Revision of the classification of mental disorders in ICD–11 and DSM–V: work in progress†

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The WHO and ICD–11

It is planned that the 11th revision of the International Classification of Diseases and Related Health Problems (ICD–11) will be submitted for approval to the World Health Assembly in 2013 or 2014. If approved, it should be in print in at least the working languages of the World Health Organization (WHO) a year or two later. Thus, ICD–11 will be released more than 20 years after the publication of ICD–10 (World Health Organization 1992a) (Sartorius 1991). This is a further change to the pattern of revision, which was originally set to happen every 10 years. There are good reasons for the prolongation of the interval between the revisions: they include the increasing complexity of introducing a new classification into (often sophisticated and sometimes understaffed) national health information systems, the emphasis on basing the proposals for change on sufficiently strong scientific evidence, the need to consult an ever larger group of stakeholders and the financial constraints at the WHO.

The new revision will contain provisions for coding groups of mental disorders – probably, but not necessarily, in a separate chapter – as well as some 20 other chapters providing a classification for other disorders. It will also contain chapters classifying reasons for contact with health services, causes of death and environmental factors relevant to the management of diseases in health services. Whether the overall structure of the classification will continue to use chapters is as yet uncertain: modern information technology might produce other ways of dealing with the information about mental illness and its care, for example by ensuring that a single number contains information about a variety of dimensions describing a disorder and that no groupings of disorders are presented.

One of the benefits of such an arrangement would be that the bitter controversies about the placement of particular categories of disorders in chapters might vanish. Placing a category in a particular chapter of the classification is a far from trivial matter. The placement of stroke and other cerebrovascular disorders in the chapter of cardiovascular diseases means that mortality statistics will show that the cardiovascular diseases produce high mortality. Departments dealing with these diseases would therefore be given most resources because it is expected that mortality rates for a population would be diminished by the action of those departments. If the cerebrovascular disorders were to be placed in the chapter of neurological disorders – a chapter that contains diseases of the brain with various causes – the ‘territory’ of neurology would become larger and neurologists could argue that their discipline deserves more attention because neurological disorders make such a huge contribution to mortality.

In ICD–10 (World Health Organization 1992a), the chapter dealing with mental disorders contains several categories that appear in other chapters as well. Thus, dementia can be found in the chapter of mental disorders, because of its predominantly psychiatric symptoms, and in the
chapter of neurological diseases, because it is a brain disease that can be the cause of death. A number of the psychiatric syndromes that occur in the course of other diseases are listed in the chapter of mental disorders as well as in chapters describing other conditions. For example, ‘general paresis’ is listed in the chapter of mental disorders and in the chapter dealing with syphilis and other contagious diseases. Some of the categories that one would expect to find in a chapter devoted to mental disorders have been placed elsewhere, mainly because of pressures exerted by those who did not want to be labelled by any particular ‘psychiatric’ diagnosis. Thus, for example, chronic fatigue syndrome, which was listed together with neurasthenia for a long time, is now in the chapter containing infectious diseases which are supposed to be causing it, and premenstrual dysphoric states are in the chapter dealing with gynaecological disorders.

The organisation of the revision process

The process of revising the ICD involves consultation with individuals and institutions that have used it and with governments that will officially approve it and introduce it as part of the system reporting on morbidity and mortality in their country and internationally. The revision process also involves a thorough review of the literature that reports on studies whose results are relevant to the classification of mental disorders. The technical preparation of the revision is the task of the technical divisions of the WHO: putting the classification together and producing it in its final form is the duty of a special unit dealing with the ICD as a whole as well as with other WHO classifications relevant to the field of health (e.g. the classification of impairments).

The processes of consultation, the assembly of proposals and their tests under field conditions, the examination of the literature, the drafting of criteria for the use of each category and other preparations of the revision usually take a long time. The preparation of the chapter on mental disorders in ICD–10, for example, which was published in 1992, started with the International Programme on Psychiatric Diagnosis and Classification in 1963.

TAG/MND and the GSPN

The WHO’s Topic Advisory Group was established in 2007 to help the Department of Mental Health and Substance Abuse Control in the production of the proposals for the classification of mental disorders within ICD–11. The group, dubbed TAG/MND, met several times to discuss the best way of proceeding with the revision process. It created subgroups that were entrusted with specific tasks. Thus, one of the subgroups examined findings in epidemiological studies (some of them carried out under the WHO’s auspices) that might be relevant for the revisions (e.g. by providing information on the frequency and form of mental disorders in different cultures). Another subgroup was to ensure that the WHO’s International Classification of Diseases and Related Health Problems (ICD–11) and the American Psychiatric Association’s (APA’s) Diagnostic and Statistical Manual of Mental Disorders (DSM–V) are as close to one another as possible. That group, called the Harmonization Group, was composed of experts working on the fifth revision of the DSM and a few members of the WHO TAG/MND.

These subgroups have now been disestablished, having completed their work (the epidemiology group) or having been replaced by other mechanisms (e.g. the Harmonization Group), and TAG/MND recommended in 2009 the creation of five new working groups focusing on the classification of:

- mental disorders seen in primary care
- health problems related to substance misuse
- childhood mental disorders
- mental retardation (probably to be called intellectual disability in ICD–11)
- personality disorders.

An additional working group has been invited to deal with the development of protocols for field tests of the ICD–11 classification.

The WHO also created a Coordinating Group, whose purpose was to establish a Global Scientific Partnership Network (GSPN), involving experts representing different disciplines and different countries’ traditions in psychiatry. The Coordinating Group comprised a team of experts, each covering one of the major languages – Arabic, Chinese, English, French, German, Japanese, Portuguese, Russian and Spanish. The Network is now established and its role is to help in the assembly and analysis of scientific evidence relevant to the classification, in the design of field trials of the proposals for the classification, in the assessment of the equivalence of the translations of the criteria and the classification, and in other tasks involving scientific expertise.

Professional non-governmental organisations were invited to participate in revising the classification. Thus, the World Psychiatric Association, the International Union of Psychological Sciences and the International Association of Social Work are represented on the WHO’s TAG/MND; these and other organisations as well as the WHO...
collaborating centres will help the organisation in the process of revision. In addition, there is a dedicated website (www.who.int/classification/icd/ICDRevision/en) open to all who wish to make a comment on the existing classification or propose changes.

The APA and DSM–V

The development of proposals for the fifth revision of the Diagnostic and Statistical Manual of Mental Disorders that will be produced by the APA has been entrusted to a special Task Force chaired by Professor David Kupfer and Dr Darrel Regier. Dr Regier is Executive Director of the American Psychiatric Research Institute (APIRE) established by the APA (Kupfer 2009; Regier 2009). In preparation for the work of the DSM–V Task Force the APA has produced a series of position papers, each of which deals with a set of issues relevant to the production of the new revision of the DSM (www.psych.org/MainMenu/Research/DSMIV/DSMV). Subsequently, supported by grants from the National Institute of Mental Health, the National Institute on Alcohol Abuse and Alcoholism and the National Institute on Drug Abuse, APIRE convened 14 conferences dealing with the groups of disorders currently included in the mental health section of ICD–10. These conferences were organised in collaboration with the WHO and the final conference, held in Geneva, examined the public health aspects of classifications of mental disorders and of changes to these classifications.

The DSM–V Task Force has established a number of working groups, each addressing one of the major groups of psychiatric disorders. The groups will produce proposals for the classification of disorders and will conduct or help to conduct field trials of proposals that are put forward. In addition to the working groups that deal with specific disorders, there will be five groups dealing with ‘cross-cutting issues’, for example the possibilities of presenting the spectrums of mental disorders in the classification, consequences of the impact of age and gender on the classification and issues that arise for a classification of disorders in treatment in psychiatry and in primary care.

Issues involved in revision

The TAG/MND advising the WHO on the classification of mental disorders in ICD–11 and the DSM–V Task Force that will produce proposals for the APA face a number of dilemmas and questions. Some of them are as old as the classifications themselves, some – such as those related to reimbursements and to the use of modern information systems – have emerged only in recent years. For most of the latter there are no clear answers. For others, such as those listed in Box 1, I will present the questions themselves and issues related to the search for answers.

Criteria for changes of the classification or its categories

The first of these questions concerns the decision about the criteria that should be used to allow the introduction of a new category or the removal of one that is no longer considered useful. There is a fair amount of consensus that these decisions will be taken on the basis of three criteria:

- the public health criterion (is the category helpful for public health purposes?)
- the practical utility criterion (is the classification easy to use and do the categories fit the disorders that are seen in practice?)
- the evidence criterion (is there new and sufficient evidence to propose a change?).

Sometimes political considerations will trump these criteria: thus, it might be that a category will be changed, removed or added because of the insistence of pressure groups or for similar reasons.

Although there is consensus that these three criteria should be used, there is much less agreement about their specific definition. Thus, the public health criterion will not be particularly helpful in deciding about the subdivision of a particular category which would not affect the prevalence of a disorder; it might, however, be of central importance if the proposed change were to affect rates of disorders considered to be of public health importance.

The application of the criterion of practical (‘clinical’) utility is even more problematic. The licensing of a new medication for use in

BOX 1 Revision: the issues involved

- Criteria for changes of the classification or its categories
- Categories or dimensions?
- One or more versions of the classification?
- Should national adaptations of the ICD be seen as the way to deal with culture-specific issues?
- Should the next versions of the classifications be directive or reflective?
- What shape should the primary care version take?
- What will happen once the classification is produced and published?
the treatment of a particular mental disorder, for example, could be of direct relevance to the practice of psychiatry in that it would make its ‘off-licence’ use (the use of the medication for disorders not mentioned in the licence) by clinicians illegal. A change of the classification would allow (or disallow) the use of that medication for potentially very large groups of patients: should the current licences for psychotropic medications be taken into account in devising the classification? From the public health point of view the classification should facilitate public health interventions – e.g. the prevention of mental disorders or the evaluation of needs for mental healthcare (and of its quality): a classification that aims to be useful for the purposes of prevention of mental disorders may well be of little utility for clinical work – at the level of primary care or at the level of specialist psychiatric care.

**Categories or dimensions?**

In both the ICD and DSM, the mental disorders are at present grouped by their symptoms in categories that compose the classifications. In other fields of medicine – in which more is known about the pathogenesis of disorders that have to be grouped – such categories have been defined by the cause of the conditions listed together. Thus, various presentations of tuberculosis are put together – although tuberculosis can affect different body systems and organs. Where this was not possible the disorders or diseases are grouped by the organ that they affect. However, the pathogenesis of mental disorders is not well known and the categories have been grouped by presumed cause (Box 2); criteria were defined to determine in which category a particular disorder appears.

This system appeared at first to avoid problems arising from our incomplete knowledge about the origin and course of most mental disorders. Soon, however, it became obvious that some disorders could be placed in more than one category and that the same symptoms are present in all or most mental disorders. Patients with ‘prototypical’ disorders are the exception rather than the majority. In addition, the border between normal experiences and states and those that should be considered pathological and deserving treatment remains unclear.

The problems that arise when mental disorders have to be placed in sharply defined categories led to the idea that categorical classification (i.e. grouping of disorders by sets of criteria) be replaced by a series of dimensions corresponding to major symptoms of mental disorders. In some instances these dimensions are bipolar (e.g. ranging from supernormal IQ to intellectual disability) and in other instances they are unipolar (e.g. anxiety). The patient’s condition would then be described by a profile produced by rating a number of dimensions. In some cases it would be possible to combine the categorical and the dimensional description of the patient’s state: thus, the categorical diagnosis ‘personality disorder’ would be accompanied by a profile obtained from the person’s characteristics on a number of dimensions. The selection of the dimensions that are most informative might present a hurdle – there are currently debates between the partisans of different numbers of dimensions describing personality traits (e.g. Skodol 2009).

Although scientifically interesting, the notion that psychiatrists and others dealing with mental disorder in practice would be willing to rate each condition on a number of dimensions and that they would communicate about their patients by citing a series of ratings of dimensions does not seem practical. Such a description might be retained for scientific investigations but it is unlikely that it will ever be proposed for use in practice. Experience with the multi-axial version of the ICD and with the five axes of DSM–III and DSM–IV (American Psychiatric Association 1980, 1994) clearly show that psychiatrists and other health professionals do not find it easy (or are reluctant) to use the axes other than for basic diagnosis. It is therefore difficult to imagine that they would be willing to rate a large number of dimensions for each patient.

In some instances the dimensional approach is included in a categorical classification: thus, ICD–10 has three categories of depressive disorder, distinguished by its severity. It is possible that the makers of the next revision of the ICD and DSM will opt for similar solutions combining the categorical and the dimensional approach in describing, for example, personality disorders, the dementias, and consequences of drug and alcohol misuse.

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**BOX 2** The current grouping of the mental disorders in the ICD

- Disorders related to demonstrable brain damage (e.g. dementias)
- Severe mental disorders with presumably genetic causes (e.g. psychoses)
- Disorders that are less severe and neither have a genetic cause nor show demonstrable brain damage (neuroses and personality disorders)
- Conditions characterised by diminished cognitive capacity due to a variety of reasons (mental retardation)
One or more versions of the classification?

In the 1970s the Mental Health Programme of the WHO proposed that the categories of the ICD chapter on mental disorders be accompanied by a brief description of the disorders that would be grouped in them. This was accepted and ICD–8 carried such brief definitions as an integral part (World Health Organization 1974). No other group of disorders in the ICD is handled in this way: the permission to do so depended on two factors. First, the diagnoses of most mental disorders cannot be validated or based on laboratory findings; and second, psychiatrists – maybe more than other specialists – seemed to have more difficulties agreeing on the definition of the diagnoses that they used.

The fact that the glossary definitions of the categories of the chapter dealing with mental disorders were included in the text of the ICD (World Health Organization 1974) and thus could be approved by the World Health Assembly made their use obligatory in all countries that are using the ICD as their official classification. This was seen as an important step to the creation of a common language that could be used in dealing with mental disorders worldwide.

The next step was to produce a more detailed operational description of each of the categories and the WHO published these in the form of clinical guidelines for use in psychiatric practice (World Health Organization 1992b). The guidelines were not excessively strict in their recommendations. They used expression such as ‘usually seen’ or ‘on or about’ – which made the guidelines welcome for clinicians but did not satisfy the requirements of research. The WHO therefore published a second set of guidelines that were meant to help researchers (World Health Organization 1993) in their efforts to define homogeneous groups of subjects for various investigations.

Neither of these two documents could be recommended to those working in general healthcare and primary care services. The number of categories in these two publications was large, the definitions of each of them complex and the practical usefulness limited. The WHO therefore produced a primary care version of ICD–10 (World Health Organization 1996). In this version of the classification the number of categories has been brought down to 22 and their description is couched in simple terms referring to symptoms that general healthcare workers often encounter. Following the description of categories the primary care classification provides specific advice about action that the physician or other healthcare worker might wish to take (see below, p. 8).

The DSM–IV uses definitions of the categories that are very similar to those contained in the research version of ICD–10; the APA also produced a primary care version of their classification, DSM–IV–PC (American Psychiatric Association 1995), a considerably more complex document than the primary care version of the ICD–10 mental disorder chapter.

The question that is now before the committees of the APA and WHO is whether a similar strategy – of several versions of the respective classifications for use in different settings (clinical psychiatric practice, research, primary care and possibly others) – should be used for ICD–11 and DSM–V. An option would be to leave the development of a research version to the DSM Task Force and have the WHO concentrate on the development of the primary care version; the core version (into which it should be possible to translate the research version and the primary healthcare version) would be developed in close collaboration and would serve as the basis for any and all other versions. Whether this option will find favour with the WHO and the APA is an open question depending to a certain extent on the policies of the publication department of the former and the pressures that the governing bodies of the latter might exert on the DSM–V Task Force.

Should national adaptations of the ICD be seen as the way to deal with culture-specific issues?

I recall that some 50 years ago an American anthropologist speaking at a meeting in Hawaii gave a paper entitled ‘Why does everybody else have culture-specific mental disorders and only we have the real thing?’ This referred to the habit of calling any form of mental illness that did not correspond to the description of mental disorders produced by the great classics of psychiatry in Europe a ‘culture-specific’ disorder. The first reaction of the psychiatrists living in countries where such disorders existed was to produce their own classifications that provided categories for the placement of conditions that they frequently saw in their practice. Sometimes the motivation for the production of a new classification had more to do with the effort to maintain the prestige of an institution than with the forms of mental disorders seen in the area. In a classic paper in 1960 Stengel, then a consultant to the WHO, wrote that any psychiatrist of note produced his own classification: the report contributed to the WHO’s decision to launch a major programme dealing with diagnosis and classification.

As time went by and our knowledge about the forms of mental disorders in different parts of the
world (and in Europe) increased, it became clear that many of the conditions that were previously considered ‘culture-specific’ also exist in European countries, although they are on the whole rare; and that some of the ‘European’ forms of mental disorders are very rare in other parts of the world. This did not prevent the creation or maintenance of national adaptations of the ICD (or of national classifications that were used by psychiatrists but could not be translated or easily related to the ICD), although their number and influence diminished over time. The existence of these national adaptations and national classification systems may in fact facilitate the abuse of psychiatry: abuse of psychiatry for political purpose in the former USSR was made easier by the fact that the national classification contained categories that could be used to label dissidents, who could then be forcibly placed and held in mental hospitals for ‘treatment’.

There is little doubt that the question of whether to produce national adaptations of the ICD will arise again. However, the chances that such adaptations will be produced will be diminished if the WHO manages to develop its proposal, in collaboration with national societies (possibly through the World Psychiatric Association), and if it convinces all concerned – professionals and governments – to use the same classification, perhaps with annotations about the use of certain categories. This will impose an extra burden on the WHO Department of Mental Health and Substance Abuse that will require resources and time, both of which are not abundant at present. Whether this ideal can be achieved is an open question.

What shape should the classification for use in primary care take?

The primary goal of the classifications of mental disorders – and other disorders – in the ICD is to facilitate statistical reporting of the work done in the healthcare system. The fact that, originally, the DSM was a statistical manual grouping diagnoses into classes for reporting to health authorities and insurance agencies has gradually waned in the mind of psychiatrists and users of the classification.

Classification can of course have other purposes, one of which could be to facilitate decisions about treatment at a particular level of healthcare. The ordering principles of a classification that will facilitate treatment will be different from those of a classification that facilitates reporting on the work done in a particular service. Thus, the categories of a classification used in primary care have to be chosen with potential interventions in mind. If all primary care patients with psychotic disorders require the same intervention – for example, to be sedated and referred to a specialist – there is little point in dividing the group of psychoses in the classification by their genetic make-up. Conditions that are rarely seen will not be given a special place in the consideration and might be grouped in a catch-all group of ‘others’. The ease of use in busy general practice units will be another important consideration: complicated systems or systems that require special tests in order to decide where to place a disorder are unlikely to be widely used.

At the same time, however, a classification that will be used in primary care must be a tool
for reporting about the work done, allowing comparisons with other services and the evaluation of performance.

The primary care version of the ICD–10 classification of mental disorders (ICD–10 PHC), now in its second edition (World Health Organization 1998), contains simple instructions about recognition and diagnosis, an indication of the treatment that would most likely be useful if such a diagnosis is made and other advice (e.g. on advising family members or other carers, on criteria for referral, on how to handle frequent side-effects of treatment) important in clinical practice. It groups disorders that are rarer and require similar interventions (e.g. psychotic disorders) into a single category and provides categories for disorders that are frequent (e.g. enuresis) even though in the full ICD they are classified at a subcategory level. Although ICD–10 PHC can be used for reporting from primary care services, it is more a guideline for recognition and treatment of mental disorders seen in primary care than a classification for statistical purposes. It was very well received by primary care physicians and is quite popular in psychiatric practice as well. It has proved to be particularly useful in countries where physicians receive little instruction in the recognition and management of common mental disorders.

The ICD–10 PHC was issued by the Division of Mental Health of the WHO and promoted as a tool for primary healthcare: the fact that it could also serve to report about mental health services was presented as a bonus. The makers of the primary care version of ICD–11 will have to decide whether to use the same principles and produce a classification that contains instructions about recognition and treatment or to take the alternative route – i.e. to produce a classification of disorders seen in primary healthcare and a separate set of guidelines about their recognition and treatment. The former would guarantee the use of the classification in daily work; the latter would allow changes of the instructions about treatment without changes to the classification. For the WHO the latter is more attractive: the classification has to be approved by the World Health Assembly and requires considerable administrative effort for any change, whereas the instructions about treatment are seen as an option for consideration by each country’s own authorities and their change therefore does not involve the Assembly.

What will happen once the classification is produced and published?

Once the work on the classification is completed and the various governances have approve it, the classification will be published and a new set of tasks will stand before its makers. First, it will be necessary to train those who use it. In the instance of the ICD, these will include the personnel who code diagnoses in health institutions as well as professionals who make the diagnoses. Second, it will be necessary to introduce quality control measures to ensure that the classification serves their purposes in practice. Third, a mechanism will be needed to record the experience of users and their suggestions about improvements of the classification. The same mechanism might also have to record scientific advances that would require changes to categories. Both ICD–11 and DSM–V are being seen as ‘living documents’: they will be changed as the need arises, rather than waiting for the major revisions that have thus far been carried out. Consequently, training materials and the training of users will have to be reviewed as changes are made to these living documents.

The translation of the classifications into the many languages of the world will require time and supervision to ensure the equivalence of the various language versions. Finding the best way of producing equivalent versions of the classification in different languages is another major issue before the WHO and its advisors. In the past, translations into several languages were done in parallel with the development of the English original, thus ensuring that the formulation of the criteria in the original version used expressions that had an equivalent in the other WHO official languages. Whether this will be possible on this occasion is unclear and it might therefore be necessary to decide how to proceed with the translations after the classifications have been produced.

Ideally, a plan for dealing with all of these matters should be produced before the new classification is released.

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A number of other issues are also facing the groups that will develop the new versions of the classifications. They include the question of the classification that will be used by the various categories of personnel who deal with mental disorders – will psychiatric social workers, for example, be willing and able to use the classification produced for and by psychiatrists? Or will it be necessary to create a bridge between the classifications used by psychiatric nurses, psychologists, psychiatric social workers and the numerous other disciplines that participate in mental healthcare?
There is also the question of the ‘meta-structure’ of the classifications. At present the meta-structure of the ICD contains nine groups – a development of the original structure of five groups of categories: ‘organic’ mental disorders (such as dementia), psychotic disorders, neurotic disorders, personality disorders, and mental retardation. The major groups of substance abuse and childhood disorders were added in the 1970s (World Health Organization 1978). Does currently existing scientific evidence allow the restructuring of the classification and the creation of a restricted number of major groups that will be different from the old structure? And, if it does, will the new meta-structure have advantages in terms of ease of communication about mental disorders with non-specialists and ease of deciding on treatment interventions?

There is no doubt that further questions – concerning both the science and the practice of medicine – will emerge in the course of preparing the proposals for ICD–11 and DSM–V. It will therefore be of great importance that those charged with this task are in constant communication with scientists and the many users of the classifications so that they become aware of issues when it is still possible to consider solutions and incorporate them into the current revisions. The decision to produce living documents that can be changed when necessary is no doubt a consequence of the awareness of their creators that this communication must be maintained after publication and that it will be necessary to constantly work on the classifications to ensure that they continue to reflect the evidence and respond to the needs of their users.

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