

In transition from children's services to adult services: the case of ADHD

Astrid Janssens, Tamsin Newlove-Delgado, Helen Eke, Anna Price



Disclaimer: Early findings as presented
at IACAPAP July 2018
Details may change



Symposium overview

- Transition, more than just a referral letter
- How big is the problem and how to get national epidemiological data?
- Where to transition to: How transparent is the UK's and/or your national service provision?
- How can we get it right? Transition experiences of young people with ADHD, their parents/carers and clinicians



Disclosure

Funded by National Institute for Health Research (NIHR) Health Services and Delivery Research Programme (HS&DR)
(Ref: HS&DR - 14/21/52)



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

This talk presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.



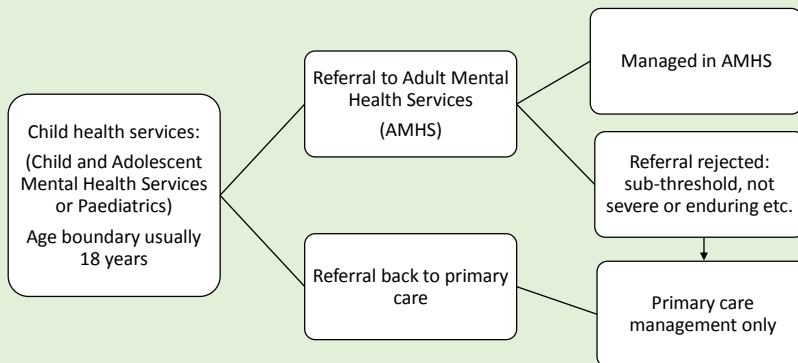
Transition: more than just a referral letter

Dr Tamsin Newlove-Delgado
Academic Clinical Lecturer/Honorary Consultant in Public Health,
University of Exeter Medical School

@TNewlove-Delgado
t.newlove-delgado@exeter.ac.uk



Simplified model of pathways from UK child to adult mental health services



Is this transition?

ADHD Clinic, Xtown CAMHS
Xtown
UK

12.7.18

Re: X (DOB 1.1.03; NHS number XXXXXXXXXXXX)

Dear Doctor Y,

I saw X today in our ADHD clinic, along with his mother. He is currently taking 36mg Concerta XL and finds this is helping him in his studies at X College. X turns 18 next month and therefore this will be his last appointment with our service, as he will no longer be eligible for CAMHS.

I would therefore like to refer him to your service for ongoing management of his ADHD and hope you will be able to offer him an appointment.

Yours sincerely

Doctor Z



Transition: definitions

“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



Child to Adult Mental Health Service transition is important to manage well

Adolescence is a **risk period**

- psychological morbidity
- propensity for risk-taking
- increasing expectations to become involved in decision making about their treatment and manage their condition
- falling between child and adult services
- greater likelihood of disengagement with services

(Lamb et al, 2008)

Young people face multiple other transitions

- Education and work
- Home and relationships



What is optimal transition?

Key elements

- Information transfer and communication
- Transition planning meeting
- Parallel care / joint care
- Continuity of care (End point = YP engaging with adult services)



Guidance and policy



Research findings on transition in practice

- In general UK services provide few of the identified features for good transition for children with long term conditions (Colver et al. 2018)
- Organizational and cultural differences between CAMHS and AMHS e.g. models of care, thresholds etc. (Belling et al., 2014; McLaren et al. 2013)
- TRACK study (Singh et al. 2010)
 - Transition from CAMHS to AMHS 'poorly planned, poorly executed and poorly experienced'
 - Less than 5% experienced 'good transition'
 - Those with neurodevelopmental disorders e.g. ADHD less likely to make a transition to adult services
- MILESTONE: EU-wide study of transition from CAMHS to AMHS (later today session CT1)

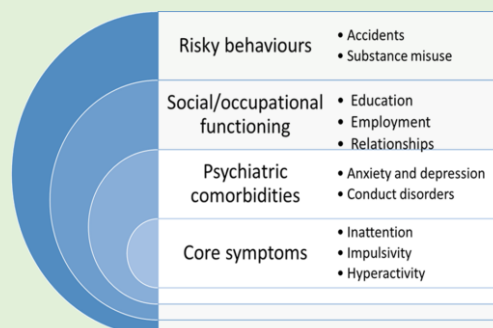


Attention Deficit Hyperactivity Disorder and Transition



ADHD

- Worldwide estimates of prevalence in children at 3-4%
(Thapar et al. 2012, Polanczyk et al. 2015):
 - Majority will experience persisting symptoms at age 25
 - Minority (approx. 15%) still meeting full diagnostic criteria (Faraone and Biederman, 2006)
- UK NICE guidelines 2018:
 - recommend **offering medication to children and adults with ADHD if their ADHD symptoms are still causing a significant impairment after environmental modifications**
 - concluded there were benefits to non-pharmacological treatment but less than for medication.
- UK and European guidance recommends specialist oversight for prescription of ADHD medication
(Kooij et al. 2010, NICE 2018)



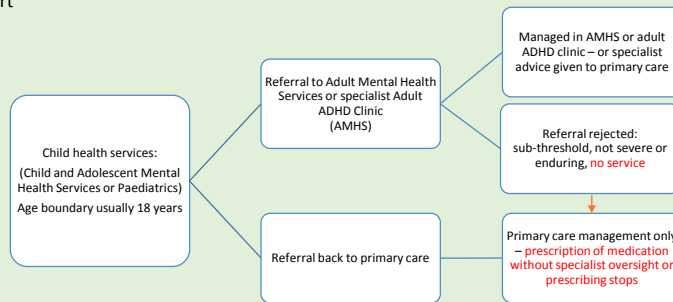
Young people with ADHD can be especially vulnerable to adverse outcomes

- The transition to adult life and the fulfilment of attendant adult responsibilities can be complicated by ADHD symptoms
- However, other than a few small local studies, little is known about how they experience transition and how this is influenced by choices and circumstances
- Professionals including adult psychiatrists may have less than optimal understanding and knowledge about ADHD in over 18s
(Matheson et al. 2013; Moldavsky et al. 2013).
- International prescribing studies suggests that many young people may be stopping medication from which they could still benefit
(e.g. Newlove-Delgado et al. 2017; Johansen et al. 2015; Geirs et al. 2014)



'Mind the Gap'

- ADHD NICE Guidance recommends:
 - specialist oversight for prescribing (e.g. prescribing in primary care should be overseen by a specialist)
 - reassessed at school-leaving age
 - formal meeting involving CAMHS and/or paediatrics and adult psychiatric services should be considered
 - full information provided to the young person about adult services
 - NICE Guidance on transition should be followed
- Previous survey-based research suggests that implementation and service provision is highly variable (Hall et al. 2015; Hall et al. 2013; Coghill 2016)
- Lack of specialist services for onward referral can contribute to 'drifting' from services and sources of support



Introducing:
 Children and adolescents with ADHD in transition between children's services and adult services – CATCh-uS



Three main research questions

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

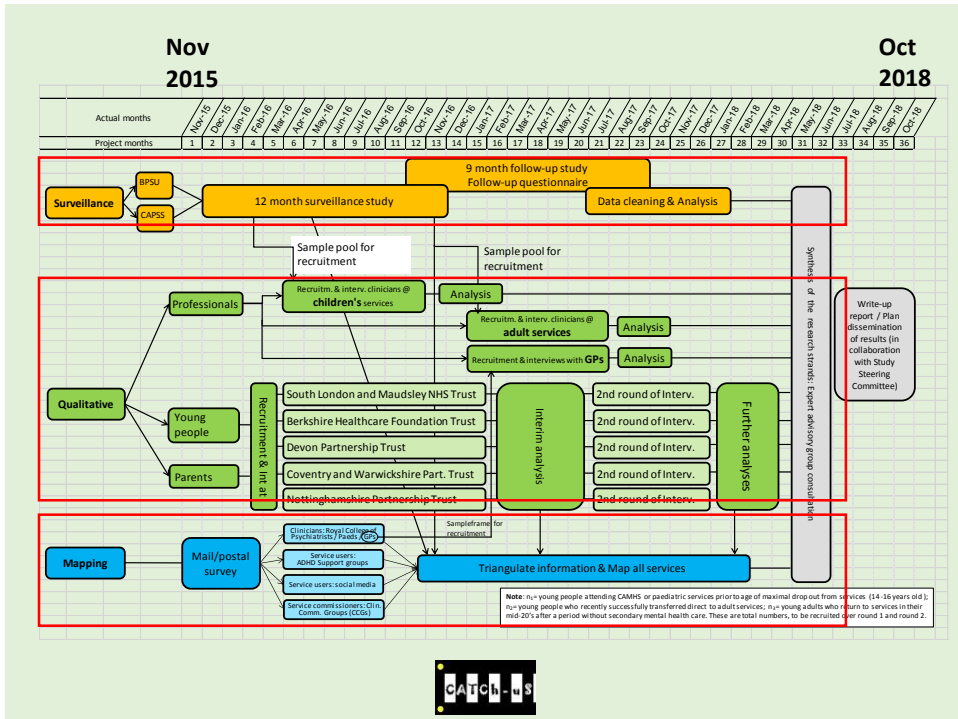
• Surveillance study

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



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