

**How does ADHD change across the
lifespan and how do services cope?**

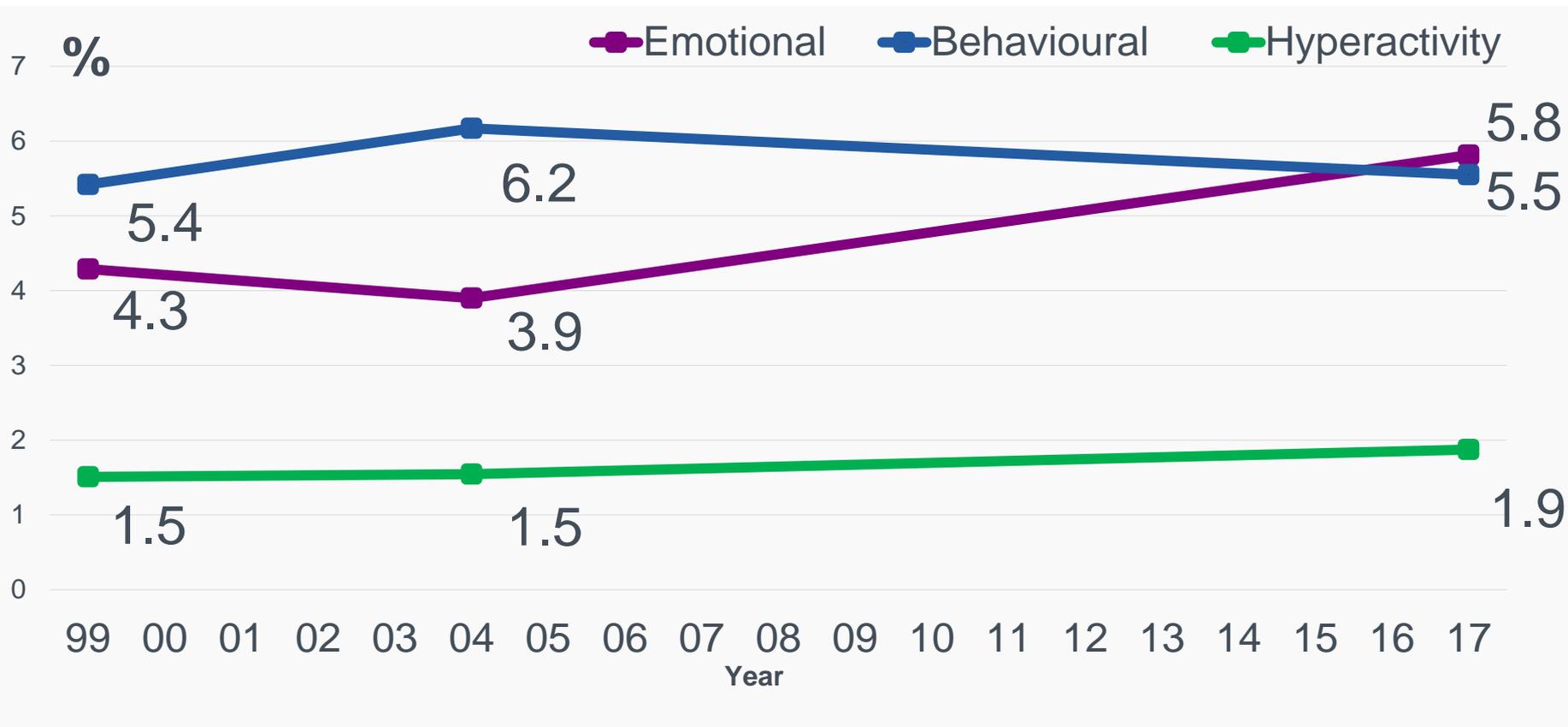
The CATCh-uS Study

Tamsin Ford

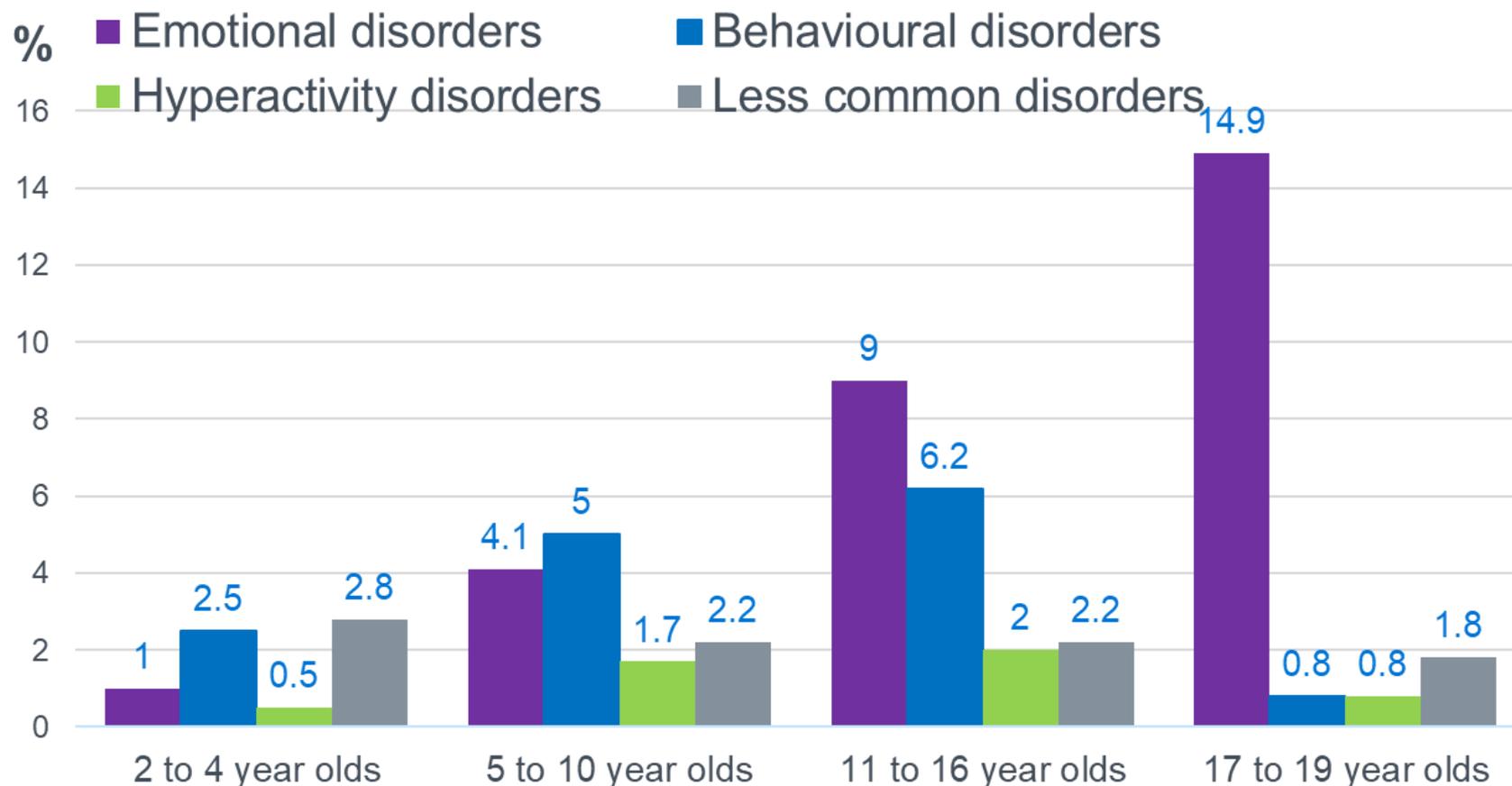
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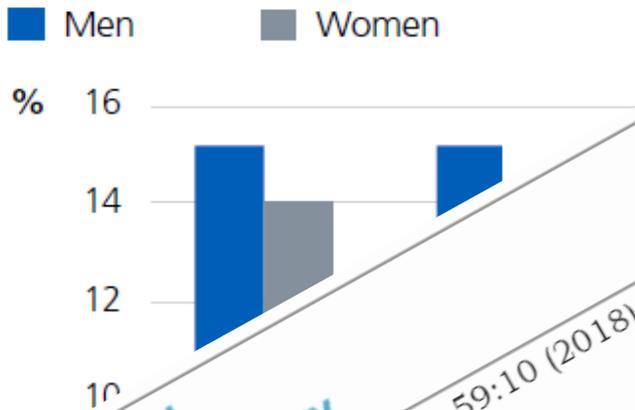
Trends in Disorders, 5-15 year olds, 1999 to 2017



Disorder types differed by age



Base: all adults



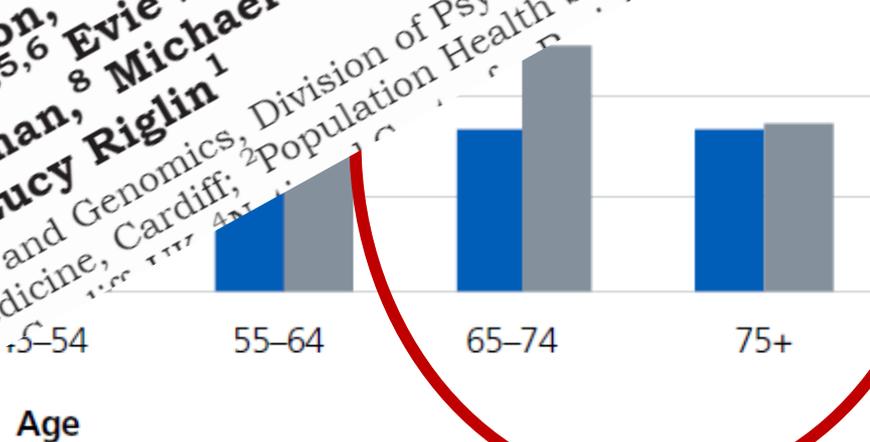
Journal of Child Psychology and Psychiatry

Journal of Child Psychology and Psychiatry 59:10 (2018), pp 1105–1113

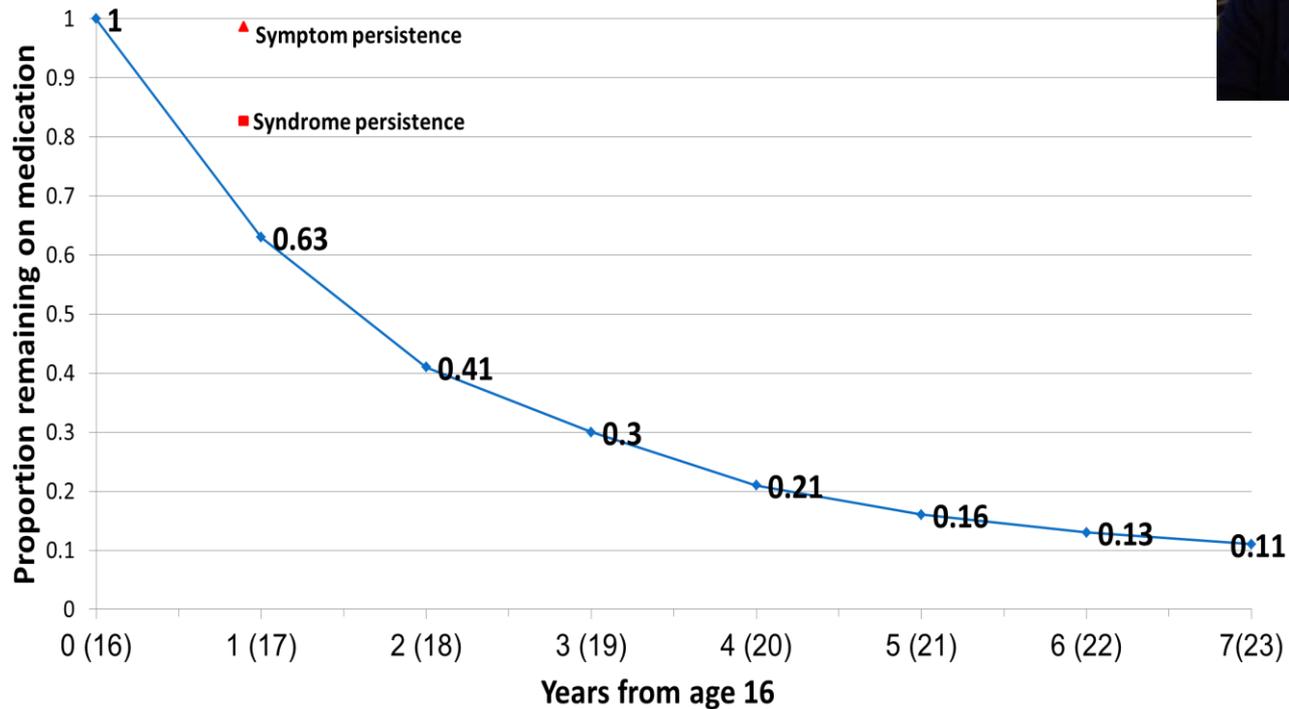
Investigating late-onset ADHD: a population cohort investigation

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Time to ADHD medication cessation from age 16 in the CPRD 2005-2013



Taken from: Newlove-Delgado *et al.* 2017 <https://doi.org/10.1007/s00787-017-1011-1>

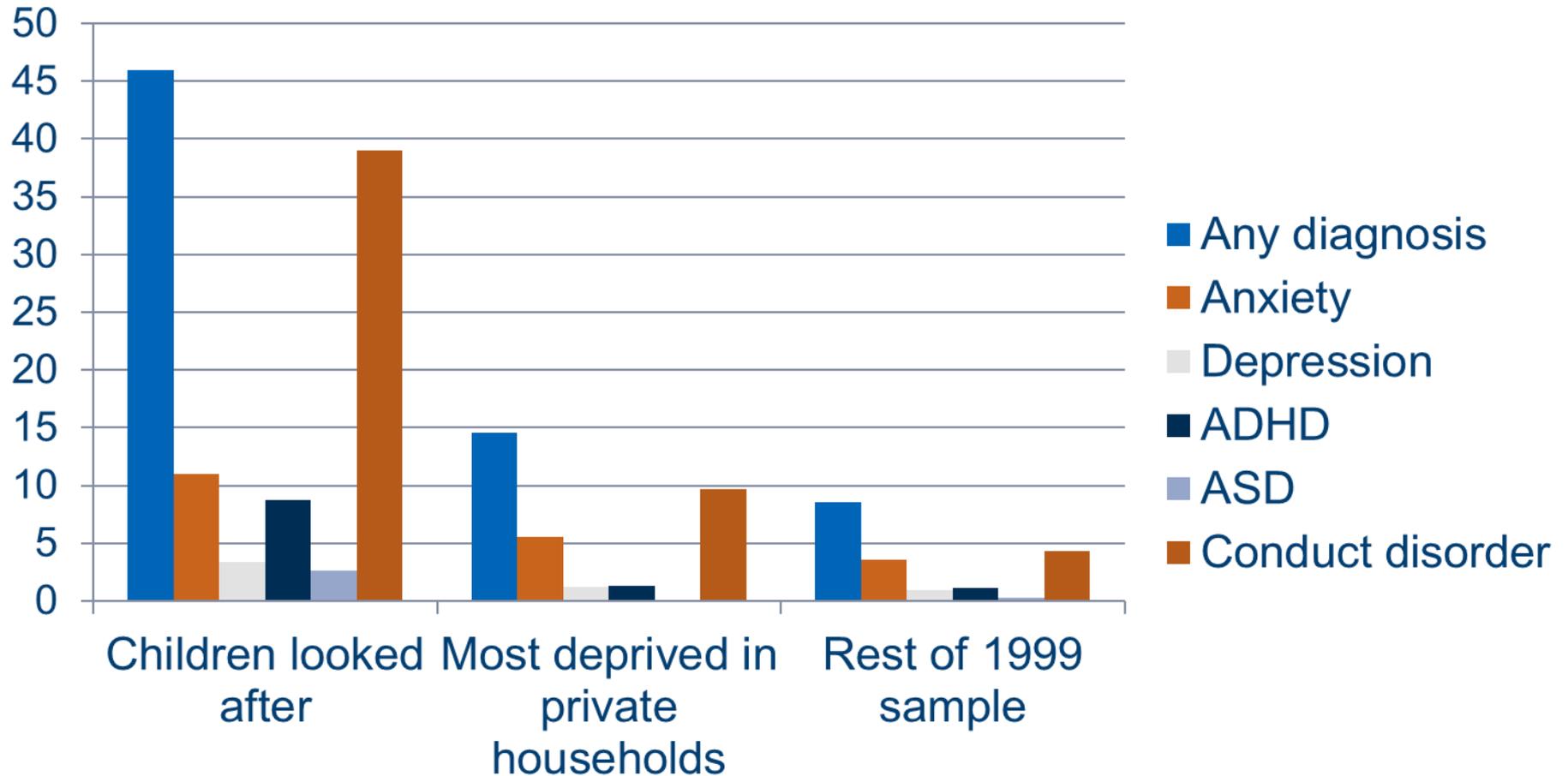
Resumption of ADHD medication following cessation aged 14-18: analysis using CPRD data

Outcome	n	Percentage
Did not restart	1,331	92.4%
Restarted age 20	66	4.6%
Restarted age 21	19	1.3%
Restarted age 22	15	1.0%
Restarted age 23	6	0.4%
Restarted age 24	2	0.1%
Restarted age 25	1	0.1%
Total	1,440	100%

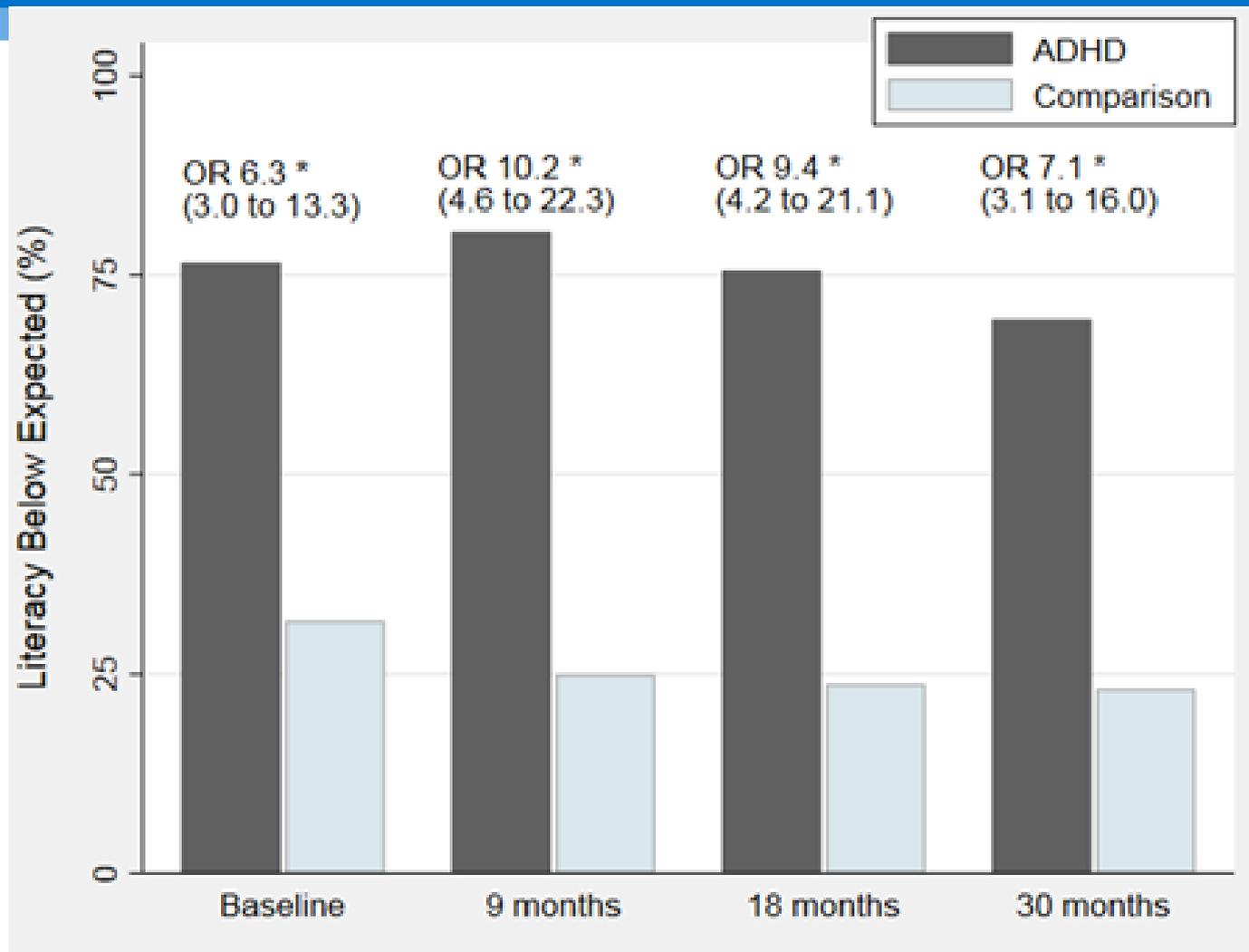
Characteristic	Number resuming medication aged 20 or over (%)
Prescription for non-ADHD psychotropic (N=395)	52 (13.2%)
Referral recorded to Adult Mental Health Services (N=142)	28 (19.7%)
Any non-ADHD psychiatric disorder (excluding learning disability) (N=348)	36 (10.3%)
Conduct or oppositional defiant disorder (N=92)	9 (9.8%)
Learning disability (N=64)	12 (18.8%)
Autism Spectrum Disorder (N=112)	13 (11.6%)
Anxiety or depression (n=125)	15 (12.0%)
Substance misuse (N=35)	6 (17.1%)
All cases (N=1440)	109 (7.6%)

Taken from: Newlove-Delgado *et al.* 2019 doi: 10.1007/s00787- 019-01325-5

Vulnerable groups are really vulnerable – the proportion of children with psychiatric disorder by deprivation



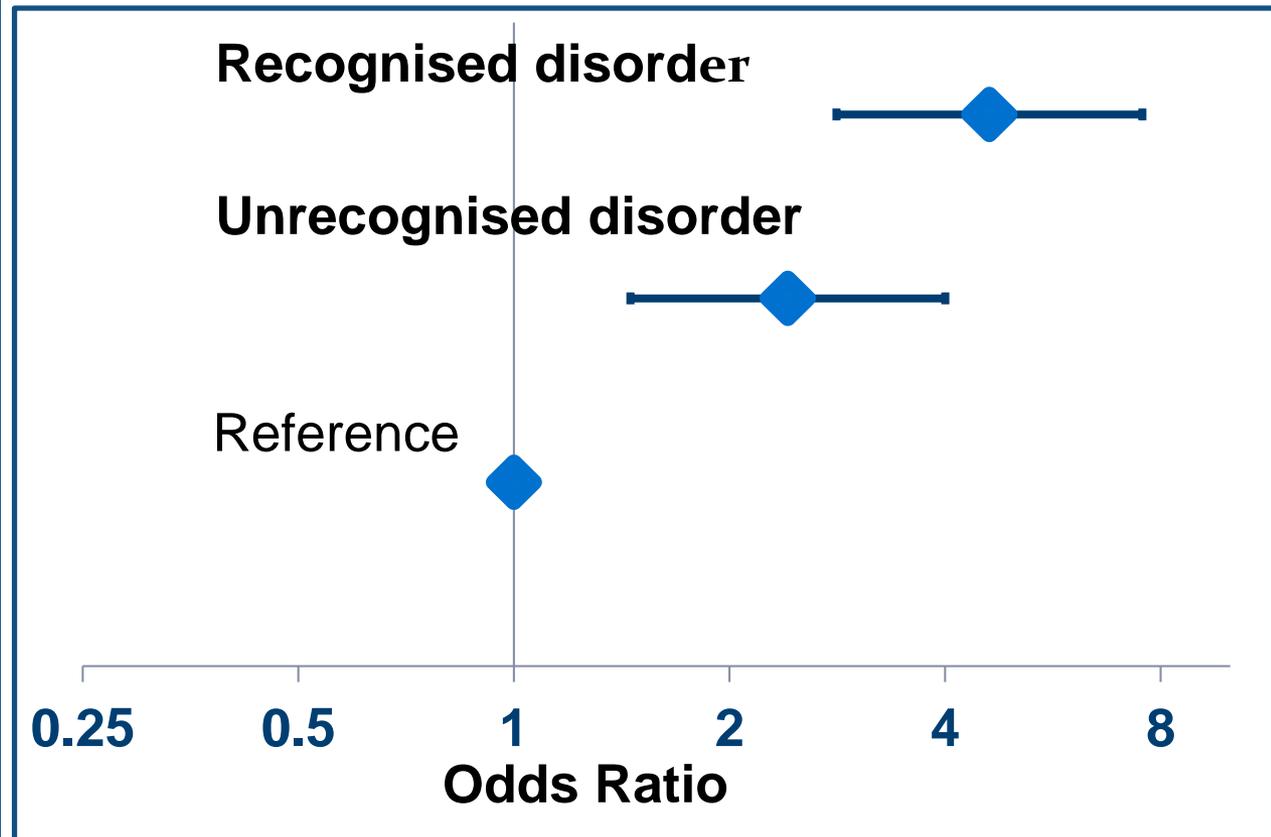
4-9 year olds in STARS cRCT



Exclusion in 2007 according to psychiatric disorder in 2004 among 5-16 year olds

Adjusted for:

age, gender, social class, neighbourhood deprivation, ethnicity, general health (parent), learning disability, mothers highest education, baseline total difficulties score SDQ



Transition

“A purposeful, planned process that addresses the medical, psychosocial and educational / vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems”

National Service Framework (NSF) for Children, Young People and Maternity Services



Relevant NICE guidance

Transition NG43 2016

- **Involvement**
- **Developmentally appropriate** support
- **Strengths-based** and **person centred**
- Responsibility of **both** child and adult services
- **Planning** early
- Support **before, during and after** transition

ADHD NG87 updated 2019

- Trusts should ensure **training** of child & adult practitioners
- **Regular contact** & structured support (specialist?)
- **Medication** if required
- **Shared care protocols** with primary care “if required”
- **Reassessment** and **information transfer** stressed in relation to transition



Overview:

The CATCh-uS project is funded by the National Institute for Health Research's HS&DR Programme (REF. 14/21/52)

How many young people need ongoing support for their ADHD once too old for children's services?

• Surveillance study

How many and which areas have services for young adults with ADHD (what do they offer)?

• Mapping study

How do YP, their families and the professionals working with them experience the transition?

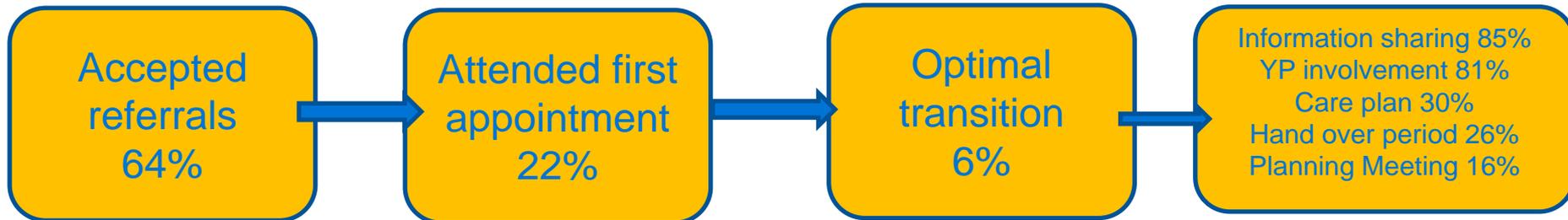
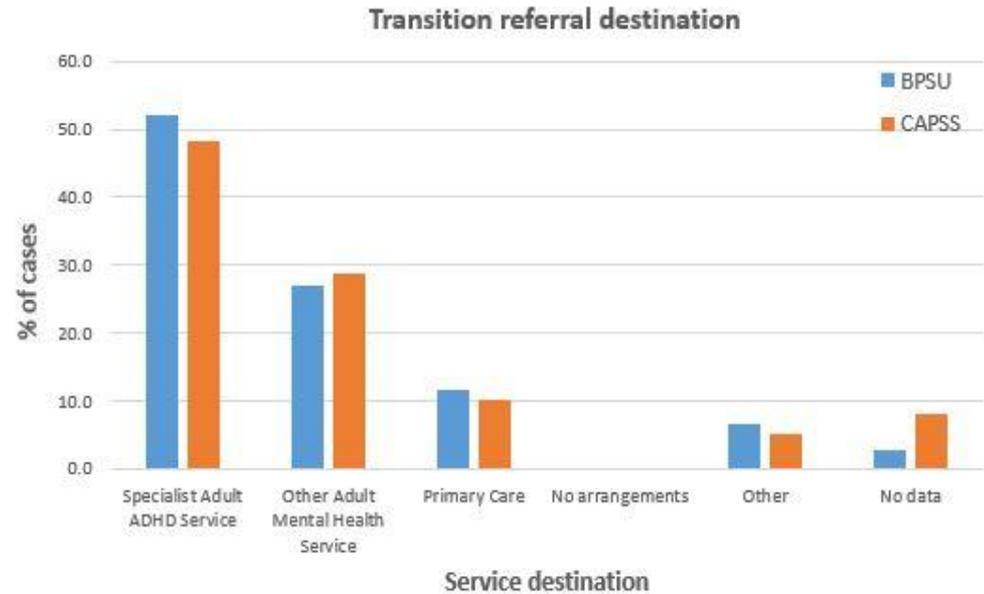
• Qualitative study



Surveillance findings about transition referral



Age boundary of child service	BPSU %	CAPS S %
14 - 14yrs 11m	0	1
15 - 15yrs 11m	0.4	0
16 - 16yrs 11m	12	0
17 - 17yrs 11m	17	12
18 - 18yrs 11m	63	83
19 - 19yrs 11m	3	1
Variable	3	0
Unknown / no data	2	3

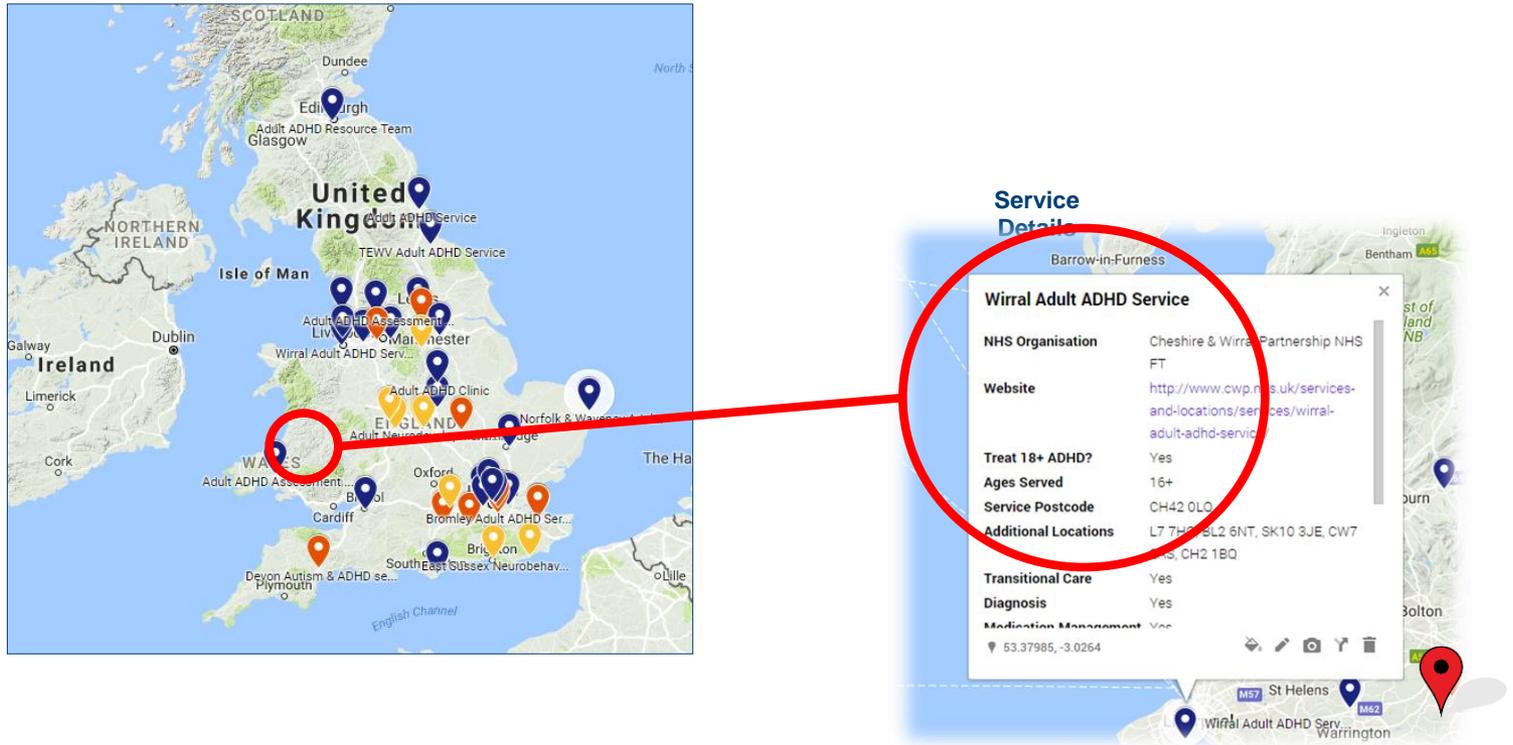


How many young people need transition?

- Each year between **270 and 599 per 100,000 people aged 17-19** will need to continue ADHD medication
- Necessarily an underestimate of the actual numbers needing services
- Figures corrected for non-response at level of cards & baseline questionnaires



Interactive map of services



<https://www.ukaan.org/adult-adhd-service-map>



Pre-transition, 14-16 years old

ADHD = Medication = To fit in at school

Transition:



I have not thought about ADHD when growing up.

I have never met an adult with ADHD – I don't know what the future holds

I'm not worried, I'm not sure what will change



Pre-transition, 14-16 yo



**Mom-ager
for ADHD**



Post-Transition: 18 years old

It's a big jump

I felt like the Doctor didn't know enough about me



It wasn't too bad



I was worried about what would happen

I didn't know what to expect; that was really annoying and scary



Mixed emotions

Re-entering services: 19+ – If only...

- *BY CHOICE*...
- Is this an informed decision?
-> Young Adult: No!
More info about ADHD = LT condition
- Clinician should push harder
- *NOT BY CHOICE*
Drift off, drop out, sliding process
(DNA, no follow-up services ...)

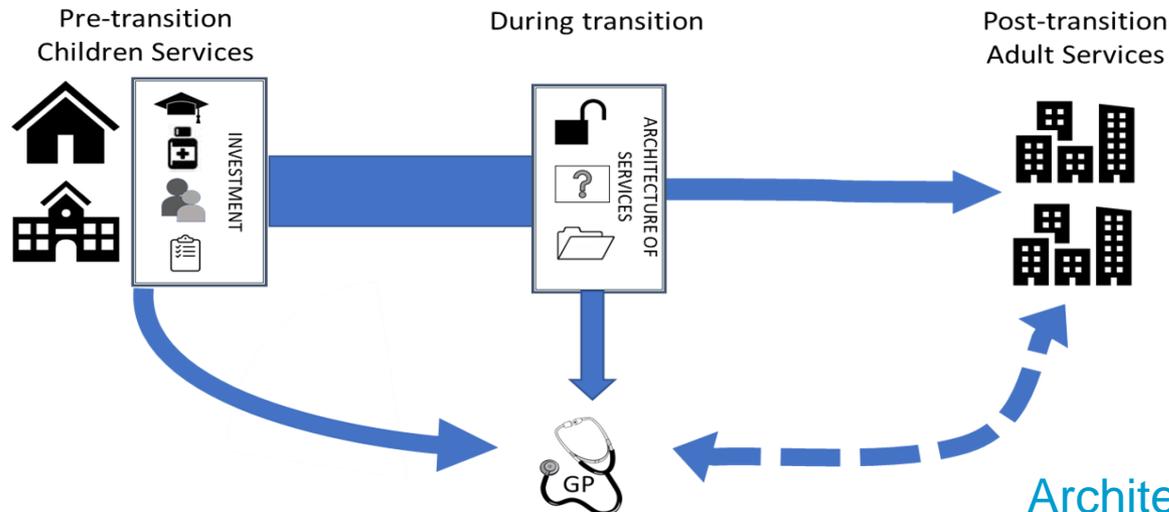
The clinician didn't ask me why I stopped. If I knew what I know today then I would never have stopped...

It's just that I didn't feel that they were pressuring me enough to stay with them. After I said I don't want to be with them they were like, 'Alright, fine. We can't really force you.'

How to re-enter?



Overview of factors impacting good transition

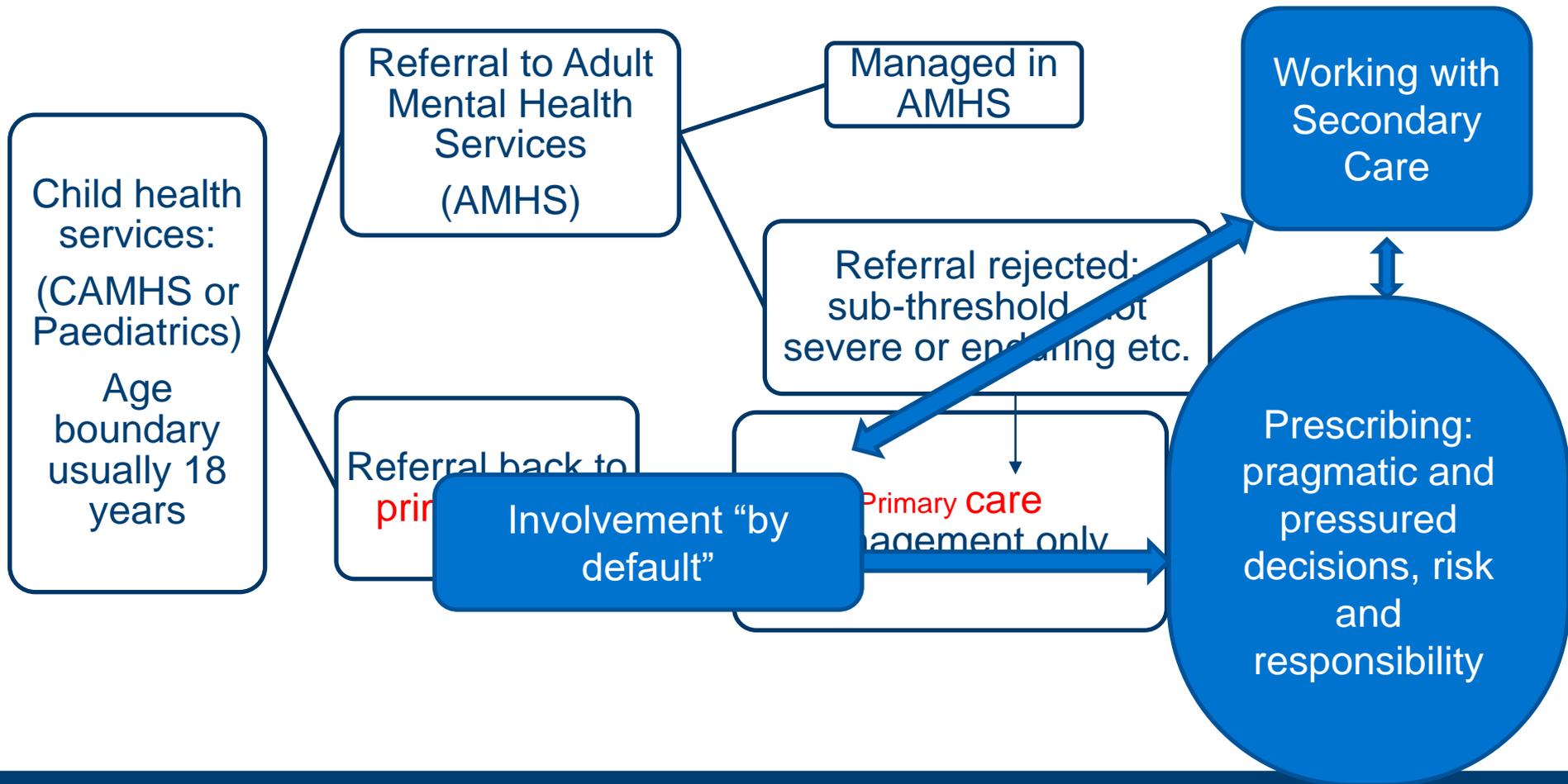


Investment:

- School: the start of the process; why they start & continue med.
- Medication: helps, meds=service access + transition, but C&YA keen for alternatives.
- Parents: crucial advocates.
- Preparation: Readiness + Information.

Architecture of services:

- Accessibility: provision, contact.
- Remit: unclear, differences btw services.
- Handover processes: information, mistrust between services.
- GP: involved by default



Summary



- Very few of those who need ongoing medication for their ADHD successfully transfer to adult services
- Even fewer experience anything that approaches optimal transitional care
- The core difficulties of ADHD make coping with transition even harder
- Transition can be supported by **parental involvement**, understanding of **ADHD as a long-term condition**, **self-awareness** of impairment, and **information**
- Tension between developmentally appropriate support and autonomy
- Problem will increase as we have an increasing number of graduates from CAMHS and community paediatrics

Disclosure

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References

- Coghill, D. (2016). Organisation of services for managing ADHD. *Epidemiology and Psychiatric Sciences*, 1-6.
- Hall, C. L., Newell, K., Taylor, J., Sayal, K., & Hollis, C. (2015). Services for young people with attention deficit/hyperactivity disorder transitioning from child to adult mental health services: a national survey of mental health trusts in England. *J Psychopharmacol*, 29(1), 39-42. doi:10.1177/0269881114550353
- Hall, C. L., Newell, K., Taylor, J., Sayal, K., Swift, K. D., & Hollis, C. (2013). 'Mind the gap' Mapping services for young people with ADHD transitioning from child to adult mental health services. *BMC Psychiatry*, 13, 186. doi:10.1186/1471-244x-13-186
- NHS England. (2017). Next steps on the NHS five year forward view. *London: NHS England*.
- NICE. (2008). *Attention deficit hyperactivity disorder: Diagnosis and management of ADHD in children, young people and adults (CG72)*. Retrieved from Available at <http://publications.nice.org.uk/attention-deficit-hyperactivity-disorder-cg72>
- Newlove-Delgado T, Janssens A, Ford TJ, Ukoumunne OC, Hamilton W, Stein K (2019). Resumption of attention-deficit hyperactivity disorder medication in early adulthood: findings from a UK primary care prescribing study. *European Child and Adolescent Psychiatry*. 28(12):1589-1596.doi: 10.1007/s00787- 019-01325-5
- Newlove-Delgado TV, Ford TJ, Ukoumunne OC, Hamilton W, Stein K (2018). Prescribing of medication for attention deficit hyperactivity disorder among young people in the Clinical Practice Research Datalink 2005–2013: analysis of time to cessation. *European Child and Adolescent Psychiatry* <https://doi.org/10.1007/s00787-017-1011-1>
- Roberts, J. H., Crosland, A. and Fulton, J. (2013) "I think this is maybe our Achilles heel..." exploring GPs' responses to young people presenting with emotional distress in general practice: a qualitative study. *BMJ Open*. 3(9), p.e002927.
- Biddle, L., Donovan, J. L., Gunnell, D. and Sharp, D. (2006) Young adults' perceptions of GPs as a help source for mental distress: a qualitative study. *The British Journal of General Practice*. 56(533), pp. 924-931.
- Tatlow-Golden M, Prihodova L, Gavin B, Cullen W, McNicholas F. What do general practitioners know about ADHD? Attitudes and knowledge among first-contact gatekeepers: systematic narrative review. *BMC Family Practice*. 2016;17(1):129
- Iacobucci G. GPs in an "invidious" position to prescribe ADHD drugs without specialist support. *BMJ*. 2017;358:j4444.
- <https://www.journalslibrary.nihr.ac.uk/hsdr/hsdr08420/#/abstract>
- <http://medicine.exeter.ac.uk/catchus/>

Resources

- Information for CAMHS, non-specialist practitioners and parents <https://www.minded.org.uk/>
- Information leaflets for young people and for parents / carers <https://www.rcpsych.ac.uk/mental-health/parents-and-young-people/information-for-parents-and-carers/attention-deficit-hyperactivity-disorder-and-hyperkinetic-disorder-information-for-parents-carers-and-anyone-working-with-young-people>
- More about the CATCh-uS project <http://medicine.exeter.ac.uk/catchus/>
- Multidisciplinary practitioner organisation for evidence-based practice in child and adolescent mental health <https://www.acamh.org/>
- NICE Guidance on the diagnosis & management of ADHD <https://www.nice.org.uk/guidance/NG87>
- NICE Guidance on transition <https://www.nice.org.uk/guidance/ng43>
- The UK Adult ADHD Network provides training and support for mental health practitioners working with adults with ADHD <https://www.ukaan.org/>
- ADHD Foundation <https://www.adhdfoundation.org.uk/>