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NOTTINGHAM TRENT UNIVERSITY

DCP Conference 2020

Caregiver Experiences of Autistic Spectrum Disorder Assessments within a Community CAMHS Setting: An IPA Study

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Context

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- ASD in children is commonly associated with mental health problems
- Approximately 1 in 10 people accessing CAMHS would meet ASD criteria
- An ASD diagnosis can have implications for
  - Treatment approaches
  - Educational approaches
  - Welfare and support services

Context

- Local commissioning determines ASD assessment pathways
- Since NICE publication, there should be specialist provision of ASD assessment outside of CAMHS access…
- BUT even in these circumstances, there is a case to be made for in-CAMHS ASD assessments

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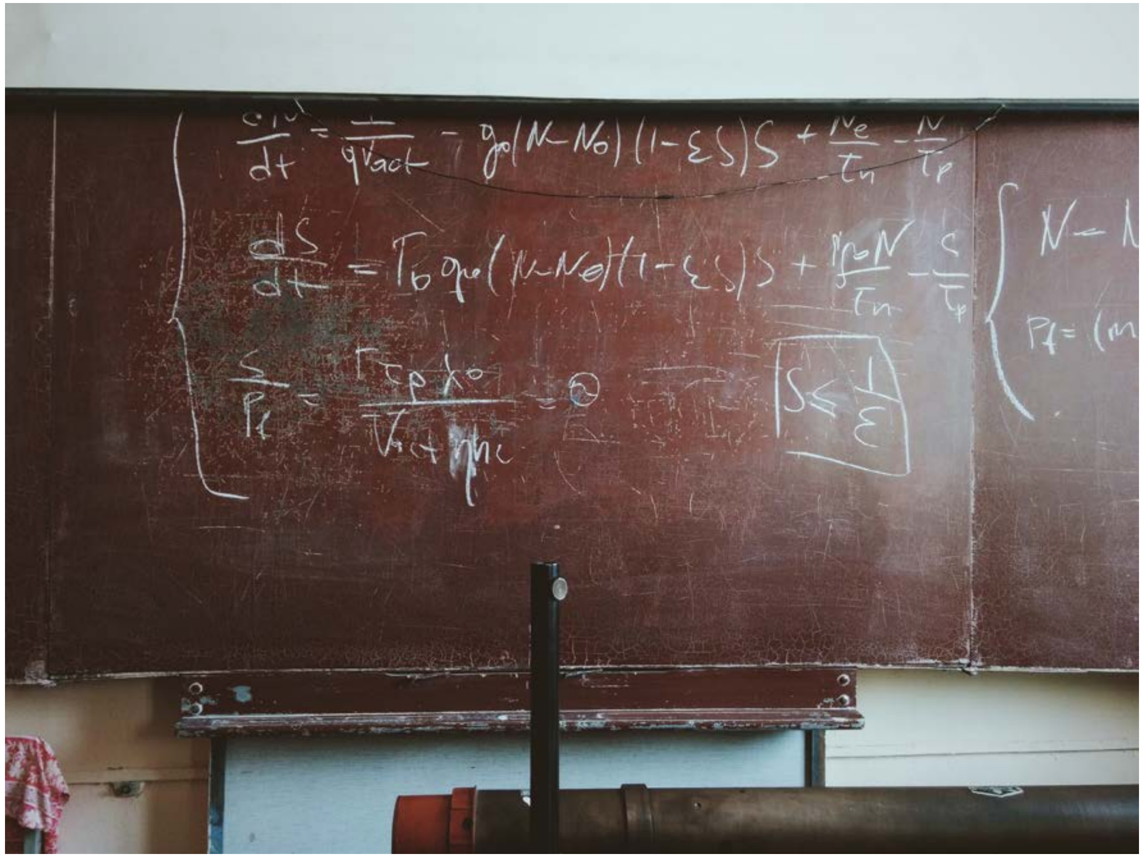
How and Why?



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- In-team referral
  - Specific clinicians who have normally undertaken specialist training in the process, such as ADI-R and ADOS
- In a formulation-driven philosophy, the assessment can fit neurodevelopmental atypicalities within the broader picture
- Qualitative evidence that it can drive sense-making and social identity development processes

Service-user and Family experiences

- Most evidence available is with non-CAMHS referrals
- General sense of dissatisfaction
- Lengthy waits
- Limited information
- All in the context of feeling pressure from other agencies to pursue diagnosis

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This study

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- Recruitment pool: All families who had completed ASD assessment within team in the last 2 years (N=35)
- 3 respondents: 2 parents, one grandparent caregiver, all female
- All had a “No Diagnosis” outcome

This study

- Semi-structured interviews
- Transcribed, and analysed using Interpretative Phenomenological Analysis
  - Detailed line-by-line coding in the process of identifying themes for each participant, brought together across all 3 participants
- Analytic structure discussed and shared between the research team

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Hurdles and Holes

- "Another hurdle to go through"
- "Dropped into a black hole"
- Post-feedback barriers

Power of the label

- School Understanding and Support Provision
- Service Engagement
- Societal Understanding and use of labels

Social Implications

- Comparison to other children
- Defining Social Identity

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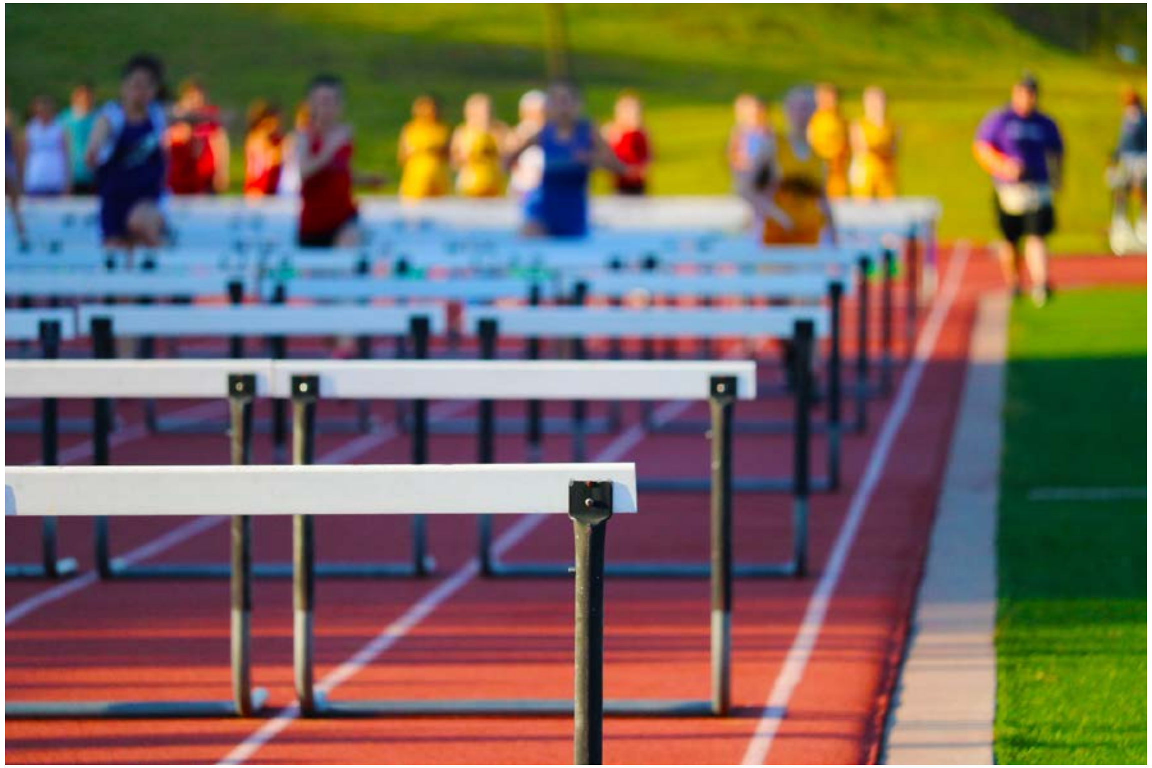
Another Hurdle to Go Through

“it’s another hurdle to go through, something else to tick off the list, I didn’t think really […] for one minute that he was gonna come out as being anywhere on the spectrum, if he was it was gonna be such a slight degree that […] there was nothing that would be able to be done for him or would affect him in any way” (Sophie; 47-51)



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Dropped into a black hole

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"until somebody says to me there's this route, that route and that route, then you don't know where to go with it, in the first [ASD] assessment there was nothing, it was like you're dropped into this black hole and well, this child is still the same, what do I do? Where do I go? What happens?"

Post-feedback Barriers

“they said basically they’ll step back to give [ASD clinic team] time to do what you needed to do, so that things didn’t get confused or whatever, but, because we did have to after we’d had the assessment and we were told the diagnosis […] I had to ring them (wider CAMHS team) and say well what are you doing now are you gonna come and see him because that’s not anything to do with it”

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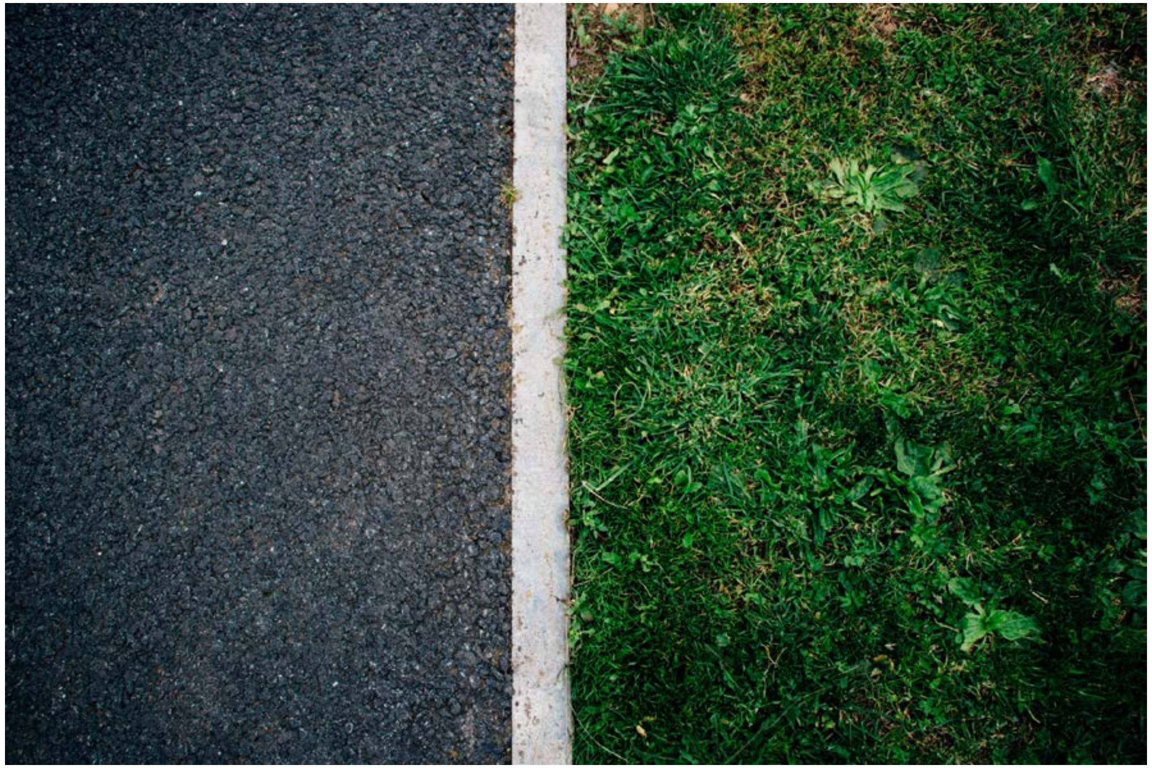
In Summary



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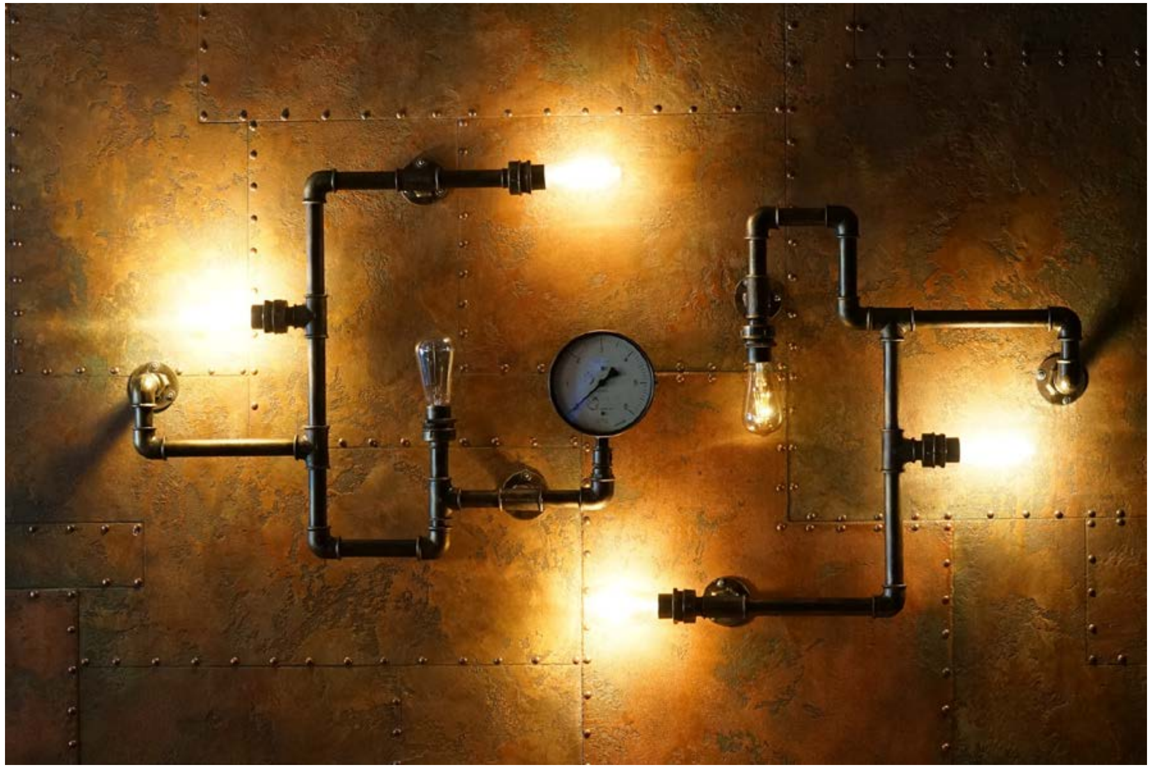
- These 3 participants felt that their treatment team had temporarily passed on their child to the assessors, rather than involving the assessors in the treatment process
- Assessment was seen as a standalone feature of service
- Does not appear to have been experienced as an integrated process of formulation

My Initial Thoughts... In Defence...

- I don’t think these accounts indicate poor clinical practice...
- Reflect on your own clinical environments, and the pressures we all face to **process** clinical work
- I think that these accounts indicate a service with pressures, passed on to clinicians, who then take opportunities for breathers



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My (speculative [but reasonable]) hypothesis

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- Clinicians in CAMHS may not be getting sufficient time for reflective considerations of young people’s circumstances
- Opportunity to access broader formulation is limited for many
- Developmental (and other) considerations are brought late in treatment, when the clinician may already feel fatigued with what to do

What are the implications of this experience?

- Modular provision of care risks losing the therapeutic value of continuous relationship with clinicians
- Reduces the possible power of clinical psychology in a CAMHS team

~~formulation-based approach~~

ticking the ASD box

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What are the implications of this experience?

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- Losing the broader benefits that could come from the involvement of a specialist formulation team
  - –Social Identity
  - –Meaning Making

What should psychologists do?

- Review your own processes
- Is the young person’s journey currently possible/likely to be experienced as modular?
- Is there capacity to create a more integrated sense of formulation in your ASD processes?
  - For colleagues
  - For young people and their families?

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Limitations

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- No young person’s voice
- All participants had a null finding from the assessment
  - How about those who were told that they DID have ASD?

Key Finding

- When families are unhappy with CAMHS ASD assessments, it might be partially about the experience of the process, not just the outcome

Key Hypothesis

- Although psychologists involved might think in terms of broader formulation, colleagues may not, and the experience of families might not reflect this

Key Implication

- ASD-assessing CAMHS should ensure that secondary assessments are seamlessly within ongoing support packages, not as a reason to pause support

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Thank you for listening!

Any Questions...?