Chapter

Development and Innovation in the ICD-11 Chapter on Mental, Behavioural and Neurodevelopmental Disorders

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This chapter describes the context of the 11th Revision of the International Classification of Diseases (ICD-11) related to mental health. It contains an explanation of the procedure adopted in making this revision, some background to the field trials and their results, and a brief account of the main changes, many of which are amplified in the later chapters. A detailed account of the changes in the ICD-11 as compared with the ICD-10 has been published elsewhere,¹ as has a detailed comparison of the ICD-11 and the DSM-5.²

The context of the development of the ICD-11 is significant. This is the first major revision of the ICD in thirty years and has followed a thorough re-examination of each ICD-10 diagnosis in light of new scientific findings, best practices, and advances in information technology for health systems. The revision was approved by the World Health Assembly on 25 May 2019 and was formally implemented as a basis for health reporting by WHO member states from January 2022. Over the next few years, WHO member states will implement the ICD-11 within their clinical and health information systems. WHO has published a range of materials intended to be useful to countries in implementing the ICD-11.³ In some systems, implementation will happen quickly and in others clinical implementation of the ICD-11 classification of mental, behavioural or neurodevelopmental disorders. This will make it possible for Scottish clinicians to benefit from the more than three decades of scientific and clinical advances reflected in the ICD-11, even if their systems are still collecting data using the ICD-10 as a framework.

The Development of the ICD-11 Classification of Mental Disorders

The ICD-11 has been developed incrementally over a Fifteen-year period. The basic structure of the ICD-11 chapter on Mental, Behavioural and Neurodevelopmental Disorders (MBND) and the brief descriptions for each disorder have been online and available for review, comment, and proposals for changes⁴ since 2014 (https://icd.who.int/dev11/l-m/en). The World Health Organization Department of Mental Health and Substance Use (MSD) has also developed Clinical Descriptions and Diagnostic Requirements (CDDR) for ICD-11, which are available online at https://icd.who.int/browse11/l-m/en#/ and will also be published as a book. The structure of the ICD-11 MBND classification, the category names and brief

descriptions for statistical use, and the detailed diagnostic guidance for clinical implementation contained in the CDDR were developed simultaneously by seventeen expert working groups in different areas appointed by MSD. Each group included experts from all WHO regions and substantial representation of low- and middle-income countries. Working groups were responsible for reviewing the available evidence related to their areas of responsibility, including the overlapping work on the development of the DSM-5.

In making recommendations for the ICD-11, working groups were asked to consider clinical utility and global applicability¹ in addition to the validity of proposed changes. Classification is the interface between health encounters and health information. If a new diagnostic system fails to provide clinicians with enough useful information that is feasible to implement given the time and resources available to them, it is unlikely to be applied consistently and faithfully. This will have implications for the overall data used for evaluation and decision making at the system, local, national, and global levels. A more clinically useful system therefore contributes to better health data. Because of the need for global applicability, the ICD-11 MBND revision was tested via a systematic programme of global field studies. The working groups included experts from all global regions, with particular attention to the representation of low- and middle-income countries. Hundreds of global experts were involved in developing the CDDR and thousands of global clinicians were involved in testing it across the world in multiple languages, as described below.

The CDDR is designed to provide sufficient and clinically useful information to enable psychiatrists and other diagnosing health professionals to consistently and accurately apply the ICD-11 MBND classification to make diagnoses in clinical settings.¹ The sections of the CDDR follow a uniform structure,⁵ which has been a major improvement over the equivalent volume for ICD-10, the Clinical Descriptions and Diagnostic Guidelines (CDDG) for ICD-10 Mental and Behavioural Disorders.⁶ Each of the main disorder entries for the ICD-11 CDDR includes the following sections: 1) essential (required) features; 2) additional clinical features; 3) boundary with normality (threshold); 4) course features; 5) developmental presentations; 6) culture-related features; 7) sex and/or gender-related features; and 8) boundaries with other disorders and conditions (differential diagnosis).⁵

The essential features present briefly the characteristics of the disorder in descriptive terms.⁵ They represent the clinical features that a clinician could reasonably expect to see in all cases of the disorder. In this way, they resemble diagnostic criteria in the DSM. The ICD-11 differs from the DSM-5, however, in avoiding algorithmic pseudoprecision in terms of symptom counts or precise durations unless these are well established and empirically based. (For example, in ICD-11 five of ten possible symptoms of a depressive episode must be present, one of which must be depressed mood or anhedonia; two of seven psychotic symptoms are required for a diagnosis of schizophrenia, etc.) The ICD-11 essential features are stated more flexibly than DSM-5 diagnostic criteria in order to focus on the clinical essence of the syndrome and allow sufficient room for cultural variability and informed clinical judgement to enhance global applicability. But the idea that there are no diagnostic requirements in the ICD-11 CDDR is obviously false to anyone who has actually looked at them, and it is important to stress that those making such claims are misinformed.

To take one specific example, the essential features of the ICD-11 diagnosis of PTSD can be summarized as follows⁷ (see CDDR, https://icd.who.int/browse11/l-m/en#/, for the complete version):

• Exposure to an event or situation (either short- or long-lasting) of an extremely threatening or horrific nature.

- Following the traumatic event or situation, the development of a characteristic syndrome lasting for at least several weeks, consisting of three core elements:
 - 1. Re-experiencing the traumatic event in the present, in which the event(s) is not just remembered but is experienced as occurring again in the here and now.
 - 2. Deliberate avoidance of reminders likely to produce re-experiencing of the traumatic event(s).
 - 3. Persistent perceptions of heightened current threat.
- The disturbance causes significant impairment in functioning.

Diagnostic requirements are clearly stated, and all must be present. At the same time, the ICD-11 essential features for PTSD are vastly simpler than the diagnostic criteria in the DSM-5, which include 20 different symptoms in four different groups, as well a list of specific experiences that 'qualify' for a diagnosis that appear to be largely based on US liability concerns. It has been calculated that there are 636,120 different combinations of symptoms⁸ that would qualify for a PTSD diagnosis under DSM-5.

Some have expressed concern that ICD-11's more flexible approach to diagnostic requirements would result in overdiagnosis and inflated prevalence rates, but there is no evidence to support this claim. Using World Mental Health Survey data, Stein et al.⁹ found that the ICD-11 diagnostic requirements resulted in fewer diagnoses of PTSD compared with ICD-10, and comparable rates compared with DSM-5. Lago et al.¹⁰ also applied diagnostic requirement in the major classifications to Mental Health Survey data for disorders due to use of alcohol and disorders due to use of cannabis. They found almost perfect concordance among ICD-11, DSM-IV, and ICD-10, but much lower concordance with DSM-5. Evans et al.¹¹ found that, compared with ICD-10 and DSM-5, the ICD-11 CDDR led to more accurate identification of severe irritability and better differentiation from boundary presentations. Participants using the DSM-5 were more likely to assign psychopathological diagnoses to developmentally normative irritability. Although relatively few head-to-head comparisons of the ICD-11 and DSM-5 have been conducted, of those that have, none has found higher rates of diagnoses using the ICD-11.

Field Testing of ICD-11 MBND

Another major area of innovation has been the extensive and systematic programme of field studies supporting the ICD-11 MBND classification and its associated CDDR.^{1,12,13} Twenty internet-based case-controlled studies have been conducted using the Global Clinical Practice Network (GCPN; https://gcp.network). The GCPN is a network of over 18,500 mental health and primary care professionals from 163 countries who took part in the development of the ICD-11 through participation in field studies. Slightly more than half of GCPN members are physicians - almost all of these psychiatrists - with a third being psychologists, and the rest a mixture of other mental health disciplines. Thirty-seven per cent are working in low- and middle-income countries. GCPN studies have been conducted in a minimum of three and up to six languages: Chinese, English, French, Japanese, Russian, and Spanish. Specific studies were also conducted in German.

Case-controlled studies for ICD-11 most commonly involved participants being randomly assigned to use the ICD-11 CDDR or the ICD-10 CDDG to assign diagnoses to standardized, validated clinical case vignettes that had been manipulated to highlight key diagnostic issues.^{12,13} The studies compared the accuracy and consistency of diagnostic judgements based on the two systems. Across these studies, ICD-11 consistently outperformed the ICD-10.^{14,15} The methodology also permitted an examination of which specific diagnostic elements were accounting for any observed confusion, which in turn permitted refinements in the CDDR before they were finalized.^{16,17}

Clinic-based studies of the reliability and clinical utility of the ICD-11 CDDR have been conducted in 14 countries covering all global regions.^{18,19} These studies focused on mental disorders accounting for the greatest proportion of global disease burden and the highest levels of service utilization – schizophrenia or other primary psychotic disorders, mood disorders, anxiety or fear-related disorders, and disorders specifically associated with stress among adult patients presenting for treatment at 29 participating centres. A concurrent joint-rater design was used, examining whether two clinicians, relying on the same clinical information, agreed on the diagnosis when separately applying the ICD-11 CDDR. Intraclass kappa coefficients for diagnoses weighted by site and study prevalence ranged from 0.45 (dysthymic disorder) to 0.88 (social anxiety disorder) and would be considered moderate to almost perfect for all diagnoses.¹⁷ Overall, the reliability of the ICD-11 CDDR was superior to that previously reported for equivalent ICD-10 guidelines. Clinician ratings of the clinical utility of the proposed ICD-11 diagnostic guidelines were very positive overall.¹⁸ The CDDR were perceived as easy to use, corresponding accurately to patients' presentations (i.e., goodness of fit), clear and understandable, providing an appropriate level of detail, taking about the same or less time than clinicians' usual practice, and providing useful guidance about distinguishing disorder from normality and from other disorders.

The reliability results from the clinic-based studies challenge the claim that some have put forward that the more clinician-friendly, less concretely algorithmic, and less highly operationalized approach adopted for the ICD-11 CDDR is inherently less reliable. The concern that the ICD-11 CDDR has sacrificed reliability is not based on any data, but rather based on assumptions that have been built into the DSM since DSM-III, including the assumptions that clinicians apply the criteria as they are written, which we do not believe is the case. In our clinic-based studies, clinicians with diverse training and experience used the ICD-11 CDDR following a relatively brief training (about 4 hours) to conduct routine clinical assessments (lasting about 1 hour) using open form interviews. They obtained reliability coefficients similar to those achieved using more complex and time-consuming structured instruments.¹⁹⁻²¹ It is possible that further gains in reliability among clinicians could be obtained by focusing greater attention on appropriate training in diagnostic skills and interviewing techniques, rather than on continuing to devote attention and resources to introducing greater precision in operationalization as a part of successive refinements in diagnostic criteria.

New Disorder Categories

Twenty-three new disorders have been added to the ICD-11 MBND chapter (see Table 1.1), reflecting either a distinct disorder that was not classifiable in the ICD-10 (e.g., Hoarding Disorder), or a disorder that is a result of extending, expanding, or subdividing an existing disorder in such a way that has resulted in a new disorder rather than a subtype (e.g., Binge Eating Disorder).²² Most of these were either already in the DSM-IV or added to the DSM-5.

| Disorder grouping | New disorder |
|---|---|
| Catatonia | Catatonia (previously a subtype of schizophrenia) |
| Mood disorders | Bipolar type II disorder (previously included in bipolar affective disorder) |
| Obsessive–compulsive or related disorders | Body dysmorphic disorder Olfactory reference disorder Hoarding disorder Excoriation (skin picking) disorder |
| Disorders specifically associated with stress | Complex post-traumatic stress disorder Prolonged grief disorder |
| Dissociative disorders | Partial dissociative identity disorder |
| Feeding or eating disorders | Binge eating disorder Avoidant–restrictive food intake disorder Rumination–regurgitation disorder |
| Disorder of bodily distress or bodily experience | Body integrity dysphoria |
| Disorders due to substance use or addictive behaviours | Substance-induced anxiety disorder Substance-induced obsessive-compulsive or related disorder Substance-induced impulse control disorder Gaming disorder |
| Impulse control disorders | Compulsive sexual behaviour disorder Intermittent explosive disorder |
| Factitious disorders | Factitious disorder imposed on another |
| Secondary mental or behavioural syndromes associated with disorders or diseases classified elsewhere | Secondary neurodevelopmental syndrome Secondary obsessive-compulsive or related syndrome Secondary impulse control syndrome |

Table 1.1 New categories in the ICD-11 chapter on mental, behavioural, or neurodevelopmental disorders

The effect of adding these categories has therefore generally been to enhance compatibility between the ICD-11 and the DSM-5.

The most consequential additions are arguably four new disorders in the ICD-11 that represent different decisions than were taken for the DSM-5. These are Complex PTSD, Prolonged Grief Disorder, Gaming Disorder, and Compulsive Sexual Behaviour Disorder, although Prolonged Grief Disorder has since been added to the DSM 5.1 and Internet Gaming Disorder appears in the DSM-5 and DSM 5.1 research appendix. We have published a detailed review of the rationale and consequences of adding these four disorders,²² concluding that each describes an important and distinctive clinical population that is an appropriate focus of health services and with specific treatment needs that would otherwise likely go unmet. WHO's announced intention to include these categories has clearly facilitated an expansion of research in each area, which has generally supported their validity and utility, as well as increased availability of appropriate services.

Complex PTSD

The essential or required features of complex PTSD include all three core symptoms of PTSD (re-experiencing in the present, avoidance, and ongoing sense of threat). Additional features of complex PTSD include three characteristic types of disturbances in self-organization: severe and persistent problems in affect regulation; beliefs about the self as diminished, defeated, or worthless; and difficulties in sustaining relationships and in feeling close to others.^{7,22} Complex PTSD is more likely to be the product of certain types of traumas, such as prolonged or repetitive events from which escape is difficult or impossible (e.g., torture, slavery, prolonged domestic violence, repeated childhood sexual or physical abuse), and typically requires longer and more complex treatments than does PTSD. However, treatments for complex PTSD are not typically as long or as complex as evidence-based treatments for borderline personality disorder. Emerging evidence indicates that complex PTSD and borderline personality disorder are quite distinct, having only the feature of affect dysregulation in common.^{22–24}

Prolonged Grief Disorder

The essential features of prolonged grief disorder include persistent longing or yearning for the deceased and associated intense emotional pain, difficulty accepting the death, a feeling of having lost a part of oneself, an inability to experience positive mood, emotional numbing, and difficulty in engaging with social or other activities.^{7,22} The severe grief response needs to persist beyond 6 months after bereavement, or for a time that clearly exceeds the norms of the person's culture, and produce significant impairment in personal, social, or occupational functioning.

There has been accumulating evidence over many years that supports prolonged grief disorder as a specific and identifiable condition that can severely impact a minority of bereaved people.²² This is not to say that the experience and expression of grief, bereavement, and mourning are not deeply personal and individual. The CDDR also attend carefully to cultural variation in mourning customs and duration. At the same time, for individuals who continue to experience constant and intense emotional pain that interferes with their ability to function 6 months or more following the death, convergent evidence from multiple controlled trials indicates that grief-focused psychotherapy is effective in alleviating their suffering.²⁵ This treatment is specific to prolonged grief disorder and distinct from interventions for depression. A more standardized approach to diagnosing prolonged grief disorder in the CDDR can therefore be helpful in directing persons with this condition to the best available care.

Gaming Disorder

In the ICD-11, gaming disorder is characterized by a pattern of persistent or recurrent gaming behaviour ('digital gaming' or 'video-gaming'), manifested by:

- 1. impaired control over gaming (e.g., onset, frequency, intensity, duration, termination, context);
- 2. increasing priority given to gaming to the extent that gaming takes precedence over other life interests and daily activities; and
- 3. continuation or escalation of gaming despite the occurrence of negative consequences.

The pattern of gaming behaviour results in marked distress or significant impairment in personal, family, social, educational, occupational, or other important areas of functioning. The gaming behaviour and other features are normally evident over a period of at least 12 months in order for a diagnosis to be assigned.^{22,26}

The CDDR for gaming disorder are particularly careful to distinguish it from nonpathological involvement in gaming activities. An international Delphi study²⁷ examined the validity, clinical utility, and prognostic value of the proposed ICD-11 diagnostic requirements, as well as the DSM-5 research criteria for Internet gaming disorder. Participating experts agreed that the ICD-11 CDDR were likely to identify the condition adequately, and more like'ly to avoid pathologizing intensive but non-pathological gaming behaviours. The global gaming industry has vigorously opposed the inclusion of gaming disorder in the ICD-11,^{28,29} and has promoted scholars who challenge the disorder and direct public attention to research highlighting the benefits of gaming.

Compulsive Sexual Behaviour Disorder

In the ICD-11, compulsive sexual behaviour disorder is characterized by a persistent pattern of failure to control intense, repetitive sexual impulses or urges resulting in repetitive sexual behaviour over an extended period (6 months or more). Symptoms may include repetitive sexual activities becoming a central focus of the person's life to the point of neglecting health and personal care or other interests, activities, and responsibilities; numerous unsuccessful efforts to significantly reduce repetitive sexual behaviour; and continued repetitive sexual behaviour despite adverse consequences or deriving little or no satisfaction from it. The symptoms cause marked distress or significant impairment in personal, family, social, educational, occupational, or other important areas of functioning.^{22,30}

The ICD-11 CDDR make extremely clear that distress related to moral judgements and disapproval about sexual impulses, urges, or behaviours is not sufficient to meet this requirement. The CDDR also carefully address concerns about false positives and the stigmatization of non-pathological sexual behaviour, alerting that particular attention must be paid to the evaluation of individuals who self-identify as having the condition (e.g., calling themselves 'sex addicts' or 'porn addicts') to verify that they actually exhibit the clinical characteristics of the disorder. There has been discussion about whether such a disorder should more appropriately be regarded as a behavioural addiction.³¹ ICD-11 adopted a more cautious policy of including it in the grouping of impulse control disorders and separating it from the addictions in the light of some differences from substance use disorders, gambling, and gaming disorder.³²

Mental Disorder Categories That Have Been Removed from the ICD-11

Those who express concern about the ever-expanding encroachment of psychiatric disorder categories on everyday life may be reassured to learn that an even greater number of mental disorder categories have been removed from the ICD-11 than have been added. The new dimensional diagnostic systems for schizophrenia or other primary psychotic disorders and for personality disorders described in later chapters in this book mean that the subtypes of schizophrenia and the specific personality disorders in the ICD-10 are no longer part of the classification. Detailed subtypes of acute and transient psychotic disorder and adjustment

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disorder are no longer included in the ICD-11. A number of 'mixed' disorders, particularly in categories describing children and adolescents, have been removed (e.g., hyperactive conduct disorder, depressive conduct disorder). Separate categories for childhood-specific forms of anxiety disorder have been dropped and are rather described as developmental presentations in the main classification of anxiety or fear-related disorders. Categories that in the ICD-10 were designed to be assigned based on a homosexual or bisexual orientation (i.e., sexual maturation disorder, egodystonic sexual orientation, sexual relationship disorder) have been eliminated.³³

Other Innovations in ICD-11 MBND

Several other innovations in the ICD-11 bear emphasis here. First, the ICD-11 has largely eliminated the 'mind-body split' that was inherent in the ICD-10 classification of mental disorders. In ICD-10, a distinction was made between 'organic' and 'non-organic' forms of cognitive disorders, sleep disorders, and sexual dysfunctions. This separation is inconsistent with our current understanding of the development and maintenance of these disorders. The ICD-11 contains a new, unified classification of sexual dysfunctions in the new chapter on Conditions Related to Sexual Health, which integrates categories previously classified as mental disorders with others that were classified primarily as diseases of the genitourinary system. Similarly, a new chapter on Sleep–Wake Disorders integrates sleep disorders previously classified as mental disorders, diseases of the nervous system. A unified syndromal description of dementia and other neurocognitive disorders, including different levels of severity and categories describing behavioural and psychological disturbances in dementia, is provided in the MBND chapter of the ICD-11. These categories can be linked to categories indicating underlying causes (e.g., diseases of the nervous system, infectious diseases, substance use disorders).

Another innovation is the integration of dimensional approaches within the categorical structure of ICD-11. There has been increasing recognition over the past 40 years that most mental and behavioural disorders are best thought of as representing several underlying dimensions rather than discrete categories.³⁴ The ICD is fundamentally a categorical system with specific nosological and formal requirements, and there are many clinical, scientific, and practical benefits to the inclusion of mental disorders alongside other classes of diseases as part of the ICD-11.35 The ICD-11 has introduced a range of important structural innovations based on a transition to a fully electronic system, which has made it possible to integrate substantial dimensional information within the ICD's categorical approach. The dimensional potential of the ICD-11 has been most fully realized in the areas of schizophrenia and other primary psychotic disorders³⁶ as well as personality disorders.^{37,38} These innovations are fully described in other chapters of this book. Overall, the dimensional approach puts a stronger focus on the current presentation and therefore treatment needs in the present, rather than emphasizing a diagnosis as something that signifies a characteristic of the person that is stable over time. This is more consistent with a recovery-based approach and makes it possible to document improvements in clinical presentation that do not necessarily alter the underlying diagnosis.

The classification of disorders due to substance use has also been changed substantially in response to global public health needs.³⁹ The range of substance classes has been updated and expanded in response to diversification of psychoactive substances and changes in their routes of administration and the contexts of their use, including the rapid development and

diffusion of new, synthetic psychoactive substances. The ICD-11 has retained the concept of harmful use of psychoactive substances, that is, patterns of substance use that cause significant harm to physical or mental health, because of its public health importance and the opportunities it provides for intervention in primary care and other non-specialist settings. Different patterns of harmful use have been specified, including a new category for single episodes as well as episodic or continuous patterns of use. Harm to others as a result of substance use has been newly incorporated into the CDDR in the section on harmful use. The diagnostic requirements for substance dependence have been reformulated so they can more easily be identified in a variety of settings. These changes present significant opportunities for prevention, treatment, and health policy at a variety of levels.

Finally, major changes have been made in the classification of gender identity in ICD-11, based on advances in research and clinical practice, and major shifts in social attitudes and in relevant policies, laws, and human rights standards.⁴⁰ What were called gender identity disorders in ICD-11 have been reconceptualized as gender incongruence and moved to the new ICD-11 chapter on Conditions Related to Sexual Health. That is, WHO no longer considers the experience of having a transgender identity to be a mental disorder. This change was supported by a programme of research indicating that distress and functional impairment among transgender people are strongly related to experiences of stigmatization and victimization rather than being an inherent aspect of being transgender.^{41,42} The categories were not removed from ICD-11 altogether because they were seen as important in many countries in securing access to gender-affirming services.⁴³

Next Steps

The ICD-11 will be implemented around the world during the next several years. WHO is actively working with member states on implementation, and the Department of Mental Health and Substance Use has established an Advisory Group for Training and Implementation of ICD-11 Mental, Behavioural, or Neurodevelopmental Disorder, including experts from all global regions as well as government health officials directly involved in implementation at the country level.

In addition, there is a huge need for psychiatrists, psychologists, and other mental health professionals to be trained in how to use ICD-11 in clinical settings. WHO has been actively collaborating with professional societies including the Royal College of Psychiatrists in advancing this agenda. A detailed online training programme consisting of 15 training units, each focusing on a major grouping of disorders, has been developed and is currently available in English (htt ps://gmhacademy.dialogedu.com) and Spanish (https://gmhacademy.dialogedu.com/cie-11). Other resources are available to members of the Global Clinical Practice Network (visit https://gcp.network/ to register). We hope that this book will be an important part of ICD-11 dissemination and training and that it will be useful to psychiatrists and other health professionals providing services to people with mental disorders around the world.

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