Practitioner Review: Continuity of mental health care from childhood to adulthood for youths with ADHD: who, how and when?

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ABSTRACT

Many youths with attention-deficit/hyperactivity disorder (ADHD) experience significant long-term

impairment and may develop concurrent mental and somatic health difficulties as adults. This is

associated with burden and costs for the individual and society which could be prevented through

continued support in youth. Yet, only few young people transition to adult mental health services for

ongoing care in different countries worldwide. We provide an overview on current transition

practices, highlighting the gaps in knowledge and the barriers to effective service transitioning, while

considering the large geographical variation in available guidelines and service provision. For ease of

use, this review is organized in a question-and-answer format covering different aspects of the

transition process and considering both service users' and clinicians' perspectives. Consensus is

needed to identify those that require continued care, the optimal timing to arrange transition, and

the most suitable services. Finally, we discuss cost-effectiveness of transition practices, consider

examples of best practice, and propose recommendations on how to improve transitional care,

including the importance of service users' input into transition planning.

Keywords: ADHD; transition; service continuity

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INTRODUCTION

Psychiatric conditions are common in children and young people and often persist into adulthood. Such persistence has been associated with adverse consequences, including poor educational and professional attainment, social dysfunction, and lower economic status (Clayborne, Varin, & Colman, 2019; Gibb, Fergusson, & Horwood, 2010; Kessler et al., 2007). Discontinuation of care at the transition between adolescence and adulthood further increases the risk of poor outcomes (Gibb, Fergusson, & Horwood, 2010; Patel, Flisher, Hetrick, & McGorry, 2007). Although guidelines have been developed to define good transitional care (NICE, 2016), there are limited examples of effective transition in psychiatry services worldwide (McGorry, Bates, & Birchwood, 2013) and only one published randomized controlled trial of a transition intervention for young people with mental health needs (Singh et al., 2023). Youths with neurodevelopmental conditions especially those with attention-deficit/hyperactivity disorder (ADHD), are among the least likely to receive optimal transition support (Singh et al., 2021). Often they do not receive transitional care at all (Appleton, Connell, Fairclough, Tuomainen, & Singh, 2019) or are offered psychiatric care on an emergency basis or for co-occurring conditions only (Banaschewski et al., 2019; Janssens et al., 2020).

ADHD typically develops in childhood and is a lifelong condition with often poor long-term outcomes if untreated (Harpin, Mazzone, Raynaud, Kahle, & Hodgkins, 2016). There is a high co-occurrence with somatic diseases (Kittel-Schneider et al., 2022). Compared to adults without ADHD, for young adults with ADHD, the risk of developing comorbid mental health problems such as depression, anxiety and substance use disorders was found to be two to nine times higher in a recent metaanalysis (Hartman et al., 2023), and the odd ratio reaches as high as 15 for a behavioural disorder such as oppositional defiant disorder (Fayyad et al., 2017) and 20 for bipolar disorder (Hartman et al., 2023). Rates of suicide, suicidal behaviors, risky sexual behaviors and unplanned pregnancies are significantly increased in this population compared to individuals without ADHD (Impey & Heun, 2012; Owens & Hinshaw, 2020). Furthermore, adults with ADHD often report poor educational and employment outcomes, are at increased risk of family breakdown (Pitts, Mangle, & Asherson, 2015), and are significantly overrepresented in the criminal justice system (Young et al., 2011). As a result, ADHD has been associated with high costs for society, mainly related to healthcare, educational support, and income losses (D'Amico, Knapp, Beecham, Sandberg, Taylor, & Sayal, 2014; Doshi et al., 2012; Le et al., 2014). The high prevalence of co-occurring disorders in ADHD, the associated adverse consequences and socio-economic impact highlight the vulnerability of youths with ADHD as they step into adulthood and their need for continued support.

The need for ongoing ADHD care must be weighed against the cost-effectiveness of transition programs and risk of stigmatization. ADHD continues to be diagnosed in adults at rates lower than the estimated prevalence in most countries outside of the USA (Fayyad et al., 2017; Song, Zha, Yang, Zhang, Li, & Rudan, 2021). Thus, many adults remain undiagnosed and untreated (Ginsberg, Quintero, Anand, Casillas, & Upadhyaya, 2014; Raman et al., 2018), and low administrative rates might falsely indicate low demand for services. Also, despite evidence showing that available interventions may moderate the adverse consequences (Faraone et al., 2021), the use of ADHD medications declines considerably during the transition from adolescence to adulthood for those previously treated (McCarthy, Wilton, Murray, Hodgkins, Asherson, & Wong, 2012; Newlove-Delgado, Ford, Hamilton, Stein, & Ukoumunne, 2018), aggravating the risk of poor outcomes and the associated costs. An earlier guidance on transitional care for individuals with ADHD is available (Young et al., 2016) and further recommendations for optimal transition emerged from an in-depth study of service transition for individuals with ADHD in the UK (Janssens et al., 2020). However, significant gaps remain in adult ADHD care provision, implementation of transition protocols, and guidance on how to identify those with ADHD that may most benefit from transition. As a result, clinicians may struggle to identify the right support, and young people and their families may feel unsupported at this critical time.

In this review, based both on literature search and expert consensus, we provide an update on service transition processes for young people with ADHD. We describe both the population-specific and institutional factors that contribute to generating the current gap in care and give guidance on how this can be improved. As the literature on transition of care in ADHD is still limited, we also consider evidence generated for other mental health conditions when meaningful.

METHODS

The International Scientific Board of Experts on ADHD (ISBEA) hosted an expert workshop entitled "Transition of ADHD Patients from Adolescence to Adulthood: A Practical Approach" in Edinburgh, Scotland, September 2018. This was to facilitate discussion on the need and provisions for continued care for individuals with ADHD at the age boundary between child and adult mental health services. The workshop was attended by experts in ADHD, working across child and adult services, and experts in transitional psychiatry. It consisted of a series of presentations summarizing the transition process from the perspective of these experts. We then generated a list of questions regarding the management of transition from child and adolescent mental health services (CAMHS) to adult

mental health services (AMHS) for individuals with ADHD. Published articles and current guidelines on transitional care in ADHD and other conditions were subsequently selected based on expert knowledge. Here, we summarize evidence and experts' views for each of the identified questions around transition and, where possible, present both service users' and clinicians' perspectives. Figure 1 shows a summary of the guidance emerging from the review.

RESULTS

Is transition needed for all young people with ADHD?

Service users' perspective

When discussing transition to adult services with youths with mental health conditions, clinicians need to explore the young person's 'developmental readiness' on becoming an adult and having a condition to manage, and their views on the level of support they may need from parents, educational and mental health services (McNamara, Coyne, Ford, Paul, Singh, & McNicholas, 2017). The levels of autonomy perceived by the young person and his/her development of an adult identity have been reported to contribute to the decision to initiate the transition process (McNamara et al., 2017; Merrick, King, McConachie, Parr, & Le Couteur, 2020).

As for ADHD, evidence confirms the importance of including the views of the young person on the need for transition and provide them with psychoeducation against stigma towards ADHD in adulthood (Janssens et al., 2020; Matheson et al., 2013; McNicholas et al., 2015; Swift, Hall, Marimuttu, Redstone, Sayal, & Hollis, 2013). Interestingly, one study reported that youths with ADHD viewed continued mental health care as unnecessary (Swift et al., 2013). This finding might indicate a lack of awareness of the persisting nature of the condition and the associated negative adult outcomes, as also supported by the results of the Children and Adolescents with ADHD in Transition between Children's and Adult Services (CATCh-uS) project (Janssens et al., 2020): whilst parents anticipated the need for continued support in adulthood, young people did not envisage needing ADHD medication past school age. However, their view changed with age and, once being adults, they also advocated for service provision and expressed frustration that pharmacological interventions were the only treatment option offered in most services (Janssens et al., 2020; Reale, Frassica, Gollner, & Bonati, 2015).

Clinicians' perspective

We were not able to identify clear guidelines to determine who with ADHD should be transferred from CAMHS to AMHS. A seminal meta-analysis showed that up to 65% of those diagnosed with ADHD in childhood experience persistent impairing symptoms in adulthood (Faraone, Biederman, & Mick, 2006). In a recent investigation, nearly 64% of people with childhood-onset ADHD displayed fluctuating presentations over time, with full or partial re-occurrence of symptoms even after apparent full remission (Sibley et al., 2022). Given the high persistence rates and the negative impact of symptoms in adult life, many youths with ADHD are likely to benefit from continued care. This however contrasts with current clinical practice. In the UK, a surveillance study examined the incidence rate of transition need and completion for young people with ADHD aged 17-19 years and in need and willing to continue taking an ADHD medication at the time of transition (Eke, Ford, et al., 2020). The analysis estimated that between 202 and 511 per 100,000 people in this group aged 17 to 19 years need transition (incidence rate adjusted for nonresponse), but only 38 to 96 per 100,000 complete this successfully (Eke, Ford, et al., 2020). Using prescription rates as a proxy of ADHD service provision, although there is heterogeneity in these rates across countries, figures clearly indicate a significant drop in care for youths with ADHD once they reach adult age worldwide (Bachmann, Philipsen, & Hoffmann, 2017; McCarthy et al., 2009; Newlove-Delgado et al., 2018; Raman et al., 2018). Further, when pharmacological treatment is interrupted during transition, only few individuals restart medication for their ADHD in adulthood (Farahbakhshian et al., 2021; Newlove-Delgado, Ford, Hamilton, Janssens, Stein, & Ukoumunne, 2019). The reasons for this are diverse and will be discussed below, but certainly the lack of recognition of ADHD by most AMHS worldwide (Goodman, Surman, Scherer, Salinas, & Brown, 2012), and differences in priorities or funding between CAMHS and AMHS (Hall, Newell, Taylor, Sayal, Swift, & Hollis, 2013) are thought to be contributing factors.

Regarding the clinical decision to refer a young person to AMHS for continued care, prior studies have indicated that youths with more severe ADHD symptoms, emotion dysregulation, psychiatric comorbidities and low everyday functioning, as well as those on ADHD medication, were more likely to be transferred to adult services (Girela-Serrano et al., 2023; Merrick et al., 2020). Conversely, those diagnosed with ADHD only were the least likely to be transferred to AMHS and were discharged or stayed in CAMHS as long as possible (Girela-Serrano et al., 2023). When planning service transition for a young person with ADHD, clinicians also need to be aware that perceived

family support as rated by parents was greater in youth with ADHD who did use AMHS at transition than in those who disengaged from services or only later returned to AMHS (Girela-Serrano et al., 2023).

When should we transition care for those with ADHD and where should they transition to?

Service users' perspective

The age at which an adolescent is considered an adult varies according to cultural and societal norms, as well as contextual factors, including access to education, living space, and employment. The psychological and physiological maturity of the individual and the presence of neurodevelopmental conditions can also affect their level of independence from caregivers. For instance, in a feasibility study of a transition support program, youths with ADHD and/or ASD identified a need for support with achieving independence, especially in day-to-day and financial responsibilities (Jonsson et al., 2021). The timing of service transition in turn is affected by these factors and whether the individual feels ready to initiate formal transition and manage their own health independently at the age boundary between services. There might be reluctance to leave a trustful and effective ongoing service provision, or young people may struggle to realize that their ADHD may need long-term clinical attention at the time of approaching adulthood. Those with ADHD may not see transition as needed (Swift et al., 2013) and only realize they are still in need of support once they have become adults (Janssens et al., 2020; Reale et al., 2015).

In terms of where a referral should be made, service users described a paucity of information of ADHD services available in their local area and reported unevenly distributed service provision across localities (e.g., in the UK, see Price et al., 2020). Youths and carers also highlighted that most clinical services focus on diagnostic assessments and medication, and do not provide the full range of treatments recommended for the management of ADHD in adults (e.g., including behavioral therapies, Reale et al., 2015).

Further guidance on the young people's preferences around the timing and destination of transition emerges from studies on transition for youths with a range of mental health conditions, including ADHD. Delayed discussions of the need for transfer can cause distress for youths and their families. Those who went through the transition process often reported that this started too late (Hovish, Weaver, Islam, Paul, & Singh, 2012; Jivanjee, Kruzich, & Gordon, 2009), and was aggravated by long

waiting times to be seen by AMHS (Gilmer, Ojeda, Leich, Heller, Garcia, & Palinkas, 2012). Investigations on service users' perspectives indicate that transition should be experienced as 'needed' and occur at a time of stability in the individual's life (and thus not during a psychiatric or psychosocial emergency), and according to their development and independent-living skills (Butterworth et al., 2017; Singh et al., 2010). They also highlight the importance of timely and sufficient preparation, and their need to be part of the discussion on the best service moving forward (Thompson, Bolte, Falkmer, & Girdler, 2018). Finally, they express the need for support in the practical preparation to adulthood, employment advice and advocacy (Butterworth et al., 2017; Singh et al., 2010), which may be offered by voluntary agencies instead of AMHS.

Clinicians' perspective

Typically transition planning for general mental health care becomes topical when adolescents reach the age of 16 to 18 years (Lamb, Hall, Kelvin, & Van Beinum, 2008; Singh, Paul, Ford, Kramer, & Weaver, 2008). The planning, management and funding of service provisions, rather than clinical need, appear to remain the main triggers for a transition to AMHS (Signorini et al., 2018). In ADHD care, this is despite clinicians' awareness that age *per se* does not represent an appropriate indicator for readiness of transition and a more flexible approach to timing of transition would be most appropriate (Price, Janssens, Woodley, Allwood, & Ford, 2019; Swift et al., 2013). Regarding the optimal timing of transition for those with ADHD, Young et al (2016) suggested starting early. Conversely, Yassaee et al (2019) concluded that a late transfer could constitute a simple but effective means of improving transition and lead to stable clinical outcomes for youths with chronic conditions including mental health disorders. Compromising between these apparently contradictory views, it may indeed be appropriate to start planning in early- to mid-adolescence but to delay actual transition until after other key transitions, e.g., from school to college or work, have been completed.

Clinicians also express uncertainty regarding which services are best suited to provide support for young adults with ADHD (i.e., community vs. specialist services) (Reale et al., 2015; Young et al., 2016). Only few services provide the recommended interventions for the management of ADHD in adulthood and services may not be available in all localities (Janssens et al., 2020). Beyond ADHD care, it has been noted that often CAMHS practitioners do not refer to AMHS as they hold the belief that they will not accept the referral or have the appropriate resources; and that AMHS might be more open and qualified to treat other psychiatric diagnoses than ADHD and neurodevelopmental

conditions (Bailey, 2003; Singh, 2009). Overall, transition to AMHS remains rare and often poorly managed for youths with ADHD (McNicholas et al., 2015; Singh et al., 2010). They may be referred by their general practitioner at a later stage due to worsening mental health or the emergence of comorbidities (Girela-Serrano et al., 2023), or access AMHS via the criminal justice and social care systems (Dalsgaard, Mortensen, Frydenberg, & Thomsen, 2002; Richards & Vostanis, 2004).

What factors prevent continuity of care for young people with ADHD?

Service users' perspective

Qualitative studies on transition processes completed by individuals with ADHD suggest that lack of adequate preparation, changes in clinicians and poor relationships with the clinician led to a poor transition experience or disengagement (Reale et al., 2015; Swift et al., 2013). Poor information on what to expect from adult services, lack of adult services with experience in ADHD and shared transition planning can also hinder the process (Price et al., 2019; Swift et al., 2013).

Adult mental health services often expect young adults to manage their healthcare independently and are reluctant to involve parents in their child's care. This poses an additional risk of disengagement with the transition process. Parents of those with ADHD often would like to be more involved (Janssens et al., 2020; Singh et al., 2010) and in recent studies youths with ADHD commonly accepted the need for ongoing parental support (Price et al., 2019; Swift et al., 2013). Conversely, some young people might prefer for their parents to not be involved (Singh et al., 2010; Swift et al., 2013), and it is important to consider their preference during transition planning (Young et al., 2016). Nevertheless, both youths and parents may struggle navigating the care system due to poor coordination between services, and a lack of information on the services and support offered (Janssens et al., 2020; Paton & Hiscock, 2019; Reale et al., 2015). Finally, in a qualitative study examining data from the CATCH-uS cohort, young people and their families noted that discharge from CAMHS or transition to adult care may occur while the young person is still in education, highlighting the danger of disjointed planning between education and mental health services (Benham-Clarke et al., 2021).

Clinicians' perspective

The lack of service provision for adult ADHD often means that affected adolescents are discharged from CAMHS to their general practitioner or continue to receive care in CAMHS beyond the age of 18 years, which limits child services' capacity to address new referrals (Maurice et al., 2022; Newlove-Delgado, Blake, Ford, & Janssens, 2019). The Transitions of Care from Child and Adolescent Mental Health Services to Adult Mental Health Services (TRACK) study, a questionnaire survey of Greater London CAMHS, showed that people with ADHD, as well as those with other neurodevelopmental disorders, are most likely to fall through the transition gap (Islam et al., 2016). This study identified several barriers, including lack of clarity about service eligibility, the young person or the carer refusing a referral to AMHS, and differences in working culture (e.g., CAMHS practitioners critical of the medical AMHS model, AMHS professionals skeptical about the validity of ADHD in adulthood). A 28-country survey across European services showed similar results (Signorini et al., 2018): irrespective of type of diagnosis, the lack of connection between CAMHS and AMHS was the most common obstacle to transition (n=23/28; 82%), followed by the lack of specific competencies about adolescents in AMHS and differences in service culture. The same survey highlighted that only few countries adopt formal policies and guidelines around transition, leading to high heterogeneity in how transition processes are implemented (Signorini et al., 2018). In most European countries, CAMHS and AMHS are separate healthcare providers without national guidelines or policies for transition planning, and services do not have access to dedicated funding to support transitional care (Signorini et al., 2018). In addition, formal training on transition is limited during psychiatry training across European countries (Hendrickx et al., 2019; Russet et al., 2019). An essential step to address these issues was the publication in 2016 of the UK national guidelines NICE to facilitate transitions between child and adult health and social services. Their overarching principles around transition and post-transition care are relevant for all durable conditions, including ADHD (NICE, 2016).

The ADHD-specific UK national guidelines issued by the NICE (2018) also recommend training on ADHD for both child and adult psychiatrists. Yet, insufficient knowledge about adult ADHD has been associated with the reported reluctance to confirm an ADHD diagnosis, diagnostic over-shadowing, and a focus on other mental health problems (Asherson et al., 2022; Maurice et al., 2022). Often there is reported stigma for those who seek a diagnosis in adulthood (Asherson et al., 2022), and concerns related to the individuals' reliability to attend appointments and adhere to treatments (Eke, Janssens, et al., 2020; Soendergaard et al., 2016), which further depletes the already limited resources (Eke, Janssens, et al., 2020). Ultimately, gaps in knowledge about treatment options,

coupled with reservations about difficulties with adherence and risk of substance abuse, may hinder the continuation of initially effective treatments set in CAMHS. In a survey carried out in the USA, most health professionals involved with young adults were reluctant to prescribe stimulants because of concern about their possible diversion or abuse (Loskutova, Waterman, Callen, Staton, Bullard, & Shields, 2020). Another specific obstacle to CAMHS—AMHS transition in ADHD is the off-label status of stimulants in some countries as this was the case until recently in France (Chappuy, Boulanger, Nourredine, Fourneret, & Rolland, 2020). Thus, a successful transition is much more unlikely, especially in the case of inadequate handover. Finally, it was highlighted that assessments and management of adult ADHD may sit predominantly within specialized centers, thus limiting access to diagnosis and treatment, which instead are provided in primary care for other mental health disorders (Asherson et al., 2022).

What is the cost-effectiveness of a continuity of care model for young people with ADHD?

Although there is yet limited information on the associated costs of ADHD and its possible negative outcomes (e.g., including poor social, occupational and health outcomes), ADHD has also been associated with high costs for society. It has been estimated that adult ADHD has an average annual incremental cost of \$204 billions (e.g., in USA) and an individual lifetime cost of £100,000 (e.g., in UK), mainly related to educational support, healthcare, and income losses (D'Amico et al., 2014; Doshi et al., 2012). For Australia, one of the countries where relatively few adults with ADHD are currently receiving treatment, a recent analysis calculated the total cost of ADHD as US\$12.76 billion a year; costs were related both to health losses and financial costs, and productivity costs made up 81% of the total financial costs, totaling US\$6.0 billion in 2019 (https://aadpa.com.au/the-social-and-economic-costs-of-adhd-in-australia/). There are therefore -strong economic arguments for ensuring that young people with ADHD are effectively supported to remain in care when needed and for strengthening services that manage adults with ADHD. Effective transition protocols should be a cornerstone of such an approach.

There are some available guidelines on optimal service transition from child-adolescent to adult services across all specialities (NICE, 2016), and some indication of optimal service transition in ADHD care in the ADHD guidelines (NICE, 2018). However, there are not yet established models on how to effectively organize transition to adult services for young people with mental health needs (Embrett, Randall, Longo, Nguyen, & Mulvale, 2016; Paul, Street, Wheeler, & Singh, 2015). In their systematic review of studies on the effectiveness of different CAMHS—AMHS transition models, Paul

and colleagues (2015) were unable to identify evidence to support the superior effectiveness of any particular model. However, some examples of cost-effective protocols are emerging. A quality improvement project in the UK showed that the implementation of an ADHD-specific transition clinic with a streamlined transition process facilitated young people's engagement, reduced burden on services and wait times for the first appointment with adult services (Moosa & Sandhu, 2015). A more recent example comes from a randomized controlled trial conducted across European countries with families of youths with a range of mental health and neurodevelopmental conditions (Singh et al., 2021). The authors tested the effectiveness of a managed transition protocol which involved the family in the decisions, included assessment of readiness, needs and preferences for transition, and cross-service liaison (Singh et al., 2021). The results showed superiority compared to care as usual, modest improvement on youths' mental health, and that this protocol could be implemented at low cost (e.g., € 17 to 63 per service user) (Singh et al., 2021). In the trial, the implementation of the managed transition protocol also did not show a substantial cost impact for the services taking over the care post-transition (Appleton et al., 2023).

How to manage transition?

Service users' perspective

For general mental health service transition, studies that included service users and carers' perspectives highlighted the need to tackle stigma and provide accessible, age-appropriate care (Paul et al., 2015). Similar findings were reported in a systematic review of qualitative studies examining the experiences of transitioning from child to adult ADHD services (Price et al., 2019). Emergent themes on what might facilitate transition centered on the importance of providing information to young people about adult services and what to expect, greater flexibility around age boundaries and the value of support from specialist adult ADHD services. In a recent editorial, Ford (2020) highlights that young people with ADHD "need help negotiating the transition from passive recipient of care to active self-management, and in building relationships with the adult team" early in their journey through CAMHS. This is true for all young people with mental health problems but perhaps even more for those with ADHD, as the associated impulsivity, emotional lability and cognitive difficulties may hinder abilities to manage healthcare and advocate for needs. A qualitative analysis of interviews conducted with families of those with ADHD revealed that parents indeed anticipate their children's limited advocacy skills and the need to support them in pursuing care (Janssens et al., 2020). As people with ADHD struggle with organization and forgetfulness, involving

their carers is also expected to help their engagement with the transition process itself (Maurice et al., 2022; Price et al., 2019).

Clinicians' perspective

Studies that have analysed the clinicians' perspectives seem to agree with the views expressed by young people that optimal transition from child to adult services requires continuity, joint care, planning meetings and information transfer, as well as using person-centered approaches (Maurice et al., 2022; NICE, 2016; Young et al., 2016). Clinicians interviewed as part of the CATCH-uS study emphasized the importance of information sharing for clinicians, e.g., on the young person's needs and available services, and for service users, e.g., about the transition process and self-management (Price et al., 2022). To facilitate a smooth transition and handover, the employment of health and social care case managers working across services has been recommended (NICE, 2016, 2018). Case/transition managers are not yet available in 57% of EU-countries and generally follow-up ends once transition to AMHS has occurred (Signorini et al., 2018). In an initial report of a USA-based randomized controlled trial of a transition programme for youths with mental health needs, clinicians found that providing services in the community and the support of mentors with lived experience (e.g., including the teamwork) was helpful in keeping young people and their families engaged in the process (Cole et al., 2023). Based on ongoing work aimed at improving understanding of the experiences of those dealing with mental health problems (Amering, Mikus, & Steffen, 2012), consideration should also be given to the benefits of involving youths and their carers in a trialogical discussion with clinicians about their care moving forward.

Premature discontinuation of ADHD treatment and disjointed care could be prevented with the introduction of clear transition protocols, that are currently lacking in many countries or localities (Hall, Newell, Taylor, Sayal, & Hollis, 2015; Signorini et al., 2018; Zadra et al., 2020). However, even where guidelines exist (e.g., NICE, 2016, 2018, in England and Wales), it is unclear how effectively they are being implemented. For instance, Eke et al (2020) observed that in the UK only a small proportion of those with ADHD identified as needing transition were successfully transferred to AMHS: although 64% of referrals were accepted, only 22% youths attended their first appointment and 6% had optimal transition. Further, in a UK-based qualitative study clinicians' consensus was that clear local protocols would facilitate professionals' knowledge and implementation of the existing guidelines, and that dedicated resources are required to implement guidelines effectively (Eke, Janssens, et al., 2020).

Transition is not only managed between mental health providers. Most published literature on transition for those with ADHD focusses on the transfer from CAMHS to AMHS, with very little attention paid to transition from pediatric care to AMHS. This transition is potentially more complex as pediatricians are less likely to have existing links with adult mental health services. Also, youths may feel confused as to why their ADHD, emphasized as a neurodevelopmental condition by the pediatrician, now falls under the remit of mental health services. Thus, better links between the services for children/youth and adults are needed.

While in some countries (e.g., Canada) much of the ADHD care for youths and adults is provided in primary care settings, in others (e.g., UK and Australia) this is less common (Newlove-Delgado, Blake, et al., 2019). For example, in England and Wales as well as in Italy, guidelines recommend that general practitioners only prescribe ADHD medication under a shared care agreement with specialist services (NICE, 2016, 2018; Panei et al., 2008). In Australia a recent government inquiry has recommended that services look at models to increase the involvement of general practitioners and nurses in the management of ADHD

(https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/ADHD/R eport/List_of_recommendations). Due to the limited adult ADHD care provision provided by specialist mental health care services, often general practitioners become the case managers 'by default' (Asherson et al., 2022), but understandably, they report feeling untrained and poorly skilled in managing these cases on their own. This was also highlighted by many submissions to the recent Senate Inquiry in Australia (*Community Affairs References Committee, Assessment and support services for people with ADHD*, 2023). Primary care services respond by trying, often unsuccessfully, to identify suitable specialist services and, when this fails, can be faced with a difficult decision about whether to continue ADHD prescribing (Newlove-Delgado, Blake, et al., 2019). Greater integration and support of primary care providers in the care of transition-aged youths with ADHD should be considered, and further study on primary care provision for young people with ADHD is ongoing at least in some countries (e.g., in England, see Price, Smith, Mughal, Salimi, Melendez-Torres, & Newlove-Delgado, 2023).

FINAL REFLECTIONS AND CONCLUSIONS

There are known significant gaps in transitioning from **child and adolescent** to adult services for those with mental health needs. However, those with ADHD fare particularly poorly, even though

pharmacological and non-pharmacological interventions are well established and have been shown to significantly improve outcomes (Coghill, 2017).

There are no specific guidelines on how to identify who should be transferred to AMHS and the optimal age for transition, and there are concerns related to availability of specialist adult ADHD services in most countries. The current evidence examining both institutional and service users' perspectives however overall indicates that clinical judgement on clinical severity and needs, combined with the young people's and their carers' views are paramount to a successful and positive transition experience. To inform the transition process, cooperative discussions should be held to identify the need (e.g., whether to transition), the mode (e.g., parental involvement, forms of support in adulthood) and timing of transition, as well as whether agencies other than mental health providers are best suited for their needs.

While parental support is important for many young people with ADHD, this is not available to all, which can result in significant inequalities. Young people without good social and parental support are likely to struggle more, due to the lack of support and potentially other disadvantages such as having to adapt to new social and health care environments while moving out of their home. It is important that clinicians nurture and support the development of other supportive relationships and consider these difficulties when discussing and arranging transition.

There is increasing recognition of **a** need to develop and/or equip existing adult services with the necessary workforce and skills to address this gap in care, as well as to improve the coordination among CAMHS and AMHS (Banaschewski et al., 2019; Maurice et al., 2022). Better coordination is also needed with health care providers beyond mental health services, such as pediatrics and general practitioners, as these often carry out a large part of the ADHD care prior or after transition (Asherson et al., 2022; Newlove-Delgado, Blake, et al., 2019). Finally, people with ADHD often access other services, from education to social services, thus a better coordination among agencies is recommended (Ford, 2020).

It is becoming clear that differences in the conceptual and clinical understanding of ADHD between CAMHS and AMHS, the different settings and protocols, as well as separate financial arrangements and remits represent barriers to providing a smooth transition for individuals with ADHD. Developing adequate protocols and appropriate service infrastructure, strengthening the dialogue between child and adult mental health services, and allocating dedicated funding to transitional care have been identified as pivotal strategies moving forward (Banaschewski et al., 2019).

Finally, there is still much to learn about how to manage service transition most effectively and efficiently for those with ADHD and there is only preliminary evidence describing on the cost-effectiveness of transition protocols. We have very little knowledge about how effective transition is for publicly funded services in countries outside the UK or for those where healthcare for ADHD is primarily or exclusively conducted within the private sector. There remain debates on what are optimal and cost-effective models of care across the transition period, and on the advantages of delivering continued ADHD care through general mental health providers over establishing specialist services (Ford, 2020). The advantages of transition clinics or all-ages ADHD services also remain understudied. It has been suggested that, similar to the efforts seen in CAMHS and community pediatrics over the last decades, adult ADHD services should employ evidence-base pathways including multi-professional and multi-agency work, stepped care and shared care approaches (Coghill, 2017; Ford, 2020). Overall, ensuring appropriate training and experience to those delivering ADHD care across child and adult services, alongside adequate funding to support clinicians' capacity and availability, is thought to be essential for a successful implementation of ADHD transition protocols (Coghill, 2017; Ford, 2020).

Conflicts of interest:

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Figure 1

