

Nobody Understands My ADHD: Exploring the Irish Experience of Diagnosis and Treatment

Dr Kate Carr-Fanning, Ph.D.

Lecturer/Course Director in Childhood and Youth Studies, **Coventry University**

Board Member, **HADD Ireland**

Board Member, **ADHD Europe**



**HADD
Ireland**



Overview

- Background – Understanding Voice
- Research Methods
- Research Findings

Understanding “Voice”

Voice within Research and Practice

- Move away from research and practice “on” or “about” ... shift to working “with” parents and Children and Young People (C/YP)
- Expert patient model of practice
- UNCRC (1989), UNCRPD (2003), Children’s Bill (2013)
- Synonyms = “respect” and “partnership”
- A route to empowerment

Nothing about us, without us!

Research Methods

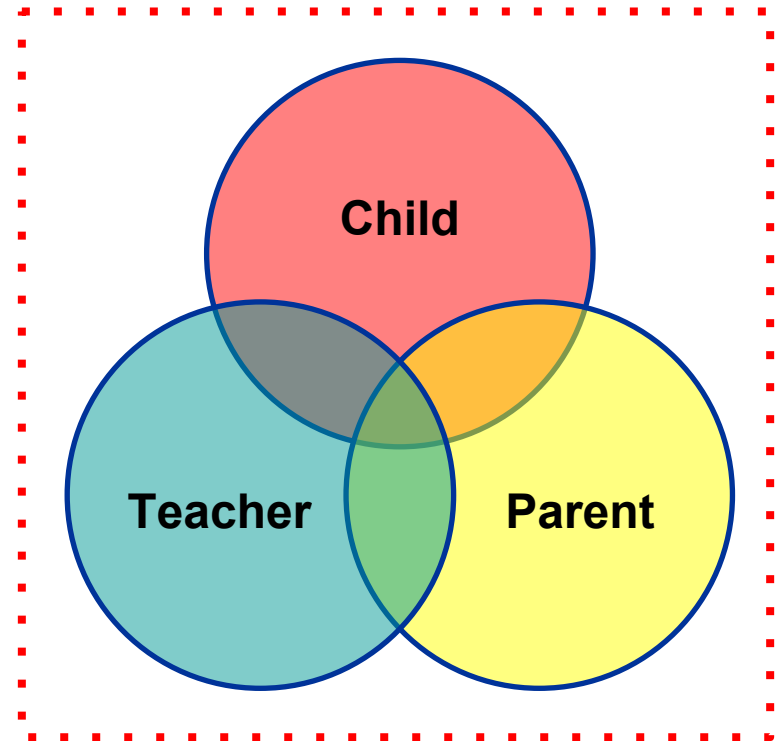
Multiple Qualitative Case Study

Single Case:

- Semi-structured interviews (student, teacher, and parent).
- Visual methodologies.
- Other evidence-based sources.

Data Analysis:

- Thematic Analysis (Braun & Clark, 2006).



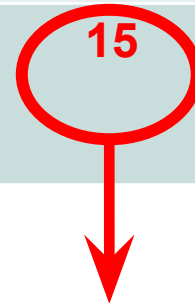


Completed Visual Tasks



Sample

	Schools		Teachers	Students with ADHD		Parent
	Stage	N		Age	N	
Primary (P)		6	4	7-12 yrs	6 (1f)	7
Post-Primary (PP)	Junior	5	6	12-15 yrs	5 (1f)	6
	Senior	4	2	16-17 yrs	4 (4f)	4
Total		15	12	7-17 yrs ($x=12.8$; S.D. = 3.085).	15	17



9 Males & 6 Females.

Research Findings . . .

But first, a question . . .

Are we **Empowering** or
Disempowering parents, children,
and young people affected by
ADHD ???

Understanding the Journey to and through Diagnosis . . .

“Looking back now the poor child she’d no one looking after her”

“... I had [ADHD] when I was six and then we went to another person ... and she was like no no she’s just emotionally has an emotional disorder. I duno what that means she said it was my emotions or something ... When I got into secondary school, they were like she can’t add she can’t subtract ... I can’t do anything like what ...”

Mam was like I knew ... schools just said that I was lazy ... So then I got to this lady for Dyscalculia ... thing to do with ADHD, and she was like she has ADHD ...” (female 16 years).

“... the first time there would ever have been a question mark about behaviour ... he started school ... But she never ever said to me like about going to a psychologist or getting an assessment ... I knew what to do ... I thought he was ... And he was ... He was ... then I went to my doctor ... [and] he was going ‘maybe you need to be more strict’ ...” (mother, son 10 years).

**“Wait to fail approach”
(Vaughn & Fuchs 2003).**

Barriers to Diagnosis

“ . . . the amount of children that are being diagnosed now under very loose I mean it's somebody's opinion it's not a blood test it's not a medical report so very much it has to be influenced by the child's own environment . . . ”
(secondary school teacher)

Schools
(Label avoidance)

“ . . . it took almost two years of linking in with the services the HSE and with CAMHS who are an absolute disaster . . . I was told with CAMHS would deal with the ADHD and CAMHS had a waiting list of two years . . . [when] we got an appointment with CAMHS . . . [the psychiatrist] went on to tell me that he believed that there was an attachment disorder and . . . it wasn't ADHD . . . So then we were moved from CAMHS back into services . . . ”

Services
(Misdiagnosis, lack of coordination, and waiting lists)

“Labels are like signposts”

“... It's just like signposts ... labels are like signposts ... Life is like a map and these are just the signposts about who you are and where you are, should be going ... If you don't know then that's bad ...” (mother, son 15 years).

“... I was delighted to get a diagnosis ... because I couldn't understand what was wrong with my son ... I just threw myself into it tried to find out everything ... the empowerment of understanding the condition ... you start to see your child in a completely different light. Instead

“... [I want] tea understand more w is ... [and that] it's concentrate and thing because I don't think they know ...” (female 17 years).

Access to Empowerment

is ALWAYS that their out. And my bashing them up ... you start to see why ... You start to understand ... you start do things differently ...” (mother, son 10 years).

Understanding the Treatment Experience . . .

Medication – Parent Reports

“ . . . There’s always concern about taking the medication that’s another thing people would say ‘oh don’t put your daughter on medication she might get addicted to it’ which is an awful concern. But then if you don’t I really think they mightn’t get an education . . . ” (mother, daughter 13 years).

Initial aversion and/or ongoing conflicting emotions.

Medication for overt behavioural and socio-emotional regulation.

“ . . . with the meds he can kinda control it more . . . it’s been like night and day’ and . . . the difference in him emotional wise . . . I just notice a difference he’s not as fiery now . . . ” (mother, son 7 years).

Medication – C/YP Reports

Medication for study and concentration.

“... you can't really concentrate for long periods of time or you can't really study really hard things without medicine am you get distracted really easily ... it's really annoying at times ... I only take them when I have to study ... hopefully I won't need them next year ...” (female 17 years).

“agitated ... anxious ... I just didn't feel like me ... quieter ...” (female 17 years).

Side effects

Medication

We may not fully appreciate the experience of medication

“ . . . so there last year we decided to take him off his tablets and he was off them for a few months and fine fine no problems with the school or the work or anything . . . he came saying ‘Mammy if I gave you my pocket money could ah I start taking my tablets again?’ And I was like aw, my god like he obviously noticed a difference in it himself . . . ”

“ . . . I feel it's makes more more quieter so I'd always be sure not to take them when I'm going out . . . my friends notice they say I'm less chatty and stuff . . . ” (female 17 yrs)

-Vs-

“ . . . I would get on peoples' nerves people . . . [but] when I'm on my medication I would feel different like I would actual feel quiet I'd feel like normal like other people . . . ” (famel 16yrs)

They may differ across C/YP

“Overreliance on Medication”

“... I feel he's being given the medication. But that's all. And I feel he needs something else around that and we need something else around that. And that's not very forthcoming. BUT ... I don't even know where to go looking for the help ... I'm really really struggling ...” (mother, son 15 years).

“... It was sorta the case that since I didn't want her on medication so they just cut me off ...” (mother, female 17 years).

“... I musta asked [CAMHS] loads of times for family therapy for the siblings of kids with ADHD. We never got that. Am that would have been a help in how to mind the other children whilst we're minding the child with ADHD ...” (mother, daughter 17 years).

“Powerlessness” – Parents

“ . . . there is just SO many vulnerable parents and vulnerable children and there’s so many professionals that don’t actually seem to realize that they are actually people with feeling and thoughts. It’s all this jargon and you feel helpless and they don’t do anything for you . . . there doesn’t seem to be the help and nobody seems to be able to direct you. And as a parent who doesn’t understand psychology or psychiatry or any of those things you go to those people in the faith that they’re going to help you and you hit a brick wall . . . That was a HUGE problem . . . I think there’s a huge lack of empathy with parents . . . you’re in an absolute void . . . there’s SO many kids neglected in this country because of that . . .” (mother, male 10 years)

“Powerlessness” – C/YP

“... we'd have a child who was traumatised for three days before and three days afterwards ...”
(mother, son 14yrs)

“... some of them [psychologists] are only there for three months they're not going to build a relationship with ya ... it wasn't a huge help ... she didn't get what they were saying ... the people who are face-to-face with the children with ADHD that they [need to] build a relationship ...”
(mother, daughter 17 years).

“... I HATE [the psychiatrist] she's a bitch I'm not going there anymore they don't listen ...”
(female 14 yrs)

“... I hate going ... they think they know what's best ... [just] because they're doctors they know and they don't really ... they're always like 'you should go back on the Ritalin', but I'm like I've already tried that and it doesn't work ... and you go back and you say the exact same thing but they are just not listening ...” (female 17 years).

Another Question . . .

Are we **Empowering** or
Disempowering parents, children,
and young people affected by
ADHD ???

Summary of Pathway Through Care

Disempowering referral process



Empowerment with diagnosis



Disempowering treatment journey

(esp. over reliance on medication and lack of child- and family-centric practice)

Take Home Message

- What did the parents and C/YP want?
 - ❑ Access to timely diagnosis
 - ❑ More information (accessibility)
 - ❑ Alternative treatment options and psychosocial supports
 - ❑ Better communication and relationship building

Kate Carr-Fanning:
katherine.carr-fanning@coventry.ac.uk