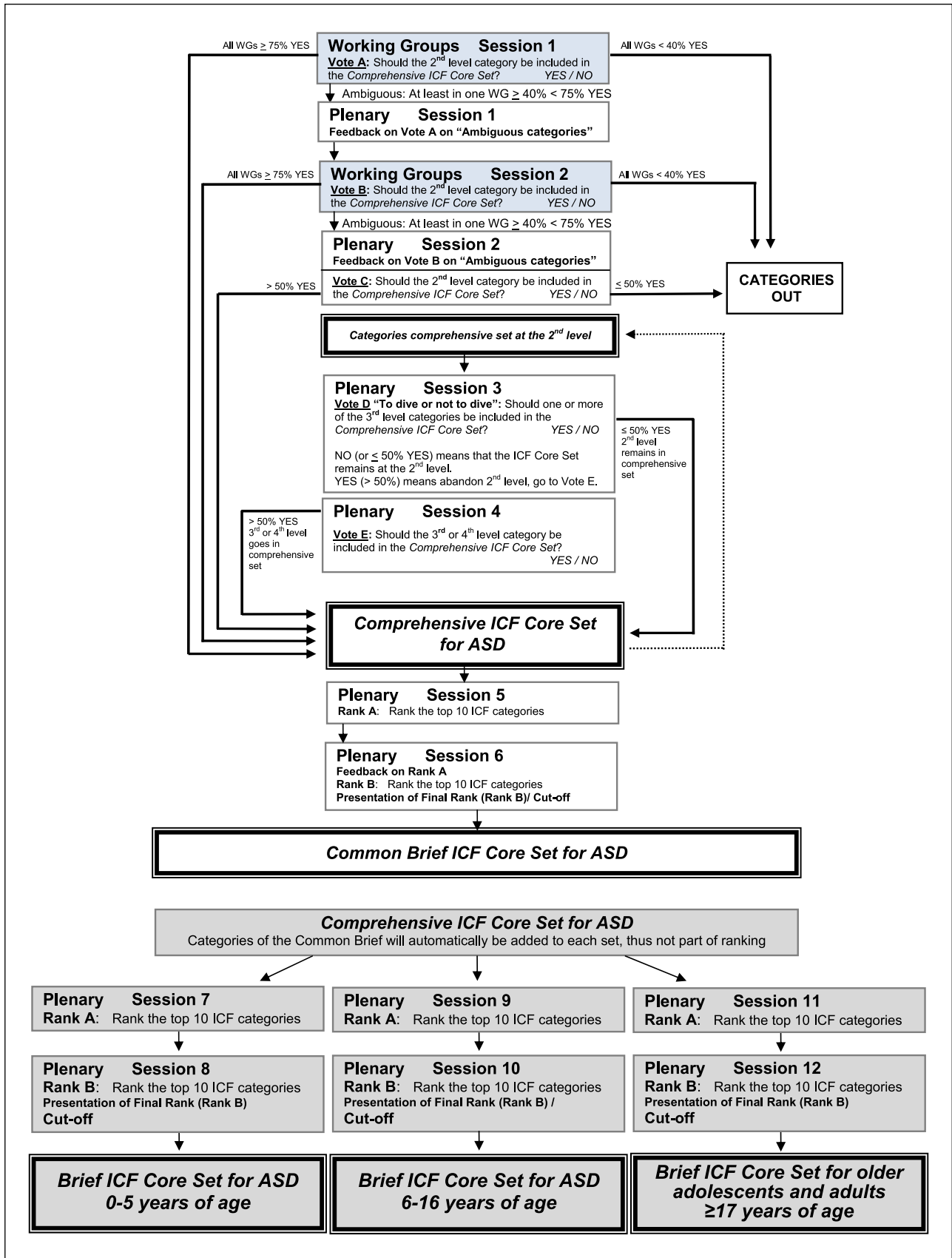


Figure 2. The iterative decision-making process at the consensus meeting.

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 voted into all of the three age-specific brief sets were included retrospectively in the Brief Common Set.

## Results

The systematic literature review identified 80 (De Schipper et al., 2015), the international survey 77 (De Schipper et al., 2016), the qualitative study 110 (Mahdi et al., 2017a), and the clinical cross-sectional study 133 second-level candidate categories (Mahdi et al., 2017b). Taken together, the four preparatory studies identified 164 unique second-level ICF candidate categories. The majority of the candidate categories came from the activities and participation component ( $k=78$ , 48%), followed by body functions ( $k=43$ , 26%), environmental factors ( $k=39$ , 24%), and body structures ( $k=4$ , 2%). Table 1 summarizes the second-level candidate ICF categories that were identified across the four preparatory studies.

### *Consensus conference participants*

Of the 29 experts who were invited to participate in the international consensus conference, four declined due to other commitments and five did not respond to the invitation. In total, 20 experts (14 females and 6 males) from 11 countries (Germany, India, Israel, Japan, Mexico, The Netherlands, Saudi Arabia, South Africa, Sweden, United Kingdom, and United States) representing all WHO world regions participated in the consensus conference (see “Acknowledgements”). Table 2 summarizes the participating experts by WG, gender, professional background, country, and WHO world region.

### *Comprehensive ICF Core Set for individuals with ASD*

Table 3 shows the categories included in the Comprehensive ICF Core Set for ASD. Of the 164 second-level candidate categories that were identified in the preparatory studies, 111 (68%) were included in the Comprehensive Core Set. A large majority of the categories in the Comprehensive Core Set were from the activities and participation component ( $n=59$ , 53%), followed by environmental factors ( $n=31$ , 28%) and body functions ( $n=20$ , 18%). Only one body structure (structure of the brain) (1%) was 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. Most of the body function categories were mental functions, followed by aspects of physical and sensory functions. The three most frequently represented chapters were b1 Mental

functions ( $n=15$ , 14%), d1 Learning and applying knowledge ( $n=15$ , 14%), and e5 Services, systems, and policies ( $n=9$ , 8%).

### *Common Brief ICF Core Set for individuals with ASD*

Table 4 lists the 60 second-level ICF categories that were included in the Common Brief Set for ASD. The 60 categories comprised the 46 categories that were included following the initial ranking and cut-off process and an additional 14 categories that were found to be common in all of the age-specific brief sets. The Common Brief Set categories came from the environmental factors component ( $n=23$ , 38%), activities and participation ( $n=19$ , 32%), and body functions ( $n=18$ , 30%). The most frequently covered chapters in the Common Brief Set were b1 Mental functions ( $n=15$ , 25%), e3 Support and relationships ( $n=7$ , 12%), e4 Attitudes ( $n=6$ , 10%), and e5 Services, systems, and policies ( $n=6$ , 10%).

### *Brief ICF Core Set for preschool age children (0–5 years)*

Table 5 summarizes the categories that were included in the brief set for preschool age group of 0–5 years. This specific Brief Set comprised 73 second-level ICF categories, of which 60 were from the Brief Common Set. Twenty-nine categories (40%) were from the activities and participation component, 25 (34%) were environmental factors, and 19 (26%) were body functions. All five chapters of the environmental factors component were covered, while the activities and participation did not cover d4 Mobility and d6 Domestic life. Enclosed body functions consisted mainly of mental functions. The three most represented chapters were b1 Mental functions ( $n=15$ , 21%), d1 Learning and applying knowledge ( $n=8$ , 11%), and e3 Support and relationships ( $n=7$ , 10%).

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

Table 6 displays the categories that were included in the Brief ICF Core Set for school-age individuals (6–16 years). It contains 81 categories (including the 60 Brief Common Set categories), with the categories distributed across the activities and participation component ( $n=36$ , 45%), environmental factors ( $n=27$ , 33%), and body functions ( $n=18$ , 22%), whereby all five environmental factor chapters were represented. Except for d6 Domestic life, all the activities and participation chapters were covered. Regarding body functions, mental functions and physical aspects of the body, such as motor skills and voice functions, were included in this brief set. The three most represented chapters in this set were b1 Mental functions ( $n=15$ , 19%), d1 Learning and applying knowledge ( $n=13$ , 16%), and e3 Support and relationships ( $n=8$ , 10%).

**Table 1.** The candidate ICF categories from each respective preparatory study.

Second-level ICF category	Systematic review	Expert survey	Qualitative study	Clinical study
<i>Body function</i>				
b110 Consciousness functions	X			
b114 Orientation functions	X		X	X
b117 Intellectual functions	X	X	X	X
b122 Global psychosocial functions	X	X	X	X
b125 Dispositions and intra-personal functions	X	X	X	X
b126 Temperament and personality functions	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	X
b163 Basic cognitive functions	X	X	X	X
b164 Higher level cognitive functions		X	X	X
b167 Mental functions of language	X	X	X	X
b172 Calculation functions			X	X
b176 Mental function of sequencing complex movements		X		
b180 Experience of self and time functions	X	X	X	X
b210 Seeing functions		X	X	X
b230 Hearing functions		X	X	X
b235 Vestibular functions		X		X
b250 Taste function		X	X	X
b255 Smell function		X	X	X
b260 Proprioceptive function		X		
b265 Touch function		X	X	X
b270 Sensory functions related to temperature and other stimuli		X	X	X
b280 Sensation of pain	X		X	X
b310 Voice functions				X
b320 Articulation functions	X			X
b330 Fluency and rhythm of speech functions	X	X		X
b435 Immunological systemfunctions				X
b455 Exercise tolerance functions			X	
b510 Ingestion functions			X	
b515 Digestive functions			X	
b525 Defecation functions			X	X
b530 Weight maintenance functions			X	X
b730 Muscle power functions				X
b735 Muscle tone functions		X		X
b760 Control of voluntary movement functions	X	X	X	X
b765 Involuntary movement functions	X	X	X	X
b770 Gait pattern functions		X	X	X
<i>Body structures</i>				
s110 Structure of brain		X	X	
s320 Structure of mouth			X	
s540 Structure of intestine		X		
s750 Structure of lower extremity			X	
<i>Activities and participation</i>				
d110 Watching	X			X
d115 Listening				X
d130 Copying	X	X	X	X

(Continued)

Table 1. (Continued)

Second-level ICF category	Systematic review	Expert survey	Qualitative study	Clinical study
d132 Acquiring information	X		X	X
d134 Acquiring additional language	X			
d137 Acquiring concepts	X			
d140 Learning to read	X			X
d145 Learning to write	X			X
d150 Learning to calculate				X
d155 Acquiring skills	X			
d160 Focusing attention	X			X
d161 Directing attention	X		X	X
d163 Thinking	X			X
d166 Reading	X		X	X
d170 Writing	X			
d172 Calculating	X		X	X
d175 Solving problems				X
d177 Making decisions	X	X	X	X
d210 Undertaking a single task	X		X	X
d220 Undertaking multiple tasks	X	X		X
d230 Carrying out daily routine	X	X	X	X
d240 Handling stress and other psychological demands	X	X	X	X
d250 Managing one's own behavior	X	X	X	X
d310 Communicating with—receiving—spoken messages	X	X	X	X
d315 Communicating with—receiving—nonverbal messages	X	X	X	X
d330 Speaking	X	X	X	X
d331 Pre-talking	X			
d335 Producing nonverbal messages	X	X	X	X
d345 Writing messages			X	
d350 Conversation	X	X	X	X
d360 Using communication devices and techniques	X		X	X
d410 Changing basic body position	X			
d415 Maintaining a body position	X			
d430 Lifting and carrying objects	X			X
d435 Moving objects with lower extremities	X			
d440 Fine hand use	X	X	X	X
d445 Hand and arm use	X			
d446 Fine foot use		X	X	X
d450 Walking	X			
d455 Moving around	X		X	X
d465 Moving around using equipment				X
d470 Using transportation	X		X	X
d475 Driving	X		X	X
d510 Washing oneself	X	X	X	X
d520 Caring for body parts	X	X	X	X
d530 Toileting	X	X	X	X
d540 Dressing	X	X	X	X
d550 Eating	X	X	X	X
d560 Drinking	X			X
d570 Looking after one's health	X	X	X	X
d571 Looking after one's safety	X	X		X
d620 Acquisition of goods and services			X	X
d630 Preparing meals	X		X	X
d640 Doing housework	X		X	X
d650 Caring for household objects	X			
d660 Assisting others	X			X



**Table 1.** (Continued)

Second-level ICF category	Systematic review	Expert survey	Qualitative study	Clinical study
d710 Basic interpersonal interactions	X	X	X	X
d720 Complex interpersonal interactions	X	X	X	X
d730 Relating with strangers				X
d740 Formal relationships			X	X
d750 Informal social relationships	X	X	X	X
d760 Family relationships		X	X	X
d770 Intimate relationships				X
d810 Informal education				X
d820 School education		X	X	X
d825 Vocational training		X		
d830 Higher education		X		
d845 Acquiring, keeping, and terminating a job	X	X	X	X
d850 Remunerative employment	X		X	X
d860 Basic economic transactions			X	X
d865 Complex economic transactions	X			
d870 Economic self-sufficiency			X	X
d880 Engagement in play	X		X	X
d910 Community life	X		X	X
d920 Recreation and leisure	X	X	X	X
d930 Religion and spirituality				X
d940 Human rights			X	X
d950 Political life and citizenship				X
<i>Environmental factors</i>				
e110 Products or substances for personal consumption			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	X
e130 Products and technology for education			X	
e150 Design, construction, and building products and technology of buildings for public use				X
e165 Assets		X		
e225 Climate				X
e240 Light		X	X	X
e250 Sound		X	X	X
e260 Air quality			X	
e310 Immediate family		X	X	X
e315 Extended family				X
e320 Friends			X	X
e325 Acquaintances, peers, colleagues, neighbors, and community members			X	X
e330 People in positions of authority			X	X
e340 Personal care providers and personal assistants		X	X	X
e355 Health professionals		X	X	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
e425 Individual attitudes of acquaintances, peers, colleagues, neighbors, and community members		X	X	X
e430 Individual attitudes of people in positions of authority			X	

(Continued)

**Table 1.** (Continued)

Second-level ICF category	Systematic review	Expert survey	Qualitative study	Clinical study
e440 Individual attitudes of personal care providers and personal assistants				X
e450 Individual attitudes of health professionals			X	X
e455 Individual attitudes of other professionals			X	X
e460 Societal attitudes		X	X	X
e465 Social norms, practices, and ideologies		X	X	X
e525 Housing services, systems, and policies				X
e535 Communication services, systems, and policies				X
e540 Transportation services, systems, and policies				X
e550 Legal services, systems, and policies			X	X
e560 Media services, systems, and policies			X	
e570 Social security services, systems, and policies			X	X
e575 General social support services, systems, and policies		X	X	X
e580 Health services, systems, and policies		X	X	X
e585 Education and training services, systems, and policies		X	X	X
e590 Labor and employment services, systems, and policies		X	X	X

ICF: International Classification of Functioning, Disability and Health.

**Table 2.** Composition of the working groups.

WG 1	WG 2	WG3	Gender	Profession	Country	WHO region
I			Female	OT	India	SEARO
	I		Female	OT	South Africa	AFRO
		I	Female	OT	United Kingdom	EURO
			Male	PT	Germany	EURO
I			Female	PedMD	Sweden	EURO
	I		Male	PsychMD	Mexico	AMRO
		I	Male	PsychMD	South Africa	AFRO
I			Male	Psychol.	Israel	EURO
	I		Male	Psychol.	Sweden	EURO
		I	Female	Psychol.	Sweden	EURO
I			Female	Psychol.	Saudi Arabia	EMRO
	I		Female	Psychol.	The Netherlands	EURO
		I	Female	Psychotherap.	Israel	EURO
	I		Female	SW	Sweden	EURO
I			Female	SW	United States	AMRO
I			Female	Special ed.	Germany	EURO
	I		Female	Special ed.	India	SEARO
		I	Male	Special ed.	Japan	WPRO
	I		Female	SLP	Saudi Arabia	EMRO
		I	Female	SLP and Special ed.	United States	AMRO

WG 1: Working group 1; WG 2: Working group 2; WG 3: Working group 3; WHO: World Health Organization; OT: Occupational therapist; PT: Physiotherapist; PedMD: Pediatrician; PsychMD: Psychiatrist; Psychol.: Psychologist; Psychotherap: Psychotherapist; 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 individuals with autism spectrum disorder (ASD) across the entire lifespan.

**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 adults (>17 years old). The experts voted to include 79 second-level ICF categories for this set. Categories were mostly from the activities

and participation component (n=34, 43%), followed by environmental factors (n=27, 34%) and body functions (n=18, 23%). Contrary to the Brief Core Sets for pre-schoolers and school-age children, all nine chapters of the activities and participation component were represented, while one of the five environmental factors chapters, that is, e2 Natural environment and human-made changes, was

**Table 3.** The second-level ICF categories included in the Comprehensive ICF Core Set for individuals with ASD across the entire lifespan.

Second-level ICF category
b114 Orientation functions
b117 Intellectual functions
b122 Global psychosocial functions
b125 Dispositions and intra-personal functions
b126 Temperament and personality functions
b130 Energy and drive functions
b134 Sleep functions
b140 Attention functions
b144 Memory functions
b147 Psychomotor functions
b152 Emotional functions
b156 Perceptual functions
b160 Thought functions
b164 Higher level cognitive functions
b167 Mental functions of language
b265 Touch function
b270 Sensory functions related to temperature and other stimuli
b330 Fluency and rhythm of speech functions
b760 Control of voluntary movement functions
b765 Involuntary movement functions
d110 Watching
d115 Listening
d130 Copying
d132 Acquiring information
d137 Acquiring concepts
d140 Learning to read
d145 Learning to write
d155 Acquiring skills
d160 Focusing attention
d161 Directing attention
d163 Thinking
d166 Reading
d170 Writing
d175 Solving problems
d177 Making decisions
d210 Undertaking a single task
d220 Undertaking multiple tasks
d230 Carrying out daily routine
d240 Handling stress and other psychological demands
d250 Managing one's own behavior
d310 Communicating with—receiving—spoken messages
d315 Communicating with—receiving—nonverbal messages
d330 Speaking
d331 Pre-talking
d335 Producing nonverbal messages
d350 Conversation
d360 Using communication devices and techniques
d470 Using transportation
d475 Driving
d510 Washing oneself
d520 Caring for body parts
d530 Toileting

**Table 3.** (Continued)

Second-level ICF category
d540 Dressing
d550 Eating
d570 Looking after one's health
d571 Looking after one's safety
d620 Acquisition of goods and services
d630 Preparing meals
d640 Doing housework
d650 Caring for household objects
d660 Assisting others
d710 Basic interpersonal interactions
d720 Complex interpersonal interactions
d730 Relating with strangers
d740 Formal relationships
d750 Informal social relationships
d760 Family relationships
d770 Intimate relationships
d820 School education
d825 Vocational training
d830 Higher education
d845 Acquiring, keeping, and terminating a job
d850 Remunerative employment
d860 Basic economic transactions
d870 Economic self-sufficiency
d880 Engagement in play
d910 Community life
d920 Recreation and leisure
d940 Human rights
e110 Products or substances for personal consumption
e115 Products and technology for personal use in daily living
e125 Products and technology for communication
e130 Products and technology for education
e240 Light
e250 Sound
e310 Immediate family
e315 Extended family
e320 Friends
e325 Acquaintances, peers, colleagues, neighbors, and community members
e330 People in positions of authority
e340 Personal care providers and personal assistants
e355 Health professionals
e360 Other professionals
e410 Individual attitudes of immediate family members
e415 Individual attitudes of extended family members
e420 Individual attitudes of friends
e430 Individual attitudes of people in positions of authority
e450 Individual attitudes of health professionals
e455 Individual attitudes of other professionals
e460 Societal attitudes
e465 Social norms, practices, and ideologies
e525 Housing services, systems, and policies
e535 Communication services, systems, and policies
e550 Legal services, systems, and policies
e560 Media services, systems, and policies

(Continued)

**Table 3.** (Continued)

Second-level ICF category
e570 Social security services, systems, and policies
e575 General social support services, systems, and policies
e580 Health services, systems, and policies
e585 Education and training services, systems, and policies
e590 Labor and employment services, systems, and policies
s110 Structure of brain

ICF: International Classification of Functioning, Disability and Health;  
ASD: autism spectrum disorder.

**Table 4.** The second-level ICF categories included in the Common Brief ICF Core Set for individuals with ASD across the entire lifespan.

Second-level ICF category
b114 Orientation functions
b117 Intellectual functions
b122 Global psychosocial functions
b125 Dispositions and intra-personal functions
b126 Temperament and personality functions
b130 Energy and drive functions
b134 Sleep functions
b140 Attention functions
b144 Memory functions
b147 Psychomotor functions
b152 Emotional functions
b156 Perceptual functions
b160 Thought functions
b164 Higher level cognitive functions
b167 Mental functions of language
b330 Fluency and rhythm of speech functions
b760 Control of voluntary movement functions
b765 Involuntary movement functions
d132 Acquiring information
d155 Acquiring skills
d160 Focusing attention
d210 Undertaking a single task
d220 Undertaking multiple tasks
d230 Carrying out daily routine
d240 Handling stress and other psychological demands
d250 Managing one's own behavior
d310 Communicating with—receiving—spoken messages
d315 Communicating with—receiving—nonverbal messages
d330 Speaking
d570 Looking after one's health
d571 Looking after one's safety
d710 Basic interpersonal interactions
d720 Complex interpersonal interactions
d760 Family relationships
d820 School education
d880 Engagement in play
d920 Recreation and leisure
e110 Products or substances for personal consumption
e115 Products and technology for personal use in daily living

**Table 4.** (Continued)

Second-level ICF category
e125 Products and technology for communication
e130 Products and technology for education
e310 Immediate family
e315 Extended family
e325 Acquaintances, peers, colleagues, neighbors, and community members
e330 People in positions of authority
e340 Personal care providers and personal assistants
e355 Health professionals
e360 Other professionals
e410 Individual attitudes of immediate family members
e415 Individual attitudes of extended family members
e430 Individual attitudes of people in positions of authority
e450 Individual attitudes of health professionals
e460 Societal attitudes
e465 Social norms, practices, and ideologies
e550 Legal services, systems, and policies
e570 Social security services, systems, and policies
e575 General social support services, systems, and policies
e580 Health services, systems, and policies
e585 Education and training services, systems, and policies
e590 Labor and employment services, systems, and policies

ICF: International Classification of Functioning, Disability and Health;  
ASD: autism spectrum disorder.

**Table 5.** The second-level ICF categories included in the Brief ICF Core Set for preschool age group of 0–5 years old.

Second-level ICF category
b114 Orientation functions
b117 Intellectual functions
b122 Global psychosocial functions
b125 Dispositions and intra-personal functions
b126 Temperament and personality functions
b130 Energy and drive functions
b134 Sleep functions
b140 Attention functions
b144 Memory functions
b147 Psychomotor functions
b152 Emotional functions
b156 Perceptual functions
b160 Thought functions
b164 Higher level cognitive functions
b167 Mental functions of language
b270 Sensory functions related to temperature and other stimuli
b330 Fluency and rhythm of speech functions
b760 Control of voluntary movement functions
b765 Involuntary movement functions
d110 Watching
d115 Listening
d130 Copying
d132 Acquiring information

**Table 5.** (Continued)

Second-level ICF category
d137 Acquiring concepts
d155 Acquiring skills
d160 Focusing attention
d161 Directing attention
d210 Undertaking a single task
d220 Undertaking multiple tasks
d230 Carrying out daily routine
d240 Handling stress and other psychological demands
d250 Managing one's own behavior
d310 Communicating with—receiving—spoken messages
d315 Communicating with—receiving—nonverbal messages
d330 Speaking
d331 Pre-talking
d335 Producing nonverbal messages
d360 Using communication devices and techniques
d530 Toileting
d550 Eating
d570 Looking after one's health
d571 Looking after one's safety
d710 Basic interpersonal interactions
d720 Complex interpersonal interactions
d760 Family relationships
d820 School education
d880 Engagement in play
d920 Recreation and leisure
e110 Products or substances for personal consumption
e115 Products and technology for personal use in daily living
e125 Products and technology for communication
e130 Products and technology for education
e240 Light
e250 Sound
e310 Immediate family
e315 Extended family
e325 Acquaintances, peers, colleagues, neighbors, and community members
e330 People in positions of authority
e340 Personal care providers and personal assistants
e355 Health professionals
e360 Other professionals
e410 Individual attitudes of immediate family members
e415 Individual attitudes of extended family members
e430 Individual attitudes of people in positions of authority
e450 Individual attitudes of health professionals
e460 Societal attitudes
e465 Social norms, practices, and ideologies
e550 Legal services, systems, and policies
e570 Social security services, systems, and policies
e575 General social support services, systems, and policies
e580 Health services, systems, and policies
e585 Education and training services, systems, and policies
e590 Labor and employment services, systems, and policies

ICF: International Classification of Functioning, Disability and Health.

**Table 6.** The second-level ICF categories included in the Brief ICF Core Set for school-age group of 6–16 years.

Second level ICF category
b114 Orientation functions
b117 Intellectual functions
b122 Global psychosocial functions
b125 Dispositions and intra-personal functions
b126 Temperament and personality functions
b130 Energy and drive functions
b134 Sleep functions
b140 Attention functions
b144 Memory functions
b147 Psychomotor functions
b152 Emotional functions
b156 Perceptual functions
b160 Thought functions
b164 Higher level cognitive functions
b167 Mental functions of language
b330 Fluency and rhythm of speech functions
b760 Control of voluntary movement functions
b765 Involuntary movement functions
d110 Watching
d115 Listening
d130 Copying
d132 Acquiring information
d137 Acquiring concepts
d140 Learning to read
d145 Learning to write
d155 Acquiring skills
d160 Focusing attention
d161 Directing attention
d163 Thinking
d175 Solving problems
d177 Making decisions
d210 Undertaking a single task
d220 Undertaking multiple tasks
d230 Carrying out daily routine
d240 Handling stress and other psychological demands
d250 Managing one's own behavior
d310 Communicating with—receiving—spoken messages
d315 Communicating with—receiving—nonverbal messages
d330 Speaking
d350 Conversation
d470 Using transportation
d510 Washing oneself
d530 Toileting
d540 Dressing
d570 Looking after one's health
d571 Looking after one's safety
d710 Basic interpersonal interactions
d720 Complex interpersonal interactions
d730 Relating with strangers
d750 Informal social relationships
d760 Family relationships

(Continued)

**Table 6.** (Continued)

Second level ICF category
d820 School education
d880 Engagement in play
d920 Recreation and leisure
e110 Products or substances for personal consumption
e115 Products and technology for personal use in daily living
e125 Products and technology for communication
e130 Products and technology for education
e250 Sound
e310 Immediate family
e315 Extended family
e320 Friends
e325 Acquaintances, peers, colleagues, neighbors, and community members
e330 People in positions of authority
e340 Personal care providers and personal assistants
e355 Health professionals
e360 Other professionals
e410 Individual attitudes of immediate family members
e415 Individual attitudes of extended family members
e430 Individual attitudes of people in positions of authority
e450 Individual attitudes of health professionals
e455 Individual attitudes of other professionals
e460 Societal attitudes
e465 Social norms, practices, and ideologies
e535 Communication services, systems, and policies
e550 Legal services, systems, and policies
e570 Social security services, systems, and policies
e575 General social support services, systems, and policies
e580 Health services, systems, and policies
e585 Education and training services, systems, and policies
e590 Labor and employment services, systems, and policies

ICF: International Classification of Functioning, Disability and Health.

**Table 7.** The second-level ICF categories included in the Brief ICF Core Set for older adolescents and adults (>17 years old).

Second-level ICF category
b114 Orientation functions
b117 Intellectual functions
b122 Global psychosocial functions
b125 Dispositions and intra-personal functions
b126 Temperament and personality functions
b130 Energy and drive functions
b134 Sleep functions
b140 Attention functions
b144 Memory functions
b147 Psychomotor functions
b152 Emotional functions
b156 Perceptual functions
b160 Thought functions
b164 Higher level cognitive functions
b167 Mental functions of language
b330 Fluency and rhythm of speech functions

**Table 7.** (Continued)

Second-level ICF category
b760 Control of voluntary movement functions
b765 Involuntary movement functions
d132 Acquiring information
d155 Acquiring skills
d160 Focusing attention
d166 Reading
d175 Solving problems
d177 Making decisions
d210 Undertaking a single task
d220 Undertaking multiple tasks
d230 Carrying out daily routine
d240 Handling stress and other psychological demands
d250 Managing one's own behavior
d310 Communicating with—receiving—spoken messages
d315 Communicating with—receiving—nonverbal messages
d330 Speaking
d350 Conversation
d360 Using communication devices and techniques
d470 Using transportation
d570 Looking after one's health
d571 Looking after one's safety
d640 Doing housework
d710 Basic interpersonal interactions
d720 Complex interpersonal interactions
d740 Formal relationships
d750 Informal social relationships
d760 Family relationships
d820 School education
d825 Vocational training
d845 Acquiring, keeping, and terminating a job
d860 Basic economic transactions
d870 Economic self-sufficiency
d880 Engagement in play
d910 Community life
d920 Recreation and leisure
d940 Human rights
e110 Products or substances for personal consumption
e115 Products and technology for personal use in daily living
e125 Products and technology for communication
e130 Products and technology for education
e310 Immediate family
e315 Extended family
e320 Friends
e325 Acquaintances, peers, colleagues, neighbors, and community members
e330 People in positions of authority
e340 Personal care providers and personal assistants
e355 Health professionals
e360 Other professionals
e410 Individual attitudes of immediate family members
e415 Individual attitudes of extended family members
e430 Individual attitudes of people in positions of authority
e450 Individual attitudes of health professionals
e460 Societal attitudes

**Table 7.** (Continued)

## Second-level ICF category

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e465 Social norms, practices, and ideologies
e525 Housing services, systems, and policies
e535 Communication services, systems, and policies
e550 Legal services, systems, and policies
e560 Media services, systems, and policies
e570 Social security services, systems, and policies
e575 General social support services, systems, and policies
e580 Health services, systems, and policies
e585 Education and training services, systems, and policies
e590 Labor and employment services, systems, and policies

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ICF: International Classification of Functioning, Disability and Health.

not covered. The three most covered chapters were b1 Mental functions (n=15, 19%); e5 Services, systems, and policies (n=9, 11%); and e3 Support and relationships (n=8, 10%).

## Discussion

The goal of the international consensus conference was to develop Comprehensive and Brief ICF Core Sets for ASD with consideration of the evidence collected through four international preparatory studies, that is, a systematic literature review (De Schipper et al., 2015), an expert survey (De Schipper et al., 2016), a qualitative study (Mahdi et al., 2017a), and a clinical study (Mahdi et al., 2017b). This goal was achieved by an international and multi-professional group of experts who concluded that the Comprehensive Core Set should highlight activities of daily living and functioning in various environments in the determination of functioning levels. Body functions and body structures found less resonance. The Brief Core Sets followed the same pattern, including categories predominantly from the activities and participation component and environmental factors. The activities and participation categories that were identified as characteristic of individuals living with ASD were diverse and in line with its operationalization in DSM-5 (APA, 2013), that is, challenges in social communication and relationships (Schmidt et al., 2015) and their impact on participation in activities of daily living from self-care (Du et al., 2015) and academic achievement (Levy and Perry, 2011) to vocational performance (Howlin et al., 2013). Contrary to activities and participation, the body function categories were less heterogeneous, consisting mainly of (b1) mental function categories. This is consistent with the conceptualization of ASD as a neurodevelopmental, mental, and largely cognitive condition. Nevertheless, some physical and sensory aspects of the body were also covered. This reflects previous findings that show that the impact of ASD extends beyond mental functions into other body processes, such as motor coordination

(Fournier et al., 2010), hypersensitivity (Marco et al., 2011), and speech fluency (Scaler Scott et al., 2014).

Interestingly, during the consensus conference, the experts were generally less inclined to include body functions categories in the ASD Core Sets as compared to activities and participation categories and environmental factors. One possible explanation might be that since the concept of ASD has evolved within a biomedical framework, and the defining features of ASD are already covered by ICD-10 and DSM-5, the participating experts perhaps saw the development of ICF Core Sets for ASD as an option of achieving a more holistic perspective, integrating personal, social, and environmental aspects of the individual (Escorpizo et al., 2013; Hwu et al., 2001a). Indeed, enriching the holistic perspective, a variety of environmental factors were included in the ASD Core Sets. The role of environmental factors on individual functioning in ASD has previously been highlighted (Dawson et al., 2012; Fein et al., 2017; Kirby et al., 2016). However, there is still a need to understand and take into account the influence of the environment on functional outcomes in ASD, and to prioritize interventions that allow individuals with ASD to achieve optimal functioning in key contexts, for example, education (Fleury et al., 2014) and vocation (Shattuck et al., 2012). The environmental factors included in the ASD Core Sets are well suited to describe possible facilitators and barriers of functioning in various environments. However, the insufficient granularity of the environmental factors or for some insufficient comprehensiveness makes it difficult to generate information that is directly applicable in interventions. For instance, the descriptions of e310 immediate family or e315 extended family, e330 people in positions of authority are not detailed enough to present an accurate picture of the social supports of a person with ASD. Furthermore, within a family, some members may be supportive while others pose barriers. There are no clear guidelines on how to handle this with interventions. Nevertheless, adequately appreciating the role of environmental factors, such as involvement in play and recreation, on individual functioning in ASD is crucial to reducing barriers and promoting facilitators, and adapting interventions to the needs of those living with ASD (Egilson et al., 2017). The ASD Core Sets can help raise awareness about environmental factors and encourage stakeholders in ASD to explore existing attitudes and social beliefs (Burkett et al., 2015; Ratto et al., 2016). Although symptoms of neurodevelopmental disorders may be similar across cultures, symptom perception, interpretation, and acceptance are not (Ravindran and Myers, 2012). With this as well as WHO's commitment toward internationality and cultural diversity in mind, the process to develop the ICF Core Sets for ASD made efforts to consider cultural and attitudinal differences. By equipping stakeholders with useful tools that explore the attitudinal environment of individuals with ASD, they will be better able to detect, communicate, and address barriers in the environment and reduce ASD-related stigmatization

by providing appropriate interventions and knowledge about ASD. Despite the numerous advantages of recognizing environmental factors, these have largely been ignored in the standardized diagnostic process of ASD. In fact, the different diagnostic systems ICD-10 (WHO, 1992) and DSM-5 (APA, 2013) do not take environmental factors into account at all. Remarkably, the significance of environmental factors is often emphasized by individuals diagnosed with ASD and their caregivers—as indicated by the qualitative study (Mahdi et al., 2017a) as compared to the systematic literature review (De Schipper et al., 2015) and expert survey (De Schipper et al., 2016).

There were some commonalities and differences found in the various age-specific brief sets. Common to all age-specific brief sets was the emphasis on mental functions. This supports the notion that ASD is a persistent neurodevelopmental condition associated with cognitive challenges (Demetriou et al., 2017; Magiati et al., 2014). Interestingly, sensory functions and sensory environment were not included in the adult group. One possible explanation could be that improvements in sensory functions and acquired strategies that have been observed in individuals with ASD as they get older (Kern et al., 2006) make adults with ASD less susceptible to noise, light, and other sensory stimuli. Another explanation might be that the experts (without ASD) were less informed about the lived experiences of adults, and perhaps an expert group of adults with ASD would have included sensory symptoms. As the age-specific core sets are a secondary focus to help tailor the process for particular patients, the Comprehensive Core Set and Brief Common Set can be used for all individuals with ASD; they provide some flexibility for individual differences within age categories. To better understand the complex associations or lack of associations between sensory functions and sensory environment with age as a modifier, further research is needed—with possible consideration of the graphical modeling approach (Kalisch et al., 2010).

All age-specific brief sets contain ICF categories in the environmental factors chapter d5 Services, systems, and policies. This demonstrates the importance of access to support, social and health care decision-making for the well-being of individuals along the continuum of care across the lifespan. For instance, the transition from adolescence to adulthood poses major challenges to individuals with ASD. To optimize functioning outcomes of individuals with ASD during major transitional events, such as moving from home, attending university, entering the labor market, and living an independent life (Schall et al., 2012), personal support may be required in various areas of life (Van Schalkwyk and Volkmar, 2017).

### *Study limitations*

There were several challenges faced in developing the ASD Core Sets that deserve attention, most of which have

been discussed in the publications on the preparatory studies (De Schipper et al., 2015, 2016b; Mahdi et al., 2017a, 2017b). First, although the six WHO world regions were represented in the preparatory studies and international consensus conference, some parts of the world were better represented than others. This was also the case at the consensus conference, potentially causing a risk that culture-sensitive categories were overlooked. Having an equal representation of WHO world regions is important, as the majority of individuals with ASD live in low- and middle-income countries, despite the fact that almost all research on ASD focus on high-income countries (Bölte et al., 2016; Durkin et al., 2015). Unfortunately, there was considerable difficulty both to identify international experts with diverse professional backgrounds and to get them to participate in the project. To address this issue, the conference participants were regularly reminded to consider the applicability of the ICF Core Sets for ASD in various parts of the world and in all resource countries.

Second, despite efforts to achieve a broad representation of disciplines, some professional groups may have been underrepresented. For instance, few physiotherapists and social workers participated in the consensus conference, and there were no nurses at all. If there would have been a stronger representation of these professions, categories related to movement and mobility or gastrointestinal functions may have had a higher chance to be included in the ICF Core Sets for ASD.

Finally, while individuals with ASD 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, limiting the extent of desirable co-production (Bölte, 2017). However, one of the participating experts was a mother of a child with ASD, therefore providing some direct lived experience perspective in the final ASD Core Set decision-making process.

### *Applications of the ICF Core Sets for ASD*

A novel and integral part of the diagnostic procedures and criteria recommended for ASD in the upcoming International Classification of Diseases—Eleventh Revision (ICD-11) is the use of categories from the ICF to describe the impact of a health condition on individual functioning (Escorpizo et al., 2013). The ICF Core Sets for ASD will guide the selection of categories used in the ICD-11 and hereby mark a paradigm shift in the diagnostic assessment of ASD. The official international operationalization of ASD will then not only contain a perspective of psychopathology, but more individually tangible functioning-related health information across disciplines in a standardized and comprehensive manner. Another area of application may be resource allocation. As the ICF and the core sets derived from it provide the possibility to more comprehensively



describe the individual challenges and strengths associated with ASD, they can also serve as a guide to more personalized rather than diagnosis-based resource allocation and reimbursement in health care and in education (Escorpizo and Stucki, 2013; Escorpizo et al., 2015; Hopfe et al., 2017). Finally, the ICF Core Sets for ASD 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, for example, in the form of functioning profile.

To promote the use of the ASD Core Sets in these and other application areas, it would be advisable to develop standardized user-friendly ICF Core Set-based tools, such as a questionnaire with a scale that applies established measurement standards, or observation schedules and interviews. The ASD Core Sets are solely a selection of the most relevant categories of functioning and environmental factors; practitioners who are unfamiliar with the ICF may find it easier and more practical to use the ASD Core Sets in a form that they are familiar with, such as a questionnaire/instrument. An example of an ICF Core Set-based instrument is the ASAS Health Index (Kiltz et al., 2014). Another example of a clinical and research application of ICF Core Sets to guide appropriate measures is the ICF-based toolbox of multi-item measures for children and youth with cerebral palsy (Schiariti et al., 2017). Beyond developing tangible tools for clinical use and research, the use of the ICF Core Sets for ASD to help improve service provision and support policy-making at the local, regional, and country level is envisioned.

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### Declaration of conflicting interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Sven Bölte declares no conflict of interest related to this article. He discloses that he has in the last 5 years acted as an author, consultant, or lecturer for Shire, Medice, Roche, Eli Lilly, Prima Psychiatry, GLGroup, System Analytic, Kompetento, Expo Medica, and Prophase. He receives royalties for text books and diagnostic tools from Huber/Hogrefe, Kohlhammer, and UTB. Petrus J de Vries declares no conflict of interest related to this article. He has been on the study steering committee and advisory board for clinical trials and guideline development in tuberous sclerosis complex funded by Novartis. Soheil Mahdi, Mats Granlund, Wolfgang Segerer, Melissa Selb, Cory Shulman, John E. Robison, Bruce Tonge, Virginia Wong, and Lonnie Zwaigenbaum declare no conflict of interest related to this work.

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