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

The CATCh-uS Study

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Trends in Disorders, 5-15 year olds, 1999 to 2017
Disorder types differed by age

Source: NHS Digital. 2 to 19 year olds identified with a mental disorder, England.
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

#### Number resuming medication aged 20 or over (%)

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

#### Outcome

<table>
<thead>
<tr>
<th>Outcome</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not restart</td>
<td>1,331</td>
<td>92.4%</td>
</tr>
<tr>
<td>Restarted age 20</td>
<td>66</td>
<td>4.6%</td>
</tr>
<tr>
<td>Restarted age 21</td>
<td>19</td>
<td>1.3%</td>
</tr>
<tr>
<td>Restarted age 22</td>
<td>15</td>
<td>1.0%</td>
</tr>
<tr>
<td>Restarted age 23</td>
<td>6</td>
<td>0.4%</td>
</tr>
<tr>
<td>Restarted age 24</td>
<td>2</td>
<td>0.1%</td>
</tr>
<tr>
<td>Restarted age 25</td>
<td>1</td>
<td>0.1%</td>
</tr>
<tr>
<td>Total</td>
<td>1,440</td>
<td>100%</td>
</tr>
</tbody>
</table>

Vulnerable groups are really vulnerable – the proportion of children with psychiatric disorder by deprivation
4-9 year olds in STARS cRCT

- OR 6.3* (3.0 to 13.3) at baseline
- OR 10.2* (4.6 to 22.3) at 9 months
- OR 9.4* (4.2 to 21.1) at 18 months
- OR 7.1* (3.1 to 16.0) at 30 months
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

Odds Ratio

- Reference
- Unrecognised disorder
- Recognised disorder
“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:

- **Surveillance study**
  How many young people need ongoing support for their ADHD once too old for children’s services?

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

- **Qualitative study**
  How do YP, their families and the professionals working with them experience the transition?
Surveillance findings about transition referral

<table>
<thead>
<tr>
<th>Age boundary of child service</th>
<th>BPSU %</th>
<th>CAPSS %</th>
</tr>
</thead>
<tbody>
<tr>
<td>14 - 14yrs 11m</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>15 - 15yrs 11m</td>
<td>0.4</td>
<td>0</td>
</tr>
<tr>
<td>16 - 16yrs 11m</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>17 - 17yrs 11m</td>
<td>17</td>
<td>12</td>
</tr>
<tr>
<td>18 - 18yrs 11m</td>
<td>63</td>
<td>83</td>
</tr>
<tr>
<td>19 - 19yrs 11m</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Variable</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Unknown / no data</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Accepted referrals 64%
Attended first appointment 22%
Optimal transition 6%
Information sharing 85%
YP involvement 81%
Care plan 30%
Hand over period 26%
Planning Meeting 16%
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 wasn’t 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
Child health services: (CAMHS or Paediatrics)

Age boundary usually 18 years

Referral to Adult Mental Health Services (AMHS)

Managed in AMHS

Referral rejected: sub-threshold, not severe or enduring etc.

Referral back to primary care

Involvement “by default”

Primary care management only

Working with Secondary Care

Prescribing: pragmatic and pressured decisions, risk and responsibility
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

- 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](https://www.journalslibrary.nihr.ac.uk/hsdr/hsdr08420/#/abstract)
- [http://medicine.exeter.ac.uk/catchus/](http://medicine.exeter.ac.uk/catchus/)
Resources

- Information for CAMHS, non-specialist practitioners and parents [https://www.minded.org.uk/](https://www.minded.org.uk/)
- More about the CATCh-uS project [http://medicine.exeter.ac.uk/catchus/](http://medicine.exeter.ac.uk/catchus/)
- Multidisciplinary practitioner organisation for evidence-based practice in child and adolescent mental health [https://www.acamh.org/](https://www.acamh.org/)
- NICE Guidance on the diagnosis & management of ADHD [https://www.nice.org.uk/guidance/NG87](https://www.nice.org.uk/guidance/NG87)
- NICE Guidance on transition [https://www.nice.org.uk/guidance/ng43](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/](https://www.ukaan.org/)
- ADHD Foundation [https://www.adhdfoundation.org.uk/](https://www.adhdfoundation.org.uk/)