



VOICES

VOICES ON IDENTITY, CHILDHOOD, ETHICS AND STIMULANTS
CHILDREN JOIN THE DEBATE



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adhdvoices.com

This website icon means you can **click here** to refer to the VOICES website for more information or resources.

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SECTION 1:

INTRODUCTION

Ritalin and other forms of enforcement and psychological policing are the contemporary equivalent of the old practice of tying up children's hands in bed, so they won't touch their genitals. The parent stupefies the child for the parent's good.

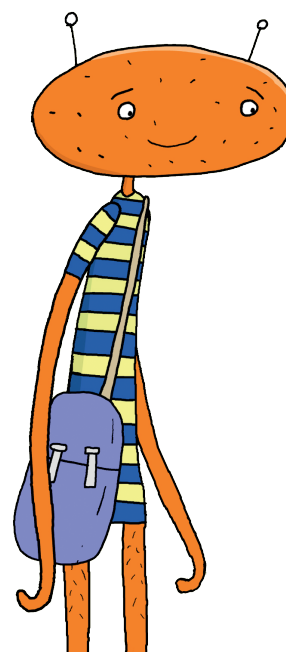
Hanif Kureishi, writing in *The New York Times*, February 2012

The goal of this report, and the accompanying *ADHD and Me* animations, is to inspire a fresh public conversation about the ethics of Attention Deficit/Hyperactivity Disorder (ADHD) diagnosis and stimulant drug treatments like Ritalin and Adderall. How will we

accomplish this? **We're going to introduce you to the ADHD frontline: the children.**

After meeting them, you may not change your overall opinion about whether or not ADHD diagnosis and drug treatments are a good thing. But you will have a more informed, more balanced and more respectful understanding of what stimulant drug treatments do and why they are used, more empathy for kids who struggle with learning and behavioral issues, and a better idea of how to help children with ADHD.

The **VOICES** study (**V**oices **O**n **I**dentity, **C**hildhood, **E**thics and



Stimulants) asked: **Is there evidence to suggest that the use of stimulant drug treatments is unethical?** Does Ritalin turn kids into zombies? Are children being drugged into obedience and conformity? How do we wade through the minefield of accusations to get to another vantage point on these sorts of questions?

Our answer was to go to children themselves, to get their perspectives. We don't claim that children's views are sufficient, in themselves, to resolve the debates over ADHD diagnosis and stimulant drug treatments. We do claim that children's voices are essential to achieving a more realistic, more informed, more balanced, and more useful view on the ethics of ADHD

diagnosis and stimulant drug treatments. This report depends on these voices to deliver key findings of the VOICES project to professionals who deal with children on a daily basis, to parents and to policy makers. The accompanying animations – *ADHD and Me* – help to communicate children's voices to a broad audience. We hope you will view them and distribute them as widely as possible.

ADHD and Ritalin-type treatments have been red hot topics for decades.

Schools in Row over Ritalin

(BBC News, July 2003)

Mother's Little Helper

(Newsweek, 1996)

RITALIN GONE WRONG

(New York Times, May 2012)

ADHD
AND ME

SECTION 2:

BACKGROUND

This section briefly reviews the state of knowledge about ADHD and stimulant drug treatments. We can't summarize everything there is to know about ADHD here. The VOICES website (www.adhdvoices.com), provides links and further reading about ADHD and stimulant drug treatments.

Attention Deficit/ Hyperactivity Disorder

(ADHD) is the most commonly diagnosed child psychiatric disorder in the world. **Its core symptoms are hyperactivity, impulsivity and inattention.**

These common childhood behaviors occur on a continuum from normal to abnormal. It can be very difficult to judge what 'normal' behavior is in children; therefore, when evaluating children for ADHD, many doctors try to assess the degree of **impairment** caused by these behaviors. Estimates of ADHD prevalence amongst school-age children vary within and across world regions and according to how prevalence rates are measured. One study suggests

that Europe and North America have lower prevalence of ADHD (5-6 per cent of school age children); and Africa and South America have higher prevalence (8.5-12 per cent of school age children). www.adhdvoices.com Approximately 75 per cent of children diagnosed with ADHD are boys.

2.1 IS ADHD A REAL DISORDER?

The VOICES study takes the view that ADHD is a real disorder, with interacting biological and environmental components. The American Association of Pediatrics recently coined the term 'eco-bio-developmental' (ecological – biological – developmental)

disorder, to describe conditions that are not determined by biological factors alone. www.adhdvoices.com

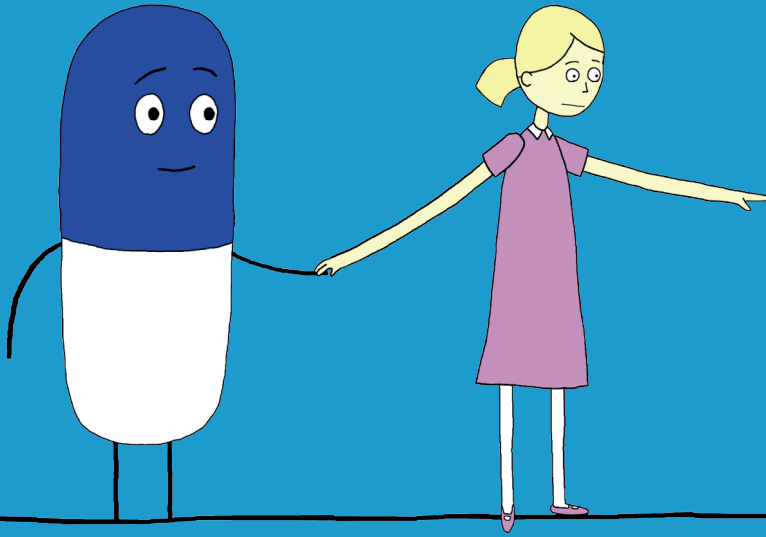
Diagnosis of ADHD presents some significant challenges. Over-diagnosis of ADHD is a problem in some geographic regions, but in other regions, under-diagnosis of ADHD is a problem. Both over-diagnosis and under-diagnosis of ADHD need further research attention. At present there is no way to know for certain if a child has ADHD; therefore, **ADHD evaluations must be carefully and rigorously performed by a team of qualified professionals, with plenty of input from parents / carers and teachers.** As a child develops, ADHD symptoms can change, so it's also important to keep checking in with a doctor after a child has been diagnosed to discuss appropriate treatment strategies. ADHD treatments are an active research area, so it's likely that new




treatments that help children manage their behaviors – both drug and non-drug treatments – will emerge. Some children do appear to grow out of their difficulties, or learn to manage them without active treatment support. ADHD behaviors can persist into adulthood.

2.2 PSYCHOSTIMULANTS

Psychostimulants, such as Ritalin, Concerta, Adderall or Vyvanse, are increasingly used as treatments for ADHD. Consumption of psychostimulants is growing rapidly and significantly in most countries around the world. The United Nations International Narcotics Control Board (INCB) monitors the manufacture and consumption of methylphenidate, which is a schedule II controlled substance and a key ingredient in many psychostimulants.



According to the INCB, the United States consumes more methylphenidate than all other countries combined. In 2005, the US consumed 80 per cent of the world's methylphenidate. 

Rising consumption of stimulant drugs has motivated considerable public and ethical debate. A major concern is their safety. Stimulant drug treatments do have common, but generally manageable, side effects, including appetite suppression and insomnia. More severe and rare risks include adverse effects on heart function, growth suppression and the development of psychosis or other psychiatric conditions. The US regulator, the Food and Drug Administration (FDA), has warned that the

use of these medications by children with heart conditions should be avoided.

Ethical concerns about the use of stimulant drug treatments

have focused on the implications of stimulant drug use for key dimensions of children's moral identity. These dimensions include children's conceptions of:

- Personal authenticity (Who do I take myself to be? Who do I wish to be? Can I be myself? Is my behavior consistent with my understanding of who I am as a person?)
- Moral agency (What can I do? What can I affect? What can I create? What can I become? What can I decide?)
- Personal responsibility (Am I responsible for my good and

bad actions? Is bad biology or a bad brain responsible for my actions?)

Ethicists and social researchers have also been worried about particular social factors that may be driving up ADHD diagnoses and stimulant drug use:

- A growing societal intolerance of normal childhood behaviors, especially in boys.
- Pharmaceutical industry influence on doctors' prescribing of stimulants, and, through direct-to-consumer advertising, on parents' views of children's behaviors and appropriate treatments.
- Doctors, teachers and parents who look to drug treatments as a 'quick fix' way to resolve some of their own burdens and deficiencies.
- School and performance-related pressures on children to succeed.

A longstanding, societal concern relates to the **stigma of mental illness**. How are children with an ADHD diagnosis perceived by others; and how are they treated by others? Many social researchers, as well as doctors and parents, worry that children are victimized as a result of an ADHD diagnosis, and that the ADHD label will define children's current and future potential.

Cognitive neuroscience is already uncovering neural markers or biomarkers for detecting the different learning difficulties, measurable in infancy.

Foresight Report on Mental Capital and Wellbeing (2008)


The key character traits... have significant cognitive elements, underpin achievements in literacy and numeracy, and may take years to acquire.

DEMOS Report on Building Character (2009)

2.3 THE SOCIAL COSTS OF ADHD

Behavioral difficulties, anti-social behavior, mental illness and learning disabilities in children are critical, expensive and growing societal problems.

ADHD is viewed as a key challenge to fostering success in children and future economic prosperity for the nation. In 2008, a prominent UK report, 'The Foresight Report on Mental Capital and Wellbeing,' reported that ADHD *'produces an estimated lifetime earnings cost of £43,000, suggesting that substantial benefits would accrue to the individual (and to the economy) from*

interventions that would reduce these problems.' 

The Foresight Report, and others like it, tend to view children's behavioral and developmental challenges in neuroscientific terms. The proposed solutions similarly draw on scientific understanding of genetics, cognitive science and neuroscience.

THE VOICES STUDY SUGGESTS THAT COGNITIVE DEFICITS ARE NOT THE WHOLE STORY.

To deal successfully with the burden of ADHD it will be necessary to address the social

and moral dimensions of ADHD behaviors. **Only when social and moral dimensions of ADHD are recognized and addressed can a child's cognitive potential be fully engaged.** Then a child can contribute to her own flourishing as well as to the public good.



SECTION 3:

THE VOICES STUDY

This section describes the primary aims and the research design of the VOICES study.

3.1 OUR FOCUS

The VOICES study set out to understand whether children's perspectives and experiences support claims about the ethical harms of ADHD diagnosis and stimulant medication. **We focused on the ethical concerns about authenticity, moral agency and personal responsibility.** We also investigated children's perspectives on broader societal concerns, including **behavioral norms, schooling expectations and academic pressures; and stigma associated with ADHD.**

3.2 WHO WE TALKED TO

We recruited 151 families from the United States and from the United Kingdom into the

Participants N=151	Gender	Mean Age	Mean SES (Socio-economic status)	Ethnicity
United States	60.9% male 39.1% female	11.41 years	Class III-IV (middle to lower-middle class)	66.7% White 23.2% Black 10.1% Other
United Kingdom	80.5% male 19.5% female	10.87 years	Class III-IV (middle to lower-middle class)	86.6% White 3.7% Black 9.8% Other

Summary Table: Demographic characteristics of participants

VOICES study. Within these families, we interviewed three groups of children: children who were taking stimulants for a diagnosis of ADHD; children who had a diagnosis of ADHD but were unmedicated; and children without a psychiatric diagnosis. We interviewed children between the ages of 9 and 14 years old. The average child in the VOICES study was an 11 year old, lower-middle class, White boy.



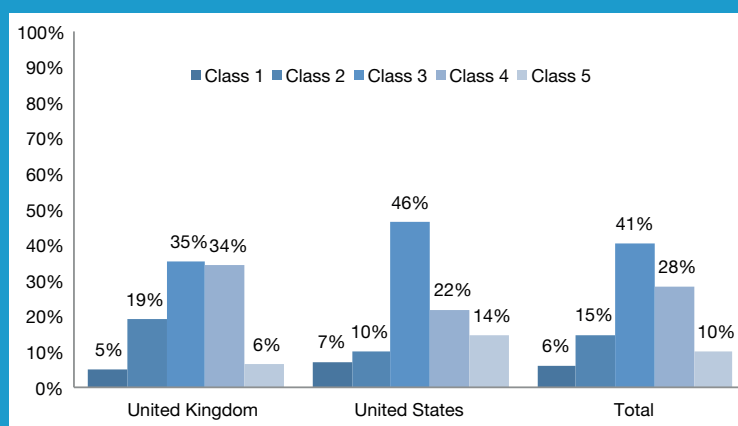
We tried to match characteristics of US and UK participants using broad demographic indicators, such as age, gender, ethnicity and socio-economic status. Graph 1 shows that the US

and UK families did not differ significantly by socio-economic status (as measured by the Hollingshead 4-factor index). US children were slightly younger, on average, than UK children we interviewed (Graph

2). As you can see from Graph 3, we had significantly more girls in the US, as compared to the UK group of children. We also had more non-White children in the US, as compared to the UK group (Graph 4).

Country	N
United Kingdom	82
United States	69
Total	151

Graph 1: US and UK socio-economic status (n=151)

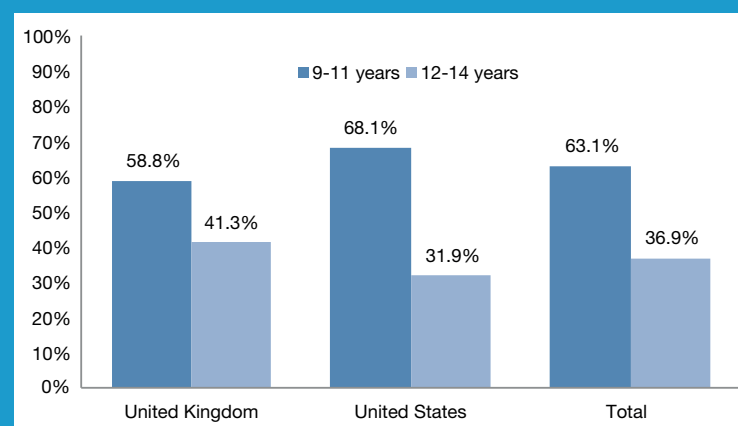


There was diversity in the socio-economic status of the study's participants, with higher proportions in classes 3 (41 per cent) and 4 (28 per cent). There was no important difference in socio-economic status of participants from the United States and United Kingdom ($p > .05$).

Class description: Class 4-5 is middle class/upper class; class 3 is middle-class/lower-middle class; class 2 is lower-middle class/working class; and class 1 is working class/poor.

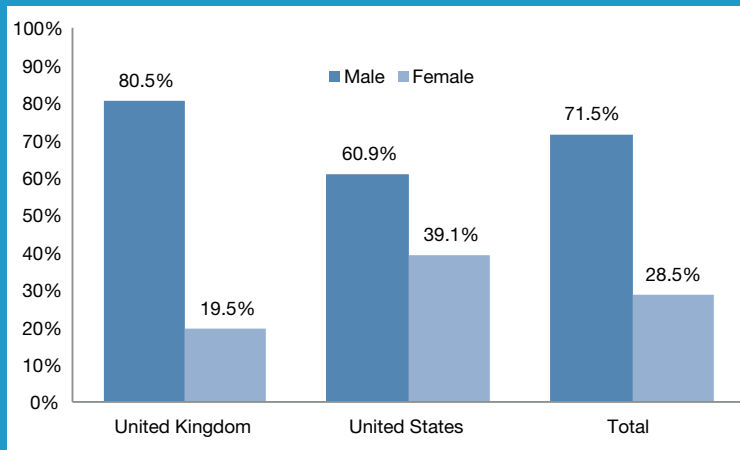
Class measured by the Hollingshead Four-Factor Index: class 1: 19-8; class 2: 29-20; class 3: 39-30; class 4: 54-40; class 5: 66-55.

Graph 2: US and UK age (n=151)



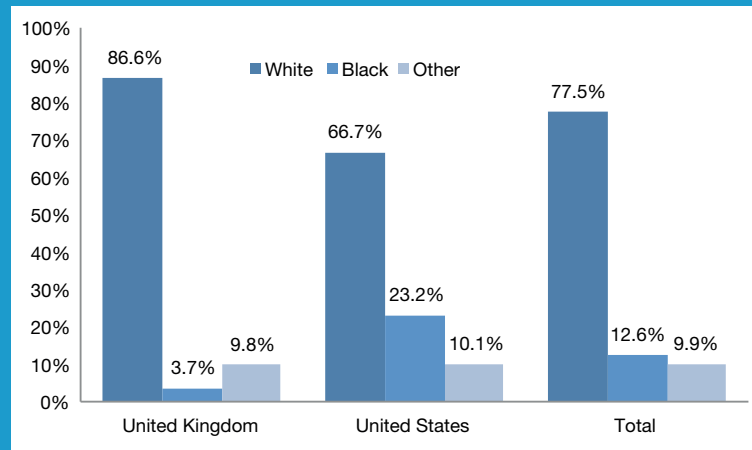
The participants' ages ranged from 9 to 14 years. Overall, 63 per cent of the participants were aged between 9 and 11 years. The mean age was 11.2 overall. The mean age was slightly higher in the United Kingdom ($M=11.41$, $SD=1.5$) than in the United States ($M=10.87$, $SD=1.6$) and this difference was significant ($p < .05$).

Graph 3: UK and US males and females (n=151)




72 per cent of participants were males. A higher proportion of UK participants were males (81 per cent) compared to the US (61 per cent) and this difference was significant ($p < .01$).

Graph 4: UK and US ethnicity (n=151)



Overall, 78 per cent of participants were categorised as being White, 13 per cent as Black and 10 per cent as Other. In the UK there was a higher participation of White kids (87 per cent) compared to the US (67 per cent), where a higher proportion was Black (23 per cent). The difference between the US and UK was significant ($p < .01$).

Stigma
 Ritalin
 Concentration
 Choices
 ADHD

We recruited families with diagnosed children into the study through NHS clinics in the UK and through university and community clinics in several US states. This method of recruitment ensured that VOICES study participants had received robust evaluations for ADHD. We made sure that the evaluations received by US and UK children were more or less the same by asking parents or caregivers to fill out a standardized measure that substantively summarized what happened in the clinic visit.  Children with another primary psychiatric diagnosis were excluded from the study.

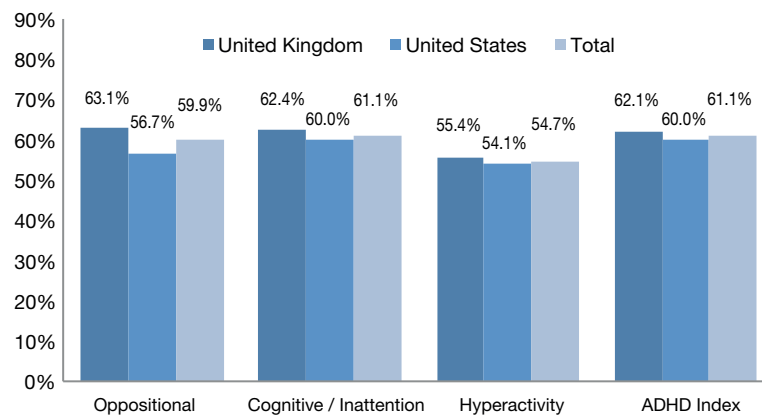
Our method of recruitment means that children in the VOICES study were likely to have had a robust and thorough evaluation for ADHD. We measured the symptomatology of children in the study using the Conners' Parent Rating Scale – Revised (S). Overall, we found no significant differences between outcomes of diagnosed US and UK children on the Conners' measure. However, diagnosed UK children scored significantly higher on the oppositional sub-scale, as compared to diagnosed US children (see Graph 5). This suggests that ADHD might look different behaviorally in the US and the UK, even though the

global behavioral deficits are more similar than different. We'll have more to say about this when we describe the findings from the US and the UK below.

We recruited children without a diagnosis using a market research firm, advertising and word of mouth.

In the UK we had difficulty recruiting children with a diagnosis of ADHD who were unmedicated. Most NHS ADHD clinics do not keep updated records on such children, because they are not in active treatment. To supplement our UK cases in this group, we also recruited through schools, focusing on children labelled 'teacher-identified ADHD.' These children had not yet received a formal diagnosis of ADHD, although the schools we worked with were treating them as potentially ADHD through their learning support services.

Graph 5: UK and US Parent Conners' results (n=151)



Participants in the UK scored significantly higher on the Conners' Oppositional scale than participants in the US (63.1 and 56.7, respectively, $p < .05$).



Four female researchers carried out the interviews. We met most families in a clinical setting, using a meeting room or an office generously lent to us by our clinical colleagues. A minority of families was interviewed in their homes, in university rooms or in other locations. In the UK, our geographic range included Greater London, Leicestershire, Lincolnshire, Northamptonshire and Sussex. In the US, we interviewed mainly on the East Coast, in Florida and in Ohio.

3.3 OUR APPROACH

We used a qualitative approach in the VOICES study, supported by quantitative measures and analyses. We held approximately one hour long interviews with all child participants; and we also talked with parents and caregivers to understand the family context, and the nature of support the family had received from health-related and educational services. We gained a broad understanding of local educational, socio-economic and political pressures by visiting support groups for parents with ADHD and by talking with local clinicians and teachers.

Our interviews with children were grounded in the belief that children are not passive victims of their behaviors,

or of ADHD diagnosis and stimulant drug treatments. We approached children as active participants who can be readily engaged, even on complex topics, although we also appreciated the limitations and the vulnerabilities associated with a child's developmental stage and with the challenge of ADHD symptoms. In this way, **we conducted research with children, not on children.**

Interviews with children focused on four overlapping areas – behavior, brain, medication, and identity, across four contexts – home, school, doctor's office and peer group. We incorporated drawing, a vignette, sentence completion tasks, standardized pictures and a sorting task into the interview to ensure that children were given the opportunity to tackle a set of complicated issues using a variety of skills and techniques.

Parents and caregivers filled out demographic forms and supplied some further information about child and family medical history. Parents also filled out standardized questionnaires.

More information on the specific measures used, as well as on our qualitative interview methods, can be found on the VOICES website www.voices-study.org/.

CHILDREN'S BRAIN DRAWINGS

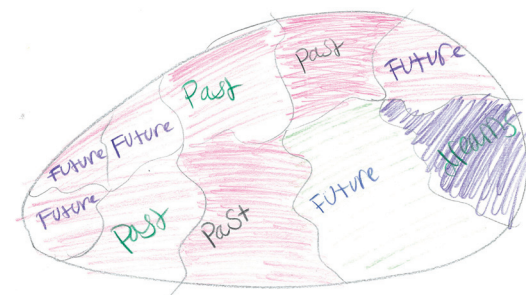


Lottie, age 12

Angie, age 11



India, age 14



QUESTIONS WE ASKED CHILDREN

Interviewer to child:

“YOU are the expert here, not me. I’m learning from you. So if I get something wrong, you tell me, ok!”

Q. Could you stop doing [problematic behavior] if you wanted to? Why or why not? Do you WANT to stop?

Q. What’s it like when you go and see your doctor?

Q. If you were to describe ADHD to an alien from another planet, what would you say?

Q. I hear from kids that sometimes they use their ADHD as an excuse to get out of trouble. Have you ever done that?

Q. Now I’m going to ask you to do something a bit weird. Would you draw me a picture of your brain?

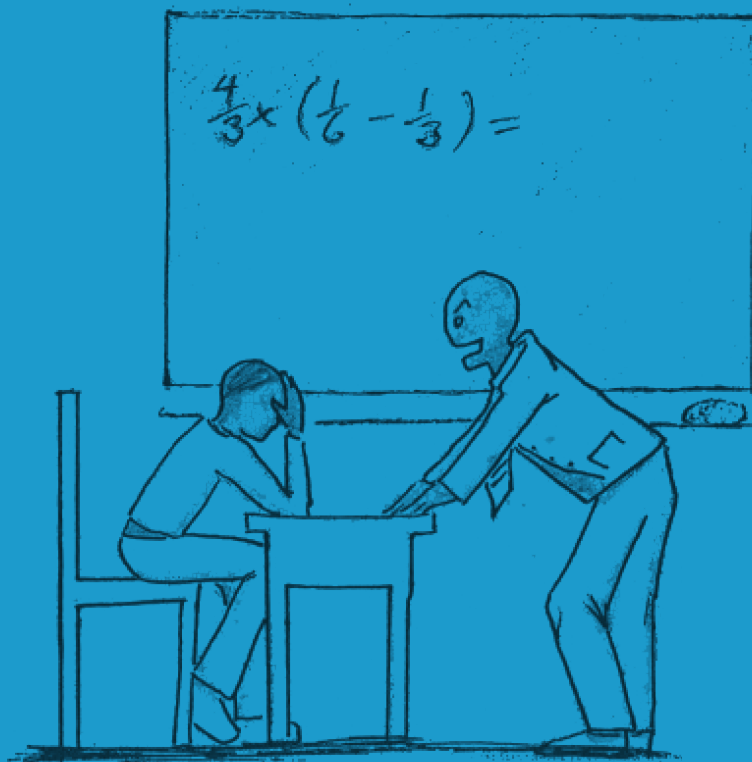
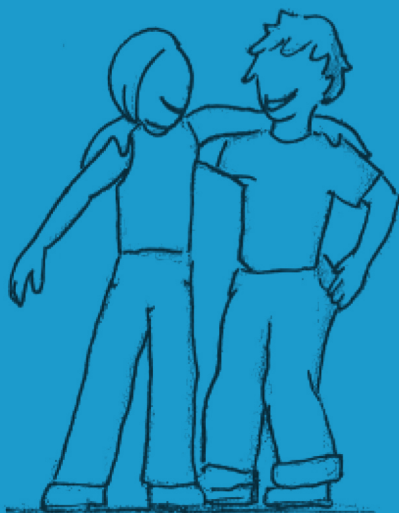
Q. Now let’s pretend you have a photo that shows me a time when you got in trouble for your behavior. What would I see happening?

Q. Some kids say that they feel like they aren’t themselves when they take their medicine. Do you ever feel that way?

Q. Let’s pretend that you have a photograph that shows me a time when you were really happy with how you behaved. What would I see happening?

Q. Do you think your brain has anything to do with how you behave?

EXAMPLE OF TWO OF THE
STANDARDIZED IMAGES USED WITH
CHILDREN IN THEIR INTERVIEWS



Q. [The friendship picture] Do children with ADHD have friendships like this?

Q. What do you think is going on in this picture?

Q. How do you think the people in this picture are feeling?

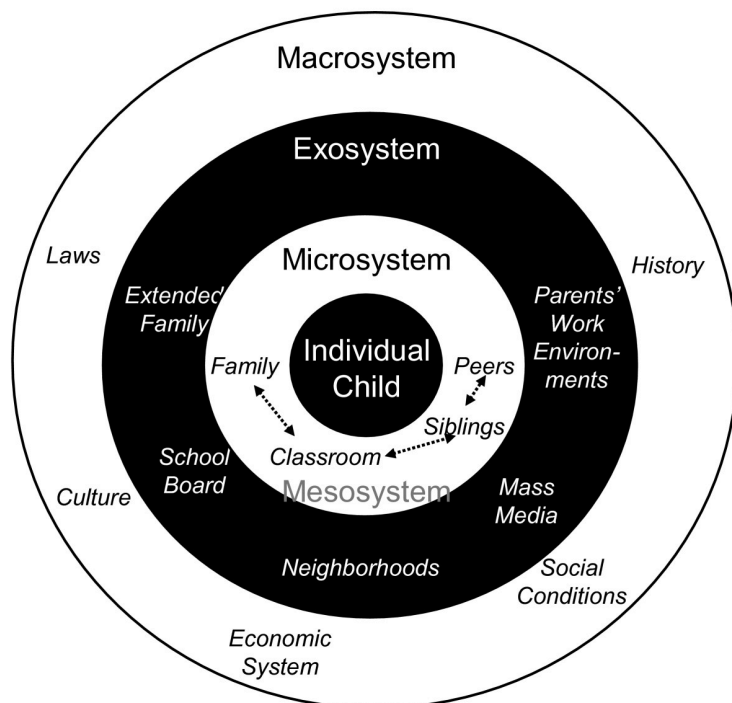
Q. [The classroom picture] Imagine that the child has ADHD, and he says to the teacher: 'I have ADHD, I can't do the work!' Is that right?

Q. Have you had experiences like this?

SECTION 4:

WHAT DID WE FIND OUT?

In this section, we introduce the concept of the 'ecological niche' and describe two kinds of ecological niche discovered in the VOICES study. We discuss the importance of these niches to children's understanding of moral behavior, and to their experiences of stigma.



Bronfenbrenner Ecological Model

4.1 TWO NICHEs: GOOD CONDUCT AND GOOD PERFORMANCE

The VOICES study used the concept of the ecological niche to analyze the complex and subtle dynamics between a child and the surrounding environment. The ecological niche was originally described by the developmental psychologist Urie Bronfenbrenner in 1979.

An ecological niche is made up of a combination of personal attributes and demographic characteristics. The niche concept allows us to analyze the dynamic influences of biological, familial, social, and national factors on a child, and to consider how a child may be impacting on this environment. In the figure here, you can see the different 'systems' that Bronfenbrenner described as making up the child's ecology. These systems expand from the micro-level to the macro-level.

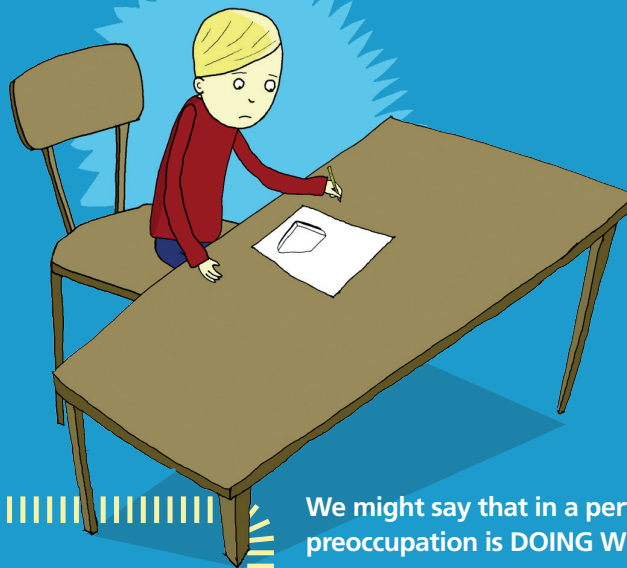
Two main niches were discovered in the VOICES study:

a performance niche and a conduct niche.

A minority of children in the VOICES study inhabited hybrid niches, in which performance niche and conduct niche values overlapped. In a hybrid niche, a key system – say, the child's neighborhood – may incorporate the values of a conduct niche, while another key system – say, the child's school – may incorporate the values of a performance niche.

Niches give rise to distinctive experiences with ADHD diagnosis and stimulant drug treatments.

4.1.A In a '**performance niche**,' children's cognitive achievements and successes are strongly emphasized, and **ADHD is viewed as a disorder of academic performance**. Children with ADHD are often thought to have learning differences and are sometimes known to undiagnosed children as kids who 'need help with school.'



CASE STUDY: PERFORMANCE NICHE

Ian is a 12 year old boy who lives in a lower-middle class suburb of a major US East Coast city with his mother and his stepfather. He attends a public (state) school. Ian was diagnosed with ADHD when he was 9 years old. He is taking Adderall extended release medication for ADHD, but he has been on three other medications for ADHD in the past 3 years. In addition to Adderall, Ian takes Clonidine to help him sleep.

Ian: I forget things a lot and I have trouble focusing and being mature. That means it's like, I'm not doing my work like I'm supposed to. The last time I felt good about my behavior was when I got all Bs and Cs on like my grade card, except for one D. That was few weeks ago. My mom freaked out she was so happy. I want to keep doing better.

My teachers are pretty nice. They don't yell at kids. It's hard to just sit [in class] and listen and work like other kids do. Sometimes I talk to other kids when the teacher is talking and she tells me to sit down. It makes me feel lame and stupid.

[At school] you have two types of fighting; punching and arguing. Punching doesn't happen at my school. You'd get in a lot of trouble and like probably be suspended. I get called names and stuff and [other kids] tease me sometimes. It's because I look like I'm 10. Next year I'm going to try really hard to get kids to actually believe how old I am.

I want to go be a doctor when I grow up.

We might say that in a performance niche, a main preoccupation is **DOING WELL**:

Interviewer: Tell me about a time when you weren't very happy with how you behaved.

Um I got my name on a board, and I got Fs on my report card, and my mom was really mad. And she told me that you need to do better, and she, and I was really happy this year, that it's really good. But last year, I wasn't paying attention.

Rose, US, age 11

Children in a performance niche articulate the effects of stimulant drugs in relation to classroom behavior, school work, intelligence and academic achievements:

[With medication] I like, I finish my homework earlier and I don't get in trouble a lot anymore. I pay attention a lot more... It feels great... The medication, it like, changes, like, what you're doing and, like what you're thinking. Like all of a sudden, like, you know that you're not doing what the teacher told you to do, so then it just changes what, so then, so then, you can do the right thing what the teacher told you, so you can pay attention more better.

Camilla, US, age 10

CASE STUDY: CONDUCT NICHE

Shaun

Shaun lives in a large village on the outskirts of a small city in the UK, with his mother and father and his younger sister and brother. His home is in a lower middle-class neighborhood near to where his parents grew up, and some of Shaun's relatives live nearby. Shaun was diagnosed with ADHD three years ago when he was nine; and he has been taking extended release Concerta for the past 2 ½ years. He also takes omega-3 supplements, which his mum hopes will help with his concentration. Shaun attends a state (public) school.

Shaun: *ADHD is like behavior, just anger, like, temper; it's like sometimes I feel really cross with other people and I just want to go lashing, lashing out. [Other kids at school] know they can wind me up easily so they do it again and again and I can't walk away that easy. [My dad says] not to throw the first punch, but if I get punched, I have to fight back. Teachers are not effective. They don't help. If someone takes the mickey [makes fun of him] I go to them and they just tell me there's nothing they can do about it. Sometimes they tell other kids to stay away from me. They know I've got problems and I'll get annoyed easily.*

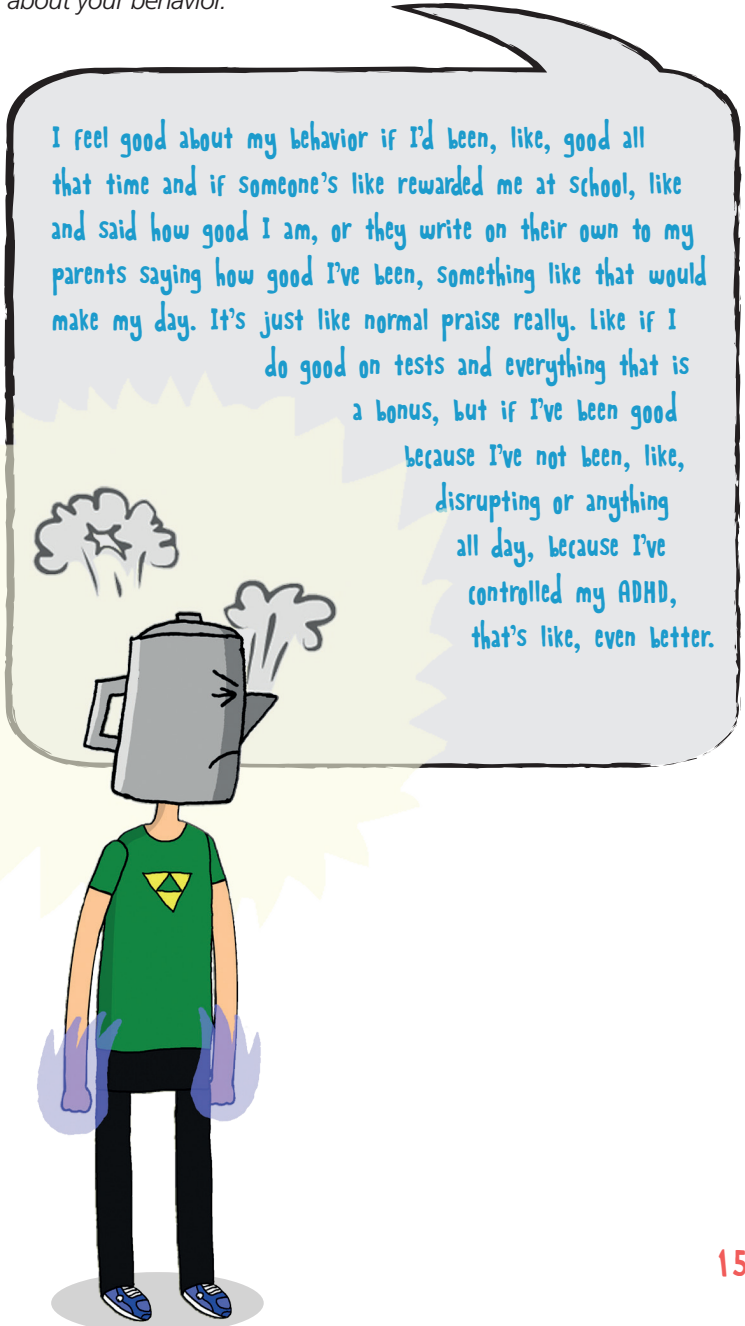
My mates look out for me. If I'm running toward somebody they would either tackle me or hold me down or something. That's what good mates do for each other. They know what I'm like.

In the future I guess I want to be less naughty.

4.1.B In a 'conduct niche', children's social behaviors and social hierarchies are a dominant preoccupation among children and adults, and academic achievement by children does not outrank other obligations.

We might say that in a conduct niche, a main preoccupation is BEING GOOD.

The interviewer asks Shaun: *Tell me about a time when you felt good about your behavior.*



I feel good about my behavior if I'd been, like, good all that time and if someone's like rewarded me at school, like and said how good I am, or they write on their own to my parents saying how good I've been, something like that would make my day. It's just like normal praise really. Like if I do good on tests and everything that is a bonus, but if I've been good because I've not been, like, disrupting or anything all day, because I've controlled my ADHD, that's like, even better.

In a conduct niche, ADHD is viewed as a **disorder of anger and aggression**, and stimulant drugs are seen by children to improve emotional self-control, aggressive behaviors, and moral decision-making.

It [stimulant medication] makes me like, helps me behave better but it don't make you behave better it can only help you, but it can make, help make better decisions for you.

Roger, UK, age 13

Alongside the association with anger and aggression, ADHD in a conduct niche was sometimes associated with being 'thick' or 'slow.' Some children wished they could be 'more clever' but far fewer children in a conduct niche associated stimulant drug treatment with helping them to achieve academically, as compared to children in the performance niche.

4.2 NICHE AND NATION

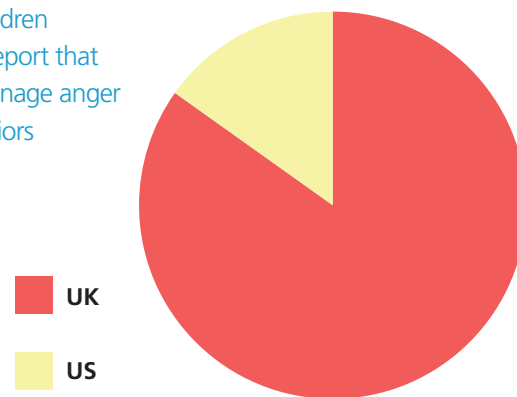
In the VOICES study, the ecological niches were associated with national differences: among US children we interviewed, the performance niche was the modal niche environment;

and among UK children we interviewed, the conduct niche was the modal niche environment.

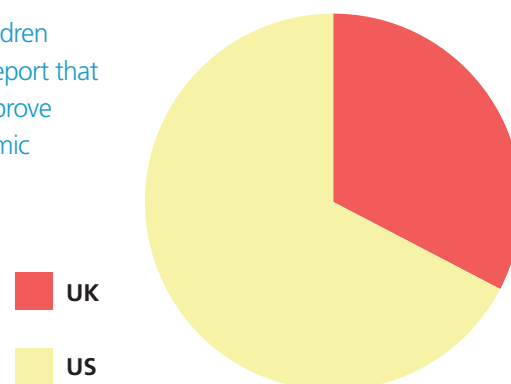
Given the size of the VOICES study sample and the lack of a random sample, these findings should be interpreted with caution. Other demographic factors in the ecological system, such as the social class of the family and neighborhood, also contribute to the niche ethos.

We expect that research in diverse geographic settings will help further characterize the ecological niches discovered in this study, and will also describe new relevant ecological niches for children with ADHD.

The proportion of children who spontaneously report that stimulants help to manage anger and aggressive behaviors



The proportion of children who spontaneously report that stimulants help to improve classroom and academic performance



4.3 NICHE AND MORAL BEHAVIOR

Children's understanding of 'good' and 'bad' behavior was associated with the niche.

Conduct niche children tended to think that being a good or bad person had to do with a person's ability to reason about their behavior before they acted.

Interviewer: *How do you know if a person is a good person or a bad person?*

Um, being good and bad is to do with thinking about your actions. Um, and I think if you're bad, then you don't really think about your actions very much...

Conrad, UK, age 13

Performance niche children were more likely to associate good behavior with academic achievement or skills.

Interviewer: *What makes a person good?*

Um, me being smart.

Vaughn, US, age 10

In a hybrid niche, children tend to describe a good person as someone who performs well and behaves well.

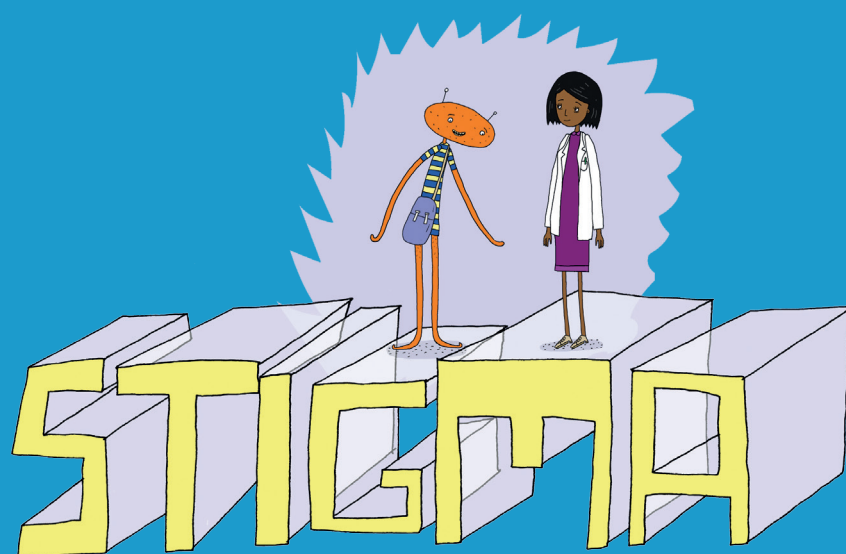
Interviewer: *What do you think makes a person a good person?*

When they don't do bad and when they get good grades.

Miles, US, age 9

The discovery that children's views of individual moral behavior differ across ecological niches is interesting, because it suggests that there are different values associated with good and bad behavior in the different niches. The values that inform children's concepts of good behavior in a performance niche have to do with individual success, intelligence and achievement. Children invest in these values in part because it is an obligation they feel to their families. Performance niche children frequently noted that good grades in school made their parents happy.

The values that inform children's conceptions of good behavior in a conduct niche have to do with reasoned and justified actions. In a conduct niche, the right action was not necessarily the action that had the most positive consequences for the individual child. Conduct niche children disliked being known as 'naughty' and loved praise from adults. But they were also invested in demonstrating good character. This investment could mean acting according to their beliefs about right and wrong, even if those actions did not achieve the best social or individual outcomes.




4.4 STIGMA AND THE ECOLOGICAL NICHE

Niche values make a difference to the public face of ADHD, and therefore to children's experiences of stigma. Children's experiences of stigma differed markedly across the two ecological niches. In the conduct niche, children with ADHD were usually well known to others as having an 'anger problem'; they were a highly visible part of the social fabric. Most children did not try to keep their diagnosis a secret.

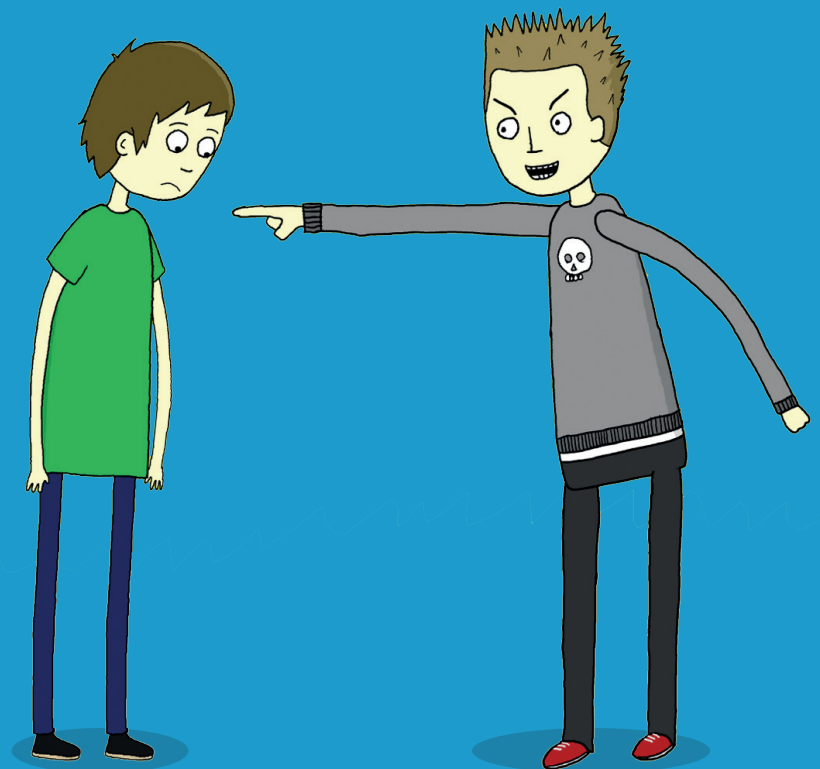
Children's experiences with stigma may be particularly influenced by national context. This is because stigma experiences are influenced by national and state laws; for example, those governing discrimination, disability rights and educational inclusion.

In the conduct niche, children with ADHD reported experiences of active and persistent bullying. Many children admitted that they were both victims and victimizers of others. As victims of bullying, children with ADHD were frequently targeted specifically for their behavioral difficulties. They were purposely 'wound up' by other children:

When a culture of bullying and aggression has taken hold in a school, or more broadly, in a niche, it can be difficult to shift. The UK government has been working on strategies to improve the situation for some years now; and the US educational sector has also begun to recognize how stressful and dangerous bullying in schools can be for children . The VOICES study suggests that an aggressive school culture is particularly difficult for children with ADHD because the culture makes it more difficult to manage ADHD behaviors.

Because I told them about my ADHD, they thought if they could wind me up I'd get really upset and they love to do that. I thought if I just ignored it then they would get really bored of doing it and stop... But they didn't. [Teachers] just say ignore it. [They] know what I'm like, but I don't think they really know how hard it is for me to cope.

Heidi, UK, age 11



In the performance niche, most children wanted to keep their ADHD diagnosis a secret – from friends, teachers (where possible) and even from family members outside the immediate family.

NO ONE KNOWS [ABOUT ADHD DIAGNOSIS] EXCEPT MY TEACHER... I DON'T WANT ANYONE TO KNOW I HAVE ADHD. THEY'LL SPREAD IT ALL AROUND SCHOOL AND THEN EVERYONE WILL LAUGH AT ME.

Brendan, US, age 11

Secrecy was more possible in a performance niche because children's difficulty with self-control tended to manifest itself in less obtrusive symptoms. Secrecy was also enabled by parents, many of whom felt strongly that children should not tell peers about the diagnosis. Parents thought that the child might feel shame or embarrassment, or might be bullied by others. In talking to parents we felt that parents had a further worry, that they themselves would receive 'courtesy stigma' – that is, they would be stigmatized for having pursued a diagnosis of ADHD

and/or having accepted stimulant drug treatment for a child.

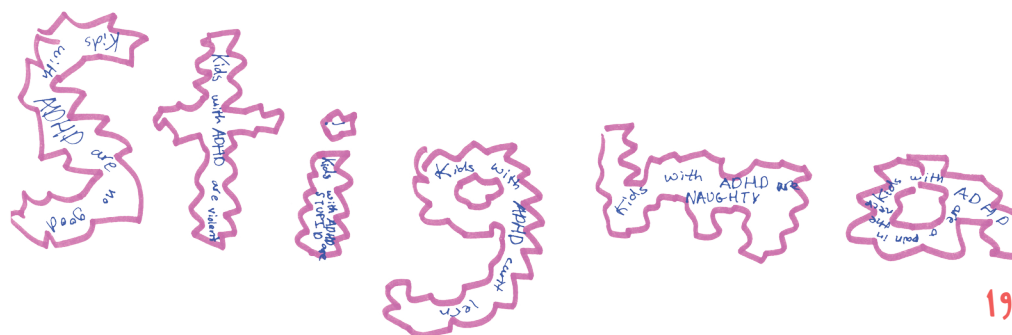
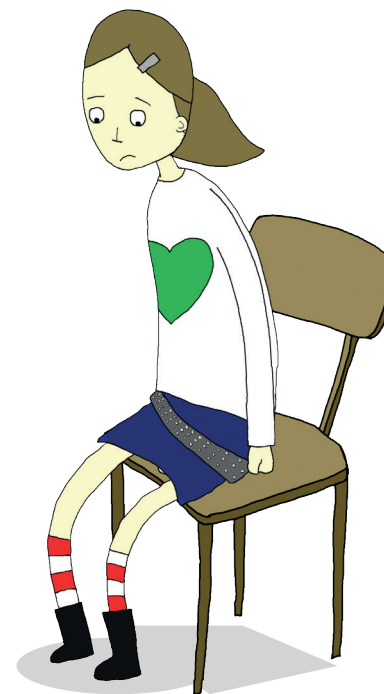
There were consequences of this secrecy for diagnosed children. Many performance niche children worried about stigma (the stigma literature calls this 'expected stigma') even though they had never had any stigmatizing experiences and they could not recall any child who was bullied or teased for having a disability in their school.

We also found that many US children did not know what ADHD is. Some children in our study, who were diagnosed with ADHD but were not taking stimulant medication, were unsure whether they had a diagnosis of ADHD.

Stigma: an attribute that discredits, shames or discounts a person in the eyes of others.

Courtesy stigma: a mark of shame attributed to family or friends of the stigmatized person.

Expected stigma: the anticipation of an experience of stigma, which may or may be realized.



Interviewer: Do you know what ADHD stands for?

No. I have no clue... Never heard of it.

Interviewer: Do you want to know?

Yeah.

Interviewer: It's Attention Deficit/Hyperactivity Disorder.

[Pause] What do those words even mean?

Nancy, formerly medicated for ADHD, US, age 11

I think like someone said I might have it, but I don't know what it [ADHD] means... I can't remember stuff a lot. I think that's what it is.

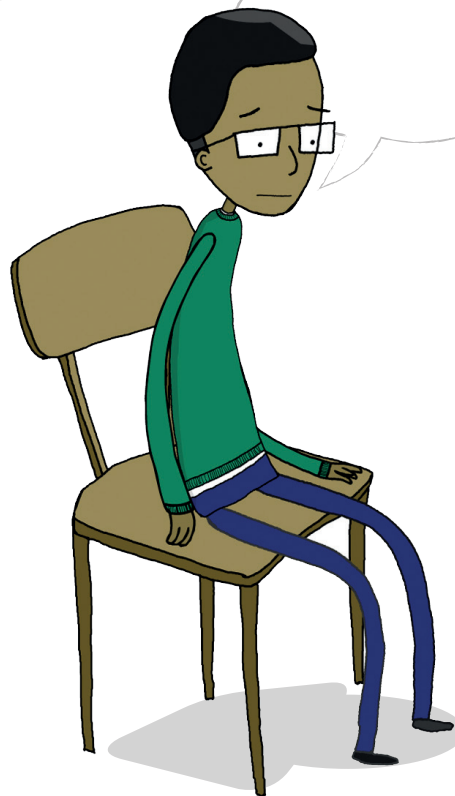
Robert, diagnosed with ADHD, but not on medication, US, age 10

ADHD is kind of like a cancer disease but you're not going to die from it.


Sylvia, US, on medication, age 11

I don't know what it [ADHD] stands for, but I know it means lying and being nosy.

Ron, US, on medication, age 10



We hypothesize that US children's lack of knowledge about ADHD may be due, in part, to the pervasive silence around the diagnosis. Children who are urged to keep ADHD a secret are unlikely to ask for clarification of what it is, or whether they have it.

Stigma research suggests that silence and secrecy are not a good way to tackle stigma. These coping strategies are likely to encourage anxiety and shame in children, and to prevent children from accessing resources to respond to inaccurate or demeaning accounts of ADHD. Secrecy can also have a negative impact on friendships. The best way to combat stigma around mental disorder is to meet a person with that disorder. 

Although the treatment of children known to have ADHD in the conduct niche is unsettling, those children have more of a chance to disprove their peers' stereotypes than children who keep their diagnosis a secret.

We think that the opportunity to have a say in what ADHD is, and to defy stigmatizing assumptions, is profoundly important.

Children should be actively supported in this opportunity by adult caregivers.

4.5 NICHE VALUES

Having read to this point, a reader may be thinking:

Is it right that children are subjected to these niche values?

Niche values are part of our human existence, and they define the norms of behavior that make up the rich and diverse social fabric in which we live. Children grow up and are socialized by niche norms. Socialization is necessary for healthy child development, and in some areas, such as language, social interactions, or food preferences, it is a little noticed part of growing up. But in other areas, people disagree about the niche values that underlie the socialization of children.


Niche values are a reason why people can disagree about the use of stimulant drug treatments in children.


ADHD diagnosis and stimulant drug treatments provide many

Our findings describe how children manage 'the public face of ADHD' at a particular stage of development: middle childhood. Adolescents may feel more confident about sharing their ADHD diagnosis with others.



children with a means to be more successful in meeting niche norms and expectations. As such, it is reasonable to view ADHD diagnosis and stimulant drug treatments as beneficial to children.

And yet, some people think that the values of a performance niche are not the right values, and that putting children on medication to help them meet the expectations of a performance niche is wrong . Other people think that it's wrong to focus on good behavior over good grades – that naughty behavior isn't a sufficient reason to put a child on stimulants. Many

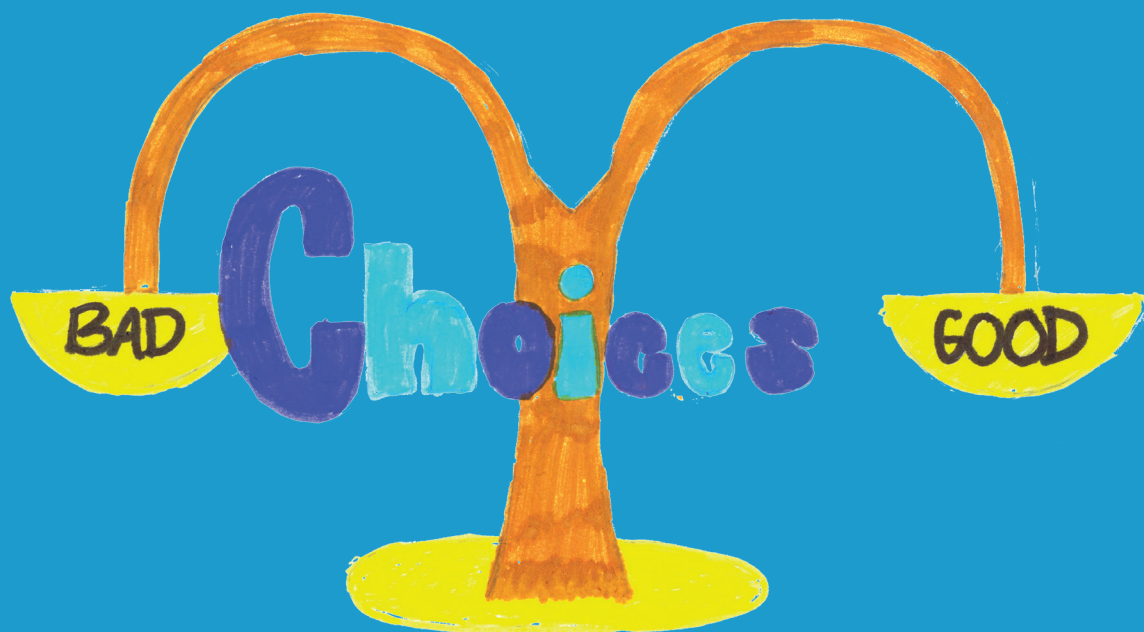
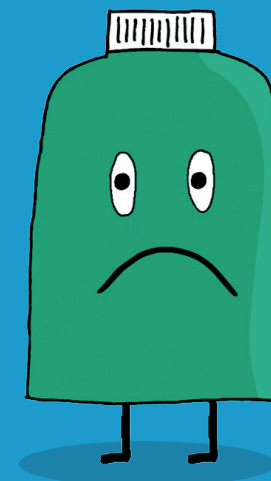
people rightly believe that pharmaceutical companies capitalize on, and help to shape, niche values in order to sell their products. 

Different values shape people's different ideas about the right and wrong reasons and means to manage children's behavior.

The continuing controversy and finger-pointing debates over ADHD diagnosis and stimulant drugs are a symptom of a deeper problem: There is little common agreement on the values that should guide those in charge of children's moral development.

A public conversation, at a national level, on the values

that should guide medical professionals, teachers and parents in shaping children's moral development is essential. Crucially, this conversation should include children themselves. If the conversation is developed systematically and thoughtfully, it can avoid the current pitfalls of accusation, finger-pointing and polemics. Instead, some genuine understanding will emerge about what common values govern people's ideas about raising healthy, happy and good children – and where there are disagreements. This process will also promote more coherent and more relevant national policies on child health and education.



SECTION 5:

ETHICAL RESILIENCE – ADHD, RITALIN AND CHILDREN'S MORAL DEVELOPMENT

In this section we address the core research questions that motivated the VOICES study. Is there empirical evidence to support claims that stimulant drug treatments pose a threat to children's moral development?

A productive conversation on values will benefit from research evidence concerning the perceived ethical harms of stimulant drug treatments for ADHD.

5.1 AUTHENTICITY: WHO DO I TAKE MYSELF TO BE? WHO DO I WISH TO BE? CAN I BE MYSELF?

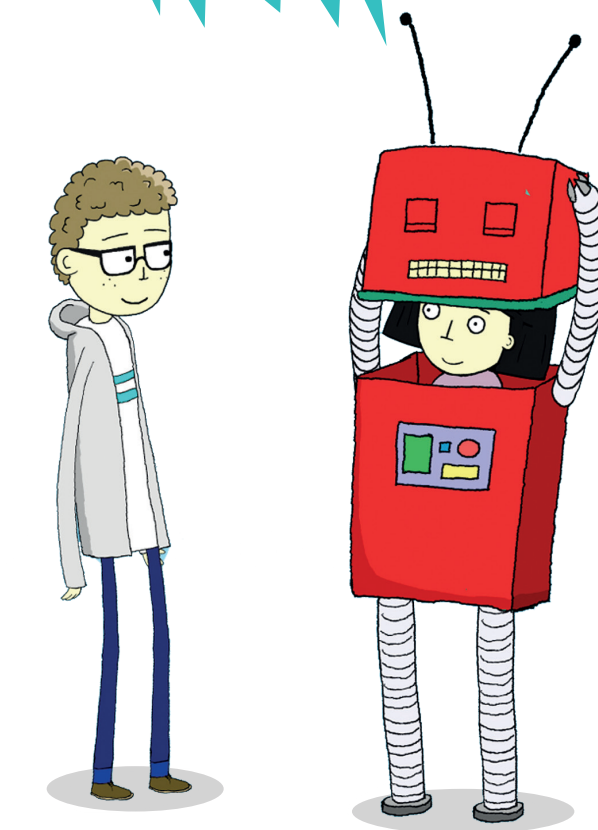
Does a stimulant medication like Ritalin or Adderall negatively affect a child's developing sense of self? Does a child feel less like him or herself while on medication? Does medication make a child feel like a different person?

Interviewer: *Some people think taking medication might turn you into a different person. What do you think about that?*

With medication it's not that you're a different person; you're still the same person, but you just act a little better. Medication will help you control yourself.

Angie, US, age 11

Interviewer: *Would you say that you're the same person when you're taking your medication, or are you different – or is that just a silly question?*



I'm a bit, I'm a bit of both, like I am a bit the same person I always are [on medication]. It's just, I act a bit different, but I'm, I actually are always, I am always the same person.

Laurence, UK, age 10

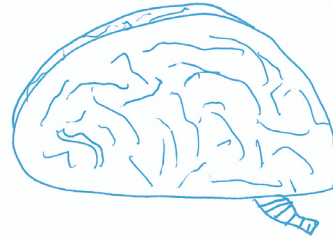
Children generally did not feel that stimulant medication negatively affected their sense of self.

Most children didn't think that the effects of medication were powerful enough to change their personalities. Children were focused on how medication affected their behavior, and for the most part, they felt the changes were neutral to positive.

[On and off medication] they're both me, just that... it's kind of like Superman. Um, when there's not somebody in trouble, he's just an ordinary person, um who gets on with his work... it's like me. Um, without my medication, I'm just like, fidgety and things and I get angry easily. But then, um when there's a scream or something, Superman turns into him, and it's like having a second personality, nearly.

Conrad, US, age 13

A small group of children felt that stimulant drug treatment gave them a 'second personality.' This personality was housed within the body and mind of the original person, and was therefore not a threat to an authentic sense of self.



Chuck, age 9



Of course what children say is likely to be influenced by what other people around them say. So it is interesting to note that parents we spoke to quite often made statements like: *He's like a different person on medication; or I feel like I hardly recognize her now that she has started taking the medication.*

Most children did not echo these sorts of categorical statements. This suggests that children have a resilient sense of self and are able to express individual experiences of their ADHD treatments. It may also mean that children of a certain age come to be more influenced by what their peers say about the impact of stimulant medication on their personalities, than what parents say.

Did any children report feeling that they were 'a different person' on medication? Yes, two groups of children did. One group was made up of some of the youngest children in the

study. About six 9 year olds, or about 40 per cent of 9 year olds with experience of medication in the study, said that they felt that medication turned them into a different person.

[With the medicine] I ain't being naughty no more... I'm not doing anything to other people now. [The medicine] makes me good again. [If I didn't take it] I'd probably get into lots of trouble. [Tablets] have changed my life... like, stopped making me bad... and pushing people over... and starting fights.

Cecil, UK, age 9

Leroy age 9

with pills



without pills



These young children felt good about their behavioral changes with medication, but we should be concerned about the fact that they attributed their ability to be a good person entirely to medication. Age is a factor in this attribution: younger children are more likely to think in dichotomous or concrete ways, and they are more likely to want to please adults. Some of the solutions at the end of this report focus on helping children to think in complex

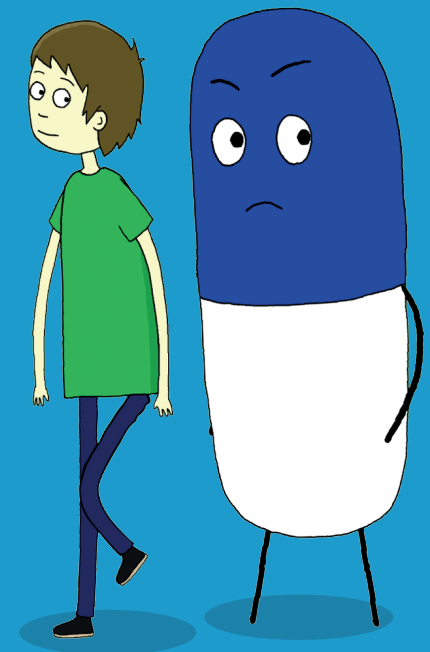
ways about their capacity to make changes in their behavior, and about personal responsibility for behaviors. Younger children need particular attention in this regard because of their developmental vulnerabilities.

The other group that felt they had become a different person on medication was children who had experienced quite severe side effects of medication. This group represented about 8 per cent of children with experience of medication in the study.

Not all of these children rejected medication on the basis that it violated their sense of self. Some had moved on to another, better tolerated medication. Because side effects of medication can feel like a violation of a child's sense of self, it is important that children feel they can talk openly with their parents and their doctors about such experiences.

There is an important discovery in the reports from this group of

children: Children are able to recognize threats to authenticity. Although their sense of self is still in development, children can feel, and report, when the self feels violated. This tells us that adults can ask children about threats to authenticity in relation to stimulant drugs and, with support, children are able to speak to this ethical concern.



5.2 MORAL AGENCY: WHAT CAN I DO? WHAT CAN I AFFECT? WHAT CAN I CREATE? WHAT CAN I DECIDE?

The US President's Council on Bioethics has this to say about Ritalin:

If the development of character depends on the efforts to choose and act appropriately, often in face of resisting desires and impulses, then the more direct pharmacological approach bypasses a crucial element... By treating the restlessness of youth as a medical, rather than a moral, challenge, those resorting to behavior-modifying drugs might deprive that child of an essential part of this education.

President's Council on Bioethics, 2003: 105-6

The President's Council worries that Ritalin offers a short-cut in moral decision-making: it 'by-passes' the essential component of struggle. Imagine a child who discovers a cellphone that has been left

behind in the classroom. The child feels torn between two options – to steal the phone, or to give it to a teacher. This is an important moment. The child feels the conflict between the right thing to do (not to steal) and the wrong thing to do (to steal). If she subsequently chooses to do the right thing even though it means she can't have something she wants very much, then we might say that she has shown good character. Does Ritalin treatment mean that a child doesn't experience the moral conflict? Does it mean that her actions are like those of a robot, who is programmed to do the right thing but has no inner conscience?

Most children told us that stimulant medication does not by-pass moral struggle. Instead, it puts children in a position of being able to '**stop and think**' before they act. In this place, they can evaluate what to do, rather than just acting impulsively. Children highly valued this position.

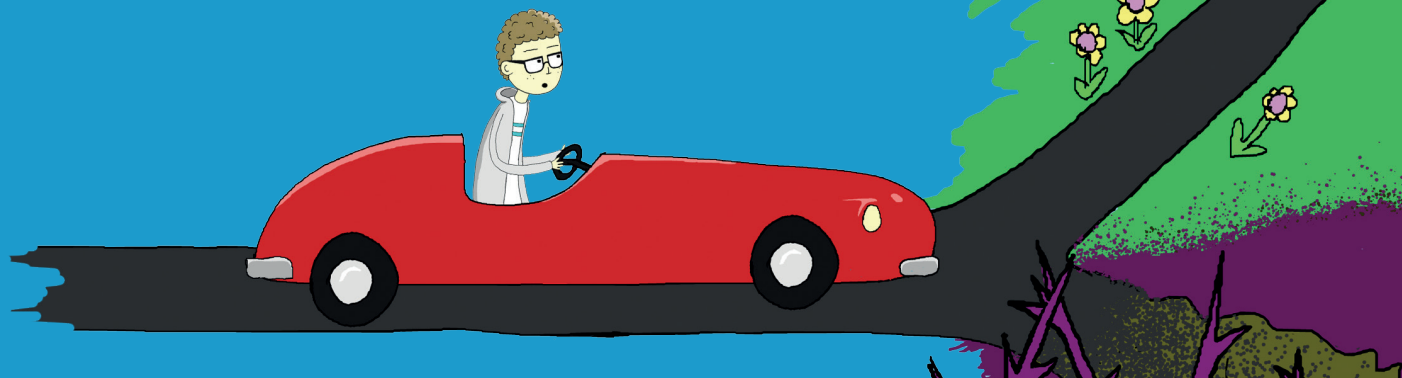
Children were also clear that being in a position from which they could consider and choose their actions also meant that they could choose the wrong action.

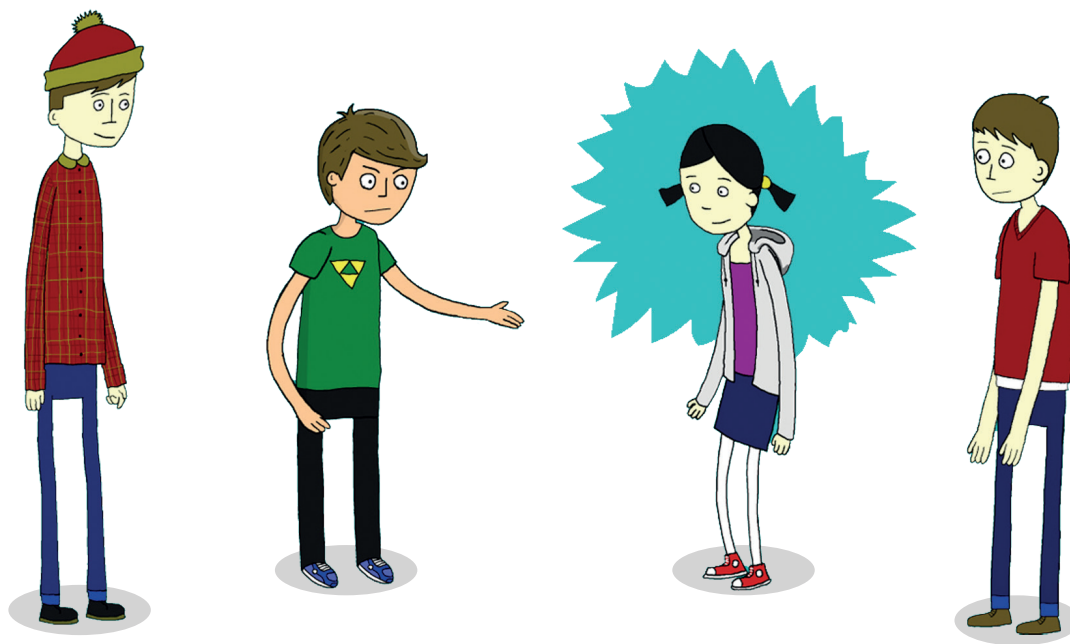
I know when [the medication] is working because I'm more quieter. I can sit still longer. And I don't have to fiddle about so much. I prefer myself like, in the middle. Like if you've got ADHD, you would prefer yourself in the middle, because you'll know when you're about to go into, when you're going to be hyper and when you can control yourself a lot more. And that's why I think I should be more in the middle a lot.

Timothy, UK, age 11

If you're like driving in a car, and like, there's two different ways, and you usually always go this way...and then one day you want to go the other way, but... the ADHD acts as like a blocker, so you can't... It [the medicine] opens the blocker so that you can go [the right] way. But you still have the choice of going the wrong way... It's harder [without medication], that's what's the truth. But it's not like [on medication] you're a robot...

Glenn, US, age 10





5.2.A Playground Ethics

In some settings, children have established moral codes of behavior, and these differ from adult moral codes. Children may choose to act in ways that adults feel is wrong, but to children, the behavior is the right thing to do. We came to think of these settings as having a 'playground ethics'.

In the VOICES study, a playground ethics was found to operate largely within the conduct niche. In the conduct niche, children who were taking stimulant medication reported that they were better able to stop and think before responding to bullying and physical aggression by peers. But **sometimes they chose to fight**. They made this choice based on two concerns; one was whether or not the bully had insulted a member of their family. The other was whether a good friend was being threatened. The

children knew they would get into trouble for their behavior, but they felt the decision to fight was justified, and they were willing to accept the consequences.

Like one day I'd kicked somebody, but, like that wasn't because he'd hurt me. It's because he'd hurt one of my friends. That's the main thing that's got me into trouble. That's why one of my friends now, he's been getting bullied... He always used to get picked on, and I always used to fight his battles for him.

Lionel, UK, age 12

It can be difficult for adults to evaluate the behavior of children in a conduct niche, if they do not understand the moral code of a playground ethics. Parents and doctors may think stimulant drug treatment is not working to contain impulsive behavior, because a child continues to fight and get into trouble. But children tell us that the medication is working the way it should: it is opening up a space for a child to stop and think. However, the child is choosing an action (to fight) that fits the local moral code.

The environment in which a child practices moral decision-making (what is the right thing to do?) plays a critical role in a child's moral judgments. This means that giving a child stimulant medication will sometimes treat only part of

the problem. If the aggressive, bullying environment of a conduct niche receives no treatment at all, then a child may not be able to – and may not be motivated to – make consistent positive changes in his own behavior, even with stimulant drug treatment.

MANAGING A DIFFICULT SCHOOL SITUATION

A child's school environment should not exacerbate illness symptoms, elevate stress levels or interfere with learning. Alongside other efforts to improve this situation in schools, we have five simple and practical observations from the VOICES study:


1. Parents, teachers and medical professionals need to work as a team.
2. The team should actively include the child, in age-appropriate ways.
3. Both the child and the environment need treatment in order for there to be real, lasting change.
4. Communication amongst team members should not be organized solely around a child's misbehavior. Find reasons to celebrate the child!
5. Evaluate strategies that are implemented to help a child. This sort of follow-through is often neglected.

5.3 PERSONAL RESPONSIBILITY FOR BEHAVIOR: AM I RESPONSIBLE FOR MY GOOD AND BAD ACTIONS? IS BAD BIOLOGY OR A BAD BRAIN RESPONSIBLE FOR MY ACTIONS?

In the course of the VOICES study, we heard some parents say:

I'm so glad to know it's his brain that's the real problem; not him.

My son doesn't have a behavior problem; he has a medical issue and can't control himself.

Parenting a child with ADHD can be enormously stressful. Managing a child with ADHD puts pressure on the whole family, especially on mothers, who often come in for a good deal of blame for their children's behavior. Mothers feel guilty and responsible for being 'bad mothers'; and they are also full of anger and grief because they feel they are losing hold of their children .

It is understandable, therefore, that parents might be particularly invested in biological or medical explanations for a child's behavior. We might think of such explanations as effecting a shift from 'mother-blame' to 'brain-blame.' If the brain, or

bad biology, is to blame for a child's behavior, then parents no longer need to feel so guilty and responsible.

Part of the debate over ADHD diagnosis and stimulant drug treatments revolves around exactly this issue: who is to blame? The finger has been pointed at everyone and everything from evolution to diet to parenting to genetics. The answer probably lies somewhere in the tangle of all these accusations. The answer most certainly involves a **two-way interaction between biological risk factors and environmental factors**.

Still, the question must be asked: *how does a child make sense of responsibility for his or her behaviors, once diagnosed with ADHD or taking stimulant medication?* Children hear the 'brain-blame' explanation from their parents, so do they also use this explanation for their own behavior? Do they use ADHD as an excuse for bad behavior?

Some children do use ADHD as an excuse for their behavior. They do it mainly to avoid getting into trouble. Interestingly, we found that conduct niche children were much more likely to use ADHD as an excuse.

Anyone who has heard about ADHD has heard the expression, 'Stay away from him; he has ADHD. Make him angry, he'll probably hit you...' The Headmaster just thinks we're violent... So I guess I can use all that to my advantage, when it suits me... It's a good excuse.

Davy, UK, unmedicated,
age 14

I don't get punished for nothing. It's easy to get away after fights because I have ADHD. I just make puppy eyes and it gets me round everything with my teachers.

(Alan, UK, age 10)

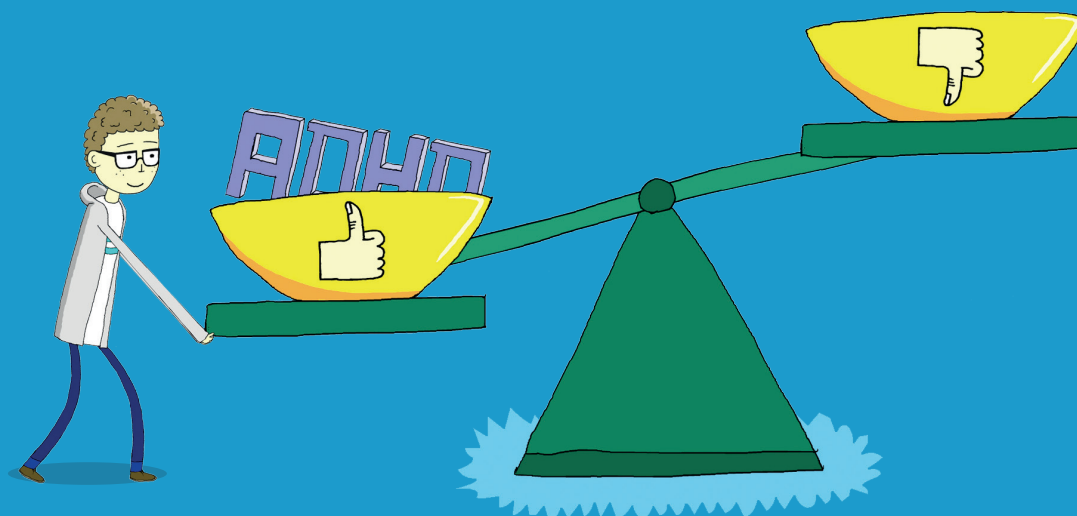
Approximately 65 per cent of children in a conduct niche told us that they had used ADHD as an excuse, either to their teachers or to their parents. They were aware that it was not the right thing to do, and they were also aware that many teachers and some parents believed that children with ADHD could not control their behavior.

Children in a performance niche rarely used ADHD as an excuse. Why? Many children said they didn't think it was the right thing to do. Some children pointed out that it isn't possible to use ADHD as an excuse if the ADHD diagnosis is a secret.

Most of the participants in the VOICES study – even those who used ADHD as an excuse sometimes – did not believe that a diagnosis of ADHD meant they could not control their behavior. But some children were willing to capitalize on adults' biases about kids with ADHD, if it was to their advantage.

I wouldn't use ADHD as an excuse for not paying attention in class. That would be kind of embarrassing. Like the other kids don't know that I have it and then I would get made fun of. Maybe my teacher knows; I guess my mom told her. I don't think kids would tell their teachers [about having ADHD]. That would be embarrassing.

Joe, US, age 10



SECTION 6:

CHILDREN'S VULNERABILITIES

We have seen that some common ethical concerns about ADHD diagnosis and stimulant drug treatment were not found to be areas of concern for children in the VOICES study. However, our research did uncover some ethical vulnerabilities in children. In this section, we review these and make suggestions for how children can be protected and enabled in vulnerable situations.

6.1 DEMOGRAPHIC VULNERABILITIES: SOCIAL DISADVANTAGE

CASE STUDY

Toby

Toby is a 10 year old boy who was diagnosed with ADHD six months ago. He lives in publicly funded housing in a US urban neighborhood that occasionally has trouble with gang violence. His father is currently unemployed, and his mother is a bus driver. Toby attends a large public (state) school several city blocks from his home. He has tried a trial of stimulant medication, but he found it gave him bad headaches.

At home I got two dogs, boxers, and I got [5 siblings], and my mom and dad. My house ok. Most parents don't let kids go outside every day because they be fighting. In my neighborhood they shoot people. My mom tell me to get under the bed when they shooting outside...


I feel happy when I get things right at school, like my spelling test. Right now my grades bad because everybody keeps picking on me... This kid, B, he be pushing me, and we hit each other.

I got bit in my face. He run away and I get punished. Then I have to stay home, do chores, my mom get mad at me. I tell my teacher [about kids picking on me] but she don't do nothing about it.

I know a kid brought a gun to school. He said he was going to shoot us One girl, she bad, she tripped this dude in the class and kicked him in the shoulder. He was leaking blood.

I don't know what [ADHD] is but I know we talked to the doctors about how my grades are and what I was doing in class. Like, do you riff or stuff like that. [It makes me sad] that I can't learn nothing and I forget stuff. My mom took me to the doctor to help my act get better. I want to act, like good and get good grades.

In the VOICES study, it was clear that children who came from socially disadvantaged backgrounds faced a unique set of challenges. Diagnosed children from such backgrounds were behaviorally similar to other diagnosed children in the study on standardized measures. However, appropriate treatments for such children need to do much more than focus on individual child behaviors. Children like Toby are unlikely to benefit in the long term if the only interventions offered are drugs.

At the same time, 'quick fix' drug treatment of poor children is just one piece of a larger ethical problem. US studies have suggested that poor children are more likely to be over- and under-diagnosed with ADHD; similarly, stimulant drug treatment may be over-used or under-used in this group of children. The ethical challenge, therefore, is to ensure just and equitable healthcare provision for these children and their families. In some cases, this will mean providing access to care and drug treatments; in other cases it will mean protecting children from medicalization and over-use of drug treatments. 

6.2 A CHILD'S ETHNICITY MAY CONTRIBUTE TO HIS OR HER VULNERABILITY IN RELATION TO ADHD DIAGNOSIS AND TREATMENT

In the VOICES study, many African-American children reported unique attitudes toward psychiatric services and stimulant drug treatments. These attitudes ranged from highly resistant and skeptical, to resigned and passive, to strongly positive. These children also tended to experience stimulant medication as more powerful than other children we interviewed. Medication could have powerfully good effects, but more often, children reported severe side effects; including headaches, burning eyes and bad stomach pains. These symptoms could be part of an active resistance to medication.

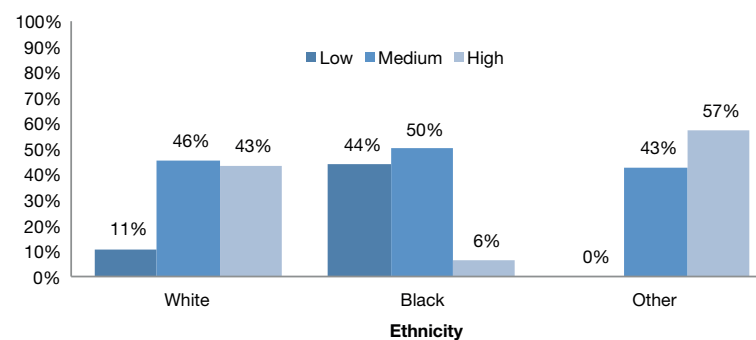
The problem [with stimulant medication] is I can't see... They say I should took it, but it doesn't work... My eyes hurt. It's strong medicine... I don't like it. I don't like it.

Vincent, US, age 11




African-American children may be more vulnerable not only because of ethnicity factors but also because these children are more likely to be socially disadvantaged. As Graph 6 shows, African-American children in the VOICES study were more likely than White children to come from socially disadvantaged backgrounds.


Graph 6: US Socio-economic status by ethnicity (n=69)



In the US, White and Black kids show different distributions in relation to SES: among White kids, only 10.9 per cent are low class while among Black kids this number increases to 43.8 per cent. The opposite can be observed for the proportions in high class. (US $p < .01$).

One way to understand these children's experiences with stimulants is to consider them in an historical context. The history of mental illness diagnosis and psychiatric drug treatment in the African-American population is fraught with medically unethical behavior. For example, during the US civil rights movement in the 1960s, threats against authority by African-American activists were sometimes interpreted as evidence of psychiatric disorder, leading to the institutionalization of some activists in mental hospitals. 

Due to the relatively small number of African-American children in the VOICES study, the observations we make here must be seen as preliminary, subject to further research.

African-American families have reason to be skeptical and concerned about psychiatric drugs as powerful political interventions. It is possible that children's reactions to ADHD diagnosis and stimulant drug treatment embody this difficult history. Families' current and historical experiences are likely to impact access to mental health services, as well as experience and compliance with treatments. 

The case of African-American children is illustrative of the more general need for particular attention by medical professionals to the ethics of ADHD diagnosis and stimulant drug treatment among children from socially disadvantaged backgrounds and from ethnic minority backgrounds.

Ethical diagnosis should include clinical attention to the social factors that may be causing a child to exhibit problematic behavior at school and at home. ADHD diagnosis and stimulant drug treatments should not be used as a quick fix for socially situated problems. Nor should a psychiatric diagnosis be a reason to avoid making needed improvements in a child's social and educational settings. Ethical diagnosis must also acknowledge and address families' attitudes to psychiatric services and treatments, and manage these attitudes respectfully and thoughtfully.

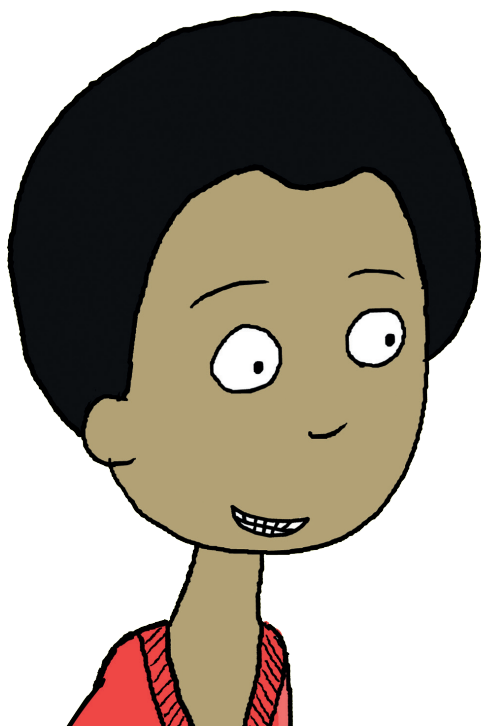
It is important to remember that ADHD behaviors are not wholly caused by an individual, biological problem, but are mediated by a child's social environment. **Therefore attention to a child's social settings and the family's social history is a critical dimension of sound ADHD treatment.**

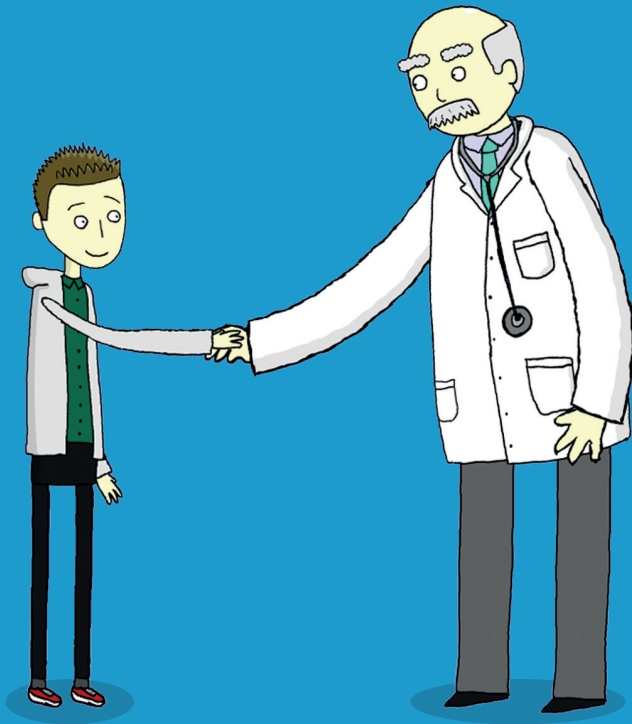
6.3 DOCTORS AS A SOURCE OF ETHICAL VULNERABILITY

Children in the VOICES study reported that they had little meaningful contact with their doctors. After the initial evaluation, clinic visits tended to focus on side-effect checks during which children were weighed and measured. Most children were not asked any questions, nor did they volunteer any questions during these visits.

I've only just started going to the ADHD clinic, but I haven't actually been to it properly, like, I've seen the doctor and he's talked about [ADHD] and I get weighed.. But ... they don't, they'll just say like, parts of what it is but then, like, they'll stop, so they will only say some of it and then, like change the subject.

Roger, UK, age 13





Interviewer: What does the medication do? Why are you taking it?

I don't know. To make me be good.

Interviewer: Do you want to keep taking it... Why?

Cos the doctor told me to.

Interviewer: Do you like your doctor?

I don't know who is my doctor.

Sebastian, US, age 10

Lack of teacher training provision about ADHD management in the classroom may be one reason why children reported neutral or negative experiences with teachers. Child mental health training provision for teachers differs between the US and the UK, and it differs by geographic area within the two countries.

Given the ethical concerns that arise from ADHD diagnosis and stimulant drug treatment, it is imperative that children are able to openly discuss the value of diagnosis and different treatments with a trusted professional. Children need to be able to protest the standards of behavior and performance demanded of them in a given ecological niche. And, children should be able to discuss and challenge the reasons for stimulant drug treatments.

As gatekeepers to stimulant drug treatments, medical professionals should provide children with opportunities to participate in healthcare decisions in age appropriate ways. A pharmacological treatment approach can include this kind of broader therapeutic orientation to the patient, where the point is to identify and manage the problems a child is experiencing, rather than just to diagnose and treat symptoms. Such an orientation acknowledges the child (and the medical professional) as actors in a social world that gives moral weight to children's cognitive and behavioral capacities.

6.4 TEACHERS AND SCHOOLING AS A SOURCE OF ETHICAL VULNERABILITY

An informed teacher and a supportive school environment make a world of difference to children with ADHD, and to their parents. In too many cases, children did not find teachers particularly helpful in managing their ADHD.

Performance niche children were less likely to know whether or not teachers had been told that they had ADHD. Perhaps in part because of the emphasis on keeping their diagnosis a secret, few children reported having meetings with teachers to discuss strategies to help them settle and learn in the classroom. Although the expectations of these children were high, they were not invited to be active collaborators in their education.

Conduct niche children found teachers to be largely uninformed about ADHD. Children frequently reported appealing to teachers to help them in bullying situations, but teachers seemed unable or unwilling to intervene.

What should I do? I shouldn't retaliate. I should go to my teachers and I go to the Headmistress and the other teachers I've had, to help get me calmed down and ask them to make him [boy who is bullying her] leave me alone. And I've been doing that but he hasn't been told; they haven't told him and he hasn't stopped.


Charlotte, UK, age 11

As we discussed in the personal responsibility section (5.3), in some cases, teachers may be contributing to the

I'll go and tell a teacher but the teacher says, 'You keep telling us and it's getting annoying.' So there's nothing really very much we can do. So it really just leaves us to sort it out. and then it just sorts it out over a fight.

Ned, UK, age 12


stigma surrounding ADHD. Children and parents reported that teachers would let children known to have an ADHD diagnosis off easily after aggressive altercations, allowing ADHD to be an excuse for bad behavior. Teachers would also tell undiagnosed children to stay away from a child with ADHD, in order not to incite the child to fight.

In general, children reported the most positive outcomes when teachers introduced creative techniques to help them keep track of time during tasks, manage their restless limbs and excess energies, and ensure their self-esteem and confidence in learning. In US primary schools, many children experienced the 'red light classroom management system,' which they thought worked quite well.  Most children we interviewed were eager to behave well and to do better. They need to be expertly guided, managed and encouraged along the way.




WHAT TEACHERS CAN DO TO ENCOURAGE CHILDREN WITH ADHD*

- Include the child in discussions about appropriate educational strategy for the child. What can they tell you is already working for them, or that they'd like to try?
- Allow children with ADHD to have a 'fiddle toy' in the classroom – something like a stress ball. Explain the rules of how this is to be used to the child or whole class.
- Use non-punishing 'time out' strategies that children can control. Put a toy on your desk that a child can retrieve, signaling that he or she needs to go to a 'bean bag' or reading corner for a five minute break.
- Keep an even temper and tone with children.
- Praise: Give an ADHD child a task they are responsible for every day. For example, a child might take the register back to the main office, or hand out worksheets. This gives you an opportunity to make eye contact and thank that child for doing a good job.

*For more examples see  .

6.5 GENDER AND ADD SUBTYPE AS SOURCES OF ETHICAL VULNERABILITY

6.5.A The ADD subtype

ADHD tends to be thought of as a 'boy's disorder' and some of the debate revolves around concerns that ADHD medicalizes boyhood or normal boy behavior. In the VOICES study, 28.5 per cent of children interviewed were girls. We were unable to interview as many girls in the UK as in the US, simply because it was more difficult to find UK girls diagnosed with ADHD. One study found that while 3.62 per cent of UK boys meet criteria for ADHD diagnosis, only 0.85 per cent of UK girls meet criteria. 

A further gender dynamic in ADHD diagnosis is the difference between ADHD and ADD

(Attention Deficit Disorder without the hyperactivity component). Children with ADD are easily distracted and have difficulty paying attention; they daydream when they should be working, and they may also be more anxious than other children. Of the diagnosed children in the VOICES study, 41 per cent of girls were diagnosed with ADD, as compared to 20 per cent of boys.

In the UK and in Europe generally, the ADD subtype is little recognized. No UK children in the VOICES study had a diagnosis of ADD. We hypothesize that this is due, in part, to the dominance of the performance niche in the US. Generally, children with ADD don't cause any trouble, so they are less likely to be noticed in a conduct niche. However, ADD symptoms can undermine school performance and achievement, so these are more likely to be noticed in a performance niche.

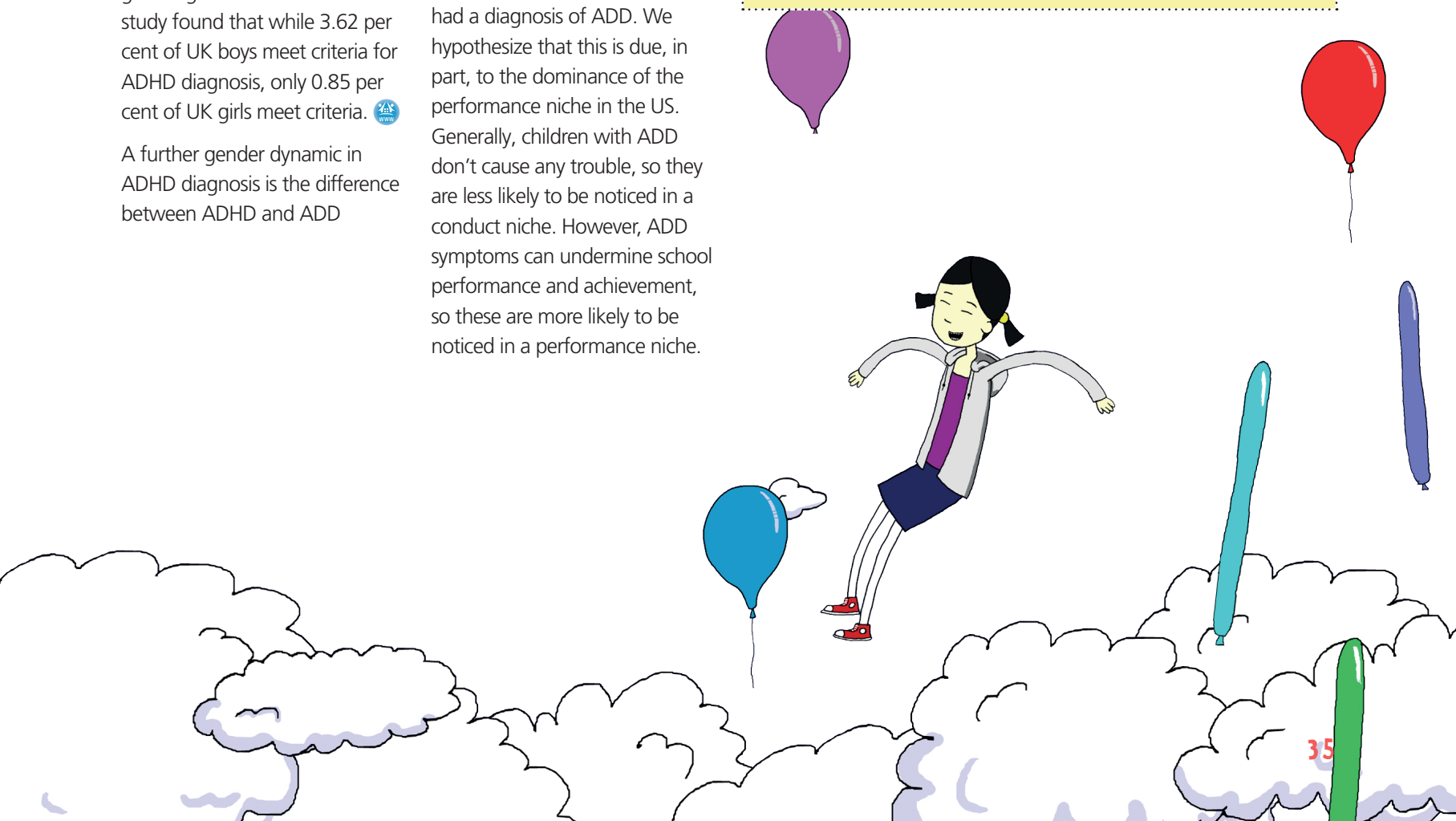
ADHD SUBTYPES:

Attention-Deficit/Hyperactivity Disorder Predominantly Inattentive Type: This subtype is used if six (or more) symptoms of inattention (but fewer than six symptoms of hyperactivity-impulsivity) have persisted for at least six months.

Attention-Deficit/Hyperactivity Disorder Predominantly Hyperactive-Impulsive Type: This subtype should be used if six (or more) symptoms of hyperactivity-impulsivity (but fewer than six of inattention) have persisted for at least six months.

Attention-Deficit/Hyperactivity Disorder Combined Type: This subtype should be used if six (or more) symptoms of inattention and six (or more) symptoms of hyperactivity-impulsivity have persisted for at least six months.

DSM-IV



6.5.B La-La Land: An imaginary space

US girls (and some boys) diagnosed with ADD frequently described a common behavior – daydreaming – using the same descriptive phrase: ‘going to La-La Land.’ Because so many children referred to an imaginary space, we were interested in what La-La Land was like. In response to our questions, children drew pictures and gave verbal descriptions.

Some readers may wonder if La-La Land was an escape from the harsh realities of school or home for these children. We did hear from some children – both with and without diagnoses – that noisy, aggressive or poorly controlled classrooms were upsetting. These children sometimes used day dreaming to escape the noise and confusion.

[In this place] I get to draw, paint, do whatever I want. And I also get to buy my own dog...I call it La-la Land. I always have a bathing suit on there and I never have to take my bathing suit off... [A]ny person can go into it, except bad people. And bugs, they can't go in; only the good people... And I always have rocking music going on... [In La-la Land] I feel like a rock star.

Sasha, US, age 10

Children described La-La Land as filled with color, light, nature, animals and music. It was a creative, restful and joyful place to be: a parallel universe into which children slipped when they should have been doing something more mundane, like school work.



Sharon, age 10



Sasha, age 10

What's wrong with La-La Land? First, children diagnosed with ADD frequently described finding it very difficult to decide when to enter and when to exit this place.


You can't stop [daydreaming], because you don't, you don't know what you're doing, and ...you're not paying attention, you don't know that you're doing it, really... It just happens without your control...

Camilla, US age 9

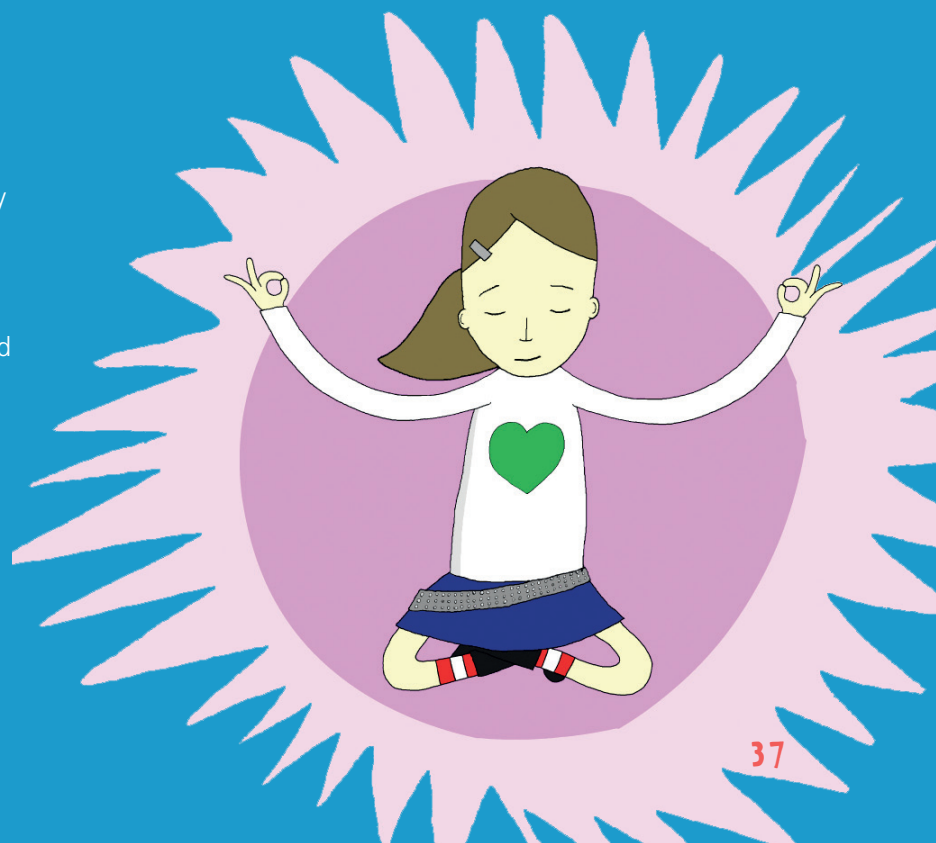
This led to the second distressing aspect: Children found that there were negative consequences for being in La-La Land: incomplete work or tests, a disorganized and messy room, repeatedly lost and forgotten items. A third consequence for some girls was that spending time in an imaginary space reduced their opportunities and desire for socializing, and led to feelings of social isolation.

Yeah, it's hard to leave [imaginary space] but it's also kind of hard to be there, you know, because it's really no fun to like, wake up and realize that you've got no idea what's going on in the class, or what the teacher's been saying...

Flora, US, age 11


La-La Land presents an opportunity for reflection on values, and how best to support a child's happiness and well-being, as well as different learning styles. These learning styles may have a gendered component.  We think it is important to acknowledge the intrinsic value to children of having a space where creativity and the imagination can joyfully flourish. The value of this space needs to be weighed against the level of distress and general dysfunction the child's distracted behaviors are causing.

If, on balance, treatment seems necessary, then parents, clinicians and teachers should still try to respect the value of this imaginary space. Encourage activities that allow children to use their creativity and indulge their imagination, whether through drawing, film making, music and reading; or through walking, gardening and indeed, day dreaming.



SECTION 7:

WHAT HELPS

There are many good resources on ADHD that outline strategies to manage and encourage a child with behavioral difficulties.  In this section, we make some specific suggestions about how to empower children with an ADHD diagnosis in their moral development. We focus on three concerns voiced by children with ADHD, and we give concise, practical suggestions on which parents, teachers, medical professionals and children can act, ideally working together *as a team*.

CHILDREN'S CONCERNS

1. I want to be able to think before I act
2. There's no one to talk to about ADHD
3. Will I be able to stop taking medication one day?



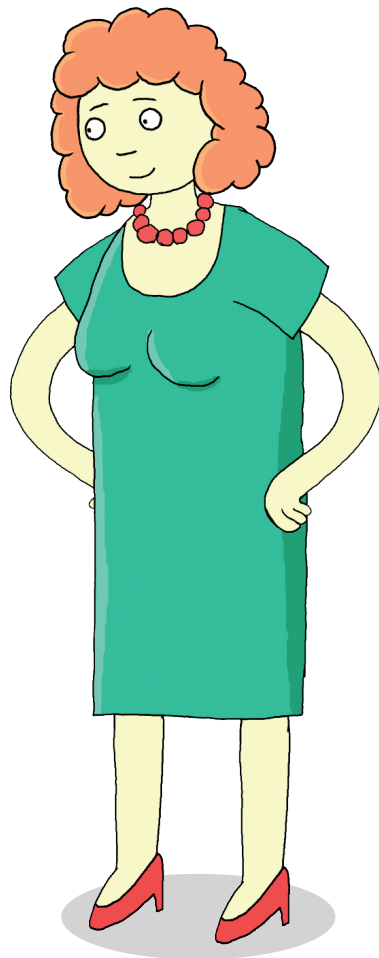
7.1 I WANT TO BE ABLE TO THINK BEFORE I ACT

WHAT YOU CAN DO TO HELP

- Enable children to 'stop and think' before they act. Medication can help with this, but behavioral reinforcement will make this ability stick.
- Children's caregivers should note children's efforts and congratulate them both for the effort and for successes.
- Acknowledge the tension between knowing what the right thing is to do, but wanting to do the wrong thing. If a child can verbalize this tension, celebrate their insight with them! Part of the point of 'stopping and thinking' is to feel that tension and figure out what to do about it.
- During the course of the day, help a child to slow down, and to make that space to stop and think. See the

strategies children propose in the box to the right.

- Use the VOICES animations to discuss the importance of the 'stop and think' space with children.



STRATEGIES TO HELP A CHILD SLOW DOWN TO STOP AND THINK

- Friends can be a huge help. Initiate a buddy system whereby a friend taps a child on the shoulder when he or she is getting unfocused or distracted, or wound up and hyperactive.
- Agree a silent but clear signal with a child that means: 'Slow down. Stop and think!' Make sure you also agree a signal back from the child that means: 'I understand. I will try.'
- Easy but effective: Teach a child to count to ten when in sticky situations.
- Martial arts, yoga, and fencing all teach children to become more aware of the link between mind and body, to slow down their thoughts and to control their movements.

7.2 THERE'S NO ONE TO TALK TO ABOUT ADHD

WHAT YOU CAN DO TO HELP

- Medical professionals – doctors, nurses, psychologists or counselors – should be seen as, and see themselves as, a key resource for children who have questions about their diagnosis and treatment. Every visit to a medical professional should include active engagement and listening between a child and a medical professional.
- Be sure that children know what their diagnosis is. Explain it to them, and then ask them to explain it back to you. Also explain their treatments to them.
- Be sure that all members of the team (parent/ carer, teacher and doctor) are knowledgeable about ADHD and are 'on the same page' when they explain to a child what ADHD is.
- Encourage children to see ADHD as a challenge. They can do a lot to help themselves to manage their behavior with appropriate support.
- Don't keep ADHD a secret. Encourage children to talk to their friends about ADHD. The initial discussion can take place with support from adults, if this is appropriate.

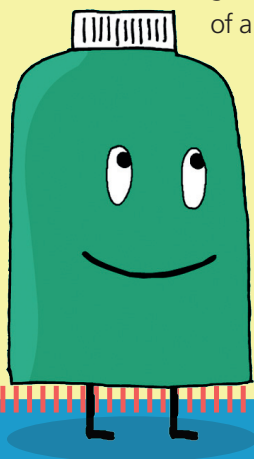
If children feel comfortable, they can view the ADHD and Me animations together with friends.

- Encourage children to discuss niche values around performance and conduct, and be open to their protest against these values.
- Medical professionals, teachers and parents should view the ADHD and Me animations to further understand what children say on the subject.
- Parents and children should view the ADHD and Me animations together.



VIEWING 'ADHD AND ME' WITH A CHILD

- **DO** remember that there are no right or wrong responses to the animations. Remember to laugh!
- **DO** ask questions that invite the child to help you understand the animation; eg, "I wonder why the boy in the car turned into a wolf? I'm not sure I really understood that part. Did you?"
- **DO** ask questions that invite the child to be an expert on their condition, like the children in the animations; eg, "The child in that video feels like he's a kettle that's going to explode. That can't be a nice feeling. Is that how ADHD feels to you?"
- **DO** encourage the child to try different modes of engagement with the animations: eg, drawing, writing, making videos. It doesn't all have to be talk.
- **DO** think of the dialogue with a child as a conversation that goes on for weeks or even months, instead of a one-time thing. Be patient, and stay curious about the child's reactions.



- **DO** correct children when they say something that is wrong.
- **DO** admit if you don't know the answer to a child's question.

- **DON'T** just ask a child: "What did you think?" You're bound to get a one-word answer.
- **DON'T** ask "testing" questions; eg, "Do you remember what the girl said about what it's like to have ADHD?"
- **DON'T** be put off if a child initially makes apparently irrelevant comments; for example about a character's appearance or the sound of his voice; eg, "I didn't like his hair."
- **DON'T** try to discuss all the ideas in the animations with the child at once. This could be overwhelming for the child.



7.3 WILL I BE ABLE TO STOP TAKING MEDICATION ONE DAY?

WHAT YOU CAN DO TO HELP

Some adults start to worry when a child asks this question: Is the child going to start rebelling against medication? Does he hate being on medication? Am I a bad parent for putting my child on medication?

The VOICES study suggests that the child is saying: **Eventually I want to be able to control my behavior myself.** This is an important desire. It should be encouraged in children because it fosters personal responsibility for behavior and independence.

There is a lot that the team of parent/carers, teacher and doctor can do to introduce strategies that help a child better manage his or her own behavior:

- Encourage a child's motivation by engaging them in discussions about what helps them to manage their own behavior. Do some experiments with different behavioral strategies mentioned by them, or by us and by others. The important thing is to consistently integrate these strategies into the child's day to see if they work over time. After a few months it will be possible to see if strategies are working.

- Parents, teachers, and the child should keep consistent notes on any strategies that are tried. If behavioral strategies appear to be successful, schedule a meeting with the child's doctor to discuss how to proceed.
- The team may agree to try some structured time off medication. Children found this most helpful when there was a brief period off medication (a day or two), followed by a period on medication. This allowed them to get a good sense of how medication did, or didn't, help them during the day. Notes should be kept by parents, teachers and the child about the experience, to discuss with the doctor.
- In the VOICES study, these experiments were a way for older children to feel more in control of their medication. It gave them a sense of responsibility and maturity and engaged them in the medical decision-making process. In some cases, it helped them have a better understanding of the effectiveness of medication.
- The use of medication appears to help some children learn behavior management strategies. Some children in the study reported that with time and maturity, they were able to come off medication and maintain good control over their behavior.

CASE STUDY: MANAGING MY ADHD

Sven is an 11 year old boy who lives in a middle-class suburb of a major UK city with his mum, dad and twin baby brothers. His mother works from home and his father is an engineer. Sven has been on short-acting Ritalin for three years.

When I'm at school... sometimes I get angry, like really angry for no reason. I'm writing and then I feel really angry, so I need to like get all my anger out... When I'm not concentrating, it's like so annoying because you want to focus, but um, you keep thinking of something [else]. [Y]ou sort of get angry and so then your body like gets all, um, tight, then you like, so that sometimes you can't control your own body.

I've been really good at school and I thought the tablets, they would last for like absolutely ages, but my um, doctor, he told me that they only last for like four hours, so then when I heard that I was like, I've been good [for longer] than that! I couldn't believe it. I was shocked! I think um, ah, well because the tablets, because I'm so used to being good now, [the tablets] have, they made me sort of, sort of made me cope... The tablets have done their job but I think partly it's me as well, trying to be determined... It's not all about the tablets. Tablets will just help me to get settled, so I think it's just me all the way by just working hard.

I told, um, my doctor and he said, 'Well, if you, if you're getting better, um, I would, I can see about taking you off the tablets.'

In the future, I want to be, well ah, I don't really know yet but hopefully something that gets paid well! ... I feel, I feel determined to be the best boy I can be because I don't want to be a bad kid.

Any changes in stimulant medication doses should first be discussed with the child's doctor.

SECTION 8:

CONCLUSION

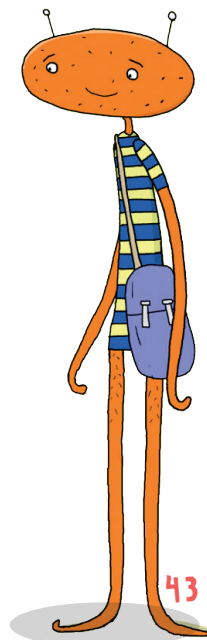
The VOICES report and the ADHD and Me animations should have inspired you to think differently about ADHD, stimulant drug treatments, and children with behavioral difficulties. We hope we have also given you some strategies that translate the lessons of the VOICES study into action.

WE LEAVE YOU WITH OUR TAKE-HOME MESSAGES:

- Children should be seen as developing moral agents who aspire to make good decisions, to be in control of their

behavior, and to take personal responsibility for their behavior.


- Stimulant medication does not compromise children's moral development; in fact it can support children's capacity for moral decision-making.



- Ethical solutions to children's behavioral difficulties address the biological and the social dimensions of these difficulties. No child should be diagnosed and medicated because it is cheaper or more convenient than providing adequate social or educational resources.
- An ethical treatment approach to ADHD supports the child as a team member with a voice in the process of medical decision-making. This process should openly acknowledge local values and expectations

of children's behavior, achievement and performance.

We have given readers a lot to think about and we look forward to hearing your reactions. Feel free to contact us through our website:

 www.adhdvoices.com,

or email us at contact@adhdvoices.com. Please do encourage children to do so as well. We'd love to hear their thoughts on the ADHD and Me animations.

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The Brothers McLeod

Ric, Alessa and Liana Lewis

Artwork: The Brothers McLeod, Alessa Lewis & Liana Lewis, and the children who participated in the VOICES study

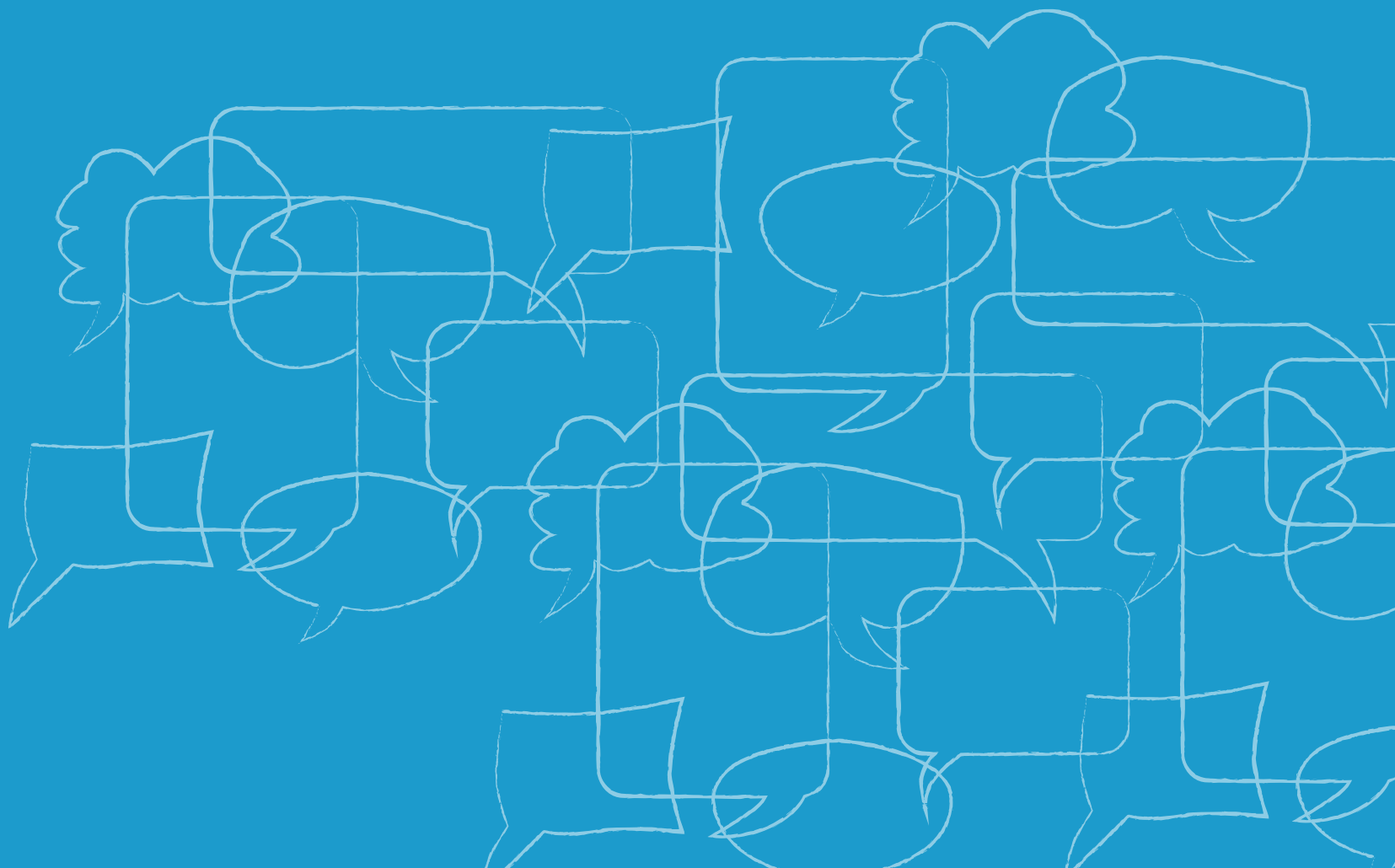
Design: LSE Design Unit (lse.ac.uk/designunit)

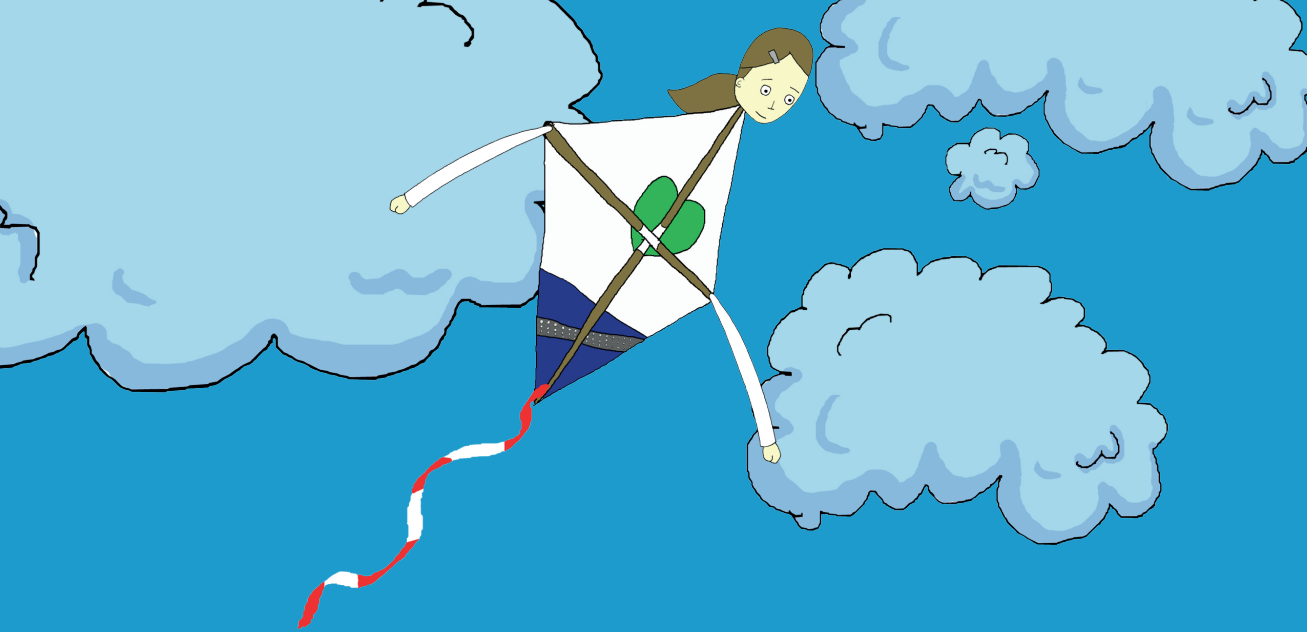




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The VOICES study investigated children's experiences with ADHD diagnosis and stimulant drug treatments. A primary aim of the study was to understand whether children's perspectives and experiences support claims about the ethical harms of stimulant medication. We interviewed 151 children, ages 9-14, in the US and the UK. Three groups of children were interviewed: children who were taking stimulants for a diagnosis of ADHD; children who had a diagnosis of ADHD but were unmedicated; and children without a psychiatric diagnosis.

With additional support from

BIOS

STICERD

Suntory and Toyota International Centres
for Economics and Related Disciplines



The VOICES report brings the perspectives and experiences of children into international debates around rising child psychiatric diagnoses and the increasing use of drugs in child psychiatry. These voices contribute to an empirical evidence base that helps to inform ethical debate, clinical judgment, and national policy.



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