ADHD transitions case note review Ireland

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Transitioning from child and adolescent mental health services with attention-deficit hyperactivity disorder in Ireland: Case note review

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Keywords

Attention-deficit hyperactivity disorder, ADHD, transition, child and adolescent mental health services, adult mental health services, CAMHS, AMHS

Abstract

Aim

In a context of international concern about early adult mental health service provision, this study identifies characteristics and service outcomes of young people with attention-deficit hyperactivity disorder (ADHD) reaching the child and adolescent mental health service (CAMHS) transition boundary in Ireland.

Methods

The iTRACK study invited all 60 CAMHS teams in Ireland to participate; 8 teams retrospectively identified clinical case files for 62 eligible young people reaching the CAMHS transition boundary in all four Health Service Executive Regions. A secondary case note analysis identified characteristics, co-morbidities, referral and service outcomes for iTRACK cases with ADHD (n = 20).

Results

Two-thirds of young people with ADHD were on psychotropic medication and half had mental health co-morbidities, yet none was directly transferred to public adult mental health services (AMHS) at the transition boundary. Nearly half were retained in CAMHS, for an average of over a year; most either disengaged from services (40%) and/or actively refused transfer to AMHS (35%) at or after the transition boundary. There was a perception by CAMHS clinicians that adult services did not accept ADHD cases or lacked relevant service/expertise.

Conclusions

Despite high rates of medication use and comorbid mental health difficulties, there appears to be a complete absence of referral to publically available adult mental health services for ADHD youth transitioning from CAMHS in Ireland. More understanding of obstacles and optimum service configuration is essential to ensure that care is both available and accessible to young people with ADHD.

Key Words ADHD, Adult psychiatry services, child psychiatry services, transition.

Introduction

Although attention-deficit hyperactivity disorder (ADHD) was formerly conceptualised as a disorder of childhood, there is growing recognition that it is a lifespan neurodevelopmental disorder that persists beyond adolescence into adulthood. Meta-analysis of 32 longitudinal studies [1] found that of young adults earlier diagnosed with ADHD, about 15% met full diagnostic criteria and a further 50% experienced only partial remission with clinical symptoms and psychosocial impairments requiring intervention [2]. Epidemiological, genetic, neuroimaging and pharmacological studies conclude ADHD is well-defined in adults and is associated with similar neurobiological findings and response to drug treatment as in children [3].

ADHD may alter in presentation, as impulsivity and hyperactivity often abate from later adolescence, but difficulties typically persist with time management, organization, education, employment and relationships, with elevated risk for unemployment, divorce, driving accidents, offending behaviours [4] and mortality [5]. Furthermore, comorbid anxiety, mood problems and substance misuse are common [6-8]; indeed, up to a quarter of adult mental health services (AMHS) attendees meet ADHD criteria, yet are typically unrecognised and untreated [9].

In the UK, the National Institute for Clinical Excellence (NICE) guidelines for ADHD [10] conclude that symptoms persist into adulthood in most cases and that adult ADHD should be managed by clinical services within the UK's National Health System. Furthermore, NICE recommends that for individuals with significant ADHD symptoms or comorbid conditions needing treatment, services should facilitate transition from child and adolescent mental health services (CAMHS) to AMHS [10].

For adults with ADHD, both pharmacological and non-pharmacological treatments can relieve symptoms and functional impairments [3,11]. NICE recommend stimulants as the first-line treatment, initiated by a psychiatrist or nurse-prescriber after a comprehensive assessment, and subsequently by primary care physicians in shared care with specialists [10]. Beyond the UK, treatment guidelines extending to adult ADHD have been developed in Ireland [12], Germany, Canada, as well as in a Europe-wide consensus statement from clinicians in the European Network of Adult ADHD [3].

The relatively recent recognition of adult ADHD exists in a context of generally poor access to mental health services in early adulthood in Europe, the USA and Australia, resulting in calls for transition-

focused professional training, shared-care policies, and inter-agency collaboration [13-16]. Mental health policy in Ireland advocated this a decade ago [17], but as elsewhere, substantial gaps remain between best practice guidelines and operational practice [18]. The impact of such gaps in mental health service provision on young people transitioning into adulthood is exacerbated by the nature of this 'critical' developmental period. Negotiating young adulthood is a complex process for all young people, during which further education, employment, independence from parents, and new relationships are encountered, requiring mastery of organisational, interpersonal, and planning skills, and abstention from serious risk-behaviours [19-21]. For most young people with ADHD symptoms, the new tasks of adulthood are particularly challenging, and an even greater vulnerability may therefore result, further underlining their need for appropriate support [22-23].

Two recent case note review studies of CAMHS-AMHS transitions in Ireland and the UK found that young people with ADHD, as well as those with emotional/neurotic, eating and other neurodevelopmental disorders, are most likely not to transfer to AMHS. In the UK TRACK study [24,25] among those not transferring (n = 52), young people with emotional/neurotic disorders were most represented followed by neurodevelopmental disorders. Reasons for non-transfer were: 23% had no further need for treatment or were due to complete treatment soon, 21% young people (or carers/families) refused referral, 10% had disengaged from services, 9% had uncertain asylum status, and the remainder were assumed not to meet AMHS criteria or multiple, other, or no reasons were given [25].

In the iTRACK study in Ireland, those most likely not to transfer to AMHS were young people with ADHD and eating disorders [26]. Lack of transfer may be influenced by lack of AMHS ADHD knowledge and services, as only 13% of adult psychiatry consultants or senior registrars surveyed in Ireland were confident in managing ADHD [27] and specialised adult ADHD services in Ireland, other than private services, are negligible, although some forms of methylphenidate, atomoxetine, and lisdexamfetamine are licensed for prescription to adults [28]. In the UK, AMHS clinicians are also often not well versed in ADHD [29] and AMHS frequently do not provide ADHD services, e.g., half of UK mental health trusts report premature discharge and no suitable adult services for CAMHS ADHD patients [30], and similar scarce provision for adult ADHD is reported for Europe [3]. However, little is known about reasons for lack of referral and transfer with ADHD in particular.

This analysis of iTRACK data focuses on characteristics of ADHD cases, including service transfer, reaching the CAMHS transition boundary in Ireland. It is the first such study of which we are aware and aims to inform future ADHD service development in CAMHS and AMHS.

Method

This study conducted a secondary narrative case note analysis of the ADHD cohort from the iTRACK case note study of CAMHS-AMHS transitions in Ireland.

The iTRACK study iTRACK examined transition policies and practice in CAMHS, and procedures, participants and analyses, which are reported in full elsewhere [18,26], are summarised here. Consultant psychiatrists in all 60 CAMHS services in Ireland were invited to participate, following ethical approval. Eight teams (13%) retrospectively identified clinical case files for data extraction for 62 young people who were approaching the service transition boundary, located in all four Health Service Executive Regions in Ireland: Dublin Mid-Leinster (40; 66%), Dublin North-East (1; 2%), South (18; 30%), and West (2; 3%) [26], and one participant for whom the extracted case notes do not specify the Region.

The UK TRACK study [24,31] data extraction tool was modified for Ireland, e.g., removing NHS references (available from the last author on request). Case note data were extracted by clinical teams or (with young people's consent) by researchers. Information extracted included CAMHS diagnoses at initial presentation and transition boundary (TB), young person's clinical and sociodemographic details, parent engagement, CAMHS clinician perception of suitability for AMHS referral, and details of referral and transfer/transition process. For those in CAMHS beyond the TB, their current status, management plan, and reasons for not referring to AMHS were extracted. Cases were categorised as *referred* to AMHS, *not referred*, *discharged* to GP, *referral refused* by the young person and/or parent, or *disengaged* [26]. A well planned and executed transition was defined as characterised by joint appointments with young person/family, CAMHS and AMHS clinicians, and detailed written information exchange.

The iTRACK ADHD cohort Of the iTRACK sample (n=62), 20 (32%; 16 males) had an ADHD diagnosis at the TB. They attended seven teams within four CAMHS services across Ireland. All 20 were White Irish (first language English) and lived in the family home, with both parents (9, 45%), mother (9,

45%) or fostered by grandparents (2, 10%). Mean age of first referral was 11.6 years (SD 3.98; n=16). In one CAMHS service within one Region, covering three cases, the age of transition was 16 years; for all other young people the TB was 18 years. Seventeen (85%) were in education full-time (two at a special school), one part-time, and two were unemployed. Parents of 16 young people (80%) attended CAMHS regularly. Fourteen provided data on family mental health problems, half of whom reported these in first-degree family (7, 50%). Most (17, 85%) young people had been prescribed medication during CAMHS treatment; 13 (65%) were on medication at the TB. Two families are recorded as having received parenting as part of treatment and three had received family therapy. Three young people had received individual therapy and three had been admitted to a mental health unit. Half (10) had co-morbidities.

Results

Service outcomes and characteristics of the ADHD cohort

None of the 20 young people with ADHD transferred from CAMHS to a public AMHS (Figure 1). One transitioned to a private AMHS at the TB and another did so two years later. One, after CAMHS discharge, was referred to AMHS by the GP and seen for 6 months. Eight young people with ADHD were retained by CAMHS for up to 2 years and eight disengaged either at the TB or later.

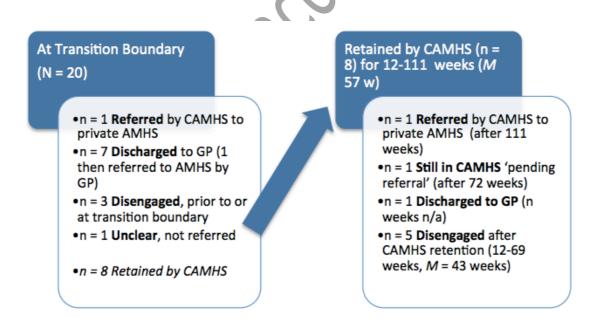


Figure 1 Summary outcomes for the iTRACK cohort with ADHD: At and after the transition boundary

Table 1 summarises characteristics and outcomes for the iTRACK ADHD cohort. Of the 20 young people, 10 were diagnosed with between one and three co-morbidities at the transition boundary: diagnoses were Autism Spectrum Disorder (n = 4), Learning Difficulties (n=3), Anxiety (n=2), Depression (n=1), Eating Disorder (n=1), Post-traumatic Stress Disorder (n=1), Substance Use Disorder (n=1) and Reactive Attachment Disorder (n=1). One had also been diagnosed with Temporal Lobe Epilepsy (and a possible psychotic episode).

The only transfer at TB, to private AMHS, was a young person on psychotropic and anti-epileptic medication with complex neuro-developmental problems, possible psychotic symptoms and aggression. This transition was well planned and executed. Two other young people were recorded as referred to AMHS. One 18 year old with ADHD and depression, on medication, was discharged from CAMHS to GP, who queried this; CAMHS recommended the GP refer to AMHS, where the young person attended for 6 months before discharge to GP as 'presenting problem resolved altogether', suggesting AMHS treated depression but not on-going ADHD. A young person with comorbid ASD and anxiety was also referred to a private AMHS, but after 2 years (111 weeks) in CAMHS beyond the age-18 TB. This young person was one of nearly half the ADHD cohort who remained in CAMHS beyond the TB (n=8; 40%), for 12-111 weeks (M=57.4 weeks, SD=32.29). Therefore, the three young people who successfully transitioned to AMHS had comorbidities and were on medication at the TB.

Of the remaining 17 young people who had not transferred to any AMHS at any stage, 10 were on medication and 7 had co-morbidities. Three were discharged to GP directly. Four more (three of whom were aged 16 at the TB) were discharged to GP after refusing an offer of AMHS referral: they and/or their families requested GP medication monitoring instead. In total, seven young people refused referral to AMHS either at or after the TB. Eight disengaged from CAMHS before, at or after the TB (Table 1), four of whom had comorbidities (ASD, substance misuse, anxiety) and five who were receiving psychotropic medication. Case notes do not record whether those who disengaged stopped medication, received it from their GP, or had disengaged from mental health-related supports altogether.

ADHD transitions case note review Ireland

Table 1 – ADHD at the transition boundary in the iTRACK cohort in Ireland

| Sex | Age first at CAMHS ¹ | First CAMHS diagnosis | Diagnosis at Transition Boundary ² | Medication at Transition Boundary | N weeks ongoing CAMHS (n sessions) | Referral detail | Outcome |
|--------|------------------------------------|---|--|---|------------------------------------|--|-------------------|
| 1. Re | ferred to, and a | attended AMHS (private or public), at ⁻ | Transition Boundary or late | er | | | |
| М | 12 | ADHD, ASD ³ , Learning Difficulties, Temporal Lobe Epilepsy (+ possible psychotic episode) | ADHD, ASD, Learning Difficulties, Temporal Lobe Epilepsy | 1 | | Referred to private AMHS ⁴ by CAMHS at the Transition Boundary | AMHS (private) |
| F | 14 | Depression, Anxiety | ADHD, Depression | 1 | | Discharged to GP. GP referred to AMHS | AMHS |
| M | 9 | ADHD, ASD, Anxiety | ADHD, ASD, Anxiety | 1 | 111 weeks (14) | Referred to private AMHS by CAMHS after 2 years | AMHS (private) |
| 2. Dis | scharged to GP | | | | | | |
| М | 15 | ADHD | ADHD | Х | | GP Discharge – YP ⁵ , family happy | GP |
| М | n/a | ADHD | ADHD | x | - 011 | GP Discharge – 'no input needed' | GP |
| F | 17 | ADHD, Depression | ADHD, ASD | X | Yes (no details) | Discharged to GP | GP |
| 3. Re | fused referral t | o AMHS at Transition Boundary or afte | er retention by CAMHS | | 10 | | |
| М | 13 | ADHD | ADHD (TB 16y) | 1 | | YP refused. GP advised referral to AMHS. Family requested GP | GP |
| M | n/a | ADHD | ADHD | х | 12 weeks (3) | YP refused, & later disengaged | Disengaged |
| F | 9 | Eating Disorder, Anxiety | ADHD, Eating Disorder, PTSD ⁶ | 1 | | YP refused referral; requested GP | GP |
| M | 14 | ADHD, ASD | ADHD, ASD (TB 16y) | | | YP refused referral; requested GP | GP |
| F | 15 | ADHD, Deliberate Self-Harm | ADHD (<i>TB 16y)</i> | √ | | YP refused; parents requested GP | GP |
| М | n/a | n/a | ADHD | X | 40 weeks (4) | YP refused, & later disengaged | Disengaged |
| 4. Dis | sengaged or out | tcome unknown (at Transition Bounda | ary or after retention by CA | MHS) | | | |
| М | 14 | ADHD | ADHD | ✓ | 69 weeks (12) | Disengaged | Disengaged |
| M | 4 | ADHD | ADHD | ✓ | | Disengaged before Transition Boundary | Disengaged |
| M | 7 | ADHD | ADHD | ? | | Not referred – further details unknown | (Unknown) |
| М | 13 | ADHD, Depression | ADHD, Substance Use Disorder | ✓ | | Disengaged before Transition Boundary | Disengaged |
| M | 4 | ADHD, Learning Difficulties, PTSD, Reactive Attachment Disorder | ADHD, Learning Difficulties, Reactive Attachment Disorder | ✓ | | Disengaged before Transition Boundary | Disengaged |
| M | 17 | ADHD, Learning Difficulties, Anxiety with Panic | ADHD, Learning Difficulties, Anxiety with Panic | 1 | 56 weeks (5) | YP refused referral; attended no sessions after Transition Boundary; disengaged | Disengaged |
| М | 15 | ADD ⁷ , ASD | ADHD, ASD | X | 39 weeks (8) | Disengaged | Disengaged |
| | se ongoing in C | | | | | | |
| M | 10 | ADHD, Separation Anxiety | ADHD | \checkmark | 72 weeks (3) | Case open pending referral | Ongoing |

ADHD transitions case note review Ireland

¹CAMHS = Child and Adolescent Mental Health Service

²The Transition Boundary was 18 in all cases except where 16 is indicated

³ASD = Autism Spectrum Disorder

⁴AMHS = Adult Mental Health Service

⁵YP = Young Person

⁶PTSD = Post-Traumatic Stress Disorder

⁷ADD = Attention Deficit Disorder

Co-morbidities and outcomes

Of the ten young people in the iTRACK cohort who had one or more comorbidities, two were referred to a private AMHS (one the TB and one two years later); two were discharged to GP (one of whom was referred to AMHS), two refused referral, reqesting GP instead; one refused referral and disengaged; and three disengaged before the TB (Table 1). This scatter of outcomes mirrors the variety of outcomes for those with ADHD only and it therefore appears there was no particular pattern of outcomes relating to comorbidities.

Clinicians' reasons for non-referral

In five cases in which clinicians had not made an AMHS referral despite perceptions that young people had on-going mental health needs, clinicians' beliefs regarding AMHS were recorded as a factor: three believed AMHS would not accept such referrals and two that AMHS did not have the service/expertise.

Discussion

This case note study reports characteristics and service outcomes for young people with an ADHD diagnosis in the iTRACK study of CAMHS-AMHS transitions in Ireland. Two-thirds of the 20 young people were taking psychotropic medication and half had co-morbid mental health diagnoses. A complex picture emerged of infrequent referral from CAMHS to AMHS, substantial retention in CAMHS, and high rates of refusal of referral and service disengagement by young people. Not one young person with ADHD transferred directly to a public AMHS from CAMHS at the TB. Two transferred to private AMHS (one at the TB, another after two more years in CAMHS), and one to public AMHS via GP. These features will be considered before service implications are addressed.

Retained by CAMHS

For the eight young people (40%) retained by CAMHS for up to 2 years, age appears not to have been a factor in retention as none attended a CAMHS with an age-16 TB. Extension of CAMHS service beyond an age-18 TB may sometimes be appropriate (e.g., if school completion is imminent, or therapeutic work is being finished), but young adults' needs are best met in adult- rather than child-oriented services [32]. Furthermore, resource challenges in Ireland, where CAMHS has only recently taken responsibility for 16-18 year olds, are likely to preclude retention in future, indicating a need for young adult ADHD services.

Refused referral

An interesting feature of this cohort was that a third refused referral to AMHS, significantly more than iTRACK patients with other diagnoses [26]. In the UK TRACK study a quarter of young people not referred (across diagnoses) also refused, although specifics are not reported for those with ADHD [25].

In three of the seven refusals, young people/families requested GP medication monitoring. If this indicates respect for patients' preferences and some measure of transition planning it may be considered a beneficial outcome, though GPs may not agree as there is no mechanism for GP ADHD management or shared care in Ireland. Although NICE advocate for GP shared care models [10], others raise concerns that GPs lack time to assess impairment and treatment response, or may lack understanding of shared care [29,32]. Clinical experience suggests that young people's AMHS refusal may also be driven by stigma and fears of what AMHS entails, or by clinicians communicating negative views of AMHS ADHD services, directly or implicitly.

Disengaged

Nearly half the young people with ADHD disengaged from services, indicating passive, suboptimal conclusions to CAMHS treatment, and echoing reports of treatment cessation elsewhere [33,34]. In some instances, disengagement may reflect reduced symptoms/impairment, effective coping strategies, or desire to establish an independent identity (an essential developmental task) [33-36], and indeed this may be the underlying cause of the 20% drop recorded in young people taking medication prior to the TB. Yet young people with ADHD are also found to underestimate their symptoms, question the diagnosis or the chronic nature of ADHD, dislike dependence on medication, or reject adult support [34-36]. Finally, in Ireland, as the Long Term Illness scheme meets ADHD medication costs only until age 16, inability to pay may lead to disengagement after this time.

Referral from CAMHS to AMHS

CAMHS clinicians' reasons for non-referral and their low referral rate suggest they do not consider public AMHS services in Ireland can meet the needs of their ADHD patients. As the only transfers from CAMHS were to private adult services, this raises questions regarding equity of service access. If CAMHS do not refer, no need is quantified, and AMHS may not be aware of the level of ADHD-related need.

Barriers to adult ADHD service development identified elsewhere address AMHS clinicians' beliefs, such as querying validity of adult ADHD, or their own ability to manage it [23, 25, 27, 29-30, 37-39]. However acceptance of the need to treat adults with ADHD and a relevant skill base may be growing in adult psychiatry with new adult treatment guidelines in the UK and Ireland [3, 10, 12]. Recently, of 91 adult psychiatrists surveyed in Ireland, three-quarters believed ADHD persists into adulthood and two-thirds said they would consider accepting childhood ADHD referrals and conducting new adult ADHD assessments [27].

Strengths and limitations of the present study

This is the first case note study of which we are aware focusing specifically on CAMHS-AMHS transitions for ADHD patients and it illuminates a particularly neglected area of young people's mental health services. It draws on a sample of young people from seven different CAMHS teams in four services, both urban and rural, in different regions in Ireland. The sample's ethnic homogeneity reflects the profile of CAMHS attendees in Ireland where 90% are White Irish [40] although this profile is changing in some areas of higher immigration [41,42].

However, there are also limitations regarding the sample and information quality. Although multiple regions and services across Ireland are represented, the sample is heavily weighted towards the Dublin Mid-Leinster (Eastern) Region and, to a lesser extent, the Southern Region, and this combined with the small sample means that conclusions cannot be drawn about regional variation in service outcomes. The iTRACK study initially enrolled more than half of CAMHS teams in Ireland, yet only 13% teams identified young people reaching the TB, resulting in an iTRACK sample of 62 with 20 in the ADHD cohort. Furthermore, the young people in this ADHD cohort represent quite a stable group with all living at home, almost all in full-time education, and many parents attending CAMHS regularly. Although many disengaged from services and some had multiple co-morbidities and problems with alcohol or substance use, they may not represent the more vulnerable end of the spectrum. However, in the absence of detailed data on ADHD CAMHS attendees in Ireland, this remains speculative. CAMHS record-keeping regarding transition was poor, as had also been found in UK for the TRACK study [43], with particularly little information regarding non-referral and later outcomes.

Future research and implications for services

This study identifies a lack of transition to adult supports for young people with ADHD in Ireland, echoing reports from across Europe, where poor services for adults with ADHD continue to be a

source of distress to them and their families [3,39]. In interviews in the UK with professionals in mental health trusts and non-statutory organisations, and with parents, the lack of service provision for ADHD was most frequently mentioned (among other conditions, e.g., autism spectrum disorder and eating disorders) [31]. It was noted that many young people with ADHD accessed adult services through drug and alcohol services, and that parents and carers had to depend on voluntary organisations for information and support [31]. In this context, many questions about transition with ADHD, and indeed about transition in general, remain to be understood. The study found that in Ireland, non-referral by CAMHS, young person's refusal, or disengagement were the norm, and there is therefore no record of the level of need, nor of the outcomes for patients who disengage. Without consistent referral by CAMHS clinicians, how can the actual level of ADHD-related need in transition be defined? Applying the dictum of 'what gets counted gets done', it is essential that CAMHS clinicians refer, recording decision rationales and noting outcomes to develop an accurate picture of the level of need among young adults, and that better AMHS-CAMHS communication and joint working are implemented.

Further questions that remain unanswered are to do with the nature of services that should be developed. Are there benefits of continued psychiatric care for ADHD? If so, what type of care should be delivered and by whom? UK NICE Guidelines [10] recommend shared care with GPs, but what are GPs' views about this? What is the optimum TB age with ADHD - given delayed executive function associated with ADHD, would later AMHS referral, or a youth-oriented service that is flexible regarding continued parental support, be preferable? What are views and experiences of those refusing transfer and how may this best be addressed in CAMHS? In the UK, service options have been considered such as AMHS expansion, youth services within AMHS, separate youth services, or closer collaboration with GP-led primary care services [31,44]. Reports from the UK Royal College of Psychiatrsits have noted a lack of AMHS provision for young people with ADHD among other difficulties, and have argued for CAMHS-AMHS agreements and protocols for transition, input from primary care, clinical psychology, social services and non-statutory organisations, and foregrounding quality of life issues for young people with neurodevelopmental disorders [44-45]. However, currently there is no clinical or economic evidence on which policy makers could base decisions, and findings from the UK TRACK study suggest that commissioners should consider developing and evaluating several different models of transitional care for this group [31].

Some answers to these many questions will emerge from two ongoing studies: the EU-wide MILESTONE study identifying transition policies, clinical outcomes, economic effectiveness, and training models for improved transition, and conducting a cluster randomized trial of managed transition versus TAU [46] and the UK/Republic of Ireland *Catch-uS* study of young people with ADHD in transition from children's services to adult services [47].

In the absence of well-established models for transition to adult ADHD care, Turgay and colleagues [35] proposed a longitudinal developmental Life Transition Model for ADHD detection and management, addressing patient and clinician awareness of changing environmental demands and the need for transition-focused plans and patient education. Planned cessation appears to yield more satisfactory outcomes than unplanned disengagement [33,34], so it may be beneficial for CAMHS to plan explicitly for the possibility that adolescents may disconnect from services, teaching adolescents to recognise symptoms and associated impairments [35]. Brief or motivational interventions, effective in paediatrics, may develop adolescents' self-control and involve them in shared decision-making [33]. As risk of unplanned disengagement is high with ADHD, the CAMHS-AMHS gap should be bridged particularly carefully where AMHS referral is proposed. Furthermore, where symptoms are controlled and cessation is warranted in adolescence, impairment may increase in the face of new young adult challenges [35]. Thus, service re-entry policies, preferably open-door, are strongly recommended [35-36,38], though this may be challenging in current structures.

Mental health service developments, e.g., extending CAMHS to age 25 or establishing adolescent-young adult services, clearly have a role to play. Integrated models of care, involving explicit links with primary care and shared care protocols, should also be considered, especially as ADHD is a relatively common issue among young people attending GPs [48]. Other options may include developing services in less stigmatised settings where substantial proportions of young people attend, such as further and higher education.

Finally, the study indicates that AMHS need to develop ADHD knowledge and services further. Comorbidity is the rule in adult ADHD [39] and untreated ADHD is high among AMHS attendees [9]. Not only does this cause individual impairment and distress, but also significant costs for society, established in the US (where health care costs account for only a quarter of total ADHD costs [49]) and in Denmark (where Danish Registry data indicate major costs are not in health care but sickness and early retirement benefits, traffic accidents and crime [50,51]). There is therefore a strong

economic argument for developing services with specialist expertise in working with adults with ADHD and (assuming that those experiencing most impairment will have been attending CAMHS) for optimising transition from CAMHS to AMHS. In Ireland, some very early-stage initiatives in services and development of psychiatrists' awareness are underway, such as the trialling of a dedicated ADHD clinic at one of Ireland's main universities [52], and the establishment of a College of Psychiatrists of Ireland ADHD Special Interest Group. However, as is the case elsewhere, almost no young people in Ireland with ADHD transfer from CAMHS to AMHS.

This study has begun the process of identifying characteristics of young people with ADHD as they approach the transition boundary. There is an urgent need to understand CAMHS clinicians' negative perceptions of referral with ADHD as well as, importantly, those of young people themselves. The broader question that then needs to be addressed is how ADHD treatment in adult services should be addressed, and whether there should be specific, standardised national policies and commissioning for such services.

References

- 1. Faraone SV, Biederman J, Mick E. The age-dependent decline of attention deficit hyperactivity disorder: a meta-analysis of follow-up studies. *Psychol Med* 2006; 36,2:159-65.
- 2. Young S, Gudjonsson G. Growing out of attention-deficit/hyperactivity disorder: The relationship between functioning and symptoms. *J Att Dis* 2008; 12: 162–169.
- 3. Bolea-Alamanac B, Nutt, DJ, Adamou M *et al*. Evidence-based guidelines for the pharmacological management of ADHD. Update on recommendations from the British Association for Psychopharmacology. *J Psychopharm* 2014; 28:179-204.
- 4. Wilens EG, Faraone SV, Biederman J: Attention deficit/hyperactivity disorder in adults. *J Am Med Assoc* 2004; 292: 61–623.
- 5. Dalsgaard S, Ostergaard SD, Leckman JF, et al. Mortality in children, adolescents, and adults with attention deficit hyperactivity disorder: a nationwide cohort study. Lancet 2015. doi:10.1016/S0140-6736(14)61684-6
- 6. Barkley RA, Fischer M, Edelbrock CS, Smallish L. The adolescent outcome of hyperactive children diagnosed by research criteria: an 8-year prospective follow-up study. *J Am Acad Ch & Adolesc Psych* 1990; 29:546-587.
- 7. Biederman J, Petty CR, Monuteaux MC *et al.* Adult psychiatric outcomes of girls with attention deficit hyperactivity disorder: 11-year follow-up in a longitudinal case-control study. *Am J Psych* 2010; 167:409-417.
- 8. Taylor E, Chadwick O, Hepinstall E, Danckaerts M. Hyperactivity and conduct problems as risk factors for adolescent development. *J Am Acad Ch & Adolesc Psych* 1996; 35:1213-1226.
- 9. Syed H, Masaud TM, Nkire N *et al*. Estimating the prevalence of adult ADHD in the psychiatric clinic: A cross-sectional study using the adult ADHD self-report scale (ASRS). *Ir J Psychol Med* 2010; 27: 195–197.
- 10. National Institute for Health and Clinical Excellence. Attention Deficit Hyperactivity Disorder:
 Diagnosis and Management of ADHD in Children, Young People and Adults (Clinical Guideline CG72)

- [Monograph on the Internet]. *National Institute for Health Care and Excellence, UK,* 2008. Available from URL https://www.nice.org.uk/guidance/cg72
- 11. Asherson P. Clinical assessment and treatment of attention deficit hyperactivity disorder in adults. *Exp Rev Neurotherapeutics* 2005; 5: 525–539.
- 12. Hughes, G Kavanagh G O'Hanrahan S, McNicholas, F. Clinical guidelines for adults with attention deficit hyperactivity disorder and their application to an Irish context. *Ir J Psychol Med* 2016 [online early]; DOI: http://dx.doi.org/10.1017/ipm.2015.62
- 13. Institutes of Medicine. *Investing in the health and well-being of young adults. Consensus Report*. [Monograph on the Internet] 2014. Available from URL http://iom.nationalacademies.org/Reports/2014/Investing-in-the-Health-and-Well-Being-of-Young-Adults.aspx
- 14. McGorry, P. Bates, T. & Birchwood, M. Designing youth mental health services for the 21st century: examples from Australia, Ireland and the UK. *Br J Psychiatry* Suppl 2013; 202: s30-s35.
- 15. McGorry PD. The specialist youth mental health model: strengthening the weakest link in the public mental health service. *Med J Aust Suppl* 2007; 187: s53–s56.
- 16. Singh S, Evans N, Sireling L, Stuart H. Mind the gap: the interface between child and adult mental health services. *Psychiatr Bull* 2005; 29:292–4.
- 17. Department of Health and Children. A Vision for Change: Report of the Expert Group on Mental Health Policy. [Monograph on the Internet]. Dublin, Ireland: Government Publications Office, 2006. Available from URL http://www.hse.ie/eng/services/publications/Mentalhealth/Mental_Health_A Vision for Change.pdf
- 18. McNamara N, McNicholas F, Ford T et al. Transition from child and adolescent to adult mental health services in the Republic of Ireland: an investigation of process and operational practice. *Early Interv Psychiatry* 2014; 8: 291–297
- 19. Tanner JL. Recentering during emerging adulthood: A critical turning point in life span human development. In: Arnett JJ, Tanner JL eds. *Emerging adults in America. Coming of age in the 21*st century. Washington, DC: American Psychological Association. 2006; 21-56.
- 20. Institutes of Medicine. *Investing in the health and well-being of young adults. Consensus Report*. [Monograph on the Internet] 2014. [Cited 8 Feb 2016.] Available from URL http://iom.nationalacademies.org/Reports/2014/Investing-in-the-Health-and-Well-Being-of-Young-Adults.aspx
- 21. Sibley MH, Kuriyan AB, Evans SW *et al.* Pharmacological and psychosocial treatments for adolescents with ADHD: An updated systematic review of the literature. *Clin Psychol Rev* 2014; 34: 218–232.
- 22. Nutt DJ, Fone K, Asherson P *et al*. Evidence-based guidelines for the management of attention-deficit/hyperactivity disorder in adolescents in transition to adult services and in adults: recommendations from the British Association for Psychopharmacology. *J Psychopharmacol* 2007 21(1): 10–41. doi: 10.1177/0269881106073219
- 23. Young S, Murphy CM, Coghill D. Avoiding the 'twilight zone': recommendations for the transition of services from adolescence to adulthood for young people with ADHD. *BMC Psychiatry* 2011; 11: 174-182.
- 24. Singh S, Paul M, Ford T *et al*. Process, outcome and experience of transition from child to adult mental healthcare: multi-perspective study. *Br J Psychiatry* 2010; 197: 305–312.
- 25. Islam Z, Ford T, Kramer T *et al*. Mind how you cross the Gap! The outcomes for young people who fail to make the transition from CAMHS to AMHS in the TRACK Study. *Psychiatric Bulletin* online 2015. doi: 10.1192/pb.bp.115.050690.
- 26. McNicholas F, Adamson M, McNamara N *et al*. Who is in the transition gap? Transition from CAMHS to AMHS in the Republic of Ireland. *Ir J Psychol Med* 2015; 32(1): 61 69
- 27. Beirne M, McNamara N, O'Keeffe G McNicholas F. Survey examining the views of Adult Psychiatry consultants and senior registrars regarding ADHD. *Ir J Psychol Med* 2013; 30: 197–203.
- 28. Health Products Regulatory Authority (nd). *Medicines* (updated list May 10 2016). https://www.hpra.ie/homepage/medicines

- 29. Coghill D. Services for adults with ADHD: work in progress. Commentary on . . . Specialist adult ADHD clinics in East Anglia. *Br J Psych Bulletin* 2014; 39(3); 140-143
- 30. Hall CL, Newell K, Taylor J *et al*. 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* 2015; 29(1): 39-42.
- 31. Singh SP, Paul M, Islam Z et al. Transition from CAMHS to Adult Mental Health Services (TRACK). A study of service organisation, policies, process and user and carer perspectives. Report for the National Institute for Health Research Service Delivery and Organisation programme. 2010. [Monograph on the Internet]. Available from URL http://www.nets.nihr.ac.uk/__data/assets/pdf_file/0010/64288/FR-08-1613-117.pdf Accessed 11.5.2016
- 32. McCarthy S, Wilton L, Murray M *et al*. Management of adult attention deficit hyperactivity disorder in UK primary care: a survey of general practitioners. *Health Qual Life Outcomes* 2013; 11(1): 22-33
- 33. McCarthy S, Asherson P, Coghill D, *et al.* Attention-deficit hyperactivity disorder: treatment discontinuation in adolescents and young adults. *Br J Psychiatry* 2009; 194:273–277.
- 34. Wong ICK, Asherson P, Bilbow A *et al.* Cessation of attention deficit hyperactivity disorder drugs in the young (CADDY). *Health Technol Assess* 2009; 13: 50-209.
- 35. Turgay A, Goodman DW, Asherson P et al. for the ADHD Transition Phase Model Working Group.

 Lifespan Persistence of ADHD:

 192-201.
- 36. Wolraich ML, Wibbelsman CJ, Brown TE, *et al.* Attention-deficit/ hyperactivity disorder among adolescents: a review of the diagnosis, treatment, and clinical implications. *Pediatrics* 2005; 115(6):1734–1746.
- 37. Moncrieff J, Timimi S. Is ADHD a valid diagnosis in adults? No. BMJ 2010; 340:547.
- 38. Swift KD, Hall CL, Marimuttu V *et al.* Transition to adult mental health services for young people with attention deficit/hyperactivity disorder (ADHD): a qualitative analysis of their experiences. *BMC Psych* 2013; 13: 1–11.
- 39. Kooij SJ, Bejerot S, Blackwell A *et al.* European consensus statement on diagnosis and treatment of adult ADHD: The European Network Adult ADHD. *BMC Psych* 2010; 10(1): 67-91
- 40. Health Service Executive. Fifth Annual Child and Adolescent Mental Health Services Report 2012–2013 [Monograph on the Internet]. Dublin, Ireland: Health Service Executive; 2013. [Cited 8 Feb 2016] Available from URL: http://www.hse.ie/eng/services/publications/Mentalhealth/camhsrpts/CAMHS12,13.pdf
- 41. McNicholas F, Skokauskas, N. Multicultural Issues in Child and Adolescent Psychiatry in Ireland. *Adolesc Psychiatry* 2013; 3 (1): 34-38
- 42. Skokauskas N, Dunne M, Gallogly A, Clark C. Ethnic minority populations and child psychiatry services: An Irish study. *Ch Youth Services Rev* 2010; 32: 1242–1245
- 43. Paul M, Ford T, Kramer T *et al*. TRACK: transfers and transitions between child and adolescent and adult mental health services. *Br J Psych* Suppl 2013; 202 (Suppl. 54): s36 –s40.
- 44. Lamb C, Murphy M. The divide between child and adult mental health services: points for debate. *Br J Psych* 2013; 202: s41–s44. doi: 10.1192/bjp.bp.112.119206
- 45. Meier R. Developing services to improve the quality of life of young people with neurodevelopmental disorders, emotional/neurotic disorders and emerging personality disorder. Royal College of Psychiatrists Occasional Paper OP77. 2011. London: Royal College of Psychiatrists.
- 46. Tuomainen H and the MILESTONE consortium. *The MILESTONE study: Strengthening transition from child to adult mental health care in Europe*. Poster presented at the STraMeHS European Youth Mental Health Conference: From Continuity of Psychopathology to Continuity of Care, Venice, Italy. 2014, December
- 47. Ford T Janssens A Asherson P et al. CATCh-uS: Children with ADHD in transition from children's services to adult services (Catch-uS): a mixed methods project using national surveillance, qualitative and mapping studies [Monograph on the Internet]. Southampton, UK: National Institute for Health

- Research; 2015 [Cited 8 Feb 2016]. Available from URL: http://www.nets.nihr.ac.uk/__data/assets/pdf_file/0006/155094/PRO-14-21-52.pdf
- 48. Connolly D, Leahy, D, Bury, G *et al*. Can general practice help address youth mental health? A retrospective cross-sectional study in Dublin's south inner city. *Early Interv Psychiatry* 2012; 6(3): 332-340.
- 49. Doshi JA, Hodgkins P, Kahle J *et al*. Economic impact of childhood and adult attention-deficit/hyperactivity disorder in the United States. *J Am Acad Ch Adolesc Psych* 2012; 51(10): 990-1002.
- 50. Dalsgaard S, Mortensen PB, Frydenberg M, Thomsen PH. Long-term criminal outcome of children with attention deficit hyperactivity disorder. *Crim Behav Ment Health* 2013; 23(2):86-98.
- 51. Daley D, Jacobsen RH, Lange A-M,, et al. Costing Adult Attention Deficit Hyperactivity Disorder. Impact on the Individual and Society. Oxford: OUP 2015.
- 52. Tatlow-Golden M, Neary M, Farrelly N et al. ADHD young adult service innovations: a combined child and adult psychiatry-led pilot university-based ADHD service. Eur Ch Adolesc Psych 2015; 24: S88-S89

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