Bridging the gap:

Optimising transition from child to adult mental healthcare

An Expert Policy Paper on the challenges associated with transition from child/adolescent to adult mental health services: practical policy recommendations to drive improvements—taking attention-deficit hyperactivity disorder (ADHD) as an example.

Authors (in alphabetical order): Philip Asherson (King's College London, UK); Andrea Bilbow, OBE (ADHD Europe); Kate Carr-Fanning (ADHD Europe); Frédéric Destrebecq (European Brain Council); Geert Dom (European Psychiatric Association); Silvana Galderisi (European Psychiatric Association); Dolores Gauci (GAMIAN-Europe); Marc Hermans (Mechelen, Belgium); Tony Lloyd (ADHD Foundation, Liverpool, UK); Ann Little (European Federation of Neurological Associations); Fulgencio Madrid (University of Murcia, Spain); Kuben Naidoo (Mersey Care NHS Foundation Trust, Liverpool, UK); J. Antoni Ramos-Quiroga (Universitat Autónoma de Barcelona, Hospital Universitari Vall d'Hebron, Spain); Donna Walsh (European Federation of Neurological Associations); Spyros Zorbas (European Federation of Associations of Families of People with Mental Illness)

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Foreword:

Improving the transition of care to adult mental healthcare

Transition of care, which is the process of planning, preparing and moving a patient with a mental health condition from child to adult mental health services, is vitally important in determining patient outcomes. It is recognised that transition of care in mental health services can be problematic for patients and is an area requiring improvement. Studies have shown that poor transition in the area of mental health leads to disengagement from services, with some young people at risk of falling through the care gap during transition. However, successful transition of care can improve recovery and reduce overall long-term healthcare costs.

Initiatives, such as the MILESTONE project in the EU, are beginning to focus on issues of transition, but there remains a pressing need to ensure that patients about to enter the transition phase are adequately supported now. Therefore, we consider this a timely opportunity to bring together expert clinicians (psychiatrists and neurologists), patient representatives, academics and mental health advocacy groups to explore the reasons why transition of care is currently suboptimal and to agree a roadmap for driving improvements in this important area. We are grateful to Shire for their support in initiating and funding this initiative.

This Expert Policy Paper and the recommendations it contains were agreed upon by a group of key experts with an interest in improving the mental health outcomes of patients in Europe. Attention-deficit hyperactivity disorder (ADHD) is often considered as one of the most neglected and misunderstood psychiatric conditions in Europe, and one in which transition issues are widespread, and for this reason has been taken as an example, illustrating what needs to be done in the most practical way.

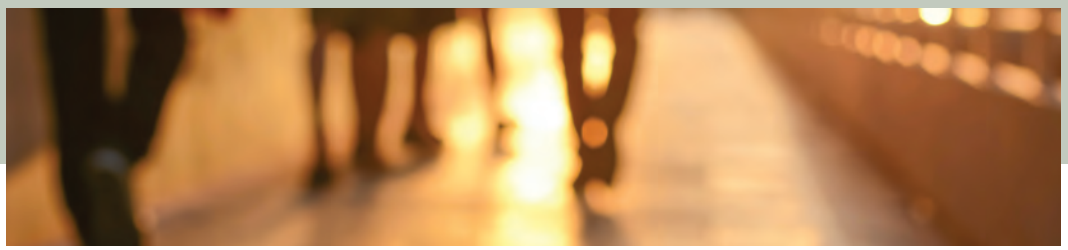
In our roles as Presidents of GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks) and of the European Brain Council (EBC), we endeavour to appraise mental healthcare provision in Europe on a regular basis, highlighting successes and identifying areas where improvement is required. It is our belief that this Policy Paper provides timely, practical and relevant policy recommendations that, if implemented, will help improve patients' transition to adult mental healthcare services across Europe.

Signed

Hilkka Kärkkäinen
President
GAMIAN-Europe

David Nutt
President
European Brain Council

Introduction



Transition to adult services is often a difficult time for young people living with a mental health condition. The journey through adolescence into adulthood is a time of significant physical, psychological and social change not only for the adolescent, but also their families. Overall rates of mental health problems can also increase during adolescence and issues become more complex, and in some cases serious disorders such as psychosis may emerge. During this period, adolescents may also have a greater tendency for risky behaviour, become lost in the system between child and adult mental health services and are also at greater risk of disengagement from services.[1]

This Expert Policy Paper was developed on the basis of an Expert Working Meeting on Mental Health and Transition, held in Brussels on 11 July 2017. The meeting brought together expert clinicians (psychiatrists and neurologists), patient representatives, academics and mental health advocacy groups to explore the reasons why transition of care is currently suboptimal,[2] discuss and agree on the principles for good transition and develop practical recommendations for improving transition to adult mental healthcare services. The group included expert stakeholders from the field of transition of care, mental health in general and attention-deficit hyperactivity disorder (ADHD).

The Expert Working Group highlighted that the problems associated with transition from child to adult services are not disease-specific; they apply to all mental health disorders, for example, epilepsy, autism and social phobia. However, to identify practical policy solutions, the Expert Working Meeting focused on ADHD as a case study in the analysis of the problems, barriers to change and potential solutions associated with transition of care.

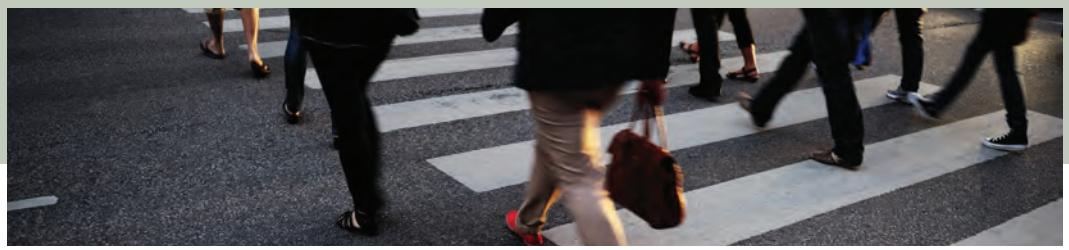
ADHD is a diverse condition characterised by symptoms of inattention, hyperactivity and impulsivity that can have a significant impact on patients' lives.[3,4] ADHD is relatively common[5,6] and often persists into adulthood.[7-10] Despite this, access to adult ADHD services and support is generally poor, resulting in frequent gaps in care.[2,11] For these reasons, ADHD provides an example in which to frame transition to adult services across the mental health sector.

Chapter 1 will provide information on what transition of care means and why it is so important for mental health services. The principles underpinning 'successful transition' will also be explored.

Chapter 2 will take a closer look at the key barriers to successful transition in the context of ADHD.

Chapter 3 will provide recommendation for improving transition services in the context of ADHD.

Executive Summary



This Expert Policy Paper aims to inform European and national-level stakeholders and policy makers on the importance and need for successful transition from child to adult mental healthcare services, to identify factors confounding this process and to make recommendations for improvement. The recommendations outline the best possible process of transition and the steps, as agreed by the Expert Working Group, that should be taken into account by policy makers and healthcare systems to make good transition a reality.

Chapter 1: Principles of successful transition from child and adolescent to adult mental healthcare services

- Transition of care is the process of planning, preparing and moving a patient with a mental health condition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS).
- Many young people do not transition smoothly to AMHS, due in part to a lack of flexibility in age of transition and the availability of adult services.
- A best-practice transition pathway needs to identify problems and provide solutions for:
  - Diagnosis and awareness of the condition
  - Ownership and accountability for patients
  - Provision and accessibility of mental health services
  - Management of mental health services.

Chapter 2: Barriers to successful transition – the example of ADHD

- ADHD is common in children and adolescents and persists into adulthood. Despite this, access to adult ADHD services is often poor, resulting in frequent gaps in care during transition.
- Several barriers to successful transition can be identified. Although discussed here in the context of ADHD, these issues are broadly applicable to other mental health conditions:
  - Timing of the transition from CAMHS
  - Availability of care
  - Differences in practices and culture between CAMHS and AMHS
  - Poor adherence to medication
  - Lack of ownership and accountability of care in the transition process
  - Social stigma of mental health issues.

Executive Summary

Chapter 3: Recommendations for improving transition to adult mental healthcare services for patients with ADHD

- Based on the barriers identified in Chapter 2, a set of recommendations and actions will be proposed that could help healthcare systems to improve patient transition to AMHS.
- In the context of ADHD, the recommendations are to:
  - Improve ADHD education of healthcare professionals
  - Increase the general public's awareness of ADHD
  - Improve management and planning of the transition process for patients with ADHD
    - Provide patient-specific development-appropriate care
    - Improve access to services
    - Ensure continuity of care is maintained during transition
    - Reduce the number of patients who drop out of care
    - Establish effective crisis–intervention contingencies
  - Promote long-term continuity of care after transition to AMHS.

Chapter 1:

Principles of successful transition from child and adolescent to adult mental healthcare services

What is transition of care?

Transition of care is the process of planning, preparing and guiding a patient with a mental health condition from CAMHS to AMHS.[12] This should be a gradual process of change, which gives all those involved time to ensure that young people and their families are prepared and feel ready to make the move to adult services. In defining the process of change as a transition, rather than a transfer, we are acknowledging a key guiding principle: that the move from child to adult healthcare services should be a *process*, not an event.[13,14]

In recent years, transition of care from child to adult services has become an important focus for both policy and practice across healthcare systems. Examples found in the UK:

- The National Institute for Health and Care Excellence (NICE) published guidelines on transition from children's to adults' services for young people using health or social care services (February 2016)[15]
- NICE guidelines on transition to UK adult services in patients with autism (August 2013).[16]

At the European level, the MILESTONE Project, launched in 2014 and scheduled to conclude in 2019, will look at strengthening the transition from child to adult services in patients with all mental health diagnoses (except those with severe learning disabilities).[17]

A named worker should co-ordinate transition of care and support

NICE guidelines (2016) on transition to UK adult services[15]

- Involve young people in the transition process, decision-making and goal-setting
- Ensure transition of support is developmentally appropriate and tailored to the patient
- Address all relevant outcomes (education, employment, health, independence, etc)
- CAMHS and AMHS should work together to make the process of transition smoother
- Transition planning should take place early; the point of transfer should not be based on a rigid age threshold
- A named worker should co-ordinate transition of care and support
- Parents and carers should be involved, if possible

Chapter 1

Involve young people in the transition process, and their parents or carers where appropriate

NICE guidelines (2013) on transition to UK adult services in patients with autism[16]

- Local CAMHS services should reassess young people with autism at ~14 years to establish the need for continuing treatment into adulthood
- If continuing treatment is necessary, arrangements for a smooth transition to AMHS are required and provide the young person with information about the treatment and services they may need
- Timing of transition may vary locally; however, the young person should complete transition by the time they are 18 years old
- Prior to transition, AMHS should carry out a comprehensive assessment of the young person, including educational, occupational, social and communication functioning along with assessment of coexisting conditions, especially depression, anxiety, ADHD, obsessive compulsive disorder, and global delay or intellectual disability
- Involve young people in the transition process, and their parents or carers where appropriate
- During transition to AMHS, a formal meeting involving health and social care and CAMHS should be conducted

MILESTONE

The ManagIng the Link and strEngthening tranSiTiON from Child to Adult MEntal Health Care (MILESTONE) study is an ongoing, EU-wide investigation of CAMHS to AMHS transitional care. It aims to identify service gaps in current mental healthcare systems and develop a standardised, best-practice model. The 5-year project is due to report its findings after study completion in 2019.[17]

Chapter 1

What makes a successful transition?

Adolescence is a period of great change in many aspects of life. In adolescents with ADHD, the associated increase in responsibility for one's own care, and reduced parental influence, mean that this is often a vulnerable time during which many adolescents may disengage with care systems and discontinue medications.[2] Furthermore, research shows that adolescence is a risk period for emergence of serious mental disorders.[18]

It is important, therefore, to ensure that transition to adult services occurs at a developmentally appropriate age, taking into account the maturity, cognitive abilities and psychological status of each patient.[15] Often, however, rigid cut-offs in patient age determine when CAMHS are terminated, regardless of the availability or appropriateness of AMHS for the patient.[18,19]

The Transitions of Care from Child and Adolescent Mental Health Services to Adult Mental Health Services (TRACK) study identified several core guiding principles from a survey of 13 transition protocols used in Greater London in patients with emotional/neurotic disorders, neurodevelopmental disorders, serious and enduring mental disorder, substance misuse, conduct disorders, eating disorders and emerging personality disorder.[20,21] These principles were mostly based on the UK National Service Frameworks[22-24] and included:

Continuity of care	Consistency in service	A seamless transition
Clarity about professionals' roles and clinical responsibility	Information sharing between agencies	Aligning of assessment processes between services
Resolution of eligibility and funding criteria	Joint working preceding final transfer	Co-operation and flexibility
User and carer involvement in decision-making	Care based on the principle of informed consent	Consideration of the most appropriate care provision for a young person

Chapter 1

Despite these well-founded principles, most patients in the TRACK study experienced poor planning and execution of their transition to adult mental healthcare services.[21] Many patients were not referred to AMHS at all, and only 4 out of 90 (4.4%) of those referred experienced optimal transition, based on the criteria of informational, relational, transfer, team and long-term continuity.[21] Data from TRACK showed that when young people did not successfully transition to AMHS, many continued to receive care from CAMHS or were referred to their general practitioner for treatment.[25]

The needs of the patient should be central to protocol and service development

TRACK study[21]

The TRACK study aimed to identify factors that facilitate successful transition from CAMHS to AMHS. Overall recommendations included:

- The needs of the patient should be central to protocol and service development
- Collaboration between agencies, patients and carers is required in developing the transition protocol
- Flexibility in age range for transition to accommodate differing needs and developmental stages of patients
- Collaboration between CAMHS and AMHS is desirable, with cross-agency working or periods of parallel care
- No discharge from CAMHS if AMHS is not immediately available

Other studies have highlighted the 'transition gap' between child and adult mental health services, which often occurs as a consequence of diagnostic uncertainty, the rigidity of boundaries and the availability of adult services.[2,11,26] For example, a UK National Health Service workshop that surveyed young people following their transition to AMHS indicated that levels of anxiety were high among those leaving CAMHS, with most perceiving CAMHS and AMHS as 'uncaring'.[27]

The Transition to Adult Mental Health Services (TRAMS) project (UK)

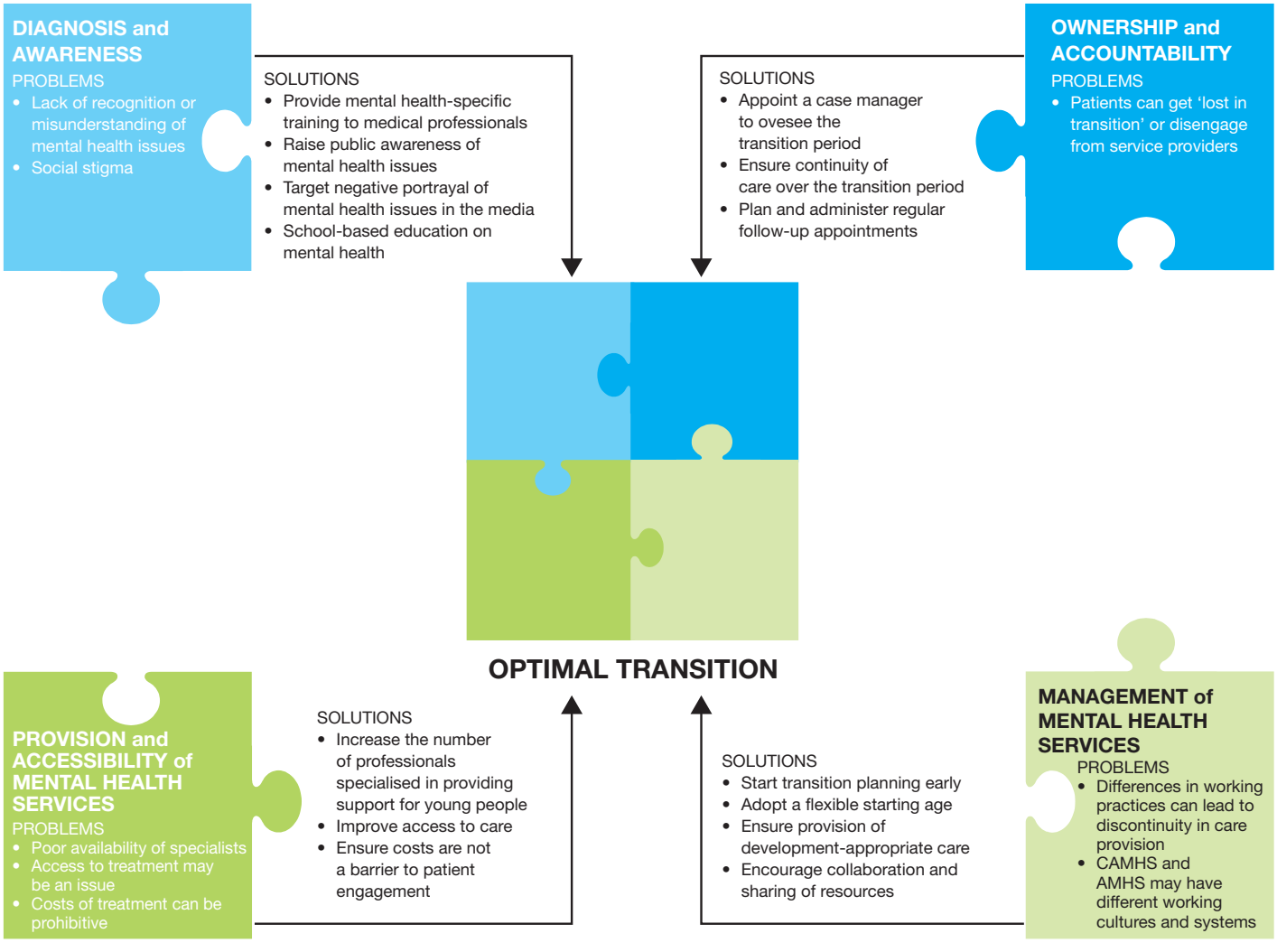
Interviews with patients with ADHD (n=10) during transition from CAMHS to AMHS identified factors associated with a positive-transition experience; these included: timely preparation, transition planning, parental support, periods of joint working and consistency in key workers.[28]

Chapter 1

What are the core elements of a best-practice pathway?

Building on existing research and available best practices, the core elements of a best-practice pathway can be visualised, as shown in **Figure 1**. The elements of this pathway are recommended as best practice by European and national-level policy makers, depending on the needs of individual countries.

Figure 1: Building a successful transition from child to adult mental health services. Figure developed from discussions during the Expert Working Meeting.



Chapter 2:

Barriers to successful transition – the example of ADHD

Ideally, transition should be a planned and purposeful process that addresses the psychosocial and medical needs of young patients as they move from child to adult services.[12,21] However, there is strong evidence that optimal transition does not occur in most cases.[18-21,28,29] The transition period is often poorly planned and can be disruptive, leading to breaks in service provision or cessation of treatment.[2,14,18,21] In this chapter, some of the barriers to successful transition are discussed.

Transition in the context of ADHD

The problems associated with transition from child to adult services apply to all mental health disorders. This chapter, however, will focus on barriers to successful transition in the context of ADHD.

ADHD is common in children and adolescents (estimated prevalence: 5.29–7.1%[5,6]) and persists into adulthood in ~50–66% of individuals (estimated adult prevalence 3.4% [range 1.2–7.3%]).[7-10]

The consequences of non-treatment for the individual can lead to negative outcomes affecting education, employment prospects, relationships, quality of life and personal finances.[30,31] Despite this, access to adult ADHD services and support is generally poor, resulting in frequent gaps in care during transition from child to adult services.[2,11] Continuity of care into adulthood for patients with ADHD occurs less frequently than persistence rates of the condition would predict, leading to many patients being 'lost in transition'.[2]

An audit of transitional care for adolescents with ADHD in a North-West England district reported that in a sample of 104 eligible adolescents with ADHD, 73% were discharged or lost to follow-up over the period of transition to adult services.[32] Similarly, results from the Irish TRACK study showed that in a sample of 20 adolescents with ADHD, none were successfully transitioned to adult healthcare services and almost half disengaged from services altogether.[29] A prospective longitudinal study of 91 young people (aged 14–24 years) with ADHD found that only 9% had transitioned to adult services, although eight reported a need for more support.[33]

Analysis of the problems, barriers to change and potential solutions associated with transition in the context of ADHD therefore provides an example in which to frame transition to adult services across the mental health sector for those patients that require continuing care.

Chapter 2

Based on the discussion and opinions of the Expert Working Meeting organised on 11 July 2017 in Brussels, and factors identified in published literature, the key factors confounding successful transition from CAMHS to AMHS are detailed below. *Please note that these are the opinions of the Expert Working Group.*

Timing of the transition from CAMHS

It should be taken into consideration that adolescence is a flexible concept; the boundaries defining this period can vary internationally, and there are no clear biological markers that indicate when transition to adulthood is complete.[34]

Similarly, there is no consensus on when it is appropriate to initiate transition. Services and policies are usually demarcated by age; however, the developmental stage of the individual can vary greatly, and rigid cut-offs in service boundaries can create discontinuity in care provision.

Availability of care

The Expert Working Group highlighted limited training opportunities in transition of care and a perceived lack of time for consultation as additional factors, confounding availability of transitional services.

In some countries, some childhood pharmacological treatments for ADHD may not be licensed for adult use, so treatment may be disrupted in cases where patients require continued care. Health insurance may be unaffordable for some patients. Costs of medication may also negatively impact the long-term continuation of treatment, both at the local provider level and at the patient level.

Differences in practices and culture between CAMHS and AMHS

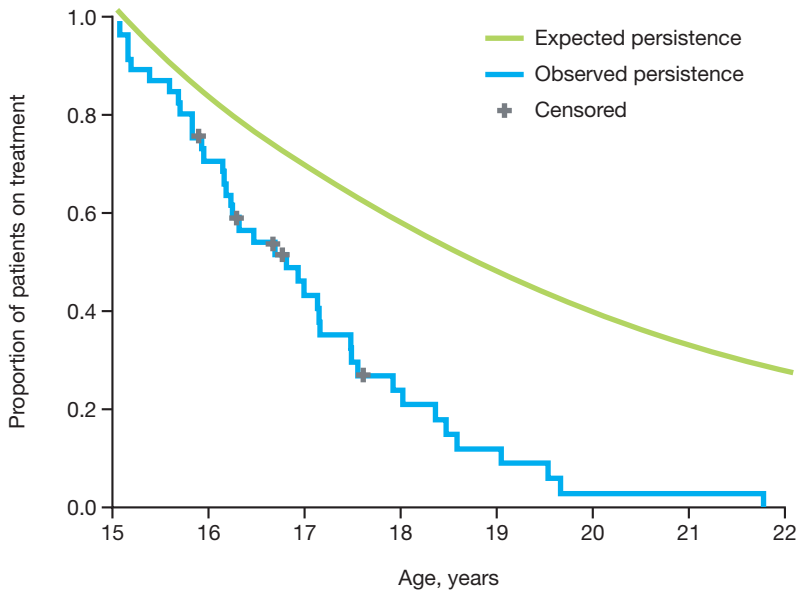
Child psychiatry often focuses on system interventions, family relations and social experiences; however, on moving to adult services, patients are treated as individuals, and sharing of treatment plans with the wider family is at the patient's own discretion.[19] Furthermore, differences in working practices related to communication and information sharing between CAMHS and AMHS may impair optimal transition of care.[35]

Chapter 2

Poor adherence to medication

Many adolescents discontinue treatment for ADHD despite ongoing functional impairment; this is a key concern, as those who stop taking ADHD medication are often lost from the system and do not receive further support. For example, a 2017 German study showed that medication rates in adolescents with ADHD (n=5593) fell from 51.8% at age 15 years to 6.6% at age 21 years, which could suggest that transition to AMHS may not be optimal.[36] This is supported by a longitudinal study of 15-year-old patients with ADHD (n=44), which reported that all participating patients had discontinued ADHD medication by the age of 21 years (**Figure 2**).[37]

Figure 2. Proportion of patients aged 15 years in 1999 remaining in treatment for each 1-year change in age (n=44). Reproduced with kind permission.[37]



The Expert Working Group discussed how the maturity and capability of the patient are key determinants of adherence in adolescents, who may display resistance to engagement with mental health services. Many factors influence medication adherence in adolescents, including the patient's perception of effectiveness and tolerability and parental influence.[38]

It was also highlighted by the Expert Working Group that patients may fear the 'punishing attitude' of their clinician if they stop taking medication, and so may be more inclined to disengage from care services than seek advice on alternative therapies.

Chapter 2

Patients may experience contact with multiple clinicians during the transition to AMHS, and inadequate handover can lead to inefficiencies and patient dissatisfaction

Lack of ownership and accountability of care in the transition process

Patients may experience contact with multiple clinicians during the transition to AMHS, and inadequate handover can lead to inefficiencies and patient dissatisfaction.[28] Differences in terminology and care provision structure between CAMHS and AMHS may hinder effective liaison and collaboration between agencies.[39]

Social stigma of mental health issues

Cultural differences across Europe affect regional perceptions towards ADHD-associated behaviours; this can have direct impact on standards of care. In some cases, ADHD can be perceived as 'stigmatising normal childhood behaviours', and parents may reject the idea that their child has a problem. Reluctance to engage with healthcare services due to misconceptions of ADHD can have negative impacts on the provision of care.

Real-life challenges

"I haven't seen [service user] for a while but reading into him not coming to the appointments more recently I think he's probably found the different approach [between CAMHS and AMHS] difficult … it was very frustrating and difficult because I wanted to engage him and I knew how important it would be to, to try and make the transition to adult services as painless as possible so I, you know, I tried to word letters and speak to him in a way which, you know, would make him feel comfortable and stuff but I just, I couldn't find a way of really engaging him." AMHS clinician account of poor engagement. Reproduced with kind permission.[21]

Real-life challenges

"Being with the adult mental health service is quite pressuring I find to be honest because there's too much transfers … I just think that it was a complete waste of time going there and maybe these services, like GPs, mental health teams, all sort of thing, they should be a bit more in the loop together, you know? Not like so separate they don't know what's going on, the service providers, not really, I just think they should be a bit more knowledgeable of each other's and what they offer and stuff like that and they should talk more, like what would be more beneficial to the patient because like I wouldn't like anyone else to like go through that really, you know, like, just go to one and then be passed on to the next one when you're 18. That's what it was like, it's like, oh, you're 18 now, you gotta go . . . " (The transition) " . . . was just all of a sudden . . . I didn't really like it." Service user accounts of transition outcome. Reproduced with kind permission.[21]

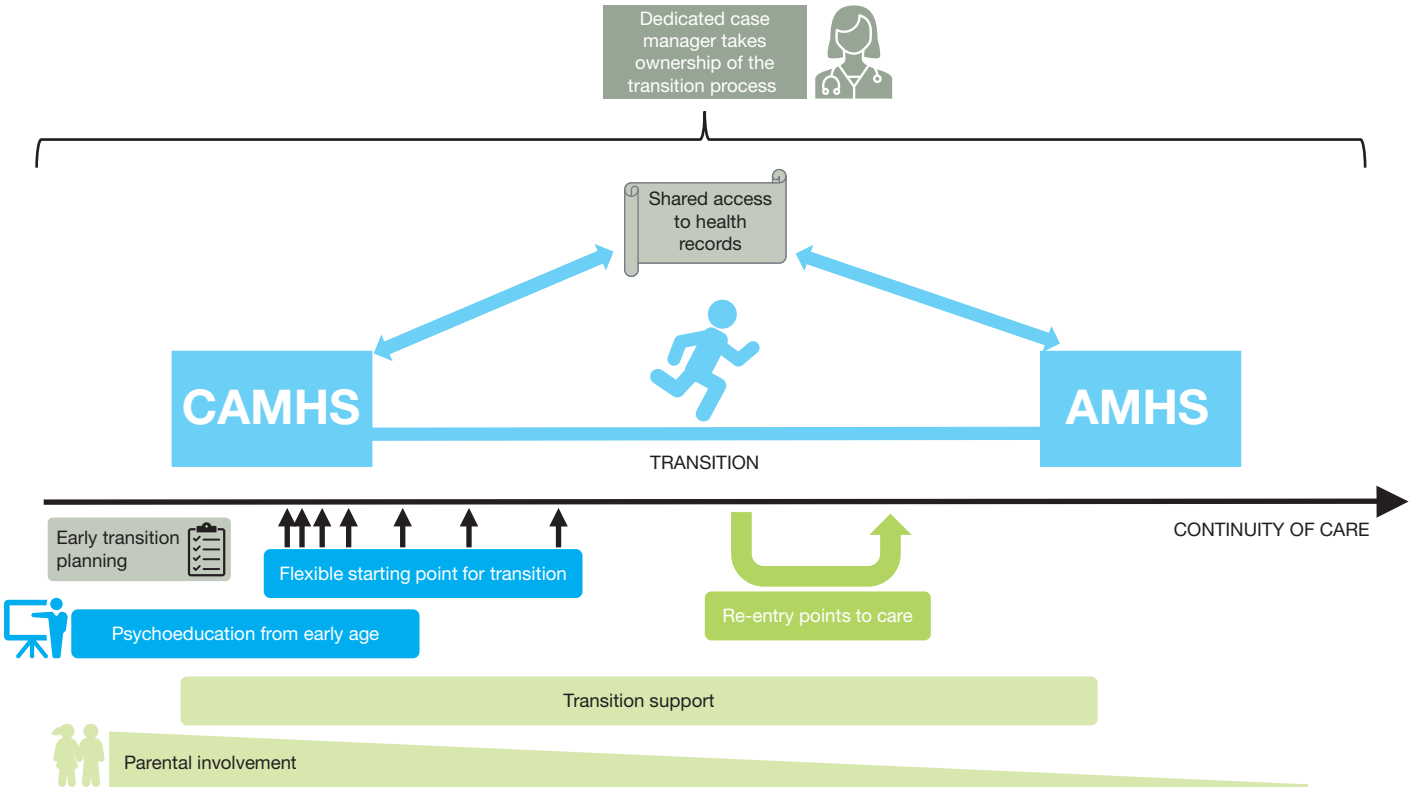
Chapter 3:

Recommendations for improving transition to adult mental healthcare services for patients with ADHD

Building a successful transition from child to adult mental health services in ADHD

Based on existing research and available best practices, a set of recommendations and actions have been developed by the Expert Working Group, which could help healthcare systems to improve the transition of patients with ADHD to adult mental health services for those requiring continuation of care. Many of these recommendations and their underlying principles could also support improvements for wider mental health conditions, where poor transition remains a problem (**Figure 3**).

Figure 3. Core elements of a recommended best-practice pathway. Figure developed from discussions during the Expert Working Meeting.



Chapter 3

Recommendation 1: Improve ADHD education of healthcare professionals

Recognising ADHD as a condition which may persist into adulthood is a key issue and should be addressed by improving the knowledge and experience of medical professionals, and by increasing access to specialists.

GOALS	ACTIONS
Provide medical professionals with access to the information regarding ADHD across the lifespan	**Medical schools** • Reappraise teaching curriculum to reflect current understanding of ADHD and its persistence into adulthood **General practitioners** • Raise awareness of adult ADHD • Provide updates on current guidelines for ADHD management in adolescent population • Provide guidance on transition management

Chapter 3

Recommendation 2: Increase the general public's awareness of ADHD

Social stigma can have an impact on the willingness of patients to engage with healthcare professionals and to continue with medications/treatment for ADHD. These influences can be particularly persuasive in young people. To address these concerns, we recommend the following:

GOALS	ACTIONS
Raise public awareness of ADHD symptoms and treatments	**General public** • Work with the media to educate the public about ADHD • Aim to ensure that ADHD is not portrayed negatively by the media • Foster appreciation of the true impact of ADHD on everyday life and the financial burden this entails (reframing of the disorder) **Parents** • Provide accessible information on ADHD and its treatment • Simplify the communication of existing clinical data **Schools** • Ensure teachers and support staff are aware of the symptoms of ADHD, and options for referral • Educate pupils on ADHD and other mental health issues

Chapter 3

Recommendation 3: Improve management and planning of the transition process for patients with ADHD

People with ADHD should have access to an integrated, comprehensive and co-ordinated standard of care, embracing the specialised knowledge and perspective that child and adolescent and adult psychiatrists, primary care physicians, social care workers, parents, teachers and nursing professionals can provide.

GOALS	ACTIONS
Provide patient-specific development-appropriate care	**General practitioners (GPs)** • Provide guidance/training to GPs on transition management • Evaluate the patient to assess the need for transition to adult services • Start transitional planning early • Be flexible in transition starting age, up to a maximum of 25 years • Ideally, transition should occur during a period of clinical stability • Transition should provide an opportunity for a re-evaluation of the patient • Involve patients in decisions on the transition process • Seek parental input where appropriate
Improve access to services	**Policy makers** • Increase the number of professionals specialised in providing support for young people • Improve access to care and ensure costs are not a barrier to patient engagement • Develop protocols for adolescents who may not meet AMHS entry criteria but require ongoing support
Ensure that continuity of care is maintained during transition	**Mental health services** • Appoint a case manager to oversee the transition period for each patient • Encourage joint sessions with child and adult mental healthcare services **CAMHS and AMHS** • Treat patients according to their individual needs • Encourage collaboration and sharing of resources • Care should not be stopped due to a lack of adult services
Reduce the number of patients who drop out of care	**CAMHS and AMHS** • Support should be based on patient needs and should not be dependent on adherence to medication • Access to ADHD-specific self-help groups may be beneficial
Establish effective crisis-intervention contingencies	**Mental health services** • Develop crisis-management plans and share with relevant stakeholders

Chapter 3

Recommendation 4: Promote long-term continuity of care after transition to adult mental healthcare services

GOALS	ACTIONS
Ensure that post-transition patients continue with AMHS	**AMHS** • Involve patients and their general practitioner (GP) in discussions concerning their care • Release adult patients into the care of the GP as their primary point of contact for follow-up and treatment monitoring • Schedule 6- or 12-month appointments with AMHS for assessment/ re-assessment

Gradually just slowly, slowly I moved up to the adult services when I was ready

Real-life successes

"Gradually just slowly, slowly I moved up to the adult services when I was ready . . . I think it was a good transition, I don't really know what could be any different. I didn't notice it too much. I thought it was good." A service user account of a transition with joint working. Reproduced with kind permission.[21]

Appendix 1:
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Appendix 2:
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