

# Challenges during the transition from child and adolescent mental health services to adult mental health services

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The transition from child and adolescent to adult mental health services for young people with mental health problems is of international concern. Despite the high prevalence of mental disorders during adolescence and their tendency to continue during adulthood, the majority of young people do not experience continuity of care. The aim of this review paper is to unravel the complexity of transitional mental healthcare to clinicians, policy makers and mental health service managers, and to address challenges to a smooth transition process at all levels.

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Young people's transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) has gained increasing international interest in recent years. At around the age of 16–18 years, young people with chronic mental health problems are confronted with two simultaneous transitions: a situational transition (from CAMHS to AMHS) and a developmental transition (to adulthood).<sup>1</sup>

Transition is defined as an efficient, planned, patient-oriented process that meets the medical, psychosocial and

educational/occupational needs of young people with chronic conditions.<sup>2</sup> Additionally, the developmental perspective is important in conceptualising transition as young people, those aged 16–24 years, are confronted with changes in various life domains.<sup>3,4</sup>

The transition age refers to the age at which the care of the young person in CAMHS is continued in AMHS, and in most cases, concerns young people in the 16–18 year age range. The following findings linked with psychopathology

are relevant for transitional care at this time point: first, psychopathology has a high persistence from an early age into adulthood<sup>5</sup>; second, the onset of many psychopathologies has been shown to coincide with the transition age.<sup>6,7</sup> Critical changes in the brain occur during late adolescence, which make this age group more vulnerable for developing psychopathology.<sup>7</sup>

Moreover, 75% of all psychiatric disorders in adults start before 24 years of age, and 50% before 14 years of age.<sup>8</sup> However, there is a discord in the pattern of increased risk of psychopathology in young people and mental health service use.<sup>1,9</sup> Older adolescents access care far less (28.9%) than 13- to 16-year-olds (50.9%) or adults over 26 years (41.1%).<sup>10,11</sup> Furthermore, the gap between CAMHS and AMHS, the so-called 'transition gap', results in a clear discontinuity of care. A sizeable number of youth and young adults who 'fall' in this transition gap access adult services at a later point in time, when more serious and chronic problems have developed.<sup>12,13</sup>

The care gap affects not only the young people, but also their families, communities and society as a whole. Mental health problems are associated with poorer physical health and poorer functioning in the social, educational and economic life domains.<sup>14</sup> At the societal level, the presence of a mental disorder during childhood leads to a 10-fold higher health cost during adulthood compared with children without mental health problems.<sup>15</sup> To date, it is unclear what the real societal impact of the care gap in late adolescence is and to what extent adequate transitional care reduces this impact.

The aim of this paper is to summarise the new insights and developments investigated since the review of Singh in 2009.<sup>12</sup> Furthermore, this paper includes research on youth mental health services and shared management components, which is one of the limitations of the review of Paul *et al.*<sup>16</sup>

Continuation of care is a complex process, with important players at the policy and organisational level, service level and at the level of individuals: patients, their families and healthcare providers. However, care discontinuity cannot be explained by only one level.<sup>4,17</sup> This paper attempts to unravel the complexity of transitional mental healthcare to clinicians, policy makers and mental health service managers, and to address challenges to a smooth transition process at all levels. The advantage of splitting the findings according to the three levels makes the extensive research regarding transition more manageable. Furthermore, it emphasises the complexity of the topic, but also makes clear that solutions are possible at every level.

## Challenges regarding transitional mental healthcare

### Policy and organisational level

Improving transitional care has been on the policy agenda in different European countries for some time now; however, it has been one of a number of competing priorities. Furthermore, there has been a gap between policy and implementation in practice, insufficient research regarding

transition, and a lack of transition protocols guiding transitional care of service providers.<sup>16</sup>

Historically, the way in which mental health services have been structured, with separate facilities for children/adolescents and adults is a significant bottleneck to transitional care.<sup>13</sup> Eligibility thresholds for referral to CAMHS and AMHS often differ; thereby causing young people to fall through the care gap.<sup>4,18</sup> Furthermore, the CAMHS-AMHS interface is characterised by different cultural approaches, a lack of communication and doubts about AMHS staff being proficient in managing young peoples' care.<sup>19</sup>

Waiting lists form another major barrier in the provision of mental healthcare to youth and young adults.<sup>20,21</sup> As a result, young people presenting with a mental health problem at 17 years of age are often referred directly to AMHS because the waiting time for CAMHS coincides or exceeds their 18th birthday, i.e. the transition boundary. Adult services, in turn, hesitate to treat these young people before 18 years of age, because the expertise or the adjusted setting for this patient group is lacking, or because internal or external regulations prevent care providers from forming a treatment plan. Young people who have attended CAMHS but find themselves on a long waiting list for AMHS – usually with no interim support in place – describe this as highly anxiety-provoking.<sup>22</sup>

Another challenge is the lack of training requirements for care providers and variations in the content of training programmes.<sup>23,24</sup> The knowledge clinicians in either child/adolescent or adult speciality acquire about young people largely depends on whether they are provided with adequate training on psychopathology of adolescents. A lack of confidence amongst mental health practitioners to work with young people in transition is an area of concern frequently identified by young people.<sup>22</sup>

Healthcare financing is another policy challenge affecting the care trajectories of young people. Gaining financial responsibility at the age of majority can have a real effect on the provision of care in some countries. Differences in financial benefits for minors versus adults may relate to the cost of a consultation, the possibility to organise family therapy or the reimbursement of medication. Some health insurance policies provide partial reimbursement for therapy sessions for young people up to 18 years of age, but not for (young) adults. Hence, although they have reached the age of majority and the ability to organise their mental healthcare independently, young people often still remain financially dependent on their parents to pay for their care. If there is a serious disruption in the parent-child relationship, the continuation of care at a new mental health service may be in jeopardy.

### Service level

Different treatment approaches at CAMHS and AMHS pose a significant challenge. In CAMHS, treatment is reported to be more family-oriented and holistic, inherent to the legal position of the parents, whereas in adult psychiatry, individual patients and their symptoms are the main focus. These differences are described by young people and their families as an important reason for discontinuing care in AMHS.<sup>25</sup> This perception may also lead to hesitance among CAMHS clinicians to refer young people.<sup>16</sup> In addition, the lack of

common registration and information systems hampers the exchange of information between services.<sup>17</sup>

### Level of the individual

#### *Youth and young adults*

Characteristics specific to young people can influence the transition process. Having a severe and enduring mental illness, e.g. schizophrenia, enhances the chance of being referred to AMHS, whereas having a neurodevelopmental disorder decreases the chance of being referred. Moreover, receiving medication, having a history of hospital admissions and living with both parents or independently are all variables that can determine whether a young person is more likely to be referred.<sup>4,26–28</sup>

Even if a transition to adult services has been carefully planned, a young person's urge for autonomy and self-determination may influence their care trajectory. For example, the young person can decide to abandon psychological care or to not make the transition to AMHS, even when a referral has been made.<sup>4,26,28,29</sup> The reasons for this are diverse: young people want to solve their problems themselves, or they may not want to repeat their story to a new clinician. The lack of information about mental healthcare, the stigma associated with mental health problems,<sup>30,31</sup> anxiety about how confidentiality is handled and the physical accessibility of mental health services can all act as barriers to seeking help or accessing care.<sup>32</sup> Young people have also suggested that further investments should be made to improve the accessibility of mental healthcare and have pointed out to the importance of e-health.<sup>17</sup>

Furthermore, service (dis)engagement is influenced by an identity change that accompanies the transition from CAMHS to AMHS. Besides adopting an adult identity, transitioning to AMHS implies adopting a new illness identity.<sup>31</sup> Although CAMHS is associated with temporary psychopathology, AMHS is associated with having a severe and enduring mental illness, as this is often the prerequisite for being referred to or accepted by AMHS.<sup>4</sup> Disengagement can be attributed to failure in adopting a new illness identity, an illness identity that is incompatible with AMHS service remit or fractious professional relationships between CAMHS and AMHS during the transition, which causes anxiety and uncertainty to the young person.<sup>31</sup>

Although young people want to make autonomous decisions and are concerned about the confidentiality of information, the loss of parental or other psychosocial support is an important negative factor for care continuation or adequate help-seeking behaviour.<sup>32</sup>

The relationship of trust with the CAMHS clinician must not be forgotten, as at the transition to adult services this relationship comes to an end. Entering into a new social and trust relationship at an AMHS can be daunting for young people. On the other hand, a positive relationship with the new clinician can enable the development of other positive relationships.<sup>33</sup>

#### *The parents and important others*

The parents' position changes the moment a young person becomes an adult, as their legal right to be involved in the

care for their child is no longer there. Furthermore, because of the distinct service cultures, CAMHS and AMHS clinicians' training regarding family involvement differs considerably; in adult psychiatry, the focus is more on the individual, not the family.<sup>25,34</sup>

The need to give a young person autonomy to make their own decisions regarding treatment can be a difficult process for the parents, who may also require additional support.<sup>35</sup> Many parents and carers would like to remain involved in the treatment, although they respect their child's wishes and their right to privacy.<sup>36,37</sup> They also want psychoeducation about how to deal with their child and to attend parent support groups where they can benefit from increased knowledge, shared recognition and exchange of experiences.<sup>38</sup>

#### *The clinician*

Mental healthcare transition should be a planned and efficient process. This implies starting on time to prepare individuals and their families for the transition. Some authors state that this process should start at 14 years of age,<sup>39</sup> whereas others stress that it should start at least 1 year before the transition boundary.<sup>40</sup> For the process to be efficient, by the time the young person reaches the transition boundary it should be clear whether they need further care or not, and whether this care will be continued in CAMHS or whether a referral to AMHS, or another type of service (e.g. private practice), is appropriate. In any case, the clinician should consider all these options to make the best possible decision.

To date, there is no consensus about this decision-making process, and the follow-up trajectory of the young person thus depends on the practitioner's clinical judgement. Because of the lack of transition protocols, this clinical judgement is not usually based on a structured assessment of transition-relevant factors, such as severity of symptoms, the patient's motivation regarding further mental healthcare and the risk and protective factors in several psychosocial domains.<sup>13</sup> CAMHS and AMHS should, therefore, be supported in the initiation, advancement and supervision of the transition process. The National Institute for Health and Care Excellence and Cleverley *et al* have produced guidelines on transition.<sup>41,42</sup> The Managing the Link and Strengthening Transition from Child to Adult Mental Healthcare (MILESTONE) project developed an instrument for assessing transition, the Transition Readiness and Appropriateness Measure, a process called managed transition, which uses the Transition Readiness and Appropriateness Measure to guide clinicians' actions, and training regarding transition.<sup>43,44</sup>

The transition process is also influenced by professional relationships between CAMHS and AMHS. Clinicians' decisions regarding referrals may depend on the (not always comprehensive) knowledge they have of the other care provider and their prior experience with the service and clinician.<sup>45</sup> Furthermore, incompatible beliefs about who is responsible for the different steps during the transition process, lack of confidence in AMHS staff in managing young people and different cultural approaches in service delivery may also impede the transition process.<sup>18,46</sup>

## Improving transition through specific interventions

Some of the above-mentioned challenges provide directions as to what should be done in clinical practice and at policy level to improve the transition process. On the other hand, effect studies are lacking and there is a need for longitudinal research about different transition trajectories and health outcomes.<sup>16,47</sup> Although care trajectories, transition experiences and quality of transition have been investigated within the UK,<sup>1</sup> Ireland,<sup>28,46</sup> the USA and Australia,<sup>16</sup> no research has been performed about the care and transition trajectories (both the experiences and the quality) in relation to their effects on mental health in the long term. The MILESTONE project contains a prospective study on the longitudinal outcomes and experiences of young people reaching the transition boundary within eight different European countries, taking into account differences in the organisation of mental health systems, the age at which transition takes place and the available services.<sup>43,44</sup> The MILESTONE study will result in evidence- and practice-based guidelines that clinicians can follow to support their decision-making and direct their actions.

To prevent young people from falling through the care gap and to tailor services to their specific needs, new service models have been developed. Examples include mental health services in Australia, Canada and some European countries that target the age group of 0–25 years. Besides solely focusing on mental health, these services take into account all aspects of psychosocial functioning.<sup>48–50</sup> Despite the aim of trying to solve the problem of a shortage of tailored services for this target group, some of these services are faced with an additional transition boundary: the first around 12 years of age and the second around 25 years of age, both of which need to be optimally managed. At the current time, it is too early to conclude if these models provide an answer to the longstanding problems of transition barriers.

An alternative approach to bridge the transition gap is by improving the liaison between CAMHS and AMHS, but keeping services as they currently exist. To achieve this, diverse models to enhance joint-working between services, including transition clinics and transition coordinators have been suggested.<sup>51–54</sup>

## Improving clinical practice

Policy makers should consider implementing the topic of transition in the training program of clinicians as 94% of European psychiatric trainees indicated further training regarding transition is necessary.<sup>23</sup> Furthermore the distinct split between CAMHS and AMHS should be revised as well as the separate funding, which may hamper collaborative efforts.<sup>13,42</sup>

To ensure that the transition process is better managed, the transition should be mentioned to the young person well in advance,<sup>17,41,42</sup> whereby the young person should be involved in the decision-making during all phases of the process.<sup>22,42,55</sup> Guidelines and criteria regarding optimal transition can guide clinicians during their clinical practice.<sup>4,41,42</sup>

Furthermore, standardised assessment of the young persons' needs when approaching the transition boundary should become routine, although it is rarely done nowadays.<sup>13</sup>

## Conclusion

The transition from CAMHS to AMHS is an important process for young people with mental health problems. Literature shows that continuation of care is a complex process, with important players at policy and organisational levels, service level and at the level of individuals: patients, their families and healthcare providers. At the moment, specific programmes for young people are being developed. However, research such as the MILESTONE project is needed to support these interventions in an evidence-based manner.

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