Transition to adult care for patients with ADHD: the Australian experience

Attention deficit hyperactivity disorder (ADHD) persists into adulthood in at least 30% of cases.[1] Some individuals are only diagnosed in adulthood, and many are not diagnosed at all.[2] Difficulty accessing medical care for adults with ADHD appears to be an international problem.[3] In Australia, transition of older adolescents with ADHD to adult care is a major problem, and there is no uniform approach or standard process for referral to adult services. The Australian healthcare system presents some opportunities, but also some particular challenges, for developing innovative and equitable models of transition. In this paper, the challenges in achieving transition to adult care for patients with ADHD will be discussed, with a focus on the Australian system, and recommendations for assisting with transition and optimising support will be presented.

School counsellors and credentialled ADHD coaches can support adolescents in the transition to adult mental health services

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Adult ADHD

The impairments associated with ADHD shift as the individual passes through developmental stages, in response to increasingly complex environmental demands. Thus, although the neurobiological basis of ADHD is continuous from childhood, the symptoms and functional problems of ADHD in adults are different from those in children, as recognised now in the *Diagnostic and Statistical Manual of Mental Disorders,* fifth edition (DSM-5).[4] Some particular areas of difficulty for adults include organisational skills required for effective study, and impulse control and mood stability required to sustain social and romantic relationships. Adults with ADHD are often highly impaired by their persisting symptoms, and are at increased risk of a range of poor outcomes, including underemployment, relationship difficulties, crime and incarceration, motor vehicle accidents and mental health problems,[1,5] such as mood disorders and substance abuse. Therefore, if adults with ADHD continue to be symptomatic, it is important that they are able to access appropriate medical care.

Some older adolescents and young adults with ADHD continue to attend paediatric services until the completion of school and commencement of tertiary education or employment. However, there comes a point at which the paediatric setting is no longer appropriate and adult services should be accessed. Unfortunately, this transition is often difficult to achieve in most countries, including Australia.

Transition of older adolescents with ADHD to adult care is a major problem

The management for patients with uncomplicated ADHD is actually not difficult, but does require a doctor familiar with medications to treat ADHD, principally the stimulants and atomoxetine. However, many patients with ADHD have co-morbidities such as learning disorders, Tourette syndrome and autism spectrum disorders, which make their management more challenging. These patients require doctors with a broader skill set and experience base. There is some evidence from the UK that adult public mental health services are more likely to engage with patients with traditional mental health co-morbidities with which they are familiar; for example, depression or self-harm.[6] Finally, young adults with ADHD ideally should have available a menu of professional services, including medical, allied health, educational and coaching services.

The reasons for the difficulties in achieving successful transition to adult ADHD care are multiple and complex, and probably vary between countries with different cultures and healthcare systems. In the UK, poor communication between regional children's services (paediatric and mental health) and adult mental health services regarding ADHD patients has been described.[7] In a survey of 96 clinicians in five NHS trusts, a number of structural and workforce problems were identified, including insufficient training in ADHD for clinicians working in adult mental health services, no dedicated adult ADHD treatment clinics (as recommended in the National Institute for Health and Care Excellence guidelines),[8] and a lack of guidelines for transitioning to adult care. Although there have been no studies published examining the transition of patients with ADHD in Australia, it is likely that different barriers are operating in this country, given the fact that the majority of paediatric patients with ADHD are seen in private practice settings.[9]

There is currently no standard pathway or established process in Australia

The Australian experience

In Australia, it is challenging to find healthcare providers for adults with a range of developmental disorders, including ADHD. Paediatricians in both the public and private sectors find it difficult to identify doctors to whom they can refer their older adolescent and young adult patients with ADHD for ongoing care. A recent audit of Australian paediatricians' ambulatory practice found that new patients with ADHD were assessed up to age 19, and patients with ADHD were reviewed up to age 24, reflecting the difficulties for both referring GPs and paediatricians in finding adult providers for these young people.[9] The Royal Australasian College of Physicians guidelines on ADHD assert that 'As the presentation and challenges of ADHD change over time, clinicians must take a lifespan approach and follow patients closely, modifying their care and treatment according to the individual's present needs';[10] however, this is not easy to achieve given the demarcation between child and adolescent services and adult services, which are characterised by differences in structure, accessibility, expertise and culture.

The prescription of stimulant medication and atomoxetine is tightly regulated by the Australian government's Pharmaceutical Benefits Scheme, and generally restricted to paediatricians and psychiatrists. GPs are permitted to co-prescribe following assessment by a paediatrician or psychiatrist, and with annual review and oversight by the specialist; however, anecdotally co-prescribing is uncommon except for in remote regions in some states. Thus, it largely falls to psychiatrists to manage adult ADHD in Australia. This fact introduces a number of problems. First, many patients who have been attending a paediatrician ('a doctor for kids') for many years find the notion of seeing a psychiatrist ('a doctor for crazy people') uncomfortable. Furthermore, psychiatric training programmes in Australia have generally included little content on ADHD (or, indeed, on developmental or behavioural problems in general); therefore, many psychiatrists have limited expertise and experience managing ADHD. Finally, given the high prevalence of ADHD (the most common diagnosis in patients seen by Australian paediatricians),[11] and the fact that there are many more paediatricians than psychiatrists in Australia, the sheer volume of patients represents a service challenge. An additional problem in Australia is that many patients and families do not attend a regular GP, which can result in poor co-ordination of medical care.

In Australia, adult public mental health services are largely consumed with treating patients with severe disabling mental illness, and so have effectively no capacity to accept referrals of patients with ADHD, which is seen as a relatively low severity problem. Therefore, the main medical professionals involved in the treatment of adults with ADHD are psychiatrists in private practice. However, anecdotally only a minority of adult psychiatrists are interested in accepting referrals for the assessment and treatment of ADHD. Those who do treat ADHD face pressure to charge only the rebated fee, resulting in a substantial reduction in income. Waiting times to see a recognised ADHD specialist can reach six months for the initial assessment, and patients need to be made aware of this when they are given the referral recommendations. There are no publicly-funded specialist ADHD clinics for adults in Australia. There are a handful of private clinics with a focus on ADHD operating in major cities. These generally incur a substantial out-of-pocket cost to the patient for assessment and ongoing treatment, and some have unconventional treatment approaches; for example electroencephalogram biofeedback and nutritional therapies.

In summary, there is currently no standard pathway or established process in Australia for the transition to adult care for patients with ADHD, resulting in a real danger that this vulnerable group will get 'lost in transition'.

Practice recommendations

In the absence of a co-ordinated, multimodal treatment programme for adults with ADHD, the following strategies are recommended to assist in the transition from paediatric to adult services.

- Individuals with ADHD should be encouraged

to develop a relationship with a single **GP**, who can facilitate transfer of care and prevent young adults becoming lost in the transition. The GP can function as a consistent checkpoint for the patient. The possibility of co-prescribing in Australia creates an opportunity for GPs to take more responsibility for the treatment of ADHD, in the same way that they manage other conditions such as depression and anxiety. Some GPs in Australia are working closely with psychiatrists and up-skilling to this end.

- **Training for both GPs and psychiatrists** should include teaching about ADHD, as well as clinical exposure to patients with ADHD and related developmental disorders.
- **School counsellors** are one of the main professional groups consulted by Australian children and adolescents with mental health problems.[12] Among other roles, they facilitate the process of applying for final exam accommodations for students with ADHD. They are well placed to provide another valuable checkpoint by handing over students in their care to university disability departments. They can also play a role in smoothing the transition to adult mental health services.
- If young adults with ADHD move to higher education they tend to prioritise their ADHD treatment in order to study effectively. The tertiary education setting can provide a valuable transition checkpoint for young adults with ADHD. Psychiatrists should refer patients to **university disability services**, which offer valuable support for students with ADHD. On the recommendation of a psychiatrist, they are able to provide accommodations, which include extra time in assessments, the use of computers or voice-to-text software and assignment extensions, without penalties. They are often located in the same building as the university health centres which provide government-funded counselling and medical consultations for students in a convenient and non-threatening setting. In addition to support and accommodations, university disability services advocate on behalf of students, and teach them the skills required for self-advocacy.
- **Credentialled ADHD coaches** can provide valuable support for young adults with ADHD. They can assist in the development of life skills and self-advocacy in this group, who often reject parental input, but lack the maturity to function effectively without assistance. In addition, coaches can visit schools, tertiary institutions or workplaces to advocate on behalf of individuals with ADHD, consulting with the treating specialists beforehand, and conveying their recommendations.
- Families provide key checkpoints. Although older adolescent and young adult patients are entitled to confidential healthcare, **parental support** is usually necessary to help young adults negotiate the transition to adult care.[6] Of course, ADHD is a strongly genetic condition and so many parents are on the ADHD continuum themselves, which may limit their capacity to assist their young adult child in arranging services. In some cases with complicated issues, it can be helpful to access **family support services**.
- Finally, individuals (professionals or consumers) should take opportunities to highlight the problem in the **media**. This may potentially result in pressure for creative solutions; for example, training to accredit GPs to manage adult ADHD (analogous to methadone prescribing).

Declaration of interest
The authors declare that there is no conflict of interest.

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Key points

- The transition from paediatric to adult care is a major challenge for patients with ADHD in Australia.
- There are no publicly-funded specialist ADHD services for adults in Australia, so patients generally need to access psychiatrists in the private sector.
- GPs play an important role in the management of adults with ADHD, both in assisting with accessing specialist care and in providing shared care.
- The support of the families of adults with ADHD is often integral to achieving a successful transition.
- ADHD coaches can provide valuable support in relation to life skills, optimising educational engagement and adherence to specialist medical treatment.