Temperament Research Can Help to Restrain the ADHD Epidemic

William B. Carey, M.D.
Occasional Temperament Conference, Lincoln, NE- 11-7-14

Intro- Aim to describe the several problems contributing to the current epidemic of the ADHD diagnosis and to point out how temperament researchers could help to bring the problem under control. This is a crisis needing prompt and expert attention.
Plan- 1) to describe the extent of the overdiagnosis problem; 2) to suggest several reasons why this is happening; 3) to emphasize that a generally unrecognized major contributor to the problem is the vague diagnostic criteria themselves; and 4) to describe some ways for professionals and other responsible citizens to try to clear up the mess. Temperament researchers could contribute to this process.

1) Present epidemic situation-

Diagnosis invented in 1980 by DSM-3 (prior incarnations) now increasing with alarming frequency. The DSM is the product of a group of psychiatrists and psychologists in conference (No pediatricians, social workers, or social scientists. No population study as basis.)

Reported in NY Times. 1year ago 20% high school boys, 11% all students
Official APA- 5-8% but both over and under dx.
17% in Norfolk schools
40 % in a private primary school in NYC.
(World prevalence of 2.2% estimate.)
Ritalin consumption huge. 85-90% of world's output of Ritalin in USA. Also other drugs like Amoxetine, alpha 2 agonists: guanfacine and clonidine.
Drug use increased by 36% between 2008 and 2012.
In 2012 $9 billion sales by drug companies.
However, no objective evidence for increase in abnormality in children's brains.

But finally some recent declaration of concern and regret.

Leon Eisenberg, father of dx, "a fictional diagnosis."
Keith Conners, author of leading diagnostic questionnaire, "A concoction to justify the giving out of medication at unprecedented and unjustifiable levels" NY Times 12/15/13.
Other criticisms: "Entering into a period of cosmetic psychiatry, when it is becoming acceptable to use drugs to change from one kind of normal to a preferred one." (Silverman &Treisman, 2006).
"ADHD a heterogeneous disorder related to multiple neuropsychological defects, executive functioning, variable reaction times, and emotional functioning," (Sjoewall et al., 2013.)
Feb. 14. Richard Saul in *New Republic*- symptom complex with ADHD diagnosis "related to more than 20 medical dx, resulting in millions of false diagnoses."
What possible harm from this trend? Not much discussion of this.

2) **Why is this epidemic happening**?

Basic facts-In UK 1-2% are "hyperkinetic" (ICD-9 classification) and really have a disabling amount of activity or inattention. Often have objective cns or cognitive problems. They need help. Stimulants useful. This group is believable.
But why the increasing use of this dx and rx? The 1-2% has become much inflated.
No objective evidence of confirmed brain malfunction in children with DSM dx.
Several contributing factors in vastly inflating the numbers given diagnosis.
(Frances A: *Saving Normal*. 2013)

Reasons for rapid rise:

1) Insufficient expertise in general physicians and pediatricians who are mainly making the diagnosis
2) Insufficient numbers of properly informed and qualified psychiatrists, neurologists, and psychologists, who should be more discriminating in dx.
3) Requirements of insurance companies that physicians spend too short a time doing evaluations for possible diagnosis. 15-20 minute office visit.
4) Flagrant bribery by drug companies of clinicians. Consultation fees, grants. Help writing study reports. Help suppressing unfavorable test results.
5) The widespread misinformation that a positive response to Ritalin and comparable drugs proves the diagnosis. The notion that the medication is correcting a "chemical imbalance" is not supported with data. We all function better with stimulants. "Disease mongering"; finding conditions for which an orphan drug may be used. Deceptive advertising. Avoiding adequate mention of toxicities. Members of DSM committee forming the dx getting salaries from drug companies. No evidence of the putative "chemical imbalances," their improvement or alteration by existing drugs (Robert Whitaker: *Anatomy of an Epidemic*. 2010) Not at all like giving insulin to a diabetic, as has been said by some supporters.
6) The social acceptability of the ADHD diagnosis, which puts blame on child's brain, exonerates the child, the parents and the teachers. No diagnostic test.
7) But a major reason is looseness and inadequacy of the current criteria for the diagnosis. Explanation follows.
   I have been pointing this out for over 15 years, and apparently nobody has paid much attention. e. g. NIH 1998; Italy- 2002, 5, 6, 7; Germany- 2003,8; J. Hopkins 2013. Etc.

3) Background and review of problems in dx of ADHD

In 1950's and 1960's psychological variation and deviation thought to be completely environmental, usually mother's fault.
But DSM starting in 1952 with precursors of ADHD- minimal brain damage and minimal brain dysfunction. Culminating in ADHD in DSM-3 in 1980 with modifications since then in 4 and 5. The DSM system does not acknowledge existence or significance of clinically observable temperament differences, demonstrated by their fellow psychiatrists Chess and Thomas, and seems to regard almost any annoying chronic behavioral trait as probably due to cerebral dysfunction. But half of all children more active and/or less attentive than average and most are doing well. Also annoying normal levels of shyness,

intensity and sensitivity. And these assumed to be due to a "chemical imbalance'' in the brain. Thus, the DSM is a catalogue of the opinions of some influential psychiatrists and psychologists, not results of detailed studies.

The diagnostic criteria for ADHD- DSM-V- 2013- The main ignored problem.
Definition- "A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development, as characterized by 6/9 symptoms of inattention and /or 6/9 symptoms of hyperactivity and impulsivity."
Examples

Often has difficulty sustaining attention in tasks or play activities.
Often is easily distracted by extraneous stimuli.
Often talks excessively.
Often has difficulty waiting his or her turn.

These traits inconsistent with developmental level and impact directly on social or academic/occupational activities.
(Notice that "often" and "excessive" are never defined.)
Are present in two or more settings (home, school, or work, with friends or relatives, in other activities) and interfere with functioning in these areas. Do not occur exclusively in course of other mental or emotional disorder
Various physical conditions (nutritional deficiencies, sleep disorders, etc.) may contribute to the ADHD symptoms but are not the cause of them.
Co-morbidity of 25-50 %
No biomarkers. DSM does not say so but all texts (incl. NEJM review) say that it is the "commonest neurodevelopmental disorder" of childhood.
Change from DSM-4 to DSM-V- Can start after age 7, up to age 12.

What are the problems of the DSM diagnosis and management of ADHD?

1) ADHD "symptoms" not clearly distinguishable from normal temperamental and other behavioral variations. Ignoring of possibly normal but aversive temperament. Atypical diversity is not the same as abnormality. 50% of children more active and/or less attentive than average and most of them are normal. Foley, McClowry, Castellanos (2008 Appl Dev. Psychol.: Rel between ADHD and child temperament.) Aversive temperament traits more common children with ADHD diagnosis. Their interpretation: ADHD either an extreme form of aversive temperament or a predisposition to it. Did not consider that normal temperamental adversity might just be misdiagnosed as disorder of ADHD. Also no data on adaptability. (See Carey, McDevitt, Baker in Dev. Med. Child Neurol. 21:765; 1979)
2) Absence of evidence that "ADHD symptoms" related to brain malfunction. No evidence of neurological basis- see Forman, Lindstrom, Taylor and others.
3) Neglect of role of environmental interactions as factor in clinical problem. DSM says they might contribute to problem but not be the cause. No recognition of variability of teachers' judgments. Louise Richards: pay more attention to biopsychosocial factors such as parental mental illness, maltreatment, etc. CCP&P 2012.
4) Diagnostic questionnaires now in use are highly subjective and impressionistic.

5) Failure to consider effects of low adaptability and cognitive problems; social problems like being bullied and possibility child is gifted but bored in school. See NY Times 11-2-14.
6) Small specific practical usefulness and possible harm from the ADHD label.
7) Failure to require adequate psychoeducational testing. And to acknowledge and check for physical problems like anemia, hypothyroidism, sleep deprivation, cns trauma, substance abuse, etc.
8) Failure to recognize that effects of Ritalin, when not placebo, are effective only for a few hours and only temporarily suppress basic "symptoms" but do nothing for adjustment problems. They do not correct any specific "chemical imbalance."
9) Educational privileges granted to children with ADHD label make some parents and teachers press for advantages of medical intervention.

Most of these criticisms offered at NIH- 1989, Hastings-2008-2009, Hopkins summit-2013, etc. but generally ignored.

4. <u>What to do about the mess</u>?

Unfortunately little average citizen can do about factors causing the epidemic besides retaining a healthy skepticism, but there are some possibilities for professionals.

1) Improve medical education- A better awareness of the nature and extent of normal. Stop medicalizing normal variants. Normal seems to be gradually disappearing (Diller). Rule out common problems like lack of sleep and abuse in the home and school before blaming the child's brain. More education about normal behavior style and content. Respect diversity. Diagnosis brain malfunction only when there is objective evidence of it.
2) Improve medical management – change organization of care. Provide sufficient time for adequate diagnostic appraisal. One dx does not fit all. More honesty from medical and psychological professions about limitations of our knowledge.
3) Rein in the drug companies. Stop advertising prescription drugs to public. Break up the connections between Big Pharma and physicians. Company profits are exorbitant. Drugs can be dangerously toxic. They can make the situation worse.
4) More counseling and psychotherapy to replace drugs. More familiarity with drug toxicities. Diet and exercise underused. If aversive temperament involved, best management is generally recognition, education, and accommodation, not attempts at eradication.
5) Revise the DSM or replace it. Normal must stop shrinking. Atypical is not necessarily disease or disorder. Improve and revive DSM-PC.
   Jensen et al. (2006) replace static categorical DSM system with one that is more adaptational, developmental, and contextual.
   Taylor 2008 JCP&P. Treat specific components rather than one plan for all.
   Thapar & Lewis. JAACAP. 2009. Should diagnose ADHD on a continuum.
   Fair et al (2012 PNAS) divide ADHD into 6 parts depending on type of cognitive disability present: memory, inhibitory control, etc.
   Karalunas et al (JAMA Psych 2014) Subdivide into 3 types based on temperament types: mild, surgent, and irritable.

Richard Saul-*New Republic* 2014- ADHD really 20 or more medical diagnoses. With resulting many incorrect diagnoses.
Carey (passim) a better division of present clinical ADHD population into 6 separate problems would be: a) real redefined ADHD; b) pathologization of aversive but normal temperament including low adaptability (unfortunately eliminated by some views of temperament); c) psychosocial problems like abusive homes, bullying in school; d) physical problems like malnutrition or lack of sleep; e) anxiety or depression; f) undetected learning problems; and bright children who are bored by inadequate stimulation. See my letter to Editor in NY Times 11-9-14.
We need a whole new diagnostic system.
Not easy. My effort with DSM-V not successful.
ICD-10 may help but unsure.
"Psychiatric" diagnosis is too important to be left to the psychiatrists.

6) Remember that fads in medicine as elsewhere come and go. Examples: demonic possession, need for bleeding or purging, routine tonsillectomies, DB splint for normal inversion of legs, patterning (Doman & Delcato) for cns problems, megadoses of vitamin C (Pauling), etc.
7) Somehow get academic and commercial vested interests to loosen their grip

<u>Some possible helpful investigations by temperament researchers.</u>

1. A critical, full analysis of a group diagnosed with ADHD according to present practices: physical, neurological, temperamental, cognitive, & behavioral evaluations. Is another diagnosis more appropriate? (See Carey, McDevitt, Baker: Dev. Med. & Child Neurol. 21, 765; 1979)
2. A longitudinal study of a general population of children starting in kindergarten with periodic clinical temperament assessments. To see who gets labels of behavior problems, ADHD, learning problems, etc. (In Chess & Thomas days before 1980 the ADHD label did not exist.)
3. Compare individual diagnosis present or absence of ADHD by different professionals to see what differences in them lead to positive diagnosis.
4. Try temperament counseling with children having ADHD to see if it is better than standard behavioral therapy. (The much advertised MTA study apparently gave same management program for all without recognizing individual differences.)

The results of these investigations should illuminate the inadequacies of the current DSM diagnosis of ADHD, which allows the inclusion of children with different problems, and should point the way to more precise, more responsible criteria.

N.B. These are lecture notes used to stimulate discussion at the Nebraska OTC meeting on November 7, 2014 and not intended for publication in this form. Most of these conclusions are already published elsewhere. References can be supplied. Thank you. W.B.C.