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Open letter regarding the reform and revision of diagnostic systems

Dear Dr. Weber, Dr. Harrison, Dr. Appelbaum, and Dr. Cuthbert,

This letter was constructed by the Task Force on Diagnostic Alternatives of the Society for Humanistic Psychology (Division 32 of the American Psychological Association [APA]). This is an official statement of the Society for Humanistic Psychology, Division 32 of the American Psychological Association, and does not represent the position of the American Psychological Association or any of its other Divisions or subunits.

In 2011, the British Psychological Society (BPS)¹ and the Society for Humanistic Psychology (Division 32 of the American Psychological Association)² responded to the American Psychiatric Association's proposals for what would become the fifth edition of its *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5)³. Both professional bodies expressed concern that:

...clients and the general public are negatively affected by the continued and continuous medicalisation of their natural and normal responses to their experiences; responses which undoubtedly have distressing consequences which demand helping responses, but which do not reflect illnesses so much as normal individual variation...

That concern, among others, appeared in an *Open Letter to the DSM-5* that was endorsed by over 15,000 mental health professionals and other individuals as well as by over 50 professional organizations, including 15 additional divisions of the American Psychological Association.

Since then, we have seen the development of various diagnostic systems and related research frameworks. Among them are the National Institute of Mental Health's new research framework, the *Research Domain Criteria* (RDoC) project,⁴ which aims to develop "new ways of classifying mental disorders based on behavioral dimensions and neurobiological measures" and the *Hierarchical Taxonomy of Psychopathology* (HiTOP)⁵; as well as the ongoing revisions of the World Health Organization's *International Classification of Diseases and Related Health Problems* (ICD)⁶ and the American Psychiatric Association's DSM.⁷

Whilst there is much to be welcomed in these initiatives, we have scientific, conceptual, and ethical concerns about each of them. The diagnostic categories proposed by these frameworks — the DSM, the ICD, and newly proposed models such as the RDoC project — are based largely on social norms about what constitutes 'normal' or desirable behavior or experience. Their definitions inevitably rely on subjective judgments, which are themselves grounded in cultural norms. As Thomas Insel⁸ has pointed out, despite billions of dollars of research investment, no biomarkers, confirmatory physical 'signs,' or pathognomonic evidence of biological causation have been discovered for the putative pathologies represented by the category labels within these systems. Many researchers have pointed out that psychiatric diagnoses are plagued by problems of reliability, validity, prognostic value, and comorbidity. Significantly, diagnostic categories do not consistently predict response to medication or other interventions.⁹

One thing that these systems have in common is that they identify and locate problems within individuals. There is clear evidence that what one is exposed to, individually or as a collective, can have adverse impacts psychologically, behaviorally, and emotionally — including for future generations. For many people, the main cause of their experiences is found in the circumstances of their lives. Locating problems within only individuals misses the relational context and undeniable social and structural influences on many of these problems. As psychologists, we are aware of the importance for mental health of people's frameworks for understanding of the world, frameworks which are themselves the product of their experiences and lifelong learning. From an ethical standpoint, we should not minimize or ignore the social and structural origins of psychological suffering by, instead, re-interpreting that suffering as a result of deficits or disorder within the individuals affected by these problems. This has implications for care.

In practice, diagnoses are not conferred in a contextual vacuum. The criteria are not culture or value-free, but instead reflect current normative social expectations. At the same time, psychiatric diagnoses have substantial impact on the social and occupational lives of those to whom they are applied. And reductionist biomedical diagnoses obscure the social determinants of our distress. This is important: as the United Nations Special Rapporteur concluded in 2017, we are under an international obligation to ensure that mental healthcare adequately addresses social contexts and relationships¹⁰.

We therefore recommend a paradigmatic revision of the empirical and conceptual frameworks used to think about mental health. A classification approach that pursues the neo-Kraepelinian goal (now nearly half a century old) of establishing biomarkers for individual conditions or symptoms would not constitute such a paradigm shift, but rather an attempt to revitalize the current paradigm. A true paradigm shift would start with recognition of the overwhelming empirical evidence that the experiences we call mental illness are understandable and essentially 'normal' human responses, and that psychosocial and structural factors such as inequity, abuse, poverty, housing insecurity, unemployment, and trauma are the most robustly evidenced social determinants. Rather than applying preordained diagnostic categories to clinical populations, we believe that any empirical classification system should begin from the bottom up — starting with the specific concerns expressed by those seeking mental health services about their experiences, behavior, problems, 'symptoms,' or 'complaints.' Statistical analysis of community samples show that people's experiences of distress do not map onto the categories contained in current or proposed classification systems. We would like to see the base unit of measurement changed from instances of putative disorders to occurrence of specific experiences identified by the individual as problems (e.g., hearing voices, feelings of social anxiety, feeling lonely, worry about the future, etc.). These would be more helpful too in terms of epidemiology. We also believe that in view of the central role played by social and structural determinants of distress (e.g., childhood trauma,

socioeconomic disparities, racism, discrimination, assault, homophobia, homelessness, and multiple deprivation), these should be centrally integrated within any diagnostic alternative, rather than included as optional or secondary considerations. These changes would also align with the growing person-centered, recovery-oriented, and cultural/structural competency movements within psychiatry and medicine more broadly.

Some people find diagnostic labels helpful. There can be a variety of reasons for this. Within our current system, a diagnosis is often needed to access help. It also conveys the impression that the problems and their causes are understood, that others share similar experiences, and that a suitable medical intervention is available. Unfortunately, this latter promise is often spurious. We believe that experientially based categories, reflecting the ways in which people themselves describe their experiences, would enable categorization for administrative purposes without some of the problematic assumptions and effects of the current and proposed systems. For the purposes of guiding individual treatment, individual formulations,¹¹ collaboratively drawn up by the clinician and the service user, are more helpful. We therefore believe that alternatives to diagnostic frameworks exist, should be preferred, and should be developed with as much investment of resource and effort as has been expended on revising existing approaches.

As diagnostic frameworks are developed and revised, we urge you to consider the following:

Standards and Guidelines for the Development of Diagnostic Nomenclatures and Alternatives in Mental Health Research and Practice

A diverse group of professionals, led by members of the American Psychological Association's Division 32, have published aspirational *Standards and Guidelines*¹² to serve as a reference for the development of scientifically sound and ethically principled diagnostic nomenclatures and descriptive alternatives. The *Standards and Guidelines* address the purposes, development, content, and scientific grounding of nomenclatures and alternative systems. They are "*intended to represent best practice in the classification and description of emotional distress for multidisciplinary mental health professionals*" (p. 2). The recommendations in the *Standards and Guidelines* should guide the current and future development of diagnostic systems, related taxonomies, nomenclatures, and alternative approaches.

The considerations below draw from the principles of the *Standards and Guidelines* for the purposes of emphasizing some of the most crucial issues at present. More specifically, for the present purposes, bearing in mind the diagnostic systems and alternatives currently in use and in development across the world, particular attention should be drawn to the following issues:

A: Guiding values and principles

The purpose of diagnostic and alternative systems must be the promotion of public health and wellbeing (as opposed to professional or commercial benefit). Once a system is developed and in place, ongoing independent review by appropriate scientists and ethicists should ensure that the system continues to serve this purpose. One reason that diagnostic terms continue to be used despite their lack of validity and the drawbacks for service users could be that they are sometimes useful to clinicians.¹³ Any privileging of the needs of clinicians or bureaucratic systems over those of service users is significant cause for concern and should be addressed in any future diagnostic system.

B: Conflicts of interest

It is well known that there are major conflicts of interest in the constitution of previous working parties developing diagnostic guidelines.¹⁴ Concerns have been raised on numerous occasions about the potential for bias when treatment recommendations are developed by researchers funded by the pharmaceutical industry.^{15, 16} Diagnostic guidelines (and other healthcare protocols) should be developed free from for-profit industry influence and based on unbiased and uncensored scientific evidence. All parties involved in the development of diagnostic guidelines should take every step possible first to be fully transparent and explicit about financial, institutional, intellectual, ideological, or other conflicts of interest, and second, to reduce and eliminate these conflicts of interest. The importance of transparency is underscored by the Institute of

Medicine's recommendations for managing and maintaining transparency about conflicts of interest in the development of clinical practice guidelines^{17, 18}.

C: Leadership

For these and other reasons, we therefore recommend that any revision of diagnostic criteria, nomenclature or taxonomies should be led (or chaired) by members of the general public, current or former users of mental health services ('experts by experience'), and family members in addition to professional representatives free from the conflicts of interest discussed earlier. All stakeholders—including service users, families, community members, and mental health professionals—should have democratic representation for decision-making that occurs during the development process. We recognize that this imperative has resource implications, because members of the public will need practical and financial support in order to participate fully. While organizations such as the American Psychiatric and Psychological Associations have substantial resources and produce work that impacts on the lives of members of the public, it is reasonable to expect active support for the participation of people with lived experience of mental health care in these initiatives.

D: Perspectives

Moreover, as outlined above, mental health is a contested area, and there is neither a single correct way to conceptualize mental distress in general nor to address the issue of categorization in particular. As the British Psychological Society has previously advised,¹⁹ describing particular experiences as "*symptoms of mental illness ... is only one way of thinking about them, with advantages and disadvantages.*" Indeed, the simple fact that there are, from time to time, revisions of diagnostic guidelines demonstrates that the accepted orthodoxies of our generation may be regarded as myths by future generations.

Diagnostic frameworks for mental health research and practice are not neutral statements; they shape healthcare provision, remuneration and funding systems, insurance coverage, and, vitally, criminal and civil law. Diagnostic frameworks also dominate media and public debate, they help shape our ways of being and behaving--what we think it means to be human.

Therefore, it is essential that the processes for reform of diagnostic guidelines include not only advocates, but also people with a range of perspectives that include critical and dissenting views – professionals who advocate for alternatives to diagnostic approaches, and people who have chosen to reject mainstream psychiatry-- as well as industry professionals.

E: Science

Philosophical and democratic principles (including the teleological purpose of diagnostic manuals, their periodic reform, and the necessity to involve the general public and persons) are important, but we must also be guided by principles of scientific integrity. Hence, appropriate (and honest) reviews of the available research literature, including research that is critical of traditional diagnostic systems in mental health care, are vital.

Diagnostic manuals must also reflect –in their content, structure, commentary, and recommendations – the overwhelming evidence for: a) continua in the experience and expression of what are termed 'mental health problems,' b) frequent social and structural causation, c) the lack of construct validity for the majority of diagnostic categories, d) the lack of predictive value in terms of both causal mechanisms⁴ and treatment pathways,⁹ and e) the problematic reliability for many diagnostic categories in field trials.

F: Alternative frameworks for service delivery

Some but not all public services, and some but not all medical specialists, rely on diagnostic categories and criteria. Moreover, while appropriate and accurate statistics are required for a range of health and social care planning, the kinds of diagnostic systems currently being developed do not always fit this agenda and often go beyond it.

As part of reform to diagnostic frameworks, taxonomies, and nomenclatures, we therefore recommend that equal recognition be given to forms of service delivery and research that obviate the need for diagnostic approaches. In the field of education, pedagogical research and educational provision are not predicated on the ‘diagnosis’ of educational ‘disorder,’ but instead respond to learners’ specific needs. Social work builds on decades of sociological, economic, and geographic research. Local government agencies respond to the needs of citizens without using diagnostic approaches. The criminal justice system (police, legal, judicial, penitential, and probation services) responds to vital societal requirements with only occasional incursions of diagnostic psychiatry. And the work of spiritual and religious communities (rabbis, priests, imams and pastors) is in no sense dependent on diagnostic theory. Even within medicine, prevention relies on accurate record-keeping and data collection, but does not rely on the identification of putative illness entities. Medical professionals frequently offer healthcare aimed at keeping well people well (whether in ‘well-man’ and ‘well-woman’ services, in providing healthcare for children and young people, including vaccination and preventative healthcare checks or medical support for pregnant women, or even as medical advisors to industry) without diagnosis.

Narrowing our focus to mental health research and practice, we would recommend an ‘applied science’ approach. This approach emphasizes clear and replicable definition of the subject matter (which includes, but is not limited to, experiences and phenomena within psychiatric diagnostic criteria), and then developing and testing hypotheses as to the origins and maintenance of, and appropriate intervention to address, those phenomena. One example of a framework which adopts this approach is the recent Power Threat Meaning Framework, co-produced with service users and funded by the British Psychological Society, which is already proving influential in UK services and beyond.²⁰ All of these alternatives to traditional medicalized diagnosis enable data collection, measurement, definition, communication, etc., thereby meeting the legitimate aspirations of a scientific approach, but – importantly – do not assume the presence of putative ‘illnesses,’ thus avoiding most of the problems identified above.

In addition to such general consideration of forms of service delivery and research that do not rely on diagnostic taxonomies, we also recommend that any reform or review should also consider:

G1. The use of existing codes for specific experiences and phenomena

Both the DSM and ICD systems include codes for specific phenomena and experiences related to mental health issues. Examples of such codes in ICD-11 include: non-suicidal self-injury (MB23.E), anxiety (MB24.3), depressed mood (MB24.5), elevated mood (MB24.8), feelings of guilt (MB24.B), and auditory hallucinations (MB27.20). Mirroring the ICD, DSM-5 includes a limited number of these codes, and we recommend that these are further developed. We recommend that any review of diagnostic systems should include significant development in, and recommendations for the regular use of such codes for specific experiences and phenomena in everyday clinical practice.^{21, 22}

G2. The use of existing codes for social determinants

Similarly, both the DSM and ICD systems include codes for many of the known social determinants of mental health problems, which incorporate descriptive information about adverse life events and circumstances. There is robust research on psychological and social determinants of mental health, and many of these codes are explicitly tagged as ‘reimbursable’ in the ICD system (ensuring that healthcare practitioners can receive compensation for primary prevention). However, these codes for social determinants are almost never used or reported either in clinical practice or in the academic literature.²³ Examples in ICD-11 include homelessness, poverty, discrimination, and adverse life events in childhood, including abuse. DSM-5 (specifically when discussing ‘other conditions that may be a focus of clinical attention’) mirrors this, and similarly includes problems related to family upbringing, as well as housing and economic problems. We recommend that any review of diagnostic systems should include significant development in, and recommendations for the regular use of such codes in everyday research, training, and clinical practice.

G3. The role of formulation

All professional bodies stress the role of individual ‘formulations’ as either alternatives to, or supplements to, diagnoses. Formulations are person-centered, detailed descriptions of the person’s past experiences and

relationship to current life goals and challenges. In the UK, both clinical psychologists¹¹ and psychiatrists²⁴ offer ‘formulation’ (or more specifically, ‘co-produced formulations’) as core elements of their profession, but also as key elements of care.

In practice, however, diagnostic approaches have dominated clinical practice (possibly because of the role of healthcare providers and insurers). This not only undermines the potential use of alternatives to diagnosis, but also negates the professional and clinical advice of professional bodies which emphasize the importance of formulation. Professional bodies, rightly, stress the importance of cultural sensitivity in mental health care. If this is to be taken seriously, then any system for identifying and naming patterns of psychological distress must give appropriate weight to the science and practice of formulation as an adjunct to diagnosis.

Conclusion

Multidisciplinary mental health professionals have, for a long time, advocated for the integration of psychological, subjective, or experiential phenomena into nomenclatures for mental distress; and some have advocated for alternative descriptive systems that address lived experience. Given the fact that all clinical assessments and diagnoses in the field of mental health rely on verbal reports and behavioral observations (rather than biological tests), a serious, collegiate, and comprehensive review of this approach could yield major benefits. Of central and crucial importance is documenting – and addressing — the social and structural determinants of psychological distress, rather than limiting diagnosis to the individuals whose lives are disrupted by them. These determinants are just as important as, and are already supported by evidence that is more empirically robust than, the pathognomonic biogenetic factors (e.g., neurocircuitry) that still elude scientists who hope that they will hasten the next taxonomic revolution.

As a next step to address these concerns, we request an online, telephone, or in-person meeting to discuss these issues in more depth. We look forward to your response.

Sincerely,

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