Shifting Boundaries: Autism in the 21st Century

KHC PH 102

Spring 2012
Tuesday/Thursday
12:30 PM – 2:00 PM
Room: KHC 107

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Course Description

In its fifth edition, forthcoming in 2014, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) will eliminate Asperger Syndrome as a separate diagnosis and subsume its features under the broader umbrella of Autism Spectrum Disorder. This likely change is proving highly controversial. Scientists disagree on whether different autism subtypes lend themselves to shared biomedical investigation; policy makers disagree on whether the educational, medical and social needs of persons with autism may be better served by a general label or by particularized diagnostic categories. This seminar adopts the current debate on the definition of autism as a privileged stand-point from which to explore the interconnection of society, science, and law in the 21st century.

Academic Dishonesty

Students are expected to abide by both UHC and BU's Undergraduate Academic Conduct Code. The Academic Conduct Code can be found at http://www.bu.edu/academics/resources/academic-conduct-code/

Grading

§ Class attendance and active participation in discussion; presentation of projects at the end of semester: 20%
§ Select commentaries (3-4 pages each) on assigned readings: 20%

§ Research assignment on autism data (quantitative reasoning): 30%
§ Research assignment on legal provisions for persons with ASD: 30%

Research Assignments

There will be two major assignments for the seminar.

1) Analysis of research data on autism, using the Interactive Autism Network database, which includes over 30,400 participants who have submitted information ranging from diagnoses to behavioral assessments to treatment histories to a secure website (http://www.iancommunity.org/). Students in the seminar will select a research question (e.g., evaluating questionnaire data to explore how diagnoses change, depending on the DSM criteria that are applied; variation in IQ with diagnostic history; impact of socio-economic status on the number and variety of treatments for a child; effect of having a child with autism on parental anxiety or depression) and analyze data from IAN to address the question. This assignment will involve quantitative reasoning skills.

2) Analysis of current accommodations and services legally provided to individuals with Asperger Syndrome and high-functioning autism in a given jurisdiction (a state or administrative district within the US). Impact of the diagnostic change (elimination of a separate Asperger Syndrome diagnosis) upon the legal entitlements of interested individuals in one of the following contexts: a) mandatory education; b) vocational training; c) health insurance; d) home and community-based services; e) employment discrimination.

The seminar has its own restricted web page, where reading and research assignments are regularly posted by the instructors. Students contribute to the web page every week by adding blog entries and external links in response to reading and research prompts. Additional seminar activities include a movie night and a field trip to two laboratories at Boston University where research on autism is currently being conducted.
The literature on autism is immense. In order not to overwhelm students with excessive assignments, we will make available to them an "autism library" of books and movies for students to borrow and utilize at leisure.

Course Outline

The seminar consists of two educational units (Science and Law of autism) and two major research assignments, one associated with each unit.

The first unit takes the students through the path of scientific investigation that led psychiatrists, in the aftermath of WWII, to identify autism as a specific and distinct condition. The classes travel through the changing diagnostic criteria in the DSM from the 1970s to 2014.

Students learn how autism is diagnosed; analyze the variety of standardized tests and measures that are used to carry out clinical evaluations and define participants for research studies; and explore current cognitive and neuroimaging studies on the mechanisms that underlie core impairments in social- communication. In the final sessions, current views on what causes autism will be introduced. The science of counting cases (epidemiology) and some of the more controversial aspects of the science and pseudo-science of autism will be discussed, within the context of the hypotheses so far developed to explain the dramatic increase in autism prevalence, ranging from epidemic spread to relaxed diagnostic boundaries. Throughout this unit, we focus on what constitutes evidence for particular scientific theories, and how such evidence must be evaluated.

Legal questions will be raised throughout the Science unit, but the first detailed exploration of the intersection between law and science will revolve around the hypothesis of a connection between childhood vaccinations and onset of autism.

On this note, the second unit introduces the students to the legal implications of both autism science and autism social movements. The growing trend towards defining autism as a broad spectrum of disorders, blending very diverse clusters of symptoms into one large diagnosis, is explored in light of legal reform, such as the demise of institutions for the "mentally retarded" and the mandatory inclusion of persons with autism in federal policy-making entities.

Students engage with the statutory and judicial instruments utilized by autism activists: special education law (legislative history, federal and local funding, class actions and individual court cases); Medicaid and publicly funded services (litigation aimed at keeping social services for person with autism accessible and generous in the face of shrinking budgets; assisted living options); regulation of private health insurance (funding of therapeutic intervention for children with autism); and employment discrimination law (judicial struggles to include persons with autism in the workforce; law and economics of disability). Against this legal background, students proceed to examine autism as business. Examples of legally complex business models include firms (such as the Danish company 'Specialisterne') that uniquely employ persons with Asperger Syndrome in tasks that require attention to detail and enhanced pattern detection; private educational enterprises that receive public funding; and start-ups promising diagnostic or treatment solutions.

Syllabus – Part I – Science

Background Reading:
U. Frith (2008). Autism: A very short introduction. Oxford University Press.

Additional readings will be posted on Blackboard or made available to students in hard copy.

Session I
The introduction of autism and Asperger syndrome

Kanner, L. (1943) Asperger, H. (1944).
Frith, U. (2008). Chapter 1.

In this session, students read the original papers which introduced the cases that formed the basis of the new diagnoses that are now called autistic disorder and Asperger syndrome. Discussion will focus on the similarities and differences in the cases and presentations by Kanner and Asperger.

Session II

The changing face of the autism diagnosis from the 20th to 21st centuries

Frith, U. (2008). Chapters 2 and 3
Eyal, G. (2010). The autism matrix – excerpts from several chapters. DSM – II (1970) DSM – III and IIIR (1980s) DSM – IV (and TR) (1990s) DSM – V
http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94#

The history of developmental disorders is reviewed, as the context in which Kanner and Asperger identified clusters of children who were distinguished by unique behaviors. We then follow through how these disorders are defined in the Diagnostic and Statistical Manuals (the official 'bible' used by Psychiatry and other clinical professions for diagnoses) from the 1970s to the proposed revisions that are planned for the new DSM 5.

Session III
Instruments used for diagnosing autism/ASD

Autism Diagnostic Interview ADI-R
Autism Diagnostic Observation Schedule – ADOS Social Communication Questionnaire
Instruments available on the web for self diagnosis (e.g., selection of measures can be found:
http://www.autismresearchcentre.com/tests/default.asp

Lord, C. & Costello, C. (2005). Diagnostic instruments in autism spectrum disorders. In F. Volkmar et al. Handbook of autism and developmental disorders Volume I. New York: Wiley.

We review the 'gold standard' instruments that are used for diagnosing ASD, comparing the symptoms included and the methods for evaluation. Research and clinical criteria for diagnoses will be compared.

Session IV
Instruments used in clinical evaluations: cognition, language and adaptive behavior.

Klin, A., Saulnier, C., Tsatsanis, K., & Volkmar, F. (2005). Clinical evaluation in ASD: Psychological assessment within a transdisciplinary framework. In F. Volkmar et al. Handbook of autism and developmental disorders Volume I. New York: Wiley.

Differential Ability Scales-II
Clinical Evaluation of Language Functions – IV Vineland Adaptive Behavior Scales
Miscellaneous other test materials

Often children with ASD have additional areas of impairment, including language, cognitive ability, adaptive behaviors etc. We will explore the instruments that are used to evaluate these areas of functioning in the clinical and research.

Session V
Exploring variability in ASD

National Database for Autism Research (NDAR) Interactive Autism Network (IAN)

This session serves as the introduction to the first major assignment for the course: conducting a project that investigates some aspect of autism using one or more databases that house information based on large of numbers of individuals. The session will introduce the databases and some sample projects will be discussed (e.g., differences in symptoms found in boys and girls with autism; age related changes in severity of autism symptoms; the relationship between language, IQ and adaptive behavior in autism).

Session VI
What causes autism?

Eyal, G. (2010). The autism matrix – excerpts from several chapters

http://autism.about.com/od/whatisautism/p/autismcauses.htm

http://www.ninds.nih.gov/disorders/autism/detail_autism.htm

From the beginning many different theories were proposed to explain where autism comes from. Early on the idea that mothers ('refrigerator mothers') were the cause was the established hypothesis based on psychoanalytic thinking. Later, theories turned to biology: genetics, the brain, immune system, gastrointestinal disease etc. We explore the range of theories and discuss the nature of scientific evidence that is needed to evaluate a theory of autism.

Session VII
Autism and the brain

Society for Neuroscience (2002). Brain facts: A primer on the brain and nervous system (4th Edition). Washington DC: Society for Neuroscience.
http://www.sfn.org/skins/main/pdf/brainfacts/brainfacts.pdf

Minshew, N., Keller, T. (2010). The nature of brain dysfunction in autism: Functional brain imaging studies. Current Opinion in Neurology, 23, 124-130.

Frith U. – Chapters 4, 5, 6.

The symptoms of autism are based in faulty brain functioning. We investigate some of the current thinking of how the brains of people with autism are different from non- autistic people.

Session VIII
The role of genes in autism

Genetics primer:
http://biology.about.com/od/basicgenetics/a/aa071705a.htm
- Use this excellent online resource for background on genetics.

Rutter, M. (2005). Genetic influences and autism. In F. Volkmar et al. Handbook of autism and developmental disorders Volume I. New York: Wiley.

Sakurai et al., (2010). Genomic architecture of autism spectrum disorders. In E. Hollander, A. Kolevzon, & J. Coyle (Eds.). Textbook of autism spectrum disorders. American Psychiatric Publishing.

Since the mid-70s there has been strong evidence that genetics is one key 'cause' of autism. Yet 40 years later, only a small number of genes have been found, and these only account for less than 15% of the autism population. Why has it taken so long and been such hard work to find the genes implicated in autism?

Session IX
Do demographic and environmental factors cause autism?

Reichneberg et al. (2010). Parental and perinatal risk factors for autism. In E. Hollander, A. Kolevzon, & J. Coyle (Eds.). Textbook of autism spectrum disorders. American Psychiatric Publishing.

Landrigan, P. (2010). Environment and autism. In E. Hollander, A. Kolevzon, & J. Coyle (Eds.). Textbook of autism spectrum disorders. American Psychiatric Publishing.

In addition to genes, other factors have also been implicated in autism. These range from demographic variables (e.g., older parents), social influences, obstetric technologies (e.g., assisted reproductive technologies), prenatal exposures to drugs
etc. We explore the science of epidemiology which attempts to find factors associated with autism and evaluate how strong the evidence is for different non-genetic etiologies.

Session X
Do vaccines (and/or thimerosal) cause autism?

Wakefield AJ, Murch SH, Anthony A, Linnell, Casson DM, Malik M, et al. Ileal lymphoid nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. Lancet1998;351:637-41 [retracted].

Editors of the Lancet. Retraction: ileal lymphoid nodular hyperplasia, non- specific colitis, and pervasive developmental disorder in children. Lancet2010;375:445.

Deer, B. (2011). How the case against MMR vaccine was fixed. British
Medical Journal

Deer, B. (2011). How the vaccine crisis was meant to make money. British
Medical Journal

http://www.ageofautism.com/

http://www.safeminds.org/

In the final science session, we confront the single most widely publicized theory of autism – that it is caused by vaccines (specifically the measles-mumps-rubella trio administered at 18 months to all babies) or thimerosal – a mercury-based preservative that was to keep vaccines. We read the original paper that led to the vaccine movement, the recent exposee of the original work and the ongoing defenders of the vaccine theory.

Syllabus – Part II – Law
[Preliminary and Subject to Change]

Readings will be posted on the website (hard copies available on request). Session I
Evidence in Science – Evidence in Law: Autism and the vaccine litigation:

1. The Vaccine Court: History and Structure
2. Damage awards in the cases of Hannah Poling and Bailey Banks
3. The other autism cases: "correlation is no causation"

Session II
Autism and Representation
1. M Osteen, Autism and Representation p 1-47 (2008)
2. S Murray, Representing Autism (2008) (excerpts)

Session III
From grass-roots mobilization to legal activism: the autism movement(s)
1. D Caruso, Autism in the U.S.: Social Movement and Legal Change, 36 Am J L Med 483 (2010) (excerpts)
2. G Eyal, The Autism Matrix (2010) (excerpts)
3. Auton v. British Columbia (Canada Sup Ct. 2004 and 2011 sequel)
4. S Bagenstos, Law and the Contradictions of the Disability Rights Movement (2009) (excerpts)

Session IV
Autism in Congress
1. The Combat Autism Act 2006 (text analysis and legislative itinerary)
2. State Legislation on Autism Insurance Mandates (2010 Massachusetts Sample)
3. Re-Authorization

Session V
Autism and Education Law
1. The Individuals with Disabilities Education Act and its implications for students on the autism spectrum (text and commentary)
2. Inclusion, Segregation, and Cost: Surviving Due Process (2004 DVD)
3. Private and Public Schools: High-Profile Litigation
Winkelman v Parma (US Sup Ct 2007)
Forest Grove School District v. T.A. (US Sup. Ct 2009)

Session VI Autism on Trial

1. Commonwealth of Massachusetts v. John Odgren (2010)
2. Science: Assessment of autism/violent crime correlation
3. Fiction: J Steinbeck, Of Mice and Men (1937)
4. Culpability and Insanity in Criminal Law (readings TBA)
5. D R Barnbaum, The Ethics of Autism (2008)

Session VII
Autism and Disability Law
1. The Americans with Disabilities Act 1990 and 2008 Amendments
2. M Perlin, Mental Disability Law (2010) (excerpts)

Session VIII
Accommodating autism in the workplace: limits of the legal mandate a. Comber v Prologue (MD 2000)
b. Jakubowski v Christ Hosp (Ohio 2009)
c. Brave Thinkers, The Atlantic Magazine (2009)
d. Temple Grandin (Movie Night)

Session IX
Autism and the Job Coach
1. EEOC v. Hertz Corp (1994)
2. EEOC v. The Home Depot USA Inc (2005): the Settlement
3. P D Blanck, The ADA and the Emerging Work Force (1998)

Session X Housing Autism

1. City of Cleburne TX v Cleburne Living Center (1985)
2. M Minow, Making All the Difference
3. Olmstead v Zimring (1999)
4. DAI v Paterson (NY 2010)

The final units are devoted to showcasing and improving upon the products of individual students' research. Roughly divided in groups based on their chosen topics or academic majors, students are asked to present their work to the class and receive feedback from classmates and instructors.