

ADHD:
Cultural Differences Between the US and the UK

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Concerns voiced in bioethics literature on psychotropic drugs

DRUGS COULD:

- Threaten autonomy and free will
- Undermine “right to self-creation”
- Undermine personal authenticity
- Threaten the “character of childhood”

Empirical Ethics

- provides an evidence base for ethical concerns and claims
- investigate the relevance of ethical concepts “on the ground”
 - How is ethics embedded in the dilemmas of daily life?
 - how do biotechnologies contribute to shaping these ethical dilemmas?
- Aims to make better normative judgments and aid decision-making in light of complexity and uncertainty

VOICES: Voices on Identity, Childhood, Ethics & Stimulants: Children join the debate

EARLY RESEARCH:

- 2004 UK interview study with children taking stimulant medication for ADHD. Ages 8-12. (20 boys, 3 girls)
- 2007 UK study commissioned by NICE. Focus groups with boys and girls ages 9-15. All taking stimulant medication for ADHD. (16 children)

VOICES STUDY:

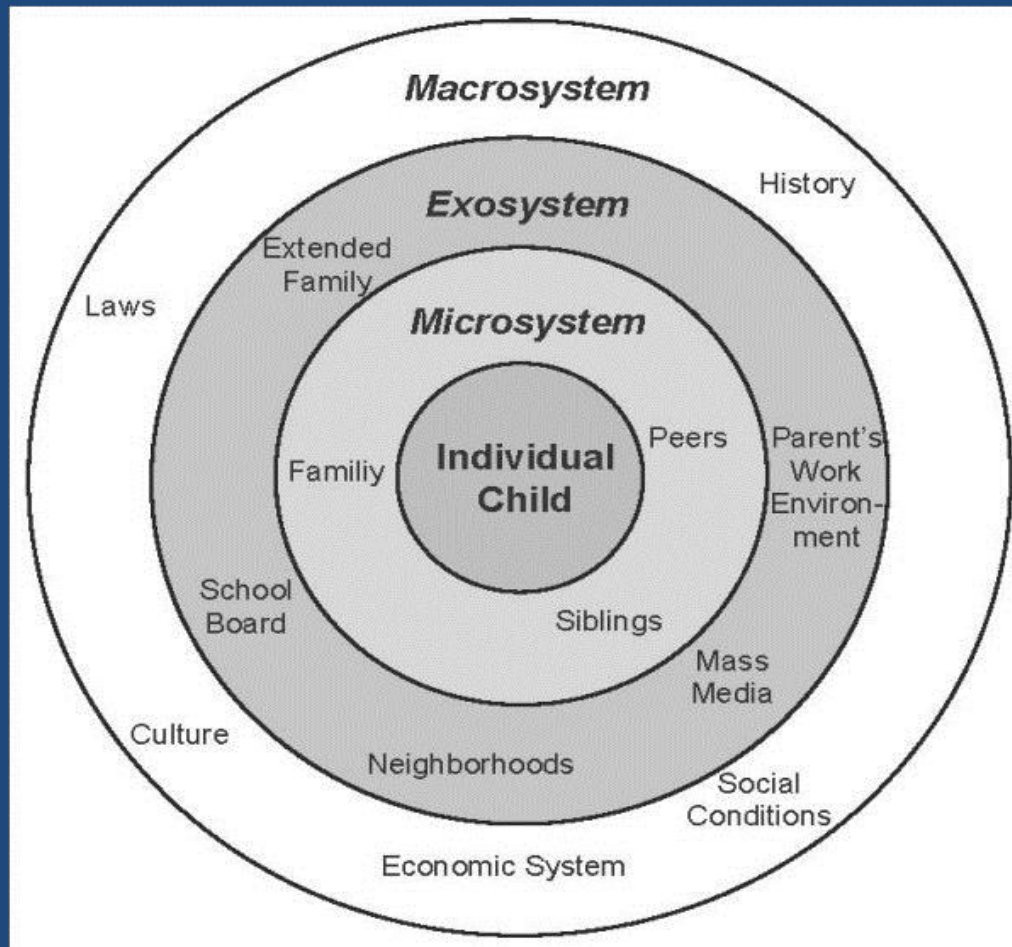
- 2006-2012 Wellcome Trust- funded VOICES study. 152 children in US and UK. Ages 9-14

VOICES Study Details

- 3 groups of children recruited:
 - children taking meds for ADHD diagnosis
 - children with ADHD diagnosis but unmedicated
 - children without a psychiatric diagnosis
- Interviewed children from Trusts across England and from 9 US states
- 4 female interviewers
- Broad matching of demographic characteristics across the 3 groups
- Collected quantitative data from parents and children and had formal and informal interviews with parents

The child in its 'ecological system'

Urie Bronfenbrenner, 1979



A Disorder of Anger and Aggression: ADHD among UK children

Singh (2011). *Social Science & Medicine*, 73(6), 889-896. (open access)

- ADHD is, like temper ... kids who are really aggressive. (Ahmat, age 12)
- ADHD means that you get angry quickly and like don't know what you're doing very much. (Sonya, age 10)

For kids with ADHD, this is an intensely *somatic* experience

- My **brain beats really fast** and that's why I mess around and get in fights... I get **really bad headaches** when it's happening. **It's not meant to go that fast** (Simon, age 9).
- When I'm angry **my body feels like it's going to explode**... I just go around hitting anything I see (James, age 11).

Perceptions of ADHD among UK children:

II. Not clever

- [ADHD] is like **you're slow** or something. **Not bright.**
(Jessica, age 10)
- **I'm not that clever** and I think that's my ADHD. (Mark, age 11)
- I think ADHD is about **being not that bright**; I mean, like **finding school hard work.**
(Adam, age 12)

Ecological context of ADHD: A 'culture of aggression' in UK schools?

In Year 5:

- 44% of students say they have been pushed
- 37% say they have been hit on purpose
- 35% say they have been kicked.

In Year 8:

- bullying is less frequent
- but experiences of physical aggression as part of bullying are more common.

Tackling Bullying Report (2003) on physical aggression in UK schools

Good Childhood Report, 2009

(Layard & Dunn)

— Survey of children aged 11-14

- 29% say other children try to disrupt lessons on a daily basis
- 43% say other children were 'always' or 'often' so noisy that they found it difficult to work

— 2008 MORI survey of teachers:

- 43% experienced disruption in their lessons on a daily basis
- 12% found themselves pushing/touching students on a weekly basis

Stimulant drug treatment targets niche-specific difficulties in self-control

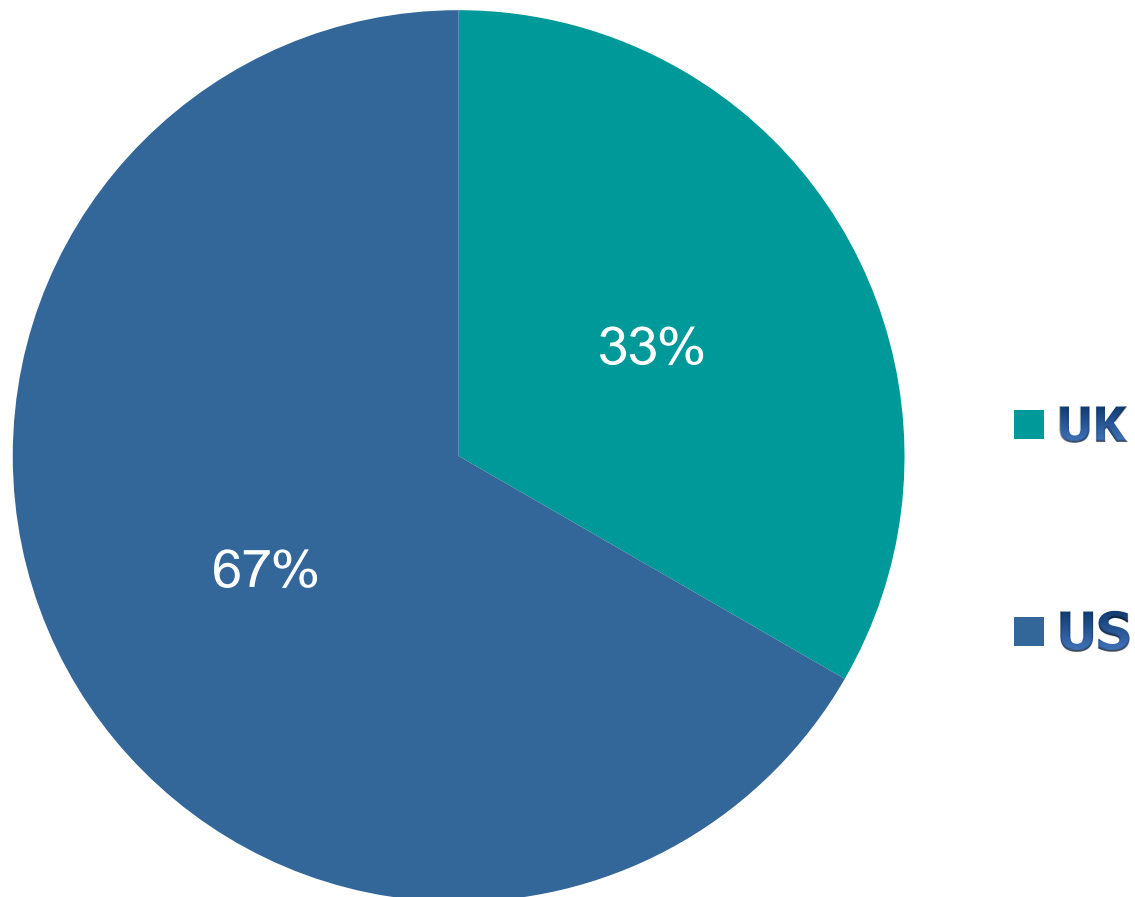
Children report that stimulants improve:

- The ability to take in directives from peers and teachers
- The ability to ‘stop and think’ before responding to perceived threats from peers or teachers
- The ability to make good decisions about how to act in response to perceived threats
- Many UK children did not directly associate medication treatment with academic performance
 - Possible sample bias

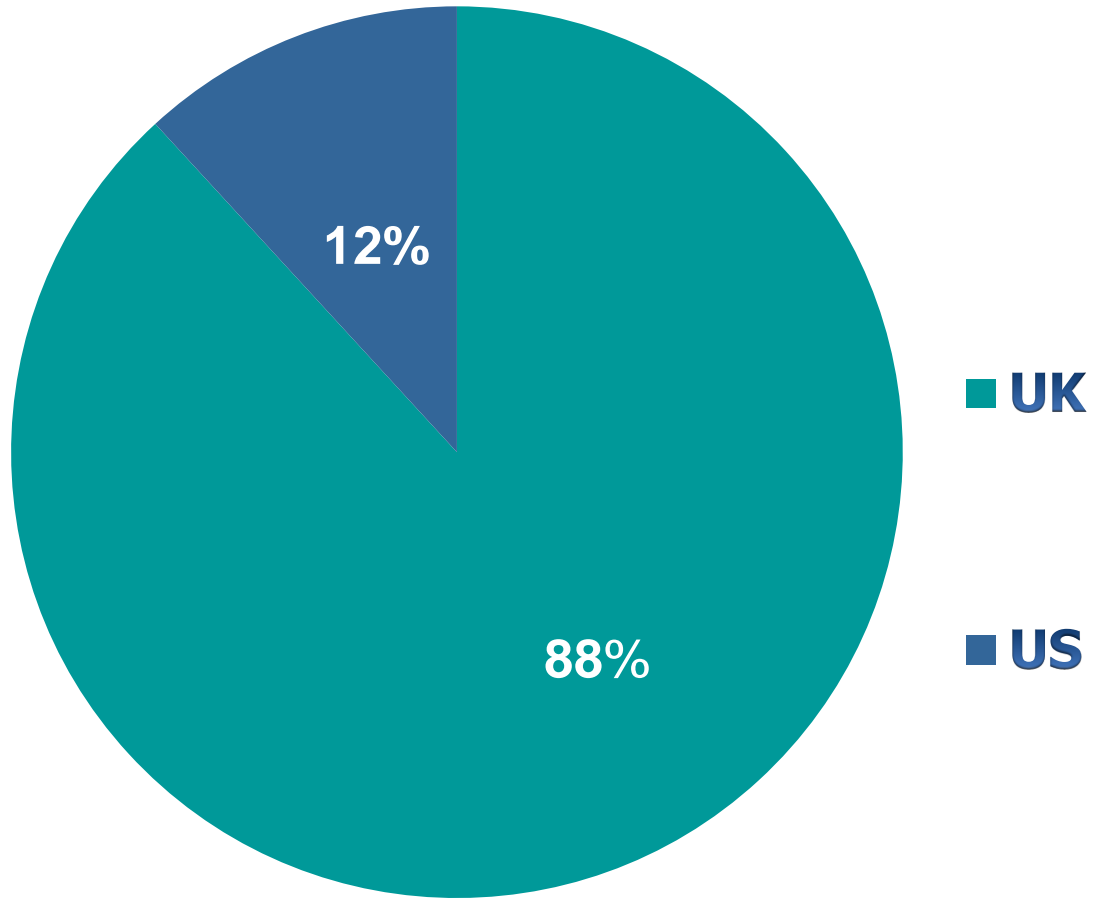
Comparisons with US children's perspectives

- Most US children viewed ADHD as disorder of academic performance
- Most US children associated medication with improvements in classroom-oriented performance; e.g. marks, ability to sit still and listen, focus on classwork and homework
- DIFFERENT FOCUS AROUND ADHD BEHAVIOURS:
'Doing well' – 'Unsuccessful children' -- US
'Behaving well' – 'Naughty children' -- UK

Stimulants help to improve classroom performance



Stimulants help to improve social behaviour and decrease aggression



NICHE and NATION

- In the US, a **performance niche** is dominant
- In the UK, a **conduct niche** is dominant
- Niche is not nation: Different countries may have different dominant niches
- Niches will overlap within countries
- Niche boundaries may be fuzzy

CONTEXT MATTERS TO ADHD:

ADHD is ecological, biological
and developmental

- ADHD is experienced as a disorder of anger and aggression by a substantial group of UK children in the VOICES study
- A culture of aggression in a subset of UK schools inflames and exacerbates behavioural symptoms, and also gives ADHD symptoms a degree of 'social capital'

The ecological niche informs:

- recognition and diagnosis of ADHD
- 'performance' and experience of ADHD symptoms and stimulant drug treatments
- take-up of and compliance with treatments
- ethics of stimulant drug treatments

An ecological view allows for:

- more relevant judgments about the impacts of drug treatments on children's moral capacities
- more informed views on the efficacy of stimulant drug and other treatments
- more informed ethical judgements of ADHD diagnosis and stimulant drug treatments

When Meds Don't Seem to be Working

Context matters to
compliance with and **perceived efficacy**
of stimulant drug treatments

Perceived Efficacy of Drug Treatments: Maintenance of aggressive behaviours in the conduct niche

- Kids still fighting
- UK parents frequently say that meds aren't working/aren't high enough dose
- Our data tells a different story...

AVOIDING FIGHTS

Getting Wound Up

- Children with ADHD experience a special kind of bullying in a conduct niche
- It's fun to wind up children with 'anger problems'
- Maintaining self-control can be humiliating
 - especially if bullies target family

Environment and individual factors *interact*
to produce behavioural outcomes
(eco-bio-developmental model)

- A child's difficulties with 'self-control' can manifest differently in different contexts/niches
- Treatment must be assessed in the context of a child's environmental challenges
- Successful treatment addresses the eco and the bio, and promotes overall developmental wellbeing
 - Longterm implications

What would successful treatment look like, from a conduct niche child's perspective?

- **Less Trouble**

- not getting in trouble so often with peers, parents and adults

- Parent and teacher training; peer workshops; community work

- **More Activity**

- structured outlets for energy and emotions during the school day

- School day changes, playground/outdoor changes

- **More Quiet**

- an inner experience of a quieter mind and a quieter body, when I want

- Skill building, classroom changes, playground changes

Successful Treatment II

- **A sense of personal competence**
 - More mental space to make good decisions
 - More self-control
 - More decision-making power in relation to meds
 - “Know what I do well”
 - Receive praise
 - More school successes (academic and otherwise)
- **More acknowledgment and recognition in schools and by medical professionals**

Children's relationship with medical services

- Children would like to see their psychiatrist more often
- They would like more adults they can talk to openly
- They express frustration at the long waiting times to access services
- They say follow-up visits are just 'to get weighed' so that they can get more meds

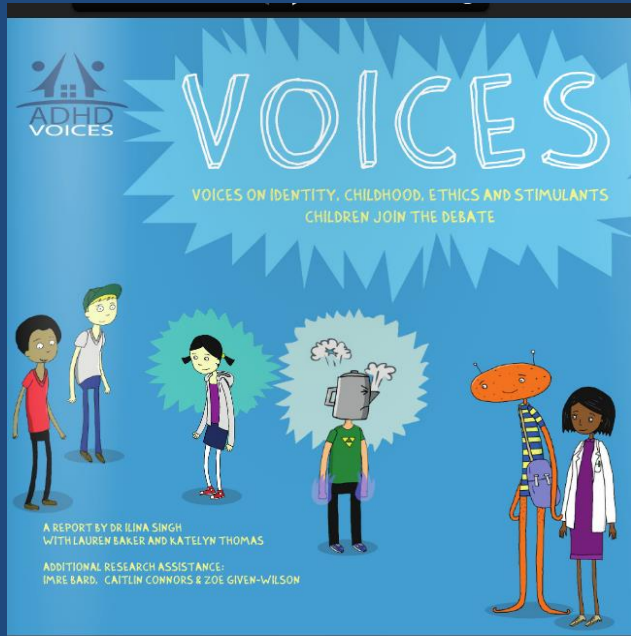
ADHD and Me: The Film

<http://www.youtube.com/watch?v=yyaVKvuEBkk>

[ADHD and Me: doctors](#)

OA publications and further resources available: www.adhdvoices.com

- VOICES report and DVD – available in hard copy upon request
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VOICES STUDY RESOURCES

◆ Website: www.adhdvoices.com

(includes pdfs of publications to date, detailed information on study methods, as well as a range of additional resources)

◆ VOICES Study report available to download on website; or for hard copies: contact@adhdvoices.com

◆ VOICES film: ADHD and Me:

<http://www.youtube.com/watch?v=yyaVKvuEBkk>