Dadansoddi ar gyfer Polisi
YMCHWIL GYMDEITHASOL Y LLYWODRAETH
GSR
GOVERNMENT SOCIAL RESEARCH
Analysis for Policy

Llywodraeth Cymru
Welsh Government

SOCIAL RESEARCH NUMBER:
37/2020
PUBLICATION DATE:
03/06/2020

Review of Evidence on all-age Mental Health Services: Summary

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.

This document is also available in Welsh.

 Digital ISBN 978-1-80038-578-8

Review of Evidence on all-age Mental Health Services Summary

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Full Research Report: Holtom D., Iqbal H. (2020).*Review of Evidence on all-age Mental Health Services*. Cardiff: Welsh Government, GSR report number 37/2020.
Available at: https://gov.wales/review-evidence-all-age-mental-health-services

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Glossary

Acronym	Definition
ADHD	Attention Deficit Hyperactivity Disorder
AMHS	Adult Mental Health Services
ASD	Autism Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Services
CAPA	Choice and Partnership Approach
CIT	Crisis Intervention Team
CMHTs	Community Mental Health Teams
CQC	Care Quality Commission
EIPS	Early Intervention in Psychosis Service
GP	General Practitioner
IT	Information Technology
LD	Learning Disabilities
LHB	Local Health Board
LPMHS	Local Primary Mental Health Services
MH	Mental Health
n.d.	No date (used for unpublished material)
ND	Neurodevelopmental Disorders
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OCD	Obsessive Compulsive Disorder
PHW	Public Health Wales
PMHSS	Primary Mental Health Support Service
R&D	Research and Development
RCP	Royal College of Psychiatrists
RTT	Referral to Treatment Target
SCIE	Social Care Institute for Excellence
sCAMHS	specialist Child and Adolescent Mental Health Services
T4CYP	Together for Children and Young People Programme

THB	Teaching Health Board
UHB	University Health Board
WG	Welsh Government

Note on the language used to describe Child and Adolescent Mental Health Services (CAMHS)

“CAMHS” is used as a term to describe all services that work with children and young people who have difficulties with their emotional or behavioural wellbeing. Specialist CAMHS (sCAMHS) are the multidisciplinary mental health teams that work with children and young people with more severe and complex mental health needs. However, because sCAMHS are generally simply referred to as “CAMHS” we have used that convention in this report.

Summary

Introduction

1.1 Most children and young people have good mental health; however a minority, around one in ten, have mental health conditions or disorders and require assessment and intervention from primary, community and secondary healthcare services, such as Local Primary Mental Health Services (LPMHS) or specialist Child and Adolescent Mental Health Services (sCAMHS)[1], commonly referred to as "CAMHS"[2] (CQC, 2017; PHW, 2016).

1.2 The focus of this report is upon the small number of children (and young people aged 11-17)[3] with more complex or severe needs accessing CAMHS who, if their needs continue, must make a transition to other services if they are to continue accessing NHS mental health (MH) services as they approach adulthood (CQC, 2017; PHW, 2016). The report focuses in particular upon their transition from CAMHS to Adult Mental Health Services (AMHS), but also considers other transitions, from CAMHS to, for example, Local Primary Mental Health Services (LPMHS) which is an all-age service. In addition, the report touches upon the wider needs of young people, including those who cannot, or choose not to, access CAMHS or AMHS. This is an important part of the context for thinking about the case for developing all-age, children and young people (e.g. 0-25) or youth (e.g. 14-25) MH services, albeit an issue largely beyond the scope of this report.

1.3 The context in which young people make a transition from CAMHS is often very challenging because it comes at a particularly vulnerable time in their lives. Around the ages of 16-18, young people are exposed to a higher risk of mental health difficulties while also going through a period of physiological change, making

[1] There is limited data on activity within CAMHS, so there is a reliance upon estimates. The "estimate of young people who, may at any one time, need a service response or support" from tier 3 services like CAMHS is around 2%. (PHW, 2016, p.72).

[2] CAMHS is used both as a term for all services that work with children and young people who have difficulties with their mental health and also the specialist NHS multidisciplinary teams, also known as sCAMHS. As this was the language used by interviewees and in much of the literature reviewed, we refer to sCAMHS as CAMHS.

[3] It is estimated that fewer than 2% of all children (aged 0-18) will access CAMHS at some point in their lives., The "estimate of young people who, may at any one time, need a service response or support" is based upon estimated prevalence, and is: "15% at tier 1; 7% at tier 2; 1.85% at tier 3 with 0.08% at tier 4, with 0.02% requiring inpatient tier 4 services." (PHW, 2016, p.72).

important transitions in areas such as education, housing (such as leaving the family home or looked after support), employment and their relationships. They are also expected to take increasing responsibility for their own behaviour and choices.

Approach and methodology

1.4 This was a primarily qualitative review. It draws upon a systematic literature review of the evidence:

- around transitions from child to adult health services, focusing in particular upon the evidence around transition from CAMHS to AMHS; and
- of all-age, children and young people MH services (e.g. services for those aged 0-25) and youth MH services (services for those aged 14-25).

1.5 The review "mined" existing systematic reviews, such as those conducted by NICE (2016) and also searched selected sources to identify any material published after these systematic reviews (focusing upon the period 2016-2019).

1.6 The literature review was complemented by interviews with a small number (n=12) of stakeholders from, or advising, the Welsh Government, CAMHS, AMHS and specialist youth MH services, such as Early Intervention Psychosis Services (EIPS) in Wales. This was vital in helping assess whether research conducted in other parts of the UK, most notably England, was likely to also apply to Wales. In addition, emerging findings were discussed at a workshop for practitioners in October 2019.

Young people's transitions from CAMHS

1.7 Research across the UK identifies that young people's transitions from CAMHS are complex and diverse, with three key groups:

- those accessing CAMHS who make a good transition from CAMHS to AMHS;
- those accessing CAMHS who transition from CAMHS to AMHS, but who do not sustain their engagement with AMHS; and
- those accessing CAMHS who either cannot transition to AMHS (e.g. as they do not meet the thresholds for AMHS, or who are never referred to AMHS) or who are referred to, but choose not to engage with, AMHS.

1.8 It is not possible to quantify the numbers of young people in each group in Wales. However, two studies, one in England (Singh et al., 2010)[4] and one in Northern Ireland (Leavey et al., 2018) provide an indication. Taken together, the two studies suggest that, of those young people accessing CAMHS at age 18:

- around one fifth to one quarter are not referred to AMHS;
- 6-11 percent of those referred to AMHS are not accepted by AMHS; and
- as many as 70 percent of those referred to AMHS, and accepted by AMHS, have been discharged by their third appointment with AMHS.

1.9 The key message from the research is that most young people accessing CAMHS either do not make or sustain a transition to AMHS, or experience a difficult transition to AMHS, and "optimal transitions[5]" are very much the exception rather than the rule (Singh et al., 2010; Leavey et al., 2018). This is supported in the main by data from the qualitative research for this review in Wales. The reasons for this include:

- the timing of the transition which, as outlined above, often comes at a particularly vulnerable point in young people's lives (Singh et al., 2010; Jones, 2005);
- the fear and anxiety associated with the transition from CAMHS, which may have offered safety and support during a very difficult period in young people's lives; and
- the cultural, structural and organisational differences between CAMHS and AHMS, which are summarised in table 1.

1.10 These factors are interlinked; for example, the differences between CAMHS and AMHS, and the timing of the transition, can exacerbate the fears of young people and their families about the transition from CAMHS.

[4] The Transition from CAMHS to AMHS (TRACK) study by Singh et al. (2010), is a particularly important study for this review given the breadth of literature reviewed (for the study), and also the extent of empirical research into transitions (which is absent from most other research in this area).

[5] This has been defined as "a safe and efficient transfer to adult care, with a focus on continuity of information and cross boundary and team continuity" (Singh et al., 2010, p.85).

Table 1. Summary of key differences between CAMHS and AMHS

CAMHS	AMHS
More family focused, more emphasis upon the young person's support network (family, friends, school etc.) who all have a vital role in recovery.	More focused upon the individual young person/young adult; success is more reliant upon their resilience and choices (they are expected to take greater responsibility).
Problem and symptom focused ethos; focus upon helping people live their lives, and cope with problems – not "chasing a diagnosis'".	More medical/diagnosis focused; more medication and crisis oriented ethos.
Thresholds are rising, but services still undertake some community (non-acute), longer term work.	Higher thresholds, mostly acute severe/complex cases.
Small multi-disciplinary team, with fewer specialists, which means young people with different conditions can be seen in the same clinic.	Large multi-disciplinary team, with more specialists and greater capacity so, for example, AMHS may have stronger crisis teams and out of hours services, but may also face greater demands (as they serve a larger age range (i.e. 18+) and may have longer waiting lists for some specialists (e.g. psychologists), compared to CAMHS.

Source: interviews, Singh et al. (2010); Lamb and Murphy (2013); NICE (2016)

1.11 Research also identified that some groups, such as looked after children, asylum seekers and those with neurodevelopmental disorders (ND) such as autistic spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD) or a learning disability (LD), are particularly vulnerable to difficult transitions (including not being able to transition to AMHS or not engaging with AMHS) (CQC, 2017; RCP, 2017).

Differences in evidence for mental health and other health services

1.12 Many of the difficulties associated with the transitions from CAMHS, such as the marked differences between the culture and structure of children and adult services (outlined in table 1) and the timing of transition, are not specific to CAMHS and AMHS. Much research suggests that, as one study puts it: “policy on transitions for young people with mental health problems should not be seen separately from those with physical health problems or those with disabilities” (Singh et al., 2010, p.181). However, interviews conducted for this study indicate that some of the difficulties may be more acute in relation to the transition from CAMHS, given:

- greater differences between the thresholds, culture and structure of CAMHS and AMHS, compared to some other health services; and
- young people’s mental health difficulties, which can make it more difficult for them to cope with change and take responsibility for their behaviour and care, or their recovery. This means that the expectation in AMHS that young people take responsibility for their care and recovery, was reported by interviewees from CAMHS and AMHS to be a reason why young people disengage from AMHS at a vulnerable point in their lives.

Good practice in transitions

1.13 Research across the UK and the interviews conducted for this study consistently identify a range of factors that support transitions from CAMHS; they include:

- ensuring and supporting the transition to AMHS where available (as noted, not all young people making a transition from CAMHS are eligible for AMHS), and identifying alternative services where this is not possible (Singh et al., 2010). This should include services proactively reaching out to engage with young people and their families, particularly for those most at risk of disengagement.
- providing information and support for young people and their families before and during the transition process so they know what to expect and can plan for the change. Many studies highlight the contribution that transition workers and teams can make to improving experiences of transition (e.g. Welsh Government, 2012a; Sloper et al., 2010);

- collaborative working between CAMHS and AMHS, including starting transition planning early, and planning effectively to ensure that young people and their families and services are prepared for transition. Furthermore, where appropriate, joint working between CAMHS and AMHS, to support young people and their families during the transition process and provide greater continuity of care;
- flexibility that enables person, rather than service, centred approaches to transitions and care. Recognising the challenge that what works for one young person and their family (in relation to the transition from CAMHS), will not necessarily work for another (so “one size fits all” solutions are not appropriate);
- ensuring that both CAMHS and AMHS get “the simple things right”; for example, that services are “welcoming, friendly and warm” and that staff have the skills and time “to develop a relationship and sense of trust and respect” with the young person (CQC, 2017, p.58); and
- effective monitoring and evaluation of users’ experiences of transition and the continuity of care provided, which is used to inform service development.

Barriers and enablers to improving transitions

1.14 Research across the UK, and the interviews conducted for this study, also identify a range of barriers and enablers to improving transitions from CAMHS. These are summarised in table 2. As the table outlines, the enablers are approaches that help young people and their families navigate the gap between CAMHS and AMHS. In addition, as discussed below, there are alternative service models that span traditional age boundaries, such as youth MH services working with 14-25 year olds, which bridge or close the gap between CAMHS and AMHS, eliminating the need for a transition from CAMHS at age 18.

Table 2. Barriers and enablers to improving transitions from CAMHS

Challenge	Barriers that hinder transitions	Enablers that help young people navigate the gap
The timing of the transition, which often comes at a particularly vulnerable point in young people's lives.	The inflexibility of services, which means young people must transition when services dictate it, rather than when young people choose to. Eligibility criteria (which determine who services work with and when) and pressure upon services, when demand is greater than their capacity, which can limit joint working between services.	Flexible, person centred services, which give young people greater choice about when and how to transition. This can be enabled by greater joint or collaborative work between CAMHS and AMHS, including flexibility about when to start and stop working with young people.
The fear and anxiety associated with the transition from CAMHS.	The cultural, structural and organisational differences between CAMHS and AMHS, which can mean fears and anxiety are well-founded (e.g. as when people fear there is no service to transition to, there is poor communication and limited information and/or little continuity of care following transition).	Transition planning, preparation and support, which helps inform and ensure that young people and families know what to expect (including expecting to be supported during the process) and what their options are; giving young people and their families greater control over the process.
The cultural, structural and organisational differences	The fragmentation of commissioning and management of CAMHS and	Joint training and working, to improve relationships between staff in CAMHS and AMHS and their understanding of

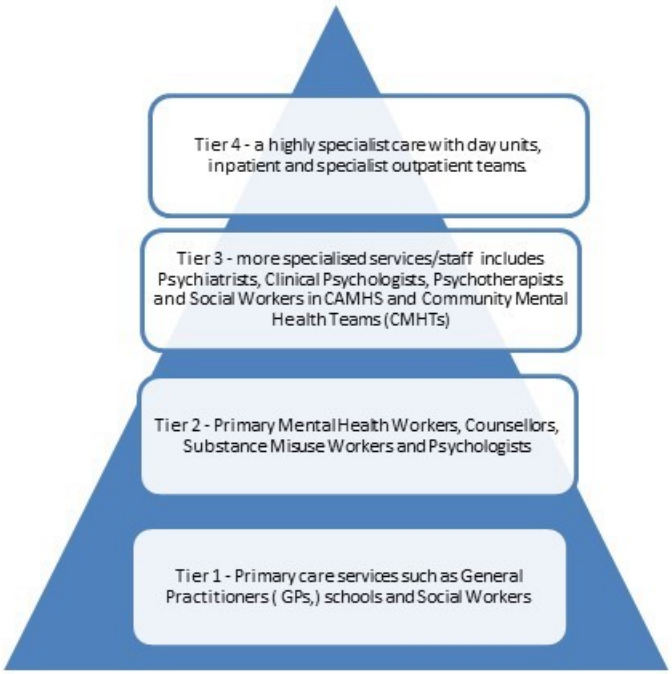
between CAMHS and AMHS.	AMHS[6]; differences in the workforces (including training for CAMHS and AMHS staff and their confidence working with young people/young adults); differences in working practices, information technology (IT) systems, priorities and thresholds; and pressure upon services, which can, for example, lead to a raising of thresholds and restriction of access to services for young people transitioning from CAMHS; failure to collaborate effectively and share information effectively or work jointly.	each other; systems wide leadership; increasing the priority attached to improving transitions by CAMHS and AMHS.

Alternative health service models

1.15 The current model for most MH services is the "tiered" model for CAMHS and AMHS. This is illustrated by figure 1.

[6] For example, in many Local Health Boards (LHBs), CAMHS sits within children's and women's health directorates, whilst AMHS sits within mental health directorates. Powys is an exception to this.

Figure 1. Tiered model of mental health services



1.16 Interviews for this study and other research (e.g. Gregory, n.d.) highlighted the strengths of the tiered model. For example, it provides a clear framework for services, allows the development of specialisation and expertise and should help ensure the prudent use of health care resources, by helping ensure that only those who need to, access more resource intensive targeted and specialist services.

1.17 However, interviews and research (CQC, 2017) also identified that the tiered model has struggled to cope with rising demand and has created inflexible boundaries between services or tiers, and while some services, such as LPMHS, are all-age services, most specialist services such as CAMHS or Community Mental Health Teams (CMHTs), are split between children and adult services. This inflexibility means that some young people, particularly those with complex difficulties, or whose difficulties fall short of diagnostic thresholds or are also bound up with social difficulties, do not easily fit into the service structure (and they fall between the gaps). It also means that some young people or their families feel that services are

not accessible[7] or appropriate to their age or development (and are not "young person friendly").

1.18 These weaknesses have led some to conclude that the current mental health system "is at its weakest" at the very time when young people are most vulnerable. As a consequence, too many young people with mental health problems struggle with the transition from CAMHS and/or do not engage with CAMHS or AMHS (Singh et al., 2010).

1.19 In response to the weaknesses, a range of different MH service models have been developed across the UK (RCP, 2017); they include:

- needs based services and teams, such as those based upon the THRIVE model[8], like the Camden Minding the Gap transition service and the Gwent Iceberg model (Gregory, n.d.), which aim to be more flexible and person, rather than diagnosis and service centred, and therefore (intended to be) better able to meet young people's needs;
- children and young people or youth MH services, such as Forward Thinking Birmingham, a 0-25 mental health partnership and the Norfolk Youth Service which works with young people aged 14-25. These span traditional age boundaries which are often designed to be need rather than service centred, and can involve a shift from clinic to community based services; and
- disorder specific services which span traditional age boundaries, including EIPS and eating disorder services in Wales, which work with young people aged 14-25 (or older). They span traditional age boundaries (like youth MH services), but differ from needs based youth MH services, in that their services are structured around diagnosis, rather than need *per se*. They are therefore much more

[7] For example, it has been identified that "families who struggle to access clinic based services are often those most at risk" (Gregory, n.d.).

[8] THRIVE is a model for thinking about children and young people's mental health needs as five overlapping groups: those who are "Thriving" (and don't need individualised advice or support); "Getting advice" (from MH services); "Getting help" (from MH services); "Getting more help"; and "Getting Risk Support". These gradations of support are in some ways analogous to the tiered model, and the model can be delivered by a range of services, such as universal, targeted and more specialist services or teams. However, the framework is intended to be needs led or centred, rather than service or diagnosis centred (as the tiered model can be). Needs are defined by service users (such as young people and families) working with professionals through "shared decision making" and "are not based on severity, diagnosis, or health care pathways" (as is typically the case under the tiered model) (Wolpert et al., 2016).

targeted, only working with those young people suspected of having, or who are diagnosed as having, a specific condition.

1.20 The evidence on the effectiveness (and also the cost-effectiveness) of all-age, children and young people's (0-25) MH services (like Forward Thinking Birmingham) or youth (11/14-25) MH services, (like the Norfolk Youth Service) is limited. There are relatively few services; most are still developing rather than fully established services, and few have been robustly evaluated. The constrained evidential base that does exist suggests that (as outlined above) there is a strong case, in theory, for the alternative service models and that they can ease or eliminate problems associated with the transition from CAMHS. Interviews with staff from disorder specific services in Wales suggest that, while transition may be deferred to 25, at that age the transition from these services is generally easier than that from CAMHS at 18, as the severity of young people's medical and social needs has generally lessened.

1.21 However, the evidence from evaluations of the new MH services for children and/or young people also highlights practical problems linked to funding, high levels of demand and recruiting and retaining a workforce with the skills needed to work with young people. Interviewees for this study from CAMHS and AMHS also reflected upon the perceived weaknesses of LPMHS in Wales (which are all-age services), most notably their adult orientation and approach, concerns also identified by the Mind over Matter report (NAfW, 2018), which means that services often struggle to engage and/or meet the needs of young people.

Conclusions

The evidence around transitions from children to adult mental health services

1.22 Transitions from CAMHS are now a well-researched area, compared to a decade ago, with different studies identifying similar issues and making similar recommendations. There is broad agreement in the research reviewed, and also in the evidence from interviewees for this study, that:

- experiences of transitions from CAMHS and continuity of care are often poor, particularly for some groups, such as young people with mental health difficulties and co-occurring conditions (such as ND disorders like ADHD or ASD) and/or young people in care or in custody. Moreover, some young people either cannot, or choose not to, transition to AMHS, increasing the risk that their needs are not met and may worsen. Therefore, it is important to also consider transitions to alternatives to AMHS, such as LPMHS; and
- although there is no single solution that ensures a successful transition from CAMHS, "what works" is felt to be well understood. However, it is important to note that there is much more research into experiences of transition and continuity of care than there is evaluation of models or approaches to improve experiences of transition and continuity of care.

1.23 The research reviewed for this study, and interviews, indicate that the problems associated with the transitions from CAMHS are not specific to CAMHS (i.e. young people making transitions from other children's health services can experience similar difficulties to young people transitioning from CAMHS. Like the transition from CAMHS, these difficulties can be caused by poor planning and communication and differences in the culture of child and adult health services). However, the research also suggests that the problems may be more acute for young people with mental health difficulties making a transition from CAMHS.

Good practice in transitions from CAMHS

1.24 The research evidence suggests that transitions from CAMHS can be improved by:

- helping young people and families negotiate or navigate the gaps between CAMHS and AMHS, as the examples in table 3 illustrate; and/or
- bridging or closing the gap between children and adult services by:
  - greater collaborative working between CAMHS and AMHS (which could be considered as a model of soft integration) and giving young people greater choice about how and when they transition; and/or
  - establishing youth or all-age MH services (a model of hard integration), so transitions are deferred (in the case of youth services), or eliminated (in the case of all-age services).

Table 3. Improving young people's and their families' transition from CAMHS

Barriers to a smooth transition	Solutions and enablers
The fear and anxiety many young people and their families experience before and during the transition from CAMHS.	Timely transition planning and preparation using, for example, transition plans and key workers to ensure that young people and their families know what to expect, what their choices are and that they are supported through the process; and providing continuity (e.g. with a trusted person) during and (for a reasonable period) after transition.
Poor planning and/or management of the transition from CAMHS so, for example, it feels rushed, poorly coordinated and/or young people have	Timely transition planning, so young people, their families and services are prepared. This can be supported by: - transition protocols (outlining what should happen, including timing[9], and services' responsibilities);

[9] The current Together for Children and Young People Programme (T4CYP) guidance is that: "agreement to transition should be sought from the young person and parents/carers a minimum of 6 months in advance of the proposed date of transition" (T4CYP, n.d., p.16). The NICE guidance is that: "for groups not covered by health, social care and education legislation, practitioners should start planning for adulthood from year 9 (age 13 or 14) at the latest… for young people entering the service close to the point of transfer, planning should start immediately" (NICE, 2016, p.7).

to constantly re-tell their story.	- service managers taking responsibility and accountability for transitions (including monitoring and evaluation of users' experiences); - information sharing protocols, shared IT systems and young people's passports (to aid information sharing). Effective multi-agency working involving other services (such as education, employment, housing and/or social services), who may also be working with and supporting young people at this time. This can include the use of care and treatment planning and key workers to coordinate the involvement of different stakeholders.
Service centred approaches, which mean transition is done "to", not "with" young people and their families. This can also mean transitions are made at a particularly difficult time in young people's lives; young people do not engage with AMHS; and/or parents/carers feel excluded.	Person centred transition planning, including flexibility about the age at which transition takes place (e.g. 15-20), so that it reflects the young person's circumstances (e.g. other challenges or transitions in their lives) and their "development, maturity [and] cognitive ability", rather than just their chronological age. The development of needs based services; - proactively reaching out to engage young people, particularly those most at risk of disengaging, this could include, for example, using peer support, coaching and mentoring, advocacy and IT; and - respecting young people's choices about family involvement and explaining this to families;
MH services for adults (including LPMHS) which are not always felt to be	Increased collaboration between CAMHS and AMHS, such as jointly reviewing current systems and practice to identify where changes are

"young people friendly"; and AMHS which have high thresholds and a very different approach and ethos to CAMHS, which can mean that there is little continuity of care following the transition from CAMHS.	needed; developing a shared vision and policy for transition; joint working before and after transition; and shared training between CAMHS and AMHS. Ensuring that where appropriate, young people are supported to access alternatives to AMHS, such as those provided by the third sector and LPMHS. Investing in services for young adults, including, for example: - workforce development (to ensure staff have the social and emotional skills required, are confident working with, and have adequate time to build relationships with, young adults); and - commissioning new, or reconfiguring existing, services for young adults (including the possible development of youth MH services) so they better match demand and young people's expectations and needs.

Source: Interviews, research reviewed for this study (e.g. NICE, 2016; T4CYP, n.d.)

Barriers and enablers to changes to improve transitions

1.25 The recommendations outlined in table 3 are well understood (and are outlined in the current T4CYP transition guidance (T4CYP, n.d)). In part, the challenge can be framed in terms of implementation (i.e. why good practice is not implemented) and understood in terms of factors like capacity (and resources) and the priority attached by services to improving transitions, relative to other service priorities.

1.26 Moreover, some barriers to smooth transitions, such as the cultural and organisational differences between CAMHS and AMHS, which can mean there is no service for young people to transition to, are structural and not easily resolved. They are likely to require a much greater degree of collaboration and possibly a "hard" integration between CAMHS and AMHS, to create overarching youth MH services. This however, brings with it a new set of challenges, such as overcoming

institutional inertia and resistance to change; the difficulties inherent in bringing together different organisations with different cultures, working practices and IT systems; difficulties in recruiting, training and retaining a workforce with the skills required; and the time, cost and potential disruption caused by reconfiguring services.

1.27 More broadly, the research and interviews for this study suggest that the case for alternative service models (such as all-age or youth MH services) is not primarily about improving transitions; instead it rests upon the broader need to improve MH services for young people and to better match capacity to need and demand. The current system is seen as complex: "with no easy or clear way to get help or support" and too many young people with needs who cannot, or choose not to, access MH services in a timely way (CQC, 2018, 2017; NAfW, 2018). Any reconfiguration of MH services for young people should also therefore aim to benefit young people who choose not to, or who cannot, access CAMHS (and are therefore not transitioning), or AMHS. Assessing how best to meet the needs of these groups is a question that lies beyond the scope of this review.

Recommendations for further research

1.28 This was a relatively small scale scoping study, intended to identify the need for further research. The key gaps it highlights (where there is a case for commissioning or undertaking further research and evaluation) are identifying:

- the barriers to implementing the current T4CYP guidance on transitions and solutions (to ensure consistent implementation across Wales);
- the effectiveness and cost-effectiveness of, and lessons from, the establishment of alternative service models, such as: youth MH services in England (where there are very few evaluations); all-age services like LPMHS, and disorder specific services, such as EIPS in Wales, that span traditional age boundaries (where no evaluations were identified); and
- assessing the case for and against developing young people's MH services, and considering questions such as the appropriate age range for services (e.g. 11-25, which would align with current Welsh Government policy, or 14-25, which was generally favoured by interviewees for this study, given the typical age of onset of

MH difficulties). This should include an assessment of how the needs and expectations of those young people who are either not eligible for, or who are not engaging with, existing CAMHS and AMHS can best be met.

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