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ETHICAL IMPLICATIONS OF THE DSM-5

Support

- The Thomas Scattergood Behavioral Health Foundation, Philadelphia, PA
- Department of Psychiatry, Mood & Anxiety Disorders Treatment Research Program, University of Pennsylvania
- Department of Medical Ethics & Health Policy, University of Pennsylvania

Agenda

- Describe the background and several important changes in DSM-5
- Explore the philosophical question: why is reclassification of mental disorder an ethical activity?
- Examine the decision-making process in regard to these changes
- Address several key questions

Where Things Stand

Criticism of DSM-5

- Too soon for new classification
- Not sufficient advances to warrant revision
- Still far from the goal of having diagnoses based mostly on objective & biologically measurable criteria
- Broadening of categories (idiosyncrasies are pathologized)

Overview of revision process

- Process began in 2000
- Preliminary research agenda published in 2002
- 2006: Kupfer & Regier appointed to head DSM task force
- Three commenting periods
- Available to public May 22, 2013

Overview of revision process

Study groups:

- Diagnostic Spectra
- Lifespan Developmental Approaches
- Gender & Cross-Cultural Issues
- Psychiatric/General Medical Interface
- Impairment Assessment
- Diagnostic Assessment Instruments

Work groups for each diagnostic category

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5 ™).* Washington, DC: American Psychiatric Association; 2013.

Revision Principles

- Useful to clinicians
- Recommendations guided by research evidence
- Continuity with previous editions
- No *a priori* constraints on the degree of change between DSM-IV and DSM-5

Revision Principles

- Development - across the life span
- Dimensional concepts - measurement of distress, disability, and severity
- Incorporation of new knowledge - risk factors, prevention, new syndromes
- "Living document" – Note the use of "5"

DSM-5 Chapter Headings

A. Neurodevelopmental Disorders
B. Schizophrenia Spectrum & Other Psychotic Disorders
C. Bipolar and Related Disorders
D. Depressive Disorders
E. Anxiety Disorders
F. Obsessive/Compulsive & Related Disorders
G. Trauma and Stressor Related Disorders
H. Dissociative Disorders
I. Somatic Symptom Disorders
J. Feeding and Eating Disorders

DSM-5 Chapter Headings

K. Elimination Disorders
L. Sleep-Wake Disorders
M. Sexual Dysfunctions
N. Gender Dysphoria
O. Disruptive, Impulse Control, & Conduct Disorders
P. Substance Use and Addictive Disorders
Q. Neurocognitive Disorders
R. Personality Disorders
S. Paraphillias
T. Other Disorders

Psychiatric Disorder

Table 2. *DSM-V proposal for the definition of mental/psychiatric disorder*

Features	
A	A behavioral or psychological syndrome or pattern that occurs in an individual
B	The consequences of which are clinically significant distress (e.g. a painful symptom) or disability (i.e. impairment in one or more important areas of functioning)
C	Must not be merely an expectable response to common stressors and losses (e.g. the loss of a loved one) or a culturally sanctioned response to a particular event (e.g. trance states in religious rituals)
D	That reflects an underlying psychobiological dysfunction
E	That is not primarily a result of social deviance or conflicts with society
Other considerations	
F	That has diagnostic validity on the basis of various diagnostic validators (e.g. prognostic significance, psychobiological disruption, response to treatment)
G	That has clinical utility (e.g. contributes to better conceptualization of diagnoses, or to better assessment and treatment)
H	No definition perfectly specifies precise boundaries for the concept of either 'medical disorder' or 'mental/psychiatric disorder'
J	When considering whether to add a mental/psychiatric condition to the nomenclature or delete a mental/psychiatric condition from the nomenclature, potential benefits (e.g. provide better patient care, stimulate new research) should outweigh potential harms (e.g. hurt particular individuals, be subject to misuse)

Ethical Issues

- Are we medicalizing normal variability?
- What are the implications of dimensional vs. categorical approaches?
- Are treatments disease-focused or patient-focused?
- Is there disease mongering by adding new disorders?
- Are these changes truly beneficent?

In the context of biomedical ethics

A Brief Introduction to the Philosophy & Ethics of Behavioral Healthcare

deontology
utilitarianism
natural law
virtue ethics
casuistry
principlism
feminism
pragmatism

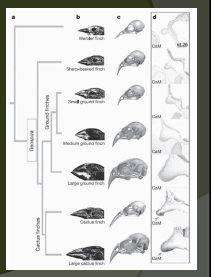
} methods in biomedical ethics

Biobehavioral Healthcare Ethics

- Subdiscipline of bioethics
- Focus on unique ethical issues in psychiatry, psychology, neurology, and clinical social work
- Unique issues include
  - Involuntary treatment
  - Capacity assessments
  - Forensics
  - Nosology
  - Free will and autonomy
  - Diagnosis, stigma, personal identity

Philosophy of Medicine 101: Kinds of Things

- Natural kind realism/platonism
  - There exist entities in the world independent of our knowledge or recognition
  - Carving nature at its joints
  - Elements as bona fide natural kinds
  - Species (?)
- Social constructionism/artificial kinds
  - Entities exist insofar as we recognize and use them or interact with them
  - Nominalism
- Pragmatic kinds, moral kinds, interactive kinds, pluralistic realism



Philosophy of Medicine 101: The Concepts of Health and Disease

- Naturalism
  - Disease as deviation of species typical function (Boorse)
    - Heart – form and function to pump blood
    - Pathogens (*ens morbi)*
  - 'Illness' = disease + social value
- Normativism
  - Diseases are value-laden constructs
- Hybrid
  - Harmful dysfunction (Wakefield)

Philosophy of Medicine 101: The Concept of Mental Disorder

- Mental illness as mythology
  - Szsaz: Strong normativist OR strong naturalist
- Mental illness as social constructs (Foucault, et al.)
  - Social control, medicalization of deviance
- Mental illness as natural kinds (Boorse)
  - Brain-based dysfunction
- Mental illness contain both biological basis and social value (Wakefield)

Table 2. *DSM-V proposal for the definition of mental/psychiatric disorder*

Features

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Other considerations

- F That has diagnostic validity on the basis of various diagnostic validators (e.g. prognostic significance, psychobiological disruption, response to treatment)
- G That has clinical utility (e.g. contributes to better conceptualization of diagnoses, or to better assessment and treatment)
- H No definition perfectly specifies precise boundaries for the concept of either 'medical disorder' or 'mental/psychiatric disorder'
- I Diagnostic validators and clinical utility should help to differentiate a disorder from diagnostic 'nearest neighbors'
- J When considering whether to add a mental/psychiatric condition to the nomenclature or delete a mental/psychiatric condition from the nomenclature, potential benefits (e.g. provide better patient care, stimulate new research) should outweigh potential harms (e.g. hurt particular individuals, be subject to misuse)

From Stein, et al. 2010

Why Nosology Matters Ethically

IDENTITY, STIGMA, NORMALITY, BLAME & EXCULPATION

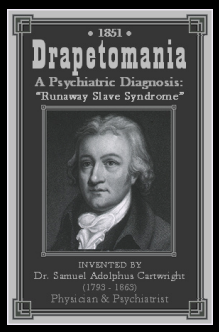
The Ethics Of Categories & Labels

Why do labels matter?

- Categorizing illness is an ethical activity
  - Concepts of health, disease, illness are value-laden
  - Many mental disorders are *not* natural kinds
- By marking out the sick, persons are relegated to sick role
- The width matters
  - Too narrow– sick are left out
  - Too wide– individual idiosyncrasies, eccentricities pathologized, liberty undermined
- Key to the ethical enterprise: Beneficent Intent
  - Proximate goal: diagnose, treat, and conduct research
  - Ultimate goal: relieve human suffering

Labeling Gone Horribly Wrong

- Analysis of intent reveals:
  - Political pressure
  - Racism, sexism
  - Appeals to religious/moral tradition
  - Medical domain expansion
  - Disease mongering
- Was maleficent intent not apparent at the time?
  - Problem of temporal and cultural relativism
- Critical analysis needed at all stages of nosology development



Labeling: a question of identity

- Illness as identity
  - Diagnosis shapes the way we think of self and others
  - Identity altering impact of physical illness
  - 'Identity work' - the process and adjusting to new identity
- Mental disorder as identity
  - 'Schizophrenic' versus 'canceric'
  - She is 'borderline' versus she suffers with borderline personality disorder
- Mental condition as gift
  - Melancholic artist
  - Aspergian genius

Identity & stigma dynamics

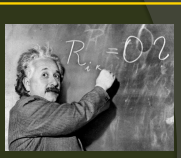
- Foucault, *Madness & Civilization*
  - Mentally ill were cordoned off from society
- According to Goffman, stigma can be:
  - Mental illness
  - Physical disability
  - Race, gender, religion, belief system
- The 'Other'

Hieronymus Bosch, The Ship of Fools, 1500

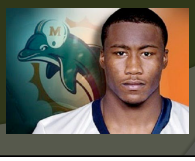
Embracing mental disorder

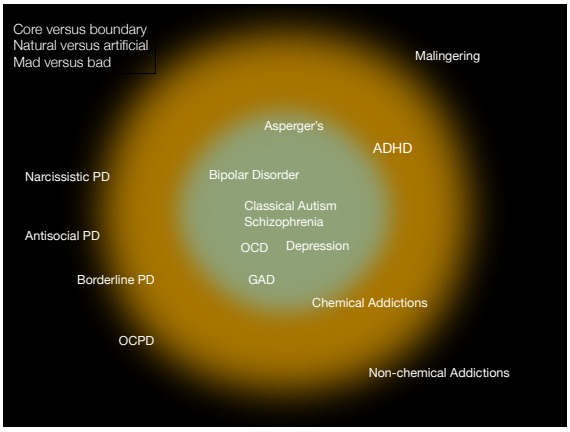
Identity disruptions

- Asperger's syndrome → ASD



- Borderline personality disorder → Public recognition, acceptance





Blame & exculpation

- Controversies surrounding expanded categories
- 'Rationalizing' or medicalizing bad, vicious, evil behavior
  - Gambling
  - Promiscuity (hypersexuality/ out of control sexual behavior)
  - Pedophilia (minor attracted persons; B4U-ACT)

Why Nosology Matters Ethically

REVISIONS, ADDITIONS & DELETIONS IN THE DSM-5

A Word About The Field Trials

Sites & Patients

- Academic outpatient settings (7 adult, 4 pediatric)
- Target enrollment of 50/disease category
- 279 clinicians/2246 patients

Design

- Assess clinical utility and feasibility, est. reliability
- Two clinical interviews (60 min.) with 2 providers
- Third interview for symptom resolution (few)
- Acceptable kappa of .4 -.6 (.6 > typical)

Clarke DE, et al. *Am J Psychiatry.* 2013;170:43-58.
See also Kupfer, D. & Kraemer, H., *Huffington Post*, 11/7/2012; Frances, A., *Huffington Post*, 10/31/2012

A Word About the Field Trials

Anecdotal reports

- Varying diagnostic abilities of clinicians
- Too little time for adequate assessment
- Lack of familiarity with all patient groups

Test-retest reliability

- Only 2/3 of disorders had significant sample size to calculate kappa
- Kappa's ranged from 0-0.8, most < 0.6
- Why low kappa's? Can it be improved?

Regier DA, et al. *Am J Psychiatry.* 2012;170:59-70.

Field Trials: Disorders

- Alcohol use disorder (adults), substance use disorder (kids)
- Binge eating disorder
- MDD, mixed anxiety depression, bipolar disorder (both adults & kids)
- Complex somatic symptom disorder
- GAD, hoarding disorder, PTSD (adults & kids)
- Mild & major neurocognitive disorder, TBI
- Schizoaffective, schizophrenia, attenuated psychosis
- Personality disorders (antisocial, borderline, narcissistic, OC, schizotypal)
- ADHD
- Autism spectrum disorder
- Avoidant/restrictive food intake
- Disruptive mood dysregulation disorder
- Conduct disorder, oppositional defiant disorder
- Non-suicidal self-injury

Mood Disorders

Revisions

- Eliminate the grief exclusion criterion from MDD

New Disorders

- Mixed Anxiety/Depression
- PMDD
- Disruptive mood dysregulation disorder (child BP)

Field Trial Data

- Mixed anxiety/depression — "needs further study" though included in ICD-10, *kappa* < 0
- Clinicians worse at MDD dx now than 1990 (*kappa* = 0.28)
- Bipolar disorder *kappa* = 0.56
- PMDD *kappa* = 0.25

Anxiety Disorders

Revisions

- New Categories:
  OCD & Related Disorders
  Trauma & Stressor Related Disorders
- Trichotillomania now "Hair Pulling Disorder"

New Disorders

- Agoraphobia a separate, coded diagnosis
- Hoarding a separate, coded diagnosis

Field Trial Data

- GAD *kappa* = 0.2
- Hoarding (n = 17) but *kappa* = 0.6

OCD and Related Disorders

Disorders

- OCD
- Hoarding Disorder
- Body Dysmorphic Disorder
- Hair-Pulling Disorder
- Skin Picking Disorder

Rationale

- Obsessions and compulsive rituals differentiate OCD from other anxiety disorders.
- Data challenge hoarding ↔ OCD/OCPD relationship
- OCRD similar to OCD → prominent obsessions & compulsive rituals (BDD), repetitive motoric behaviors like compulsions (hair pulling, skin picking)

Field Trial Data

- OCD *kappa* = .3

Trauma & Stressor Related Disorders

Disorders

- PTSD (adults & kids)
- Acute stress D/O
- Adjustment D/O
- Reactive attachment D/O
- Disinhibited social engagement D/O

PTSD Revisions

- Clearer definition of trauma (sexual assault, recurring exposure)
- Symptom clusters: re-experiencing, avoidance, negative cognitions/mood, arousal
- Eliminate acute, chronic features
- Subtypes: PTSD preschool; PTSD dissociative
- PTSD *kappa* = 0.7

Schizophrenia Spectrum & Other Psychotic Disorders

Revisions

- Schizophrenia threshold raised → 2 symptoms
- Must have delusions, hallucinations, or disorganized speech
- Subtypes removed,

Field Trial Data

- Schizophrenia *kappa* = .46
- Schizoaffective disorder *kappa* = .5
- Attenuated Psychosis Syndrome (individuals at increased risk for developing psychotic disorder) "needs more research" *kappa* = .46

Somatic Symptom & Related Disorders

Rationale

- Significant diagnostic overlap & lack of defining boundaries between diagnoses

Revisions

- Somatic Symptom Disorder: somatic symptoms (no set #) + abnormal thoughts, feelings, & behaviors
- Hypochondrias & Illness Anxiety Disorder
- Psychological factors affecting other medical conditions & factitious disorder

Field Trial Data

- Somatic Symptom Disorder *kappa* = .46

Feeding & Eating Disorders

Revisions

- Pica, Rumination, Avoidant/Restrictive Food Eating (ED in child)
- Eliminate fear of gaining weight, amenorrhea from AN
- Binging only need occur 1x/week for BN

New Disorders

- Binge Eating Disorder *kappa* = .56
- Avoidant/Restrictive Food Eating *kappa* = .48

Sexual Dysfunction Disorders

Revisions

- Hypoactive Sexual Desire → Hypoactive (♂); Sexual interest/ arousal (♀)

New Disorders

- ~~Sex addiction~~ → Hypersexual Disorder (Appendix)
- Gender Dysphoria* in childhood & adult

*no "disorder" in the label

Neurodevelopmental Disorders

Revisions

- Autism Spectrum Disorder:
  Autistic Disorder, Asperger's, PDD, Childhood Disintegrative Disorder
  --Must show symptoms from childhood
  --Continuum
- ADHD: ↑age of onset from 7 yrs to 12 yrs
- Motor Disorders: Tourette's
  Tic disorders

Field Trial Data

- Autism *kappa* = .7
- ADHD *kappa* = .6

Substance Abuse & Addictive Disorders

Revisions

- Behavioral addictions: Gambling Disorder
- Substance abuse/dependence → Substance use dimension (mild → severe)
  subcategories: use, intoxication, withdrawal

Additions

- Substance-Induced Disorders
- Further research: Internet Gaming disorder
  Caffeine use disorder
- Alcohol use disorder *kappa* = .4

Personality Disorders

Reasons for change

- Increase clinical utility & improve patient care
- Final decision not to make any changes

Field Trial Data

Borderline *kappa* = .5
Schizotypal & Narcissistic < 7 pts
Antisocial *kappa* = .2
OCPD *kappa* = .3

Personality Disorders

Revisions Proposed

- Evaluate a limited set of personality disorder types
  -antisocial -borderline -schizotypal
  -avoidant -narcissistic -OCD
- Assess core impairments in functioning
  Sense of self: identity, self-direction
  Interpersonal relationships: empathy, intimacy
- Overall measure of dysfunction severity

Categories and proposals

Controversies & Concerns

British Psychological Association (2011)

- Grief
- Psychosis risk syndrome
- Schizophrenia
- Social causes of mental illness
- Reductionism

APA Division 32:
Society for Humanistic Psychology

- Letter/petition of concern
  http://www.ipetitions.com/petition/dsm5/
- 14K signatures - professional societies & APA divisions
- Concerns:
  - Lowering thresholds
  - Vulnerable populations
  - Sociocultural variation
  - Reductionism
  - PD revisions

Research Domain Criteria

NIMH director, Thomas Insel

- More biologically based nosology of mental disorders incorporating genetics, imaging, etc.
- Said RDoC project will replace DSM -- "*a first step towards precision medicine*."

apa president, Jeffrey Lieberman

- got Insel to agree that DSM and ICD "*remain the contemporary consensus standard to how mental disorders are diagnosed and treated*," but "*what may be realistically feasible today for practitioners is no longer sufficient for researchers*."

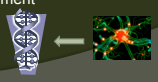
Research Domain Criteria

NIMH: http://www.nimh.nih.gov/research-funding/rdoc/

RDoC classification rests on three assumptions:

1. mental illnesses are brain disorders
2. dysfunction in neural circuits can be identified with the tools of clinical neuroscience (electrophysiology, fMRI, PET, etc)
3. data from genetics and clinical neuroscience will yield biosignatures that will augment clinical symptoms and signs for clinical management

Primary focus is on neural circuitry:



Research Domain Criteria

NIMH & APA agree —

- *"..laying the groundwork for a future diagnostic system that more directly reflects modern brain science, will require openness to rethinking traditional categories. It is increasingly evident that mental illness will be best understood as disorders of brain structure and function that implicate specific domains of cognition, emotion, and behavior."*
- *"DSM-5 and RDoC represent complementary, not competing, frameworks for this goal."*

Question 1:

Will dimensional traits of disordered personalities increase stigma and labeling of patients?

ON HOLD UNTIL DSM-5.x

PDs in DSM-5

- Not much has changed.
- Still three clusters
- Goal was to apply a dimensional model to the categories.
- Dimensional model discussed in Section III and anticipated in future edition

Personality Disorders, Dimensions, & Traits

- Excessive heterogeneity in DSM-IV
  > 256 ways to meet criteria for BPD!
- Arbitrary boundaries between "disordered" & "normal" personality
- No consideration of personality itself--only Disorders
- Gender-laden values still permeate criteria
  - Relationship instability
  - Career flux
  - Coping strategies within oppressive society

Personality Disorders, Dimensions, & Traits

- DSM-IV does not systematically capture variations in personality that do not meet criteria for a disorder

But do variations that are not "disordered" require assessment?

- DSM-5's trait system assesses strengths and impairments along cognitive, self, emotional, behavioral, physical, interpersonal, occupational, and recreational dimensions

But does this aid diagnosis? Is it beneficent?

Ethical Implications of Dimensions

- Traits ascribed to individuals who are otherwise healthy.
  - Risk of stigma
  - Medical misuse
  - Blurring the lines of normalcy
- Traits may be seen as prodromal or predisposing patient of full blown personality disorder
  - Analogous to biomarkers?
- Diagnostic creep/expansion of medical categories
- Important to note: Categories & traits not mutually exclusive

Question 2:

Will new categories of non-chemical addiction influence our understanding of free will and personal autonomy?

Ethical Implications

- Dimensional view of "use" versus categorical
- New criteria increases inclusion of people "at risk" for abuse
- Confusion between "addiction" and "use"
- There is choice in behavior

Pathological Gambling → Gambling D/O

- Connection with other addictions– neurological evidence, genetic evidence, etc.
- Lowering diagnostic threshold
  - Removal of criminal behavior criterion
  - "Is preoccupied with gambling" will be "Is often preoccupied with gambling" to clarify that one need not be obsessed with gambling all of the time to meet this diagnostic criteria.
  - "Gambles as a way to escape from problems" will be "Gambles when feeling distressed."
  - Long term 'chase', not simply short term 'chase' of losses.
- See National Center for Responsible Gaming (NCRG) white paper, titled "The Evolving Definition of Pathological Gambling in the DSM-5."
  - http://www.ncrg.org/resources/white-papers

Question 3:

What has been the impact of advocacy or interest groups in shaping the new nosology?

Ethical Implications

"Major family support groups such as NAMI have expressed concern that this research [attenuated psychosis] continue so that early identification of children at risk for psychoses and non-pharmacologic interventions including cognitive behavioral therapy and Omega-3 Fatty Acids be made available to prevent the toxic effects of psychosis on the brains of developing children and adolescents." – APA

- Is a diagnosis determined by science or social opinion?
- What place is there for prevention in setting diagnostic criteria?

Ethical Implications

"We are trying to make diagnostic criteria more accurate to better describe the symptoms and behaviors of people who are currently seeking clinical help." APA

- Are diagnoses determined by the symptoms with which patients present?
- Are these changes truly beneficent? For individuals? For society?

DSM-5 is...

…an opportunity to put into practice some of the ethical and philosophical lessons reviewed today

…a challenge to clinicians and researchers to understand and translate the point of categories to answer critics and educate public

Solutions

- Classification and reclassification should continue to be a transparent and semi-democratic process
- Be up front about values, evidence, and uncertainty
- Emphasis on goal of classification: the relief of human suffering

Determining Disorders Democratically

Should advocates and patients have influence in shaping the new nosology? If so, how much?

Feedback & Commenting

- Underlying principle: to engage the broader public on issues related to DSM revisions.
- Three Open commentary periods via DSM5.org
- Thousands of comments were received from patients, advocacy groups, professional societies, and the general public.

Ethical Issues

"Major family support groups such as NAMI have expressed concern that this research [attenuated psychosis] continue so that early identification of children at risk for psychoses and non-pharmacologic interventions including cognitive behavioral therapy and Omega-3 Fatty Acids be made available to prevent the toxic effects of psychosis on the brains of developing children and adolescents." – APA

- Should a mental health diagnosis be determined by science, a vote, or both?
- What if any other field of medicine- say oncology- held their nosology up for social commentary?

Autism Speaks & ASD's

- Asperger's inclusion under Autism Spectrum Disorders
- *Autism Speaks*, in an open letter to the Work Group, accepted the scientific bases for the proposed changes
- Concerns about "real-world" impact of the new nosology on patients & families
  (insurance reimbursement, special education eligibility, other support services)

****

Should these pragmatic concerns influence the classification of Aspergers?

NAMI & Psychosis risk syndrome

- NAMI is committed philosophically to the medical model of mental illness
- Initially supportive of controversial diagnostic expansion of psychosis
- The DSM-5 Work Group ultimately withdrew inclusion of psychosis risk syndrome
  - illustrates the profound effect of a group's philosophical position on psychiatric nosology—that all mental illnesses are forms of biological function analogous to diabetes or asthma

B4U-ACT & Pedophilia

"To publicly promote services and resources for self-identified individuals (adults and adolescents) who are sexually attracted to children and seek such assistance; to educate mental health providers regarding the approaches helpful for such individuals; to develop a pool of providers in Maryland who agree to serve these individuals and abide by B4U-ACT's Principles and Perspectives of Practice; and to educate the citizens of Maryland regarding issues faced by these individuals"

- Further refine pedophilia → Hebephilia
  (attraction to pubescent minors aged 11-14)
- Concerned that "hebephilic" desires:
  --inappropriately labeled as pathological
  --individuals expressing such desires will be improperly stigmatized or detained under involuntary civil commitment laws

Observations

- Advocacy groups vary in their influence
- Unclear how the DSM-5 task force has incorporated public feedback and commentary.
- Questions remain about the degree to which democratic processes should influence a process that aims to be evidence-based.

The Optics

How Will The DSM Revision Process Affect Public Perceptions Of Behavioral Healthcare? How Will This Affect Access To Care?

Issues of public outcry

Medicalization of 'normal life processes' (grief)

"Excuse making" for bad behavior (e.g., nonchemical addictions)

- Issue in Health Reform
- Public funds for '*treating*' sex, internet, gambling addiction

Conflict of interest & influence of pharma on DSM

- Policies in place to minimize potential effect

DSM-5 is...

…an opportunity to put into practice some of the ethical and philosophical lessons of history, when medical labeling went horribly wrong.

…an important exercise in developing a system by which both science and social values can transparently coexist.

…a challenge to clinicians to understand and translate the point of categories to answer critics and educate public

Ethical Solutions

- Classification and reclassification should continue to be a transparent and semi-democratic process
- Be clear about values, evidence, & uncertainty

Focus on the goal of all medical classification systems: *The relief of human suffering*