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Review of Evidence on 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n.d.	No date (used for unpublished material)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.

1. Introduction

Young people's mental health

1.1 The majority of children and young people in Wales experience good levels of mental wellbeing. However, around one in five report low life satisfaction and it is estimated that around one in eight has a mental health problem. The incidence of mental health problems tends to increase with age, and some more serious mental illnesses, such as schizophrenia and bipolar disorder, only tend to emerge in late adolescence (PHW, 2016).

1.2 The needs of many young people with mental health problems can be met by "universal" services[1], like schools and they may only require time limited support. However, a minority of young people's mental health problems will continue and, in some cases, be lifelong. The severity of their disorders means they will require assessment and intervention from more targeted or specialist primary, community and secondary care services, such as Local Primary Mental Health Services (LPMHS) or specialist Child and Adolescent Mental Health services (sCAMHS), commonly referred to as CAMHS[2]. Data on activity in CAMHS is limited, but it is estimated that 1.85 percent of young people will, at any one time, need a service response or support at tier 3 (the level of CAMHS) (PHW, 2016, p.72)[3].

1.3 The ages 16–18 are a particularly vulnerable time for young people. They are exposed to an increased risk of mental illness, while also going through a period of physiological change and maybe making 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 (JCPMH, 2013; Singh et al., 2010). The context in which young people make a transition from CAMHS is therefore often challenging, and poorly planned transitions, abrupt ends to services

[1] This reflects the continuum of services running from universal services like schools, through more targeted services, such as school counselling services, to specialist services like CAMHS.
[2] CAMHS is used as both 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] The estimate of young people who may at any one time need a service response or support 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).

and a sudden change in culture can lead to young people slipping through the service gap.

Increasing demand for mental health services

1.4 Demand for CAMHS and AMHS is increasing. There is evidence that mental health disorders[4] have increased, albeit at a slower rate than the rise in mental health difficulties; for example, the proportion of 5-15 year olds in England experiencing any mental disorder rose slightly from 9.7 percent in 1999 to 11.2 percent in 2017 (NHS Digital, 2018). This is likely to reflect a number of factors, including increasing awareness of mental health difficulties and a reduction in the stigma attached to them (so difficulties are more likely to be identified); changes to diagnostic thresholds (so more difficulties are classified as disorders) and societal changes (CQC, 2017). This has contributed to increases in referrals to mental health (MH) services, which have struggled to cope with the increasing demand, leading to longer waiting lists and a raising of thresholds (restricting access to services[5]) (NAfW, 2018). As a result, in England: "it is estimated that only 25% of children and young people who need treatment are able to receive it" (CQC, 2017, p.40).

Policy context

1.5 Improving the emotional and mental health of people of all ages is a key priority for the Welsh Government. Over the last two years, there have been a range of reviews, legislation and programmes. In this section, we focus upon four in particular: Everybody's Business; The Mental Health Wales Measure; Together for Mental Health; and the Together for Children and Young People Programme (T4CYP).

[4] "Mental disorders were identified according to International Classification of Diseases (ICD-10) standardised diagnostic criteria, using the Development and Well-Being Assessment (DAWBA). To count as a disorder, symptoms had to cause significant distress to the child or impair their functioning." The most common problems are: conduct disorders, attention deficit hyperactivity disorder (ADHD), emotional disorders (i.e. anxiety and depression) and autism spectrum disorders (ASD). (NHS Digital, 2018).

[5] This can include: limits on who can access a service, based upon: age, the severity of need, the type of condition, evidence that support to address the need has already been tried, and restrictions on which professionals can refer into the service (CQC, 2017).

Everybody's Business

1.6 The Welsh Government's 2001 CAMHS strategy, Everybody's Business (NAfW, 2001), introduced a broader "CAMHS concept" in which a range of services, including in particular education and social services, deliver children and adolescent MH services together with specialist CAMHS (sCAMHS).

The Mental Health (Wales) Measure

1.7 The four parts of the measure introduce:

- all-age local primary mental health services (LPMHS) for people with milder or more stable mental health problems, offering assessment and short term support and, where needed, referral to secondary services (part 1);
- care coordination and care and treatment planning[6] for those needing more specialised care and support (part 2);
- rights for those who are discharged from MH services to refer themselves back to those services (part 3); and
- access to an independent mental health advocate for in patients (part 4).

Together for Mental Health

1.8 Together for Mental Health, the Welsh Government's strategy for mental health and wellbeing, covers people of all ages[7] and aims to ensure that transitions between services: "are based on need and not on artificial age boundaries." (Welsh Government, 2012b, p.5).

The Together for Children and Young People Programme

1.9 The Together for Children and Young People Programme (T4CYP) was launched in February 2015 in order to reshape and refocus emotional and MH services for children and young people. One of its work streams focuses upon all aspects of transition for children and young people between services and developing appropriate guidance (NHS Wales, n.d.). This led to T4CYP identifying and articulating the principles "Underpinning a Good, Seamless Transition" (see boxed

[6] The plan should be co-produced. It sets out the goals the person (patient) is working towards and the services that will be provided by the NHS and others to help them realise them.
[7] As the strategy outlines: "previously we have had separate strategies for children, for adults of working age and for older people, yet feedback we have had from those using the services is that it is at the points of transition between services that care and treatment can break down."

text) (T4CYP, n.d.). The guidance aims to change the emphasis from a fixed age for transition (at 18)[8] and instead focus on the young person's best interests (NAFW, 2018, p.104).

Principles Underpinning a Good, Seamless Transition

In developing local transition protocols and undertaking transition, health boards should have regard to the following principles:

- The young person must be treated as an equal partner, be listened to with their needs understood and taken seriously.
- The young person needs to receive safe continuity of care.
- The young person's physical health needs must be considered alongside their mental health needs.
- The young person should be supported via peer support, coaching and mentoring, advocacy and the use of mobile technology.
- Young people and their families need to be involved, given information and choice that promote early access to support, particularly for those in crisis and young people with protected characteristics.
- Services need to take account of the wishes of the young person to have their family involved or explain to the young person and family why this is not practical.
- Seamless, flexible transition should be a shared process centred around the wishes and needs of the young person. It requires coordinated, multiagency planning with a range of professionals from different disciplines, the young person and their representatives.

[8] Since 2012, 16 and 17 year olds have been supported by CAMHS, rather than AMHS, and at around age 18, young people (as adults) would normally be expected to make a transition to AMHS. However, the transition between services should be determined by need, rather than age, so CAMHS should be able to continue working with young people as they become adults and AMHS should, where appropriate, be able to work with and support young people aged 16 and 18 (T4CYP, n.d.).

- An 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.
- Specialist CAMHS and adult services should jointly agree: a shared transition protocol, an information sharing protocol and approaches to practice.
- The Young Person's Passport should be used as way of enhancing the experience and managing expectation.
- Transition should be implemented in the context of the young person's development, maturity, cognitive ability and not on service criteria.
- Services need to consider other transitions and complexities that could put additional pressure on the young person.
- Specialist CAMHS should continually review young people's experience of transition and what works.

Source: T4CYP programme (n.d.)

1.10 The guidance is supported by a Young Person's Passport, which is: "designed to empower and support young people to take ownership of the process [of moving from CAMHS to AMHS] and enable them to have a good transition". The passport is developed by the young person with the support of their transition worker and takes a person centred and strengths based approach to help ensure that the transition helps the young person realise what is important to and for them.

Transitions from CAMHS

1.11 Since 2012, 16 and 17 year olds have been supported by CAMHS, rather than AMHS, and at around age 18, young people (as adults) would normally be expected to make a transition to AMHS. However, the transitions between services should be determined by need, rather than age, so CAMHS should be able to continue working with young people as they become adults and AMHS should, where appropriate, be able to work with and support young people aged 16 and 17. Where appropriate, there should also be a period of shared care between CAMHS and AMHS services. Where young people do not meet the eligibility criteria for AMHS,

alternative pathways to, for example, LPMHS (established under the Mental Health (Wales) Measure), will be needed (T4CYP, n.d.).

Difficulties in making transitions

1.12 For those young people who need ongoing support and care, the transition from CAMHS to AMHS is vital, but can be challenging, and difficulties have been well documented by multiple reviews (see e.g. Children's Commissioner for Wales, 2019; Hafal, 2016; NaFW, 2014). These reflect differences in the organisational cultures, practice and policies of CAMHS and AMHS, including eligibility criteria and, for example, the difficulties that vulnerable young people may often have in "letting go" of relationships of trust with those they know in CAMHS. Smooth transitions can also be undermined by poor planning, coordination and communication, and/or service centred planning and processes, which can also exclude family members, and which mean that transition is: "often seen as something which is done to them, rather than a process which they own and in which they are fully engaged" (T4CYP, n.d.). Transitions can also be complicated by the other transitions that a young person is making (e.g., from school to college, university or employment and/or from the family home to independent living) which can add to their stress and uncertainty (Welsh Government, 2012a).

Good transitions

1.13 Young people's transitions from CAMHS to AMHS are now a well-researched area and there are a number of resources available outlining what good transition may look like (e.g. Street, 2019), including those produced by the T4CYP (n.d.) (discussed above) and NICE (2016). These typically focus upon person centred planning and practice (including effective communication and support for young people and their families). Enacting this requires effective and coordinated planning with young people and their families and across the different services and professions involved in the transition. This should ensure that, for example, there is continuity of care and support for both mental and physical needs and young people's and their families' wishes are respected.

Aims and objectives of the review

1.14 The **aim** of the review is to provide an overview of the evidence on all-age MH services and transitions from CAMHS to AMHS. It is expected that this will "further inform the guidelines" developed by the T4CYP. The objectives of the review are:

- to summarise the evidence around transitions from CAMHS to AMHS across primary, community and secondary care specifically, and the effectiveness of different models;
- to provide an overview of the evidence on transitions of care from child to adult health services more broadly, and the key differences between the evidence for these services and MH services;
- to provide a summary of good practice in transitions in MH
- services;
- to undertake a small number of exploratory stakeholder interviews to identify potential facilitators and barriers to improving transitions, with a view to informing further research in this area.

Structure of the report

1.15 The remainder of the report is structured as follows:

- section 2 outlines the review's approach and methodology;
- section 3 discusses young people's transitions from CAMHS and the difficulties that can be encountered. It also discusses why young people are sometimes either not accepted by, or disengage from, AMHS and the commonalities and differences between the evidence base in relation to MH services and other health services.
- section 4 describes the evidence of what constitutes good practice in young people's transitions from CAMHS.
- section 5 outlines the evidence about alternative service models that span traditional age boundaries, such as all-age, children and young people's MH

services (e.g. services for those aged 0-25) and youth MH services (e.g. services for those aged 14-25).

- section 6 outlines the reviews conclusions; and
- section 7 outlines recommendations for further research.

2. Methodology

Introduction

2.1 This was a primarily qualitative review. As this section outlines, it draws upon systematic literature reviews complemented by interviews with a small number (n=12) of stakeholders and a workshop with practitioners to discuss emerging findings.

Literature review

2.2 The purpose of the desk based literature review was to identify and then assess the evidence:

- around transitions from CAMHS to AMHS, including the effectiveness of different approaches to supporting transitions between services and different models, such as all-age MH services; and
- on transitions of care from child to adult health services more broadly.

2.3 Because two high quality systematic reviews had already been conducted in this area, the literature reviewed focused upon:

- a review of evidence identified and included in the systematic reviews of young people's transitions from child to adult services undertaken by NICE (2016) and Cochrane (Campbell et al., 2016);
- identifying and reviewing other evidence that was not included in these earlier systematic reviews, because, for example, it was published after the reviews were conducted (i.e. after 2016); and
- identifying and reviewing evidence specific to practice in Wales that might not meet the quality criteria required for inclusion in the systematic reviews, but which was considered relevant in understanding how practice in Wales might differ from that in the other UK nations, and in particular England, where much of the research was undertaken.

Reviewing existing systematic reviews

2.4 As well as extracting the key finding from the systematic reviews undertaken by NICE (2016) and Cochrane (2016), their bibliographies were "mined" to identify

research specific to MH services. This helped identify how the evidence base in relation to transitions between MH services might differ to that covering transitions between other health services.

Identifying other evidence

2.5 In order to identify other evidence that would not have been included in the systematic reviews conducted by NICE (2016) and Cochrane (2016), a search protocol was developed. The key inclusion criteria for the review were:

- relevance: the item must include research (including evaluations) around transitions from child to adult health services (including in particular, but not limited to, MH services) in Wales, the other UK nations and selected European countries, that was not included in the NICE or Cochrane reviews; and
- languages: the item must be published in the English language.

2.6 The sources searched were:

- Google scholar to identify academic literature;
- NHS Evidence;
- Google, to identify unpublished "grey" material, such as evaluation reports;
- PubMed; and
- The British Medical Journal (BMJ).

2.7 The search terms used were the string of search terms: Research OR evaluation OR review AND transition* OR transfer AND "mental health" OR CAMHS OR "health Service* AND 2016 OR 2017 OR 2018 OR 2019 [9].

2.8 A two stage sift was used to identify items that met the inclusion criteria. Those meeting the inclusion criteria were then reviewed as part of a second stage sift to assess the quality of evidence. Those included following this second sift were then reviewed to identify (and extract) material relevant to the study objectives.

[18] These search terms were used to help ensure that items considered by earlier systematic reviews could be excluded at the search stage.

Assessing the quality of evidence

2.9 The approach taken to assess the quality of evidence was based upon NICE guidelines (2018) and focused upon assessing whether:

- there was sufficient discussion of the approach and methods used to enable a judgment on quality to be made;
- the approach taken was appropriate, given the aims and objectives of the research or evaluation;
- the methods used to collect data were appropriate, and sufficiently robust, to give confidence in their likely validity and reliability;
- the approach taken to analyse the data was appropriate and sufficiently robust to give confidence in the findings; and
- the findings were adequately supported by the data presented in the study.

2.10 A flexible approach to assessing quality was taken to enable reviews, such as those undertaken by the National Assembly for Wales (NAfW) Children and Young People's Committee, to be included. These were used to provide valuable information about practice in Wales, even though the nature of the reviews meant they would not meet the demanding standard of evidence of "what works" required by the NICE guidelines. Given their nature, these reviews were only used as supporting, rather than primary evidence of what works.

2.11 Table 2.1 outlines the results of the searches and sift process.

Table 2.1. Results of the search and sift

	# of items identified by the search	# of items included after the first sift	# of items included after the second sift
Google scholar	983	70	24
Google	210	20	9
BMJ	97	6	4
PubMed	0	0	0

2.12 A full list of items identified through the search is outlined in the appendix. In addition to items identified through the search (outlined above) studies identified by stakeholders, by initial scoping work and snowball sampling (where, for example, studies referred to in items included in the review were followed up), were identified and then reviewed to assess if they met the inclusion and quality criteria.

Interviews and practitioner workshop

2.13 A small number of interviews (n=12) with stakeholders from CAMHS, AMHS and specialist youth MH services, such as EIPS, in Wales were undertaken. These are summarised in table 2.2. Stakeholders were identified by CAMHS or AMHS once permission had been secured from Local Health Board (LHB) research and development departments. Delays in securing permission delayed the fieldwork and limited the range of LHBs that could be included. Additional interviewees from AMHS were identified through an open call made by the Welsh Government to contribute to the review, once it was decided not to hold a second workshop for practitioners (discussed below). Despite the challenges, the number of interviews undertaken (12) exceeded the targets set for the study of 7-10 interviews. In addition, a small number of stakeholders in other parts of the UK were also consulted by email to gather additional material about children and young people's or youth MH services.

Table 2.2. Interviewees by service and LHB area

LHB	CAMHS	14-25 service (e.g. Early Intervention Psychosis service (EIPS)	AMHS (e.g. Community Mental Health Teams (CMHTs)
Aneurin Bevan University Health Board (UHB)	2	1	
Betsi Cadwaladr UHB			2
Cardiff and Vale UHB	2	1	1
Cwm Taf Morganwg UHB	1		1
Powys THB			1

Practitioner workshops

2.14 Two workshops with practitioners from CAMHS and AMHS respectively were planned. In practice, only one workshop, open to participants at the Children and Young People's Mental Health: A Home Countries' Perspective Conference in October 2019, could be organised within the timescale available for the review. This workshop was well attended and provided an opportunity to share and help test and disseminate emerging findings with practitioners and other stakeholders, such as parents or carers of young people with mental health difficulties.

Strengths and weakness of the approach and methods

2.15 The scope to review and mine two high quality existing systematic reviews (NICE, 2016 and Cochrane, 2016) provided a solid evidential base outlining what was known about what works in relation to transitions from child to adult health services. This was updated and extended through the additional searches and inclusion of material identified by stakeholders, providing reassurance that the review could draw upon a comprehensive and up to date body of evidence. It also enabled extensive triangulation of findings, and it was reassuring that most studies identified similar findings. Although, as outlined in sections 3, 4 and 5, the review identified considerably more research about transitions, as distinct from evaluations of models and approaches, this appears to reflect weakness in the evidential base, rather than weakness in the search strategy. This has informed the recommendations for further research outlined in section 7.

2.16 Because much of the research and, where available, evaluations, were undertaken outside of Wales, and were heavily weighted toward those conducted in England, this raised questions about whether findings from other countries could be generalised to Wales. The qualitative research with stakeholders and small numbers of reviews identified that those specifically focused upon Wales, such as Children's Commissioner for Wales (2019); NAfW (2018) and Hafal (2016), were vital in helping assess whether it was appropriate to generalise findings to a Welsh context. Although the evidence from qualitative research and reviews specific to Wales suggested that in general they could, the small number of interviews and limited geographical coverage increased the risk that differences in practice across Wales were missed. Therefore, whilst evidence about what works can be reasonably safely inferred to apply to Wales as, for example, the current T4CYP guidance (T4CYP, n.d.) does, findings about current practice in Wales should be treated with caution.

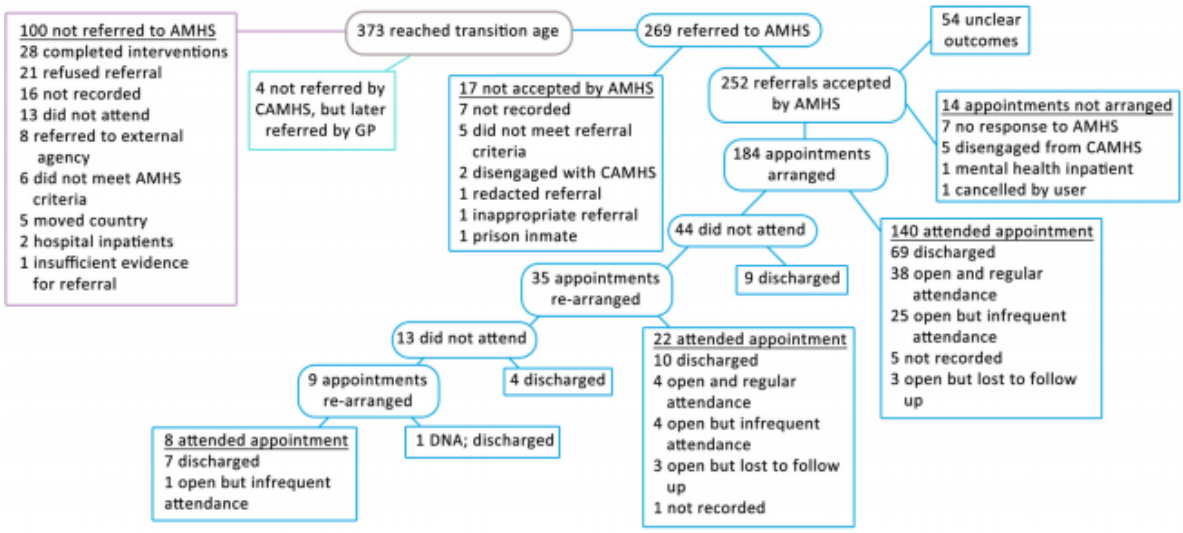
3. Young people's transitions from child to adult mental health services

Introduction

3.1 In the last 10 -15 years, the transition of young people from CAMHS to AMHS has been extensively explored in the literature, both nationally and internationally. The research identifies that young people's transitions from CAMHS are complex and diverse, and that many young people do not make or sustain a transition to AMHS. Data on Wales is not available, but as figure 3.1. below illustrates, research in Northern Ireland identified that[10]:

- around a quarter of young people supported by CAMHS (n=373) were not referred to AMHS (n=100) when they reached transition age, for a variety of reasons outlined in Figure 3.1 below; and
- of those young people whose referrals were accepted by AMHS (n=252), only around 30 per cent (n=72) remained "open" and in contact with AMHS after three appointments[11] (Leavey et al., 2018).

Figure 3.1. Transition pathways mapped by Leavey et al., 2018



Source: Leavey et al., 2018

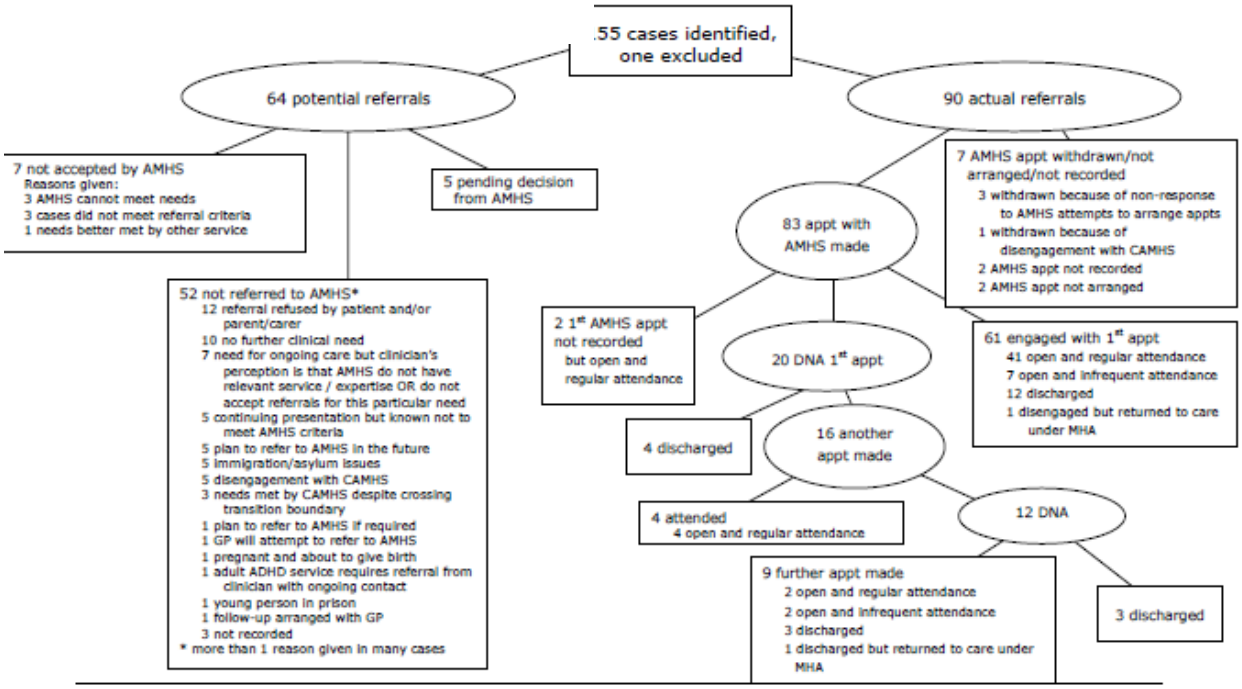
10 The research analysed the transitions of 373 young people in Northern Ireland, using records and "case notes of young people eligible to transition to adult mental health services over a 4-year period", in addition to interviews and workshops with professionals.

11 I.e. had "regular and open attendance" (n=42) or "open but infrequent attendance" (n=30).

3.2 As figure 3.2. illustrates, based upon research in England (Singh et al., 2010)[12]:

- around a fifth (n=29) of young people reaching the transition boundary between CAMHS and AMHS and thought suitable for transition by CAMHS (n=131)[13] were not referred to AMHS because it was felt that AMHS could not meet their needs or they would not be accepted by AMHS (n=12); a parent or carer refused (n=12), or they had not yet been referred to AMHS (n=5); and
- of those accepted by AMHS (n=90), around 65 percent (n=58) remained open to contact with AMHS[14] (i.e. had some continued attendance with AMHS and were not for example discharged).

Figure 3.2. Transition pathways mapped by Singh et al., 2010



Source: Singh et al., 2010

[12] The process of transition was evaluated: "using a case note survey, to identify all actual and potential referrals from CAMHS to adult services in the preceding year, to 'track' their progression through the service boundaries and evaluate their outcomes in terms of referral process and engagement with adult services" (Singh et al., 2010, p.44).

[13] 102 of 131 cases were referred, with 90 accepted, seven refused and five pending decision from AMHS. Of the remaining 29 cases, in 12 cases the young person and/or a parent/carer refused referral to AMHS; in 12 cases referrals were not made because CAMHS thought AMHS would refuse the referral or could not meet the young person's needs; and in five cases referral to AMHS was planned but had not been made (Singh et al, 2010, p.53).

[14] The 58 includes 41 with "open and regular attendance"; seven with "open and infrequent attendance" after the first appointment; four with "open and regular attendance", who did not attend the first appointment, but attended a second appointment; two with "open and regular attendance" and two with "open and infrequent attendance", who did not attend a second appointment; and a further two who were discharged but returned to care (Ibid.).

3.3 This section discusses why:

- transitions for those who are accepted by AMHS can be very difficult; and
- some young people are not accepted by AMHS (e.g. due to differences in eligibility criteria for CAMHS and AMHS) or disengage from AMHS (e.g. due to poorly planned transitions and gaps and differences between services).

Timing

3.4 Both the literature reviewed (e.g. McGorry, 2007, 2013) and interviewees identify that a transition at the age of 18 can come at a very difficult time in young people's lives; as one interviewee put it: "at 17 they have often lived in the same area, they have no experience of the adult world. Going to university can be very stressful …or not going as you're too unwell and all your friends are…your world is changing massively…[you're] feeling vulnerable, isolated and you've also got secondary mental health needs....there is a lot of change and a lot of turbulence".

3.5 Other interviewees stressed the other transitions and changes that could be going on in a young person's life, such as leaving education and looking for employment, leaving the family home and living independently, and forming new relationships. As a consequence, as one concluded: "why create chaos in the middle of all this?" (by requiring them to also transition from CAMHS to AMHS at this time in their lives).

Fear and anxiety

3.6 Change can foster fear, confusion and anxiety, particularly where the nature and direction of change is uncertain (as is the case for many young people making transitions) and/or communication is poor (Children's Commissioner for Wales, 2019). This can be compounded by factors such as "adolescent resistance to change" and transition, fears on the part of families and also negative perceptions of adult services (Singh et al., 2010).

3.7 As a consequence:

- Colver et al.(2019) identify (based upon a large study in England[15]): "transition and transfer of health care were disorientating and disrupting for young people and their families ";
- Hill et al. (2019) identify that for the young people who contributed to their study, the concept of transitioning was something to be fearful and anxious about; and
- Singh et al. (2010) identify: "transition is daunting for young people and carers – trusting therapeutic relationships built over time with CAMHS, and there is uncertainty about AMHS. Professionals reported feelings of loss and concerns about terminating therapeutic relationships with young people who anyway had difficulties in building trusting relationships".

3.8 Research and reviews in Wales suggest a similar picture (see e.g. Children's Commissioner for Wales, 2019; NAfW, 2018).

Poor preparation, planning and partnership working

3.9 Interviews for this review identified a commitment to improving transitions and recognition that they could be difficult, but there were practical problems and barriers that impeded this; for example, as one interviewee put it:

> "In an ideal world, referrals would be made six months before their 18th birthday. We would be honest about what adult service can do and try to reduce the support from CAMHS...[so the young person] is not stopping one minute and starting something different the next [on their birthday - no continuity of care]. The aim is phased transition...but it's a nightmare to get the transfer of care meeting organised before they are 18".

3.10 A lack of time, due to competing priorities and/or delays starting transition planning and poor communication and/or coordination within and between services can undermine transition planning and preparation. Young people's experience of transitions can therefore be disjointed; for example, an interviewee reflected upon the practical difficulties arranging a time that was convenient for CAMHS and AMHS staff to meet, and the very limited scope for joint working. Some also reported that

[15] The longitudinal study followed 374 young people as they transitioned from paediatric to adult health services.

there were further delays after transition, while AMHS waited for notes from CAMHS. As a consequence, as one interviewee described it: “we have a CAMHS policy and protocol [but in practice] ...it’s generally a handover meeting, and maybe a little joint work”.

3.11 Interviewees also reflected that while transition planning might give services enough time to prepare, it might not give young people and their families enough time; for example, as one observed, an initial assessment at 17 to 17.5 means: “we can plan ahead and if they are accepted, we can make a plan but it’s a massive change for them”.

3.12 Research in Wales (e.g. Children’s Commissioner for Wales, 2019), England (e.g. Colver, et al., 2019) and Northern Ireland (Leavey et al., 2018) identifies that the basic building blocks of transition planning, like having a transition plan, are often absent and young people feel transition planning is done “about” them rather than “with” them (Children’s Commissioner for Wales, 2019). Leavey et al. (2018) identified that, of the 252 cases that were in CAMHS at the time of transition, and whose referrals were accepted by AMHS, a transition planning meeting was only recorded to have taken place in 38 percent of cases, and joint appointments even less so (18 percent). As the boxed text illustrates, the TRACK Study in England (Singh et al., 2010) identified a similarly poor picture in terms of the process.

How many young people achieve an “optimal transition”?

Singh et al. (2010) used a “case note survey”, to identify all actual and potential referrals of young people from CAMHS to AMHS in Greater London and the West Midlands, over the course of year. These young people’s progress was tracked. to identify, for example, if they made and sustained a transition to AMHS, and to identify the characteristics of the process. The study was able to track the cases of 155 young people, 90 of whom were referred to and accepted by AMHS.

The study used four criteria to define an “optimal transition”:

- "continuity of care (either engaged with AMHS three months post-transition or appropriately discharged); AND
- a period of parallel care (a period of joint working where the service user is involved with both CAMHS and AMHS); AND
- at least one transition planning meeting (meeting discussing the transition from CAMHS to AMHS, involving the service user and/or carer and key professionals, prior to the handover of care from CAMHS to AMHS); AND
- optimal information transfer (any or all of the following transferred from CAMHS to AMHS: referral letter, summary of CAMHS contact, any or all CAMHS notes and a contemporary risk assessment)" (p.66).

Based on these criteria, it identified that only four of the 90 young people (4 percent) had an "optimal transition".

The study identified a "suboptimal transition" as one in which one or more of these criteria was missing; of the 90 cases:

- 63 "had continuity of care"[16];
- 36 "had at least one transition planning meeting"[17];
- 24 "had good information transfer"[18]; and
- 22 "had a period of parallel care/joint working between CAMHS and AMHS"[19] (p.67).

The cultural and organisational gap

3.13 A key theme in the literature reviewed for this study is the distinctive difference between the culture of child and adult health services, creating a "gap" between services which young people must negotiate or "jump" across (Chance, 2016); for example:

[16] Of these 63 cases, 18 "had a period of parallel care", 28 "had at least one transition planning meeting" and 20 "had good information transfer".
[17] Of these 36 cases, eight "had a period of parallel care"; 16 "had good information transfer" and 28 "had continuity of care".
[18] Of these 24 cases, six "had a period of parallel care"; 16 "had at least one transition planning meeting" and 20 "had continuity of care".
[19] Of these 22 cases, eight "had a transition planning meeting"; six "had good information transfer" and 18 "had continuity of care" (Singh et al., 2010, p.67).

- as Lamb and Murphy (2013) put it: “young people and their parents describe the change in service philosophy between child and adult services confusing, especially in relation to the role and involvement of families”;
- as Hill et al. (2019) put it: CAMHS was perceived as “nurturing” and “protective” and AMHS as “autonomous”, “individualized” and “acute disorder led”; and
- Singh et al. (2010) report that: “cultural philosophies differed between CAMHS and AMHS; the former was described as more person-centred, holistic and family-oriented, and the latter as medication- and crisis-oriented”.

3.14 Many of the interviewees for this study highlighted the differences in the culture of CAMHS and AMHS; for example, as one described it: “CAMHS is different, the professional’s relationship to the patient is that of “trusted adult” as much as a doctor”, and that CAMHS works with families. The focus is upon “mental health rather than mental illness”, and young people tend not to be in crisis, so CAMHS role is often about maintenance. As vulnerable adults, these young people “need a prolonged launch into independence”, but AMHS find it “difficult to accommodate them” so they “get nothing”. Even if they can access AMHS, the relationship between professionals and patients is much more traditional and focused upon the individual, rather than the family and the wider context. They also observed though that the much larger size of adult MH teams increased the scope for specialisation and development of expertise, and that some young people were ready and wanted a more adult oriented service.

3.15 Interviewees also highlighted the ways in which the use of the Choice and Partnership Approach (CAPA), (see boxed text) in CAMHS, but not in AMHS, could further deepen divides between the two services.

The Choice and Partnership Approach (CAPA)

CAPA aims to systematically match a service user's need to the capacity of the services, through a "choice" appointment with a clinician. It enables a more flexible approach to access for patients and a wider range of interventions from practitioners (CQC, 2017).

3.16 Equally, some interviewees from AMHS took issue with some of the descriptions of AMHS, stressing that while they communicated directly with the young person, they thought "about the system the child lives in" and understood that "they [the young person] still need the support of the family". The problem was that they could not involve the family without the consent of the young person. Both interviewees and some of the literature reviewed (e.g. Singh et al., 2010) stressed that young people's level of maturity and understanding was critical and that some young people may welcome the change in culture and ethos when they made the transition from CAMHS to AMHS. This led to the recommendations for "developmentally appropriate services" rather than services based upon what was felt to be a largely arbitrary age threshold (Colver et al., 2019). The question for most young people is therefore, **when** they can and should transition to AMHS (and an adult approach/model), rather than **if,** they should transition to AMHS (and an adult approach/model). Equally, it was observed by one interviewee that having a fixed boundary meant that: "age is one less thing [for services] to argue about". This reflected the pressure upon services, which in turn has increased pressure to restrict access to those services.

Managing risk

3.17 There were differing discussions around risk. As one interviewee from AMHS put it: "services can manage risk with adults more than with children – adults are expected to be able to look after themselves but with children a service must take responsibility." However, other interviewees from CAMHS expressed the view that: "AMHS were more constrained by rules and risk assessments than CAMHS".

Involving families

3.18 The need to get young people's consent to involve parents and carers was seen as a key challenge by AMHS; for example, as one interviewee from AMHS described it:

> "The biggest issue is intensive family work. CAMHS don't need parental consent to work with the family...but at 18 if you don't want your family involved [you don't have to] you can say no. it's a massive problem…if there's no consent there is nothing we can do, therefore we are encouraging referrals before the age of 18, to enable this [to let the services start working with parents] [ideally] when transfer of care meeting, to start joint work with CAMHS, and to start to build the relationship at an earlier stage [but the reality is] waiting lists, they're accessing treatment and come to our service and expect it to be there and then [but it's not] psychologists in our team have huge waiting lists and lots need therapy".

3.19 As another interviewee from AMHS put it, the need to get consent made things "very difficult"; for example, parents are: "used to phoning up and getting advice, we can't give it without the young person's consent and parents get very frustrated". Some young people: "say they don't want their parents involved...want to get out of their parents' house, all in turmoil and to us they're still feel very young, immature, they're struggling with the transition to adulthood, but we've got to treat them as adults". As another put it: "young people may not open their post, we might have the wrong telephone number [as young people often change mobile numbers] and they don't get the prompts, [or] the support needed from family that anyone at that age needs" (irrespective of whether they have mental health difficulties).

Confidence and competence working with young people

3.20 Staff confidence and competence working with young people was highlighted by a number of interviewees. This was seen as a particular concern in relation to staff in AMHS. One interviewee reflected on how the policy change in 2012, which extended CAHMS to 18, had inadvertently deskilled staff in AMHS who had previously worked with 16 year olds, but who now saw it as "outside their competence".

Structural differences

3.21 The literature reviewed for this study also highlighted structural differences between CAHMS and AMHS; for example, as Lamb and Murphy (2013) describe it:

> "Children's mental health services provide for children and young people with a wide range of disorders, including mental illnesses such as depression, anxiety, eating disorders, obsessive-compulsive disorder and psychosis, as well as autism spectrum disorders, intellectual disabilities, attention-deficit hyperactivity disorder (ADHD) and conduct disorder. In addition, specialist and targeted services provide for children and young people in difficult circumstances that put them at risk of mental disorder. For example, those in the care system, young people involved with the criminal justice system, and children and young people who have experienced abuse and neglect…The remit of secondary care AMHS is narrower in the main, focusing on adults with more severe mental illness. The majority of adults with mental disorders are cared for within primary care" (Lamb and Murphy, 2013, p.43).

3.22 Similarly, as one of the interviewees for this study observed, CAMHS and AMHS have "very different structures", which "don't mirror each other". As they described it, whilst CAHMS has some similarities to AMHS, there are important differences; for example, ND services sit in CAMHS but not in AMHS, and the CIT [Crisis Intervention Team] work differently to the outreach team in AMHS. As they summed it up there is a "different ethos no like for like" and as they concluded, this means "provision is not based upon the child's [or young person's] needs but what the services provide".

3.23 Two interviewees raised particular concerns about the (un)suitability of adult in-patient provision for young adults. This is also highlighted by other research (see RCP, n.d.; CQC, 2017), This was beyond the scope of the study, but is illustrative of the difficulties young people may experience in accessing age appropriate provision following transition.

Pressure upon services

3.24 Pressure upon services, a result of rising demand alongside frozen or reduced budgets (outlined in section 1), were felt to have increased the gaps between CAMHS and AMHS. As Singh et al. (2010) identify: "threshold and eligibility criteria

are currently being rigidly interpreted in a way to reduce the caseloads of AMHS workers already struggling with complex and demanding work". The Care Quality Commission (CQC) identified that services restricted access by placing limits on who can access a service based upon: age, the severity of need, the type of condition, evidence that support to address the need has already been tried, and/or restrictions on which professionals can refer into the service (CQC, 2017). The pressure upon services means demand exceeds capacity and, for example, two interviewees from AMHS identified that waiting lists, particularly for psychology, were a challenge, and exacerbated the gap between services offered by CAMHS and AMHS.

Minding the gap: the impact of structural and cultural differences

3.25 As Singh et al. (2010) conclude:

> "Ideological, structural, functional and organisational differences between CAMHS and AMHS produce complex challenges for all those involved in negotiating the boundary, including service users, carers and clinicians... CAMHS and adult services differ in their theoretical and conceptual view of diagnostic categories and aetiological processes [causes], in treatment focus, in service organisation, delivery and availability, and in professional training, all of which accentuate the problems at the interface..".

3.26 The ways in which services are configured, such as a diagnosis-led approach (with a focus upon providing access to and treating those with a diagnosable condition), can mean that young people with multiple difficulties, but which fall short of diagnostic criteria, cannot access a service that meets their needs (CQC, 2017). For example one interviewee from children's services described what happened in these cases: "those with emotional mental health needs, anxiety, OCD, depression, recurrent self-harm cannot transition easily… they've got to self-refer to PMHSS [primary mental health support services] - we have tried direct referral [to PMHSS], but it didn't work well: young people don't engage, so we're trying to prepare them more".

3.27 They went on to describe the sort of preparatory work they undertook, including looking at the local primary mental health services (LPMHS) website with the young person, to show them what they can access directly, and what they need a GP's

referral to access. They explained that after discharge, they do not know if the young person accesses LPMHS or not. As they put it, the problem with LPMHS was not what was offered, it is: “not that it’s [not] clinically effective, it’s how it’s delivered that matters”, and that it was not “young person friendly”. There were also concerns raised that while young people might meet thresholds for Community Mental Health Teams (CMHTs), without ongoing support, they ended up “in and out” of crisis teams.

3.28 Gaps between services, caused by factors such as differences in thresholds and referral criteria, can create tensions and mean young people are bounced between different services and/or fall between the gaps between services. Perceived weakness in alternatives to AMHS, such as LPMHS, mean that, as one interviewee from AMHS put it: “feel like at 18, [young people] almost get dropped, if we [AMHS] can’t take them on, who will?”

3.29 As one interviewee described it there can be a “no man’s land” between child and adult services where “nothing is done” to support a young person until they are 18 and become eligible for adult services, “[which is] very damaging as all the time the clock is ticking” and opportunities to intervene to address mental health difficulties and stop them escalating or becoming entrenched, are delayed.

3.30 Even when young people can access AMHS, they may feel or find that the service cannot meet their needs. For example, some studies identify: “inadequate education and training for adult care providers on adolescent disorders” (Singh et al., 2010) and workforce development, and ensuring that staff in both CAMHS and AMHS have the skills and confidence needed to work with young people, is seen as a key challenge.

3.31 Nevertheless, as Singh et al. (2010) identify:

> “Some clinicians may find that mental health services are not in the best interest of their clients and the so-called ‘natural’ ending of CAMHS services at the age of 18 is an ideal time to discharge a young person who may not have been in need of such services anyway, possibly having been wrongly referred to CAMHS in the first place”.

They also report that:

> "Some young people's difficulties unexpectedly improved to such an extent that there was no longer a clinical need by the time they crossed the transition boundary".

The different groups of young people CAMHS and AMHS work with

3.32 The structural and organisational differences outlined above, mean CAMHS and AMHS work with different groups of young people; for example, as Singh et al. (2010) report:

> "CAMHS were perceived as working with a 'different' user group, becoming involved at lower thresholds encompassing low mood, relationship difficulties and self-harming. In contrast, AMHS were perceived as operating at higher thresholds relating to serious mental illness (e.g. psychosis) forensic histories and those requiring inpatient admissions. Concerns were also expressed that it was difficult to transfer young people to AHMS when they were in a stable state following treatment; in other words, not in a crisis state".

3.33 These differences can foster fears about transition, and also reduce continuity of care (given changes in, for example, professional and therapeutic relationships) and mean that some young people cannot transfer from CAMHS to AMHS, as there is no service for them. Interviewees in CAMHS reflected that the "majority" of the young people they support did not transition to AMHS. Interviewees reported that young people who did not have a Care and Treatment Plan (under the Measure) generally found it hard to transition to secondary AMHS.

The expectation gap

3.34 Gaps and differences between services are a structural constraint on the effectiveness of transition planning. As a consequence, as Lamb and Murphy (2013) identify: "professionals can experience difficulties in meeting the expectations of young people and families at transition". Even when, for example, there is good communication between young people, their families and services; as one interviewee put it: "managing expectations about what is coming is important …[we] explain the differences between CAHMS and AMHS...[it is] important to do this [it's not that] AMHS are bad - but they are different …patients can seem shocked…[as there] seem to be more services in CAMHS than in AMHS".

Vulnerable groups

3.35 Research (e.g. CQC, 2017; Singh et al., 2010) identifies a number of groups of young people who have a higher risk of poor transitions (including not being able to make a transition to AMHS, disengaging from AMHS, or poor experience of transitions from CAMHS to AMHS); these include:

- young people living in challenging circumstances, such as looked after children, those leaving Local Authority (LA) care; those who are homeless, asylum seekers or from a Gypsy, Traveller or Roma background: "may be particularly vulnerable to mental health problems…. [and also] particularly vulnerable to problems during transition (Lamb et al., 2008, cited in Singh et al., 2010); and
- young people with neurodevelopmental disorders (NDs) such as ADHD, autism spectrum disorders (ASD) and learning disabilities (LDs) (RCP, 2017).

3.36 Singh et al. (2010) report, as an example, that: "the situation for young people with a learning disability is particularly complex. They may not meet the eligibility criteria for either the Adult Learning Disability Service or the Adult Community Mental Health Team, yet require ongoing support and psychiatric intervention" (p. 20).

3.37 Research in Wales (e.g. Children's Commissioner for Wales, 2019) supports this, although this research and some interviewees stressed that whilst thresholds changed at 18, which could mean young people were no longer eligible despite their needs not changing, this did not mean that all young people with LD were ineligible. In one area interviewees reported that the "flexibility" on the part of adult LD teams, meant transitions for young people with LD as well as mental health difficulties were often easier than other groups.

3.38 Similar problems (not fitting into adult MH or LD teams) are reported for:

- "high-functioning young people with an autism spectrum disorder or Asperger syndrome, especially in the absence of clear-cut comorbid psychiatric disorder" (Lamb et al., 2008); and
- young people with Attention Deficit Hyperactivity Disorder (ADHD)/Hyperkinetic Disorder (RCP, 2017).

3.39 Previous research in Wales (e.g. Welsh Government, 2016; Welsh Government, 2019) and interviews largely confirmed this; as one interviewee described it: "ADHD

- we pass on the information, but only offer medication, so no joint work *per se* – [there] is no shared medication protocol with AMH and also GPs" and as a consequence "there were delays, problems". The situation in relation to autism was more complex. Some autistic young people were supported by CAMHS if their mental health difficulties were severe enough[20], but were often not eligible for support from AMHS and did not always engage with the new Integrated Autism Service (IAS). The absence of services to transition to is a key issue here (CQC, 2017; Singh et al., 2010).

Disengagement

3.40 Hill et al. (2019) noted that fear and anxiety about the change can contribute to young people disengaging from services and the CQC (2017) report that getting the "simple things" wrong, like having settings that feel cold, unwelcoming and/or rushed, can also contribute to disengagement. This is seen as a particular risk when young people feel vulnerable because they have complex needs and are interacting with a multitude of different services and professionals. There are also concerns that services will discharge patients who do not engage. At the risk of stating the obvious, this is crucial, because, as Singh et al. (2010) report: "the most disruptive outcome of poor transition is that young people with ongoing needs disengage from services during the transition process".

3.41 Interviewees in adult services discussed the challenges here; for example, as one described it, when a young person does not engage:

> "We try to make contact by telephone to get them familiar with your voice, explain what you can offer and try to arrange to meet [at the service, in their home, even in their car] somewhere they are comfortable [we need to encourage them to] take responsibility for their care and explore the ways we can help. If they don't engage [respond to phone calls] we send an opt in letter...if we are very concerned about the risks [e.g. of suicide, self-harm, neglect, vulnerability, threats to others], we cold call...try to visit ...[but] if risks are not highlighted by CAMHS they can be discharged [by AMHS]".

20 ND services within CAMHS are generally focused upon assessment and diagnosis, and offer little post-diagnostic support (Welsh Government, 2019).

Young people's autonomy and responsibility

3.42 It was noted by interviewees that mental health difficulties could make it harder for young people to, for example, take responsibility or motivate themselves, and also that some young people were not very emotionally mature at 18. The challenge for AMHS is that responsibility rests with young people to engage. As one interviewee explained: "if you don't want to [you don't have to] it is up to them - they have the freedom and choice and the right to make 'unwise' choices"; as another explained:

> "[If they are assessed and not eligible – or don't want to access secondary services] we tell them what is available, maybe do a referral with them or on their behalf, give information and contact details, sit down with them while they phone, but adult services assume the person has capacity and can make their own choices…to choose a service or no, the responsibility is with the [young] person some are quite mature at 18, others are like, "I want to live my best life"".

3.43 They reflected that being able to follow up these young people "would be good", but is not something they can routinely do.

3.44 Re-engagement was a key issue here. Some interviewees reflected on not knowing whether young people knew how, or how easy it was for them, to re-engage with AMHS. It was noted though, that young people can only self-refer if they have been accepted by the service and then discharged, and that it was much harder if they had never been accepted by AMHS.

Primary mental health services

3.45 LPMHS is intended to be an all-age service. However, interviewees raised concerns, also highlighted by the Children, Young People and Education Committee that the: "creation under the Mental Health (Wales) Measure 2010 of all-age LPMHS services (to replace the previously separate adult and child services) risked leaving "an inferior CAMHS service for children and young people", focused on "adult models of care" (NAfW, 2018). Similarly, the committee's earlier report identified that the Mental Health (Wales) Measure: "better reflects adult orientated services and that Primary Mental Health Workers who are not trained or experienced to work in child and adolescent mental health are expected to do so" (NAfW, 2014).

Commonalities and differences between the evidence for mental health services and other health services

3.46 As Lamb and Murphy (2013) identify: "difficulties in transition from one service to another are not unique to mental health services… nor to the adolescent–young adult transition". This is a common finding across the literature reviewed; for example, research focused upon transitions between other health services identifies similar challenges to those specific to MH services:

- Ludvigsson et al. (2016) examined literature on young people with coeliac disease and their transition to adulthood. The study identified that barriers to successful transition included having an adult healthcare provider without adequate disease experience, inefficient or lack of communication, and cultural differences between paediatric and adult providers;
- Sebastian et al.'s survey (2012) on requirements for a smooth transition for adolescents with inflammatory bowel disease found that preparing for transitions early was more helpful for a successful transition and felt flexible transfers were important; and
- Colver et al.'s longitudinal study (2019) followed 374 young people as they transitioned from paediatric to adult health services[21] and identified that implementation of good practice recommendations[22] for aid transition was patchy. However, the study also identified that services for young people with diabetes tended to be better organized. This was partly because diabetes services have been interested in improving transition for at least a decade and because 14-18 is seen as a target for careful diabetes management.

3.47 However, there may also be additional complexities associated with young people's transitions from CAMHS to AMHS given, for example, the associations between:

- mental health difficulties and young people's circumstances; for example, those with "complex life events, such as parental mental illness, substance misuse,

[21] Participants had type 1 diabetes, cerebral palsy or ASD with additional mental health issues.
[22] They investigated the extent to which the young people were receiving nine proposed beneficial features which include: age-banded clinic; meet adult team before transfer; promotion of health self-efficacy; written transition plan; appropriate parent involvement; key worker; coordinated team; holistic life-skills training; transition manager for clinical team.

poverty, neglect, abuse, domestic violence and sexual exploitation" are at higher risk of developing mental health difficulties; and

- mental health difficulties and disabilities, ND and long-term conditions; for example, nearly 40 percent of children and young people with LD will develop significant mental health needs (CQC, 2017) and young people with ND disorders like autism have a high risk of developing mental health difficulties. This both increases the complexity of young people's needs and may mean that there is no AMHS either available or appropriate.

3.48 Moreover, the long-term nature of many mental health conditions may also make transitions harder. Haggerty et al. (2003, cited in Singh et al., 2010) concluded that: "continuity of care in mental health services differs from health care provision in its explicit and much greater emphasis on continued contact between service users and professionals". Similarly, McDonagh (2006, also cited in Singh et al., 2010), identifies: "changes in established, long-term therapeutic relationships between young people and health professionals" as a key challenge.

Conclusions

3.49 There are multiple reasons why young people:

- experience a difficult transition from CAMHS to AMHS;
- are not accepted by AMHS (e.g. due to differences in eligibility criteria for CAMHS and AMHS); and/or
- disengage from AMHS (e.g. due to poorly planned transitions and gaps and differences between services).

3.50 As section 4 outlines, the number of different contributory factors means there are no simple solutions to improve transitions from CAMHS.

4. Good practice in transitions and facilitators and barriers to improving transitions between CAMHS and AMHS

4.1 This section outlines how the interface between CAMHS and AMHS can be improved, and discusses the barriers and enablers for improvement.

Access to services

4.2 As section 3 outlines, transition can only happen when there is a service to transition to. Where young people have ongoing needs, and there is a service they can access, they should be referred. However, this is not always straightforward; for example, Singh et al. (2010) identify that: “CAMHS and AMHS staff found the thresholds and eligibility criteria to be highly complex, bureaucratic and confusing”. Training and joint work between CAMHS and AMHS is seen as important here in improving each service’s understanding of the other, and where there is no service, studies recommend that this should be highlighted to service commissioners (see Singh et al. (2010).

Getting the simple things right

4.3 The CQC (2017, p.58) report that: “according to the literature, many children and young people say it is often the simple things, done well, that can really make the difference to how they feel about themselves, their overall experience and whether or not they will access and continue to engage with services”.

4.4 It is therefore vital that individual staff and settings are “welcoming, friendly and warm”, “flexible and approachable” and staff have the skills and time “to develop a relationship and sense of trust and respect” with the young person. They conclude that: “often some of the simplest things are key to improving the experience of children and young people during these difficult times in their lives.” (CQC, 2017, p.58).

Collaborative working

4.5 Smooth transitions between CAMHS and AMHS require collaborative working. Several interviewees stressed the importance of personal relationships between staff in CAMHS and AMHS as critical. One interviewee from AMHS recommended, when asked what could improve transitions: “more work together…I don’t know what CAMHS offer…they probably don’t know what we offer - a clearer

understanding of what we offer...realistic views of how it will work and what the young person will get".

4.6 Singh et al. (2010) argue this: "should be developed through joint training and continuous professional development regarding transition issues as well as modifications to service structure and functioning"; this could include:

- joint work between staff from CAMHS and AMHS (e.g. through joint planning meetings and multiagency work);
- joint training and professional development for staff from CAMHS and AMHS;
- shared posts, such as family therapists, who work with families in both CAMHS and AMHS; and
- co-location of CAMHS and AMHS.

4.7 Sloper et al. (2010) researched the transitions to adult services for disabled young people and those with complex needs, and identified a range of factors which helped multiagency working, including a shared culture, vision and relationships, good communication and effective information and resource sharing, joint planning and multiagency meetings.

Transition planning and preparation

4.8 As outlined in section 3, transition is daunting for both young people and carers. Therapeutic relations with trusted professionals are ending and need to be developed with new professionals. Singh et al. (2010) identify, in this context: "transition planning meetings were considered helpful in allaying some parents' fears about transfer. Periods of parallel and joint working, supportive roles of transition workers and early preparations for transition which allowed time to establish new relationships were also seen as helpful".

4.9 Similarly, Price et al.'s study (2011) on transition pathways for young people with diabetes found that the young people valued being able to meet staff from adult services prior to transition and having time to begin building relationships.

4.10 Swift et al.'s qualitative study (2013) explored experiences of transition from CAMHS to AMHS for young people with ADHD. Ten young people were interviewed for the study. The young people in the study felt the relationship with the clinician

had a strong impact on how well they viewed the transition service. Professionals who were supportive, informative and non-judgmental and, in particular, those who were good at listening were best perceived by patients. Patients also appreciated their clinician working hard for them even if it was a difficult process. The study noted that young people could be prepared for transition by meeting their new clinician in addition to having a consistency of clinicians across the process, and being given a written overview of the process. Overall, it was important to young people and their parents that they knew what to expect from adult services and that their expectations were realistic.

4.11 Access to accurate information about adult health services was also key to a successful transition because it helped young people to feel more confident and less anxious. Beresford and Stuttard (2014) explored the experiences of young people (and their parents and professionals) with life-limiting conditions and their transitions to adult services. The interviews with the different groups across six case studies (of condition specific pathways) found that factors which helped the process of transition included a visit to the adult service with opportunities to meet the relevant staff. They also valued being provided with information, particularly that which noted the differences between the practice and procedures of the services. It also helped for adult clinical staff to be aware of the young people's recently transitioned status and young people being able to choose the role their parents played in the process.

4.12 Interviewees highlighted the role care coordinators should play in the transition planning. They were described as having a "key role". As one put it, their responsibility (as care coordinator) was to identify "what is our plan?... How best to engage with the patient?" They also reported that the Mental Health Wales Measure had helped get patients' views incorporated into transition planning.

4.13 Day et al. (2007) also explored the role parents and carers play. They examined transition arrangements for adolescents with acute mental health problems, conducting interviews and focus groups with 13 young people with mental health problems. They found that the young people wanted services that supported them but also gave them more autonomy and less emphasis on parents' involvement.

Transition workers and teams

4.14 Dedicated transition workers are identified by some studies as essential to "bridging the gap" between services by supporting communication and joint working between child and adult services (Cadario et al., 2009; see also e.g. Sloper et al., 2010 and Welsh Government, 2012a). Transition key workers can also provide continuity during transitions (RCP, 2017) and for example, Freeman et al. (2002) highlight: "the need to provide one or more individual professionals with whom the service user can maintain a consistent professional relationship".

4.15 The Care Quality Commission's review of children's transition to adult health services (CQC, 2014) found that continuity of support and person centred planning was key to effective transition and that staff valued transition workers and teams, as opposed to individual transition workers. Crowley et al. (2011) found that patient education and specific transition clinics were strategies most commonly used in successful transition from paediatric to adult healthcare.

Professional development and training

4.16 Hill et al. (2019) identified the benefit of AMHS staff getting training for adolescent issues so that they were aware of what to expect, an issue also highlighted by several interviewees. In a similar vein, Leavey et al. (2018) highlight the importance of youth friendly services.

Flexible person centred approaches

4.17 One key message which ran through the literature almost universally, was that no single transition process or model was most successful, and instead, flexible person centred models were required to reflect developmental stages and needs (Leavey et al., 2018); for example:

- Kime et al.'s review (2013) of transition models for young people with long-term conditions identified 16 systematic reviews and 142 primary studies. They conclude that transition should be young person focused, taking into account maturity and cognitive ability as well as the person's condition, circumstances and family, as opposed to being tied to a rigid schedule.
- Day et al. (2007) undertook qualitative case studies of 13 young people aged 15-20, with acute mental health problems and experiencing transitions, highlighting questions of control, identifying that young people felt that transition should be

"planned, gradual and flexible" with an understanding that patients should decide when they are ready; and

- Leavey et al. (2018) (discussed above) emphasise that the timing of transitions should reflect developmental stage and needs.

4.18 Leavey et al. (2018) made a point on developmental stages and needs which was also made by several interviewees; as one put it, it was crucial to be: "thinking about the most developmentally appropriate approach". The problem as they saw it was that adult services were structured to work with: "develop**ed** adults, not develop**ing** young adults", and as they succinctly summed it up: "nothing magical happens at [age] 18".

Young people's preferences

Dunn's (2017) study involved coproducing a CAMHS Transition Preparation Programme (TPP) using creative, participatory research workshops. This involved 18 young people aged 17-22 from three NHS MH trusts; Norfolk and Suffolk, Cambridgeshire and Peterborough, and Hertfordshire University Partnership. Parents and clinical staff also took part.

The group put forward a number of recommendations as part of the TPP, these included:

- a youth service model up to age 25, although the transition age should be 18/19. This needs to be flexible and gradual with a six month planning period.
- shared decision making which includes the young person, and preparation that is asset focused.
- a red-flag system that reminds clinicians to trigger transition six months before transition age,
- dedicated transition peer support workers during this time, and joint meetings with CAMHS and AMHS and the young person.

- a transition booklet to be presented to clinicians as a means to identify goals, needs and decisions of the young person. Information should also be good quality and easily accessible.

Continuity of care

4.19 Ensuring continuity of care in MH services is seen as a key aspect of effective service provision (Leavey et al., 2018; Singh et al., 2010). It provides another lens through which to think about transitions. Continuity of care is not synonymous with an effective or smooth transition, as transitions may involve significant changes in care, but abrupt changes in care can result from poorly planned or managed transitions and can negatively impact upon service users' and families' experiences.

4.20 Like the literature around transitions, continuity of experience, where service users experience "a co-ordinated and smooth progression of care" over time is seen to:

- depend upon factors like: flexible, person centred care that is accessible, available and responsive to changes as service users' needs and interests change, and which continues as long as is needed; and
- effective collaboration and communication between services and service users;

4.21 In addition, research suggests that continuity depends upon the continuation of therapeutic relationships and the involvement of the minimum number of professionals required to meet needs. (Freeman et al. (2002) Joyce et al. (2004) cited in Singh et al. (2010).

4.22 Allen et al.'s evaluation study (2012) of mechanisms which contribute to smooth transition from child diabetes care, highlights the particular importance service users attached to continuity of care from a clinician they had already developed a relationship with. Haggerty et al. (2003) conclude that: "continuity of care in mental health services differs from health care provision in its explicit and much greater emphasis on continued contact between service users and professionals".

4.23 Transitions between services with large differences in culture and organisation, such as the differences between CAMHS and AMHS discussed in section 3, threaten continuity of care. In response, Singh et al. (2010) suggest that: "CAMHS needs to pay greater attention to biomedical approaches and AMHS to psychosocial

interventions. The ‘holistic CAMHS’ versus the ‘medical AMHS’ are simplistic caricatures: good practice requires both services to adopt a holistic biopsychosocial approach”.

4.24 They note that continuity of care and also transitions in services like EIPS (discussed in section 5), which have sought to bridge these ideological divides, are generally experienced as smoother and more successful.

4.25 However, Singh et al. (2010) also identify that not all gaps are easily closed; for example:

> “Differences in levels of parental involvement in CAMHS and AMHS present an interesting clinical and ethical dilemma. A child mental health professional expects to see a child in the waiting room; an adult mental health professional, an adult. Families want greater involvement even after their child moves to AMHS; service users want lesser involvement from families as they develop autonomy and independence. Movement between these different cultures inevitably requires a process of adaptation by young people and their families”.

Barriers to collaborative working

4.26 As outlined in section 3, differences in organisational culture, practices and priorities in CAMHS and AMHS, coupled with pressure upon services struggling to cope with demand, can lead services to focus inward and upon their organisational priorities, rather than “thinking about the ‘whole child’” (CQC, 2017). Even where services look outwards, a range of barriers can impede collaboration, including differences in: “terminology and language”; priorities, working practices, service structures[23] and capacity; confidence working with young people/young adults[24], professional registration, and “a mismatch or unrealistic set of expectations” about what partners can do.

[23] Interviewees in Cardiff and Vale and Cwm Taf, for example, reflected that CAMHS and AMHS sat in different clinical directorates: children and women and (adult) mental health. In Contrast in Powys, CAMHS and AMHS share common management

[24] For example, as one interviewee described it: “staff are afraid of working with age groups they are not used to – they specialize in working with adults or with children very early in their training and few are exposed to working with the other group in their careers” – as a result people who work with adults say they cannot work with children and vice versa.

Enablers to collaborative working

4.27 The CQC (2017, p.55) identifies that: “agreeing a shared set of values, a view of ‘what is important’” and also taking the time to understand other services’ culture, strengths and constraints, are important in enabling effective partnership working. This can be fostered through the work of designated leads and also joint working and joint training. Similarly, interviewees stressed the importance of “good relationships to make it work at the interface” and of “finding ways to work together… in enjoyable ways” as important.

4.28 Some interviewees also reflected on the need, as one put it, for: “overarching executive steer…to be curious, to challenge, scrutinise…making it [transitions between CAMHS and AMHS] more of a priority…” and making sure that transitions were “not forgotten compared to other front line priorities that are always competing for attention…anything that’s not a RTT [referral to treatment target] gets less attention”. Linked to this, some interviewees reflected on the need to have adequate time; as they put it: “given the pressure on waiting targets…we don’t have the clinical time to make transitions smoother”.

Conclusions

4.29 In principle, improvements in transition planning and preparation, the exchange of information and joint working during transition, ought to be possible without either large additional investments or the reconfiguration of services (Singh et al., 2010), which the next section considers. However, both the literature reviewed and interviews conducted for this review indicate it is not so simple. As the National Institute for Health and Care Excellence (NICE, 2016, p.32) identifies: “there is a wealth of policy and guidance on agreed principles in respect of good transitional care, but there is also evidence that these principles are often not reflected in practice”.

4.30 Similarly, the National Assembly for Wales committee report (NAfW, 2018, p.104) on the emotional and mental health support for children and young people in Wales noted that:

> “Evidence from frontline staff and the Children’s Commissioner recognised that the guidance produced is sensible and good, but that implementation – and moving away from adult and children “silos” – remains a challenge”.

and that:

> As one Clinical Director of CAMHS, giving evidence, said: “each time there’s a new document, it’s saying the same things—all sensible stuff—to make it really smooth for the young person going into adult services. It’s not that we need a brand new idea; we need to deliver on it”.

4.31 As the CQC (2018) report, getting the “simple things” right can make a big difference to transitions but that this requires effective systems (rather than just effective individual services and processes) underpinned by:

- strong leadership;
- clear pathways between services;
- clarity of roles and responsibilities (across the system);
- workforce development;
- collecting and using quality data;
- young people’s participation; and
- effective funding, accountability and commissioning arrangements.

4.32 Moreover, other changes, such as: “lowering eligibility thresholds, updating protocols, training AMHS staff to increase their confidence and capabilities in working with young people, and the creation of transitional worker posts to help staff navigate the boundaries between services…have major resource implications”. (Singh et al., 2010).

4.33 Finally, it is worth noting that when Kolehmainen et al. (2017) explored the barriers and contributors to a successful transition for young people with long-term conditions they concluded that due to “…..complex and nuanced processes entangled with other local and organisational structures, processes and relationships” what worked for one young person may not work for another.

5. Alternative mental health service models

Introduction

5.1 As Singh et al. (2010) conclude:

> "There are two basic and contrasting approaches to improving care for young people undergoing transition from CAMHS to AMHS. We can improve the interface between CAMHS and AMHS as they currently exist [as outlined in section 4], or we can develop a completely new and innovative service model of integrated youth mental health services. Each has its own advantages, limitations and resource implications".

5.2 The latter option has led to proposals to develop children and young people's services (typically for those aged 0-25) or youth services for adolescents and young adults (e.g. those aged 14-25) (Leavey et al., 2018; Appleton et al., 2019). In this section we consider these alternative models.

5.2. As this section also outlines, the case for alternative service models only rests in part upon smoothing and improving transitions between CAMHS and AMHS. More importantly, the case for considering alternative service models rests upon the need to improve mental health services for young people (RCP, 2017). As outlined in the introduction, evidence suggests that as few as a quarter of young people who need to access CAMHS, do so. Recent reviews have highlighted that, despite improvements in specialist CAMHS in Wales, as a result of additional funding and the CAMHS Framework for Improvement and guidance:

- quality and capacity of CAMHS (including both specialist CAMHS and in particular, LPMHS) still varies across Wales; and
- young people who have emotional health problems, but who fall short of thresholds and eligibility for specialist CAMHS (based upon a medical model), often struggle to access a service that meets their needs (NAfW, 2018).

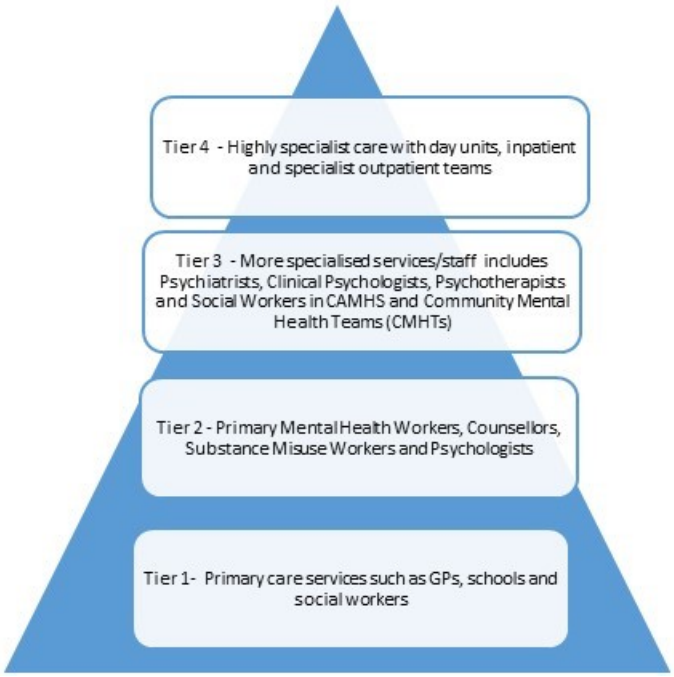
5.3 Similarly, there is evidence, outlined in section 3, that many young people do not make and sustain a transition to AMHS and also evidence that AMHS can struggle to meet the needs of young adults in particular (i.e. those aged 18-25) (see e.g. CQC, 2018; Plaistow et al., 2014).

5.4 This brief discussion provides the broader context for thinking about alternative models. However, a comprehensive assessment of the capacity and quality of MH services for young people is beyond this review's remit.

Tiered models of care

5.5 As figure 5.1 illustrates, mental health provision in Wales is based upon four tiers of services, with higher tiers providing care for more severe and/or complex mental health problems.

Figure 5.1. The tiered model of mental health services



5.6 This model: "means that children and young people have to fit the services, rather than the services fitting the changing needs of the child or young person" and has been criticised for: "unintentionally creating barriers between services, embedding service divisions and fragmentation of care" (Department of Health and NHS England, 2015, p.41). As section 3 outlines, the structures and differing eligibility criteria can also mean that some young people fall through the gaps between services, if their difficulties do not fit easily into diagnostic criteria. They may be bounced between services, their needs may not be met, opportunities for early intervention can be missed, and the severity and complexity of their difficulties may escalate (CQC, 2017).

Needs based services and teams

5.7 In order to address the problems associated with the tiered model, some areas in England and also Wales have experimented with more flexible models of care that aim to build services and teams around the child or young person's needs. Examples of this type of needs based approach include CAPA (discussed in section 3), THRIVE (see boxed text) and The Children and Young People's Improving Access to Psychological Therapies programme (CYP IAPT) in England, that aims to create: "collaborative children and young people's mental health service partnerships across existing services provided by the NHS, local authority, voluntary and independent sector" (CQC, 2017).

THRIVE Thrive is a model for thinking about children and young people's mental health needs as five overlapping groups:	
Group: children, young people and families who are:	**Needs**
• **Thriving**: children young people and families "experiencing the normal ups and downs of life but [who] do not need individualised advice or support around their mental health issues"	"Support to maintain mental wellbeing through effective prevention and promotion strategies"
• **Getting advice**: "young people and families adjusting to life circumstances, with mild or temporary difficulties, where the best intervention is within the community with the possible addition of self-support. This group may also include, however, those with chronic, fluctuating or ongoing severe difficulties, for which they are choosing to manage their own health and/or are on the road to recovery"	"Advice and signposting"

• **Getting help:** "children, young people and families who would benefit from focused, evidence-based help and support [i.e. an "intervention"]"	"Specific interventions focused on agreed mental health outcomes"
• **Getting more help:** the small number of children, young people and families with the most severe and complex needs, such as young people with co-occurring conditions "who would benefit from focused, evidence-based help and support" [i.e. an "intervention"]	Focused and "extensive and specialised goals based help"
• **Getting Risk Support**: "those who have not benefitted from or are unable to use help, but are of such a risk that they are still in contact with services"	"Managing risk"
These gradations of support are in some ways analogous to the tiered model (see figure 4), 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 services 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). *Adapted from CQC (2018) and Wolpert et al. (2016)*	

5.8 To work, research suggests needs based services should be co-produced between service users and professionals and require:

- greater expertise at the "front end of delivery systems" to determine the most appropriate intervention, given a child or young person's needs, and they often use a single point of access to enable this initial assessment and triage of children or young people;

- effective partnership working across a range of services (including, for example, schools and colleges, employment services and the voluntary sector, as well as health services), to both aid early identification of needs and ensure holistic support that meets different needs can be provided; and
- access to a range of skills and interventions, which often means changes to the way specialist services are delivered; for example, specialist CAMHS may need to adopt a model that includes a greater emphasis upon outreach, advice, training, consultation and liaison (Wolpert and Martin, 2015). This model can enable a shift from a "team around the young person" to "team around the worker" model[25] (Wilson et al., 2017).

5.9 In relation to this final point, several interviewees reflected on how, in recent years, CAMHS has moved from being a consultation, liaison and advice service to become more like adult services, focusing on diagnosis and treatment. These interviewees felt that CAMHS needed to go back to the role it originally had, or, as the boxed text on the Gwent Iceberg model illustrates, develop a radically new role.

The Gwent 'Iceberg Model'

The "iceberg model" is intended to highlight and address the "hidden" mental health difficulties of those who do not meet the thresholds for specialist services and/or who do not: "have the practical and psychological resources to engage with clinic and specialist services as currently designed" (NAfW, 2018, p.73; see also Gregory, n.d.). It has informed a redesign of services for children with emotional or mental health needs in Gwent. This is intended to improve access to specialist expertise in community based services, and enable community based services to "hold on to" rather than "refer on" to specialist services (so "we're not fetishizing access to CAMHS", as one interviewee put it).

5.10 Finally, it is worth noting that the case for developing needs based services goes beyond the weakness of MH services. It reflects the broader concern that young people with complex needs, which may include, but not be limited to, mental health

[25] This focuses upon sustaining and working through the "individual therapeutic attachment relationship" that a young person has with a particular worker, "regardless of profession or agency" .

difficulties which do not easily fit into existing service “boxes” or structures, are more likely than other groups to struggle to access services that meet their needs. This would suggest a systems wide reorganization of health (and not just MH) services on the basis of need, rather than condition/diagnosis. However, addressing this question lies far beyond this study’s scope.

Youth mental health services

5.11 Youth MH services for those aged, for example, 14-25, can be based upon either a tiered or needs based model (such as THRIVE). The rationale for developing youth MH services is fourfold:

- significant developmental changes occur during adolescence (Fusar-Poli, 2019). As one interviewee put it: “there are more development stages between 0-16 than there are for 16-65, so the current structure of children/adult/old age services “doesn’t fit the evidence” and, as another put it: “brain development, even without mental health complexity, continues up to the mid-20s”.
- the peak onset of some disorders is also during adolescence (McGorry, 2007); for example, as one interviewee put it: the “epidemiology ‘tail’ builds for 14-15 year olds” and: “severe mental ill health before this is rare, especially if you exclude ND and ACEs conditions”.
- the multiple changes and transitions in young people’s lives during the ages of 16-25, such as leaving education and entering employment, leaving the family home and living independently, and forming new relationships. These can be difficult, particularly when young people have mental health problems, and they may need stability and continuity of care to help them manage these changes, before they make another transition (i.e. from CAMHS to AMHS). This has led to the extension of policy in areas like education, where the ALN system now covers 0-25; and
- the failures of current services for children and adults to meet the needs of young people aged 16-25 (CQC, 2017; RCP, 2017).

5.12 Crucially, as McGorry (2007) puts it, the child/adult service split means that:

“The pattern of peak onset and the burden of mental disorders in young people means that the maximum weakness and discontinuity in the system occurs just

when it should be at its strongest. Young people need youth-friendly services that recognise and respond to their special cultural and developmental needs".

5.13 The development of youth MH services in England and also internationally for young people aged around 16-25, aims to address this. Examples include: Orygen Youth Health[26] and Headspace[27] in Australia, Headstrong in Ireland, Youthspace in Birmingham, the City and Hackney CAMHS Extended Service in London and the Liverpool and Sefton Youth Service[28] (McGorry, 2007; Lamb and Murphy, 2013; RCP, 2017). They can replace elements of existing CAMHS and AMHS, or complement them, by sitting alongside them.

Minding the Gap – Camden

Minding the Gap works with people aged 16-24. It is a service for agencies working with young people that are seeking advice and help with the transfer and management of people who are moving from children's mental health settings to adult mental health settings, and professionals who are concerned about service users disengaging and/or risky behaviours in the context of their mental health needs. Senior clinicians from adult and young people services assist referrers in developing a management plan for young people. Fortnightly case discussion meetings are open to professionals from all agencies. In addition, clinicians are based within specific teams to champion the cause of young people and help develop a more "young people friendly" environment.

The service was established as only three percent of young people were successfully transitioning between CAMHS and AMHS: thresholds for adult services were high and waiting lists for those below the thresholds were too long. Some young people were 'bounced' around the system with no team /organisation taking accountability.

[26] The ORYGEN service aims to provide care to young people, aged 12–25 years, with emerging, potentially severe or complex mental disorders, such as psychoses, emotional, personality and substance use disorders (McGorry, 2007).
[27] Additional information is available at The Headspace website.
[28] The Liverpool Young Person's advisory service provides a range of support and therapeutic services to children aged 5 to 15 years, young people aged 16-25 years and their families in Liverpool. The services they offer include counselling and psychotherapy services aimed at children, young people, families and also targeting specific areas such as domestic abuse and youth justice. Specific support services are also provided, such as LGBTQ support and secondary school wellbeing clinics.

Adapted from a Presentation on Mind the Gap by the NHS Camden Clinical Commissioning Group

The effectiveness of youth mental health services

5.14 As table 5.1. illustrates, children and young people's and youth mental health services such as Forward Thinking and the Norfolk Youth Service (see boxed text) are reported to have improved provision for young people but are not a panacea and have also experienced challenges, including:

- large and unanticipated increases in demand, which services have struggled to cope with, leading to longer waiting times and gatekeeping;
- organisational challenges associated with developing new services, which have caused delays and disruption;
- partnership challenges associated with the need for multiple different services to work to collaborate and share information; and
- problems with staff recruitment, skills, retention and morale (see e.g. Birchwood et al, 2018; Wilson et al., 2017; RCP, 2017).

Table 5.1. Summary of key findings from evaluations of children and young people's or youth mental health services in the UK

Service*	Key findings/messages from research or evaluation of the service
Forward Thinking Birmingham – 0 to 25 years Impact and Process Evaluation of Forward Thinking Birmingham	• There was "strong support for the model" including "in particular, the extended age range and the integration of practitioners for children and young people's mental health services and those from adult mental health services in the community hubs." (Birchwood, et al, 2018, p. 6). • The model improved access to mental health services for young people, but this success meant that demand was considerably greater than capacity, and "the service had been overwhelmed with referrals" which increased waiting times and also signposting to voluntary sector services; referrals which were not always appropriate (ibid., p. 85). • There were significant challenges linked to workforce recruitment, retention and the skills of staff, and also finding suitable and age appropriate physical spaces and equipment. • There was disruption to existing services (which was a concern where they had worked well) and also professional networks. • Involvement of the voluntary sector was limited and (as noted above) excess demand was met in part by signposting to the voluntary sector. • Differences in data systems limited data sharing. The lack of data on activity and outcomes also meant that the evaluation could not assess the model's impact upon young people's mental health, nor could it assess the impact of not requiring transitions for 16-18 year olds. The evaluation noted concerns that a new transition point at 25 was being created and also that the service did not align with other service boundaries. For example, young people with complex needs could access services up to 25, but those

	with, say, mild mental health difficulties and a learning disability, could only access services up to age 19.
Norfolk Youth Service	No evaluation was identified. However, a research paper (Wilson, et al, 2017) identified that: • The service was felt to have improved young people's awareness of access to services, but that, (as in the case of Forward Thinking Birmingham), this success meant the service had experienced very high levels of referrals leading to long waiting lists and "overwhelming caseloads". • The "challenges of commissioning and culture change across the system for a service model such as this" were "difficult". (Wilson et al., 2017, p.12). Other reviews have also highlighted continuing problems for young people accessing mental health services in Norfolk, given high levels of demand and the complexity and fragmentation of services (see e.g. Norfolk & Waveney Children and Young People's Mental Health Commission, 2019).
Jigsaw[29]	A number of research reports have been published, including O'Keefe et al. (2015) which identifies "emerging evidence" that: "*Jigsaw* is an accessible and effective service", based largely upon evidence of the accessibility of, and take up of the service and also CORE questionnaires[30] administered to young people pre- and post- intervention which indicated "reduced levels of psychological distress" (ibid, p.6).

[29] *Jigsaw* is an early intervention mental health service in Ireland for young people, aged 12–25 years, with mild and emerging mental health difficulties.
[30] These are self report questionnaires to be used before and after a therapeutic intervention, to measure areas such as "Subjective well-being" "Problems/symptoms"; "Life functioning" and "Risk/harm". More information on the CORE system is available on the Core website.

* Evaluations for other services of interest, such as Minding the Gap – Camden (see boxed text), I-Rock[31], Liverpool and Sefton Youth Mental Health Model[32] or 42ND Street[33] could not be identified or accessed.

Norfolk Youth Service for ages 14 to 25

The Norfolk Youth Service comprises a pragmatic, assertive and "youth-friendly" service for young people aged 14 to 25 that transcends traditional service boundaries. The service was developed in collaboration with young people and partnership agencies and is based on an engaging and inclusive ethos. The service aims to be different in vision and culture from traditional mental health services, maintaining an ethos of "youth and family focus" whilst prioritising functional and social improvement, rather than only diagnosis, pathology or symptom reduction.

As well as being in response to national drivers, the service was a response to locally identified concerns regarding young people with complex mental health needs who were otherwise excluded from local service structures. This included data revealing that, whilst demand for services from 17 to 18 year olds was high, contact rates dropped substantially, implying that young people were not successfully engaging with services. Additionally, it was observed that young people with the most complex needs did not always access mental health services in a timely manner, often leading to long and multiple help-seeking pathways.

Adapted from Wilson et al., 2017

Children and young people's services

[31] I-Rock offers advice and support on emotional and mental health and wellbeing, employment, education and housing. See the I-Rock website for more details.
[32] The Liverpool and Sefton Youth Mental Health Model includes the provision of early intervention and support for children and young people aged 0-15 from mental health hubs, which offer information, advice, guidance and support for those with mild to moderate difficulties. More information is provided in the Liverpool Children and Young People's Mental Health and Emotional Wellbeing Transformation Plan
[33] 42nd street is a charity that supports young people (aged 11-25) years with their emotional wellbeing and mental health. More information is available at the 42nd street website.

5.15 The rationale for developing children and young people's (0-25) services, such as Forward Thinking Birmingham (see boxed text), is similar to that for youth services (outlined above). It is also founded upon evidence of the emergence of some risk factors during childhood, and the benefits of preventative work and also of intervening as early as possible when problems emerge (Fusar-Poli, 2019).

Forward Thinking Birmingham

Forward Thinking Birmingham is the city's mental health partnership for 0-25 year olds (or up to 35 for the first episode of psychosis). It was established in response to a Case for Change report where findings included:

- discontinuities in care for those aged 16-18, which meant too many young people were "lost in transition" as they moved from CAMHS to AMHS;
- a lack of provision, and long waiting lists for young people with some ND disorders such as ADHD; and
- too many young people not engaging with AMHS.

In response, a children and young people's (0-25) service was proposed, founded upon "whole system change". By offering support, care and treatment for all 0-25 years through one organisation, with a single point of referral, Forward Thinking Birmingham aims to ensure it is easier to access the right support at the right time. Through the partnership a range of services are provided. These services include an access centre where referrals are managed, community hub sites – most of the directly provided support is via the hubs, a crisis team, talking therapy, online therapy and drop-in support, specialist services for those with ASD, LDs, eating disorders and first time psychosis, home support and hospital support. Although as table 5.1. illustrates, the model has been welcomed and it is judged to have improved access, the service has struggled to cope with demand.

Adapted from Birchwood et al., 2018

5.16 Looking beyond MH services, there are examples of children and young people's health services, like the all-age disability team for 0-25 year-olds run by NHS Southwark, and Cambridgeshire, which is specifically for those with a high or severe level of disability. As a result, only a small number of children and young people in CAMHS meet the eligibility criteria (Southwark Council and NHS Southwark CCG,

2018). The provision includes activities, breaks, respite, care arrangements, or a personal budget. Similar services exist for Cambridgeshire, although less information is available.

Norfolk Children and Family Service – for those under 14 years of age

Alongside the development of the Norfolk Youth Service (see boxed text above) there is a Child and Family Team with close links to the Youth Service. This team focuses on young people below the age of 14 and specialises in early, family-orientated treatment of developmental and attachment problems, incorporating a Perinatal and Infant MH Service. This team similarly aims to work with other agencies such as health visitors and children's centres. The aims are for genuine flexibility around the age ranges between teams, smooth transitions and joint working based on the needs of young people. The Children and Family and Youth teams have shared management and team members integrated in both services maintain links and across-boundary working. This single management structure also incorporates Neuro-Developmental Disorder, Early Intervention Programme, in-patient and eating disorders. It is anticipated that this will improve the experience of transitions, engagement, communication and joint working.

Disorder specific services

5.17 Another model is the development of targeted, diagnosis specific services, like early intervention in psychosis services and eating disorder services in England and Wales. These focus upon meeting the needs of groups of young people who do not easily fit into existing service structures (RCP, 2017) but, as interviewees reported, the evidence base for "intervening early and offering a specific package of care" is strong. They span the traditional CAMHS and AMHS age boundaries, working with, for example, young people aged 14-25 (or 14-35 in the case of the Gwent EIPS), because, as one interviewee described it, young people with psychosis "present primarily in this age group".

Early Intervention Psychosis Services

The majority of mental health difficulties associated with psychosis present by the age of 25 and there are significant adverse effects associated with psychosis if not treated, and difficulties can escalate if not identified and treated early. As one interviewee put it: “you can’t wait, the clock Is ticking”.

The EIPS in Cardiff and Vale and Gwent are standalone services, supported by T4CYP funding with additional investment from the LHB. They replaced specialist staff distributed across CMHTs and aimed to develop expertise and a youth friendly service and ensure supervision for staff, better communication and multi-disciplinary work between staff and a consistent approach to psychosis.

There is a good evidence base, as this is a well- researched area for service delivery and organisation and the model is reported (by the service) to work better than generic CAMHS/ CMHTs as it is more likely to identify, reach out and retain and also to offer the full range of interventions shown to be effective (i.e. not just medication); and family support. It was also observed that as a youth (rather than children’s) health service staff: “don’t worry about having to get over the big wall coming at 18 to get into adult services”.

The service works with young people for three years, sometimes up to five, usually then they are discharged to primary care, but sometimes when this is not possible, service users are transitioned to AMHS.

It was reported that setting up a new service rather than merging existing services made it easier to establish the service, as they did not experience too much organisational resistance.

Source: interviews

Eating disorder services

5.18 The issues linked to transitions for eating disorder services are somewhat different to EIPS, as the typical age of onset of eating disorder services is earlier (around the ages of 13-14) and therefore does not coincide with transitions from child to adult services to the same extent as psychosis. However, the combination of physical

and mental health difficulties can mean young people do not fit easily into either CAMHS or paediatrics and a multi-disciplinary approach is required, and transitions from child to adult services can still come at a "critical point" in young people's illness (RCP, 2019).

Gwent's eating disorder service

In Gwent, eating disorder services are provided at tier 2 by CAMHS and CMHTs. A tier 3 specialist eating disorders service offers consultation and joint assessment where, for example, there is uncertainty about diagnosis or a child or young person is not making progress, or risk or complexity is increasing. They also collaborate with CMHTs to work with very high risk or complex cases. Although there is not a fully integrated service for children and young people, interviewees reported that there was trust between professionals in children and adult services, with good joint working and nursing across the age range for this group. In addition, there is shared training, which means that there is "no step change in the service" when a young person makes a transition from child to adult services. The main challenge was reported to be the reluctance of psychologists in adult MH services to engage in an area that is seen as a specialism.

Adapted from interviews and *Aneurin Bevan University Health Board: Specialist Eating Disorders Service* website

The effectiveness of services

5.19 Some interviewees reflected that creating more teams increased complexity and could create new "silos". However, there was consistently positive feedback on the new teams, like the EIPS and eating disorder services that had been created; for example, as one interviewee put it: "our experience of the two teams [EIPS and eating disorder service] is very positive....in both cases systematic working and thinking is integral to their thinking". Similarly, as Singh et al. (2010, p.180) identify (drawing upon evidence from England):

> "The Early Intervention in Psychosis model has been instrumental in overcoming some of the barriers between CAMHS and AMHS. EI services extend the holistic approach of CAMHS into AMHS, while the disease-specific focus of AMHS

allows young people to get the best possible evidence-based care from highly trained staff".

5.20 One of the risks of creating intermediate youth services that sit between CAMHS and AMHS is that they create new points of transition. Interviewees reported that the impact of this was modest. Few people made a transition into the services, as most problems occurred after the age of 14 and transitions from these services were reported to be somewhat smoother than those from CAMHS to AMHS. The older age at which young adults made the transition was felt to help. Nevertheless, the smoothness of transitions was still seen as dependent upon the willingness and capacity of the service they were making a transition to, to accept the case and engage with the service and the service user.

The cost-effectiveness of integrating services

5.21 Many of the new MH models seek to integrate different services. There is no single model of integration, with, for example, Kodner and Spreeuwenberg (2002) describing a continuum from cooperation between entirely separate organisations through the coordination of services in multidisciplinary networks (e.g. managed clinical networks), to fully integrated services with pooled funding, joint planning and management and multidisciplinary teams. This is reflected in the range of new services that have developed for children and young people (and which are discussed above). Ham and Walsh (2013, p.4) conclude that: "there is no evidence that any one form of integration is superior to others". They go on to argue that:

> "The main benefits of integrated care occur when barriers between services and clinicians are broken down, not when organisations are merged. A fundamental building block is the creation of integrated or multidisciplinary teams comprising all the professionals and clinicians involved with the service or user group around which care is being integrated".

5.22 Although (as outlined above) positive impacts are reported for the new services, overall, the evidence of the impact of integration and joint working upon improved outcomes for health service users remains patchy (Cameron et al., 2015; Hillary, 2011). As the experience for services like Forward Thinking Birmingham (Birchwood, et al, 2018), and in Wales, Children's ND Services and the Integrated Autism Service (Welsh Government, 2019), illustrate, and the evidence from other

services also suggests, integration is likely to be costly, time consuming and challenging (Ham and Walsh, 2013). This reflects the difficulties of integrating different systems of management, staffing, funding, information sharing, quality assurance and accountability (Goodwin et al., 2012).

Conclusions

5.23 The literature reviewed (e.g. NAfW, 2018; CQC, 2017; RCP, 2017; Gregory, n.d.) and interviews, identified a range of potential weaknesses and challenges associated with the current service model, including:

- the fragmentation of services given, for example, the current tiered model, and divides between mental and physical health and mental health and education, which can make it difficult for young people to access care, and which increase the chances that intervention is delayed and/or needs are not met, and contribute to difficulties making a transition between CAMHS and AMHS;
- workforce recruitment, retention and professional development needs;
- inadequate funding; and
- weakness and gaps in data on, for example, young people's needs now and in the future (forecasts to inform commissioning) and the effectiveness of service delivery, including differences in the way data is collected by different LHBs and services, which hampers benchmarking.

5.24 Given these challenges, Singh et al. (2010) argue that: "a consensus is now emerging that health services should consider the health and developmental needs of two groups: children under 12 years and young people aged between 12-24 years". However, while there was support for the model, there was no consensus amongst either the literature reviewed or interviews about the most appropriate age range for youth MH services. Most interviewees favoured or suggested 14-25, given the age at which most mental health disorders emerged. However, 11-25 would align better with Welsh Government policy toward young people. It is also notable that other than LPMHS, very few examples of genuinely all age MH services were identified. Most services either focused upon children and young people (e.g. 0-25 services) or young people (e.g. 14-25 services).

5.25 In thinking about new models, interviewees suggested that it was important to recognise both the strengths and limitations of CAMHS and AMHS. For example, as one put it: “this is the menu CAMHS brings – this is the menu AMHS brings”, “they are different”, and the “aim is somewhere from around age 14 you start to use less of the CAMHS and more of the AMHS menu…until by age of 25, all your needs are met by AMHS”.

Potential barriers to establishing all-age, children and young people or youth mental health services

5.26 The literature reviewed, and interviews, identified a range of potential barriers to creating all-age or youth MH services including:

- the risk that an all-age service becomes an adult model, as the experience of LPMHS suggests, because, as one interviewee observed, 80 percent of their caseload is adults, and it: “pulls the service in the wrong direction” (see also NAfW, 2018).
- the challenges associated with recruiting and retaining a workforce with the skills and confidence needed to work with young people (see e.g. CQC, 2017). As one interviewee observed: “building teams able to work below 16 and up to 25 is a training challenge”. They described how, for example, an adult psychiatrist is usually trained and registered to work with adults, but not children, and how staff in AMHS are often less confident about questions of capacity and constraint in relation to those aged 17 and below.
- the potential disruption of existing services. For example, as one interviewee reported: creating new services “is difficult” particularly if you are “merging existing services” and that they felt it would be “complicated” to pull CAMHS and AMHS together, and that you would not want “massive change in a short space of time”, which would suggest a phased approach to developing new services. Similarly, as another interviewee put it: “I get worried when we talk about restructuring services....[it has] lots of clinical implications” given the potential disruption to existing services.

- the danger that demand for new services that address previously unmet needs can overwhelm their capacity, leading to long waiting lists and restrictions on access, as happened to the new ND and Integrated Autism Services in Wales (Welsh Government, 2019).

5.27 Despite these barriers, and also the weakness in the evidential base, the (small number of) interviews for this study, and also the examples from across the UK and wider world, suggest that the weakness of the existing system means there is an appetite to consider reconfiguring services, by creating youth MH services.

6. Conclusions

The evidence around transitions from CAMHS to AMHS

6.1 Young people's 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. Whilst there are pockets of good practice, practice remains very variable and 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, are more likely to have difficult transitions from CAMHS.
- some young people cannot, or choose not to, transition to AMHS, increasing the risk that their needs are not met and may worsen. It is therefore important to consider the needs of three distinct groups: (i) those young people who can transition to AMHS, (ii) those who cannot, and (iii) those who choose not to, as often different actions are needed to help each group.
- requiring young people to make a transition from CAMHS at 18 is often not appropriate, as it can coincide with a particularly vulnerable period in young people's lives, at a time when they are also required to take increasing responsibility for their own care and actions. Their vulnerability and circumstances can increase the fear and anxiety associated with transitions from CAMHS and a transition at this age can increase the risk of young people disengaging from services. Transitions should therefore be made when young people are ready, rather than on the basis of what was seen as an arbitrary age boundary.
- 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. There also appears to be less research or evidence on good practice to support young people with mental health difficulties in accessing CAMHS, who do not (as they are not referred, or disengage) or cannot access AMHS. In part this may be because this group is hidden or lost, and therefore less accessible to researchers. There are also gaps in the evidential base in relation to vulnerable groups of young people such as those leaving care or in young offender institutions, who often experience very difficult transitions (RCP, 2017).

6.2 The research reviewed for this study, and interviews, indicate that the problems associated with the transitions from CAMHS are not specific to CAMHS and AMHS, but may be more acute for young people with mental health difficulties making a transition from CAMHS, who may have weaker resilience and motivation.

Good practice in transitions from CAMHS

6.3 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, and improving transitions to alternatives to AMHS, such as LPMHS, as the examples in table 6.1 illustrate;
- bridging or closing the gap between CAMHS and AMHS 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 6.1. 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 to constantly re-tell their story.	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[34], and services' responsibilities); - 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

[34] The current 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).

	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, and which 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 “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.	Increased collaboration between CAMHS and AMHS, such as jointly reviewing current systems and practice to identify where changes are 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 change improving transitions

6.4 The recommendations outlined in table 6.1. are well understood (and are outlined in the current T4CYP Transition Guidance (T4CYP, n.d.) and, 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. As NICE (2016, p.32) identifies: "there is a wealth of policy and guidance on agreed principles in respect of good transitional care, but there is also evidence that these principles are often not reflected in practice". Given the pressure upon health services, it is also important to bear in mind that increasing the priority MH services attach to transition may put pressure upon other parts of the service. Improving transitions could help prevent mental health difficulties from escalating and lessen demands upon crisis teams, creating cost savings (RCP, 2017), but this is far from certain and cost savings may accrue to other services or parts of the system.

Assessing the case for youth mental health services

6.5 Given the weaknesses with the current system, there was considerable interest amongst the (small number of) interviewees for this study in the case for developing youth MH services. Equally, for some there was recognition of and concern about the potential challenges and barriers inherent in the reconfiguration of services.

6.6 The peak onset of many mental health difficulties during adolescence, while young people are also going through a period of physiological change, and making other important transitions in their lives, means the division between CAMHS and AMHS makes the system weakest where it needs to be strongest (Singh et al., 2010).

Despite the T4CYP guidance, which advocates for flexible transitions, the (limited) qualitative research identified for this study identified little evidence of this happening in practice. Greater flexibility and more joint working between CAMHS and AMHS could address this (without requiring hard integration of CAMHS and AMHS to create youth MH services). However, the current pressures upon services appear to be holding this back.

6.7 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 by focusing upon implementing existing guidance. Soft integration of CAMHS and AMHS could help (so again, hard integration of CAMHS and AMHS to create youth MH services, is not the only option). However, unless demand for services lessens, there would also likely need to be additional investment in services to increase their capacity and widen access to AMHS.

6.8 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 cannot, or choose not to, access MH services in a timely way (CQC, 2017, 2018; NAfW, 2018).

6.9 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.

6.10 It is also important to bear in mind that the evidence of the benefits of integrating services is mixed (see e.g. Ham and Curry, 2011; Cameron et al., 2015). As the experience of establishing the IAS and ND services in Wales illustrates, hard integration of services is likely to be costly and time consuming, given challenges such as workforce recruitment and retention, managing the interfaces between services, matching capacity with demand, and bringing together different services’ systems and cultures (Welsh Government, 2019). This message is broadly

consistent with the limited evidence from evaluations of children and young people's MH services, such as Forward Thinking Birmingham, and youth MH services, such as the Norfolk Youth Service. Equally, as Singh et al. (2010, p.181) argue:

> "We certainly need evidence for any models of transitional care that we test in the future, but the search for that evidence should be a goal, rather than a prerequisite without which change to existing service structure, is not initiated. We need to ensure that the vital need for improving youth mental health is not ignored for fear of dismantling longstanding but increasingly unhelpful service barriers".

7. Recommendations for further research

7.1 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 its 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, like 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 mental health 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.

8. Bibliography

Allen, D., Cohen, D., Hood, K., Robling, M., Atwell, C., Lane, C., Lowes, L., Channon, S., Gillespie, D., Groves, S. and Harvey, J. (2012) 'Continuity of care in the transition from child to adult diabetes services: a realistic evaluation study'. *Journal of Health Services Research & Policy*, *17*(3), pp.140-148.

Appleton, R., Connell, C., Fairclough, E., Tuomainen, H. and Singh, S. P. (2019) 'Outcomes of young people who reach the transition boundary of child and adolescent mental health services: a systematic review', *European child & adolescent psychiatry*, pp.1-16.

Beresford, B. and Stuttard, L. (2014) 'Young adults as users of adult healthcare: experiences of young adults with complex or life-limiting conditions', *Clinical Medicine,* 14(4), pp.404-408.

Birchwood, M. J., Street, Cathy, Singh, Swaran P., Lamb, Clare, Anderson, Yvonne , WarnerGale, Fiona , Sedgewick, Jane , Thompson, Andrew D. and Upthegrove, Rachel (2018*) Impact and process evaluation of Forward Thinking Birmingham, the 0-25 Mental Health Service : Final Report*. University of Warwick ; University of Birmingham ; GIFT (Great Involvement Future Thinking) ; CLAHRC-WM. Accessed online at University of Warwick publication services website

Cadario, F., Prodam, F., Bellone, S., Trada, M., Binotti, M., Trada, M., Allochis, G., Baldelli, R., Esposito, S., Bona, G. and Aimaretti, G. (2009) Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: a hospital-based approach. *Clinical Endocrinology,* 71(3), pp.346-350.

Cameron, A., Lart, R., Bostock, L. and Coomber, C. (2015) *Factors that promote and hinder joint and integrated working between health and social care services.* [online], Social Care Institute for Excellence website

Campbell, F., Biggs K., Aldiss S.K., O'Neill, P.M., Clowes, M., McDonagh, J., While, A., Gibson, F. (2016*) Interventions to improve the care of adolescents with long term health conditions as they transfer from child to adult health services* [online], Cochrane website

Care Quality Commission (2014) *From the pond into the sea: Children's transition to adult health services.* Care Quality Commission [online], Care Quality Commission website

Care Quality Commission (2017) *Review of children and young people's mental health services. Phase One supporting documentation: Summary of recent policy and literature,* Care Quality Commission [online], Care Quality Commission website

Care Quality Commission (2018) *Are we listening? Review of children and young people's mental health services Phase Two supporting documentation Quantitative analysis*, Care Quality Commission [online], Care Quality Commission website

Chance, L. (2016) *The transition to AMHS from a secure inpatient environment: An Interpretative Phenomenological Analysis of the experiences of nursing staff*, doctoral dissertation, Department of Neuroscience, Psychology and Behaviour.

Children's Commissioner for Wales (2019) *'Don't Hold Back' Transitions to adulthood for young people with learning disabilities,* Welsh Government [online], Children's Commissioner for Wales website

Colver, A., Rapley, T., Parr, J., R. McConachie. Dovey-Pearce, G., Couter, A., McDonagh, J., Bennett, C., Hislop, J., Maniatopoulos, G., Mann, K., Merrick, H., Pearce, M., Reape, D., and Vale, L. (2019)' Facilitating the transition of young people with long-term conditions through health services from childhood to adulthood: the Transition research programme', *NIHR Journals* [online], National Institute for Health Research website

Crowley, R., Wolfe, I., Lock, K. and McKee, M., (2011) 'Improving the transition between paediatric and adult healthcare: a systematic review', *Archives of disease in childhood*, 96(6), pp.548-553.

Day, P., Turner, J., and Hollows, A. (2007) 'Bridging the gap: transitioning from children to adult services', *British Journal of School Nursing* 2(146).

Department for Health and NHS England (2015*) Future in Mind - Promoting, protecting and improving our children and young people's mental health and wellbeing* [online], Department of Health website

Dunn, V. (2017) *Young people, mental health practitioners and researchers co-produce a Transition Preparation Programme to improve outcomes and experience for young people leaving Child and Adolescent Mental Health Services (CAMHS)*. BMC health services research, 17(1), 293 [online], BMC Health Services Research website

Freeman, G., Weaver, T., Low, J., de Jonge, E., Crawford, M. (2002) *Promoting continuity of care for people with severe mental illness whose needs span primary, secondary and social care: a multi-method investigation of relevant mechanisms and contexts*. London: NCCSDO.

Fusar-Poli, P. (2019) 'Integrated Mental Health Services for the Developmental Period (0 to 25 Years): A Critical Review of the Evidence', *Frontiers in Psychiatry,* 10 (355), pp.1-17.

Goodwin, N., Perry, C., Dixon, A., Ham, C., Smith, J., Davies, A., Rosen, R., Dixon, J. (2012) *Integrated Care for Patients and Populations: Improving outcomes by working together. A report to the Department of Health and the NHS Future Forum,* London: The King's Fund [online], King's Fund website

Gregory, L. (n.d.). *An Alternative Model of Children's Mental Health Services Is it time to move on from the age of the Pyramid?* [online], National Assembly for Wales website

Hafal (2016) *Making Sense: A report by young people on their well-being and mental health January 2016. A response to the 'Together for Children and Young People' Programme.* [online], Children in Wales Website

Haggerty, J.L., Reid, R.J., Freeman, G.K., Starfield, B.H., Adair, C.E., McKendry, R. (2003) Continuity of care: a multidisciplinary review. *British Medical Journal* 327: 1219-1221.

Ham, C., and Curry, N. (2011) *Integrated Care Summary: What is it? Does it work? What does it mean for the NHS?* London, The King's Fund [online], King's Fund website

Ham, C., and Walsh, N. (2013) Making integrated care happen at scale and pace London, The King's Fund [online], King's Fund website

Hill, A., Wilde, S. and Tickle, A. (2019) 'Transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS): a meta-synthesis of parental and professional perspectives', *Child and Adolescent Mental Health*, pp.1-12.

Hillary, R. (2011*) Integration of health and social care. A review of literature and models - implications for Scotland* [online], Royal College of Nursing website

Joint Commissioning Panel for Mental Health (JCPMH) (2013) *Guidance for commissioners of mental health services for young people making the transition from child and adolescent to adult services,* JCPMH, [online], Joint Commissioning Panel for Mental Health website

Jones, G. (2005) *The thinking and behaviour of young adults (aged 16 - 25), literature review for the Social Exclusion Unit, Wirral Learning Partnership* [online], Wirral Learning Partnership website

Kime, N.H., Bagnall, A. and Day, R. (2013) *Systematic review of transition models for young people with long-term conditions: A report for NHS Diabetes*. NHS Yorkshire and Humber.

Kodner, D. L. and Spreeuwenberg, C. (2002) 'Integrated care: meaning, logic, applications, and implications – a discussion paper', *International Journal of Integrated Care, 2*.

Kolehmainen, N., McCafferty, S., Maniatopoulos, G., Vale, L., Le-Couteur, A. S., and Colver, A. (2017)' What constitutes successful commissioning of transition from children's to adults' services for young people with long-term conditions and what are the challenges? An interview study', *BMJ paediatrics open* 1(1) pp.1-8.

Lamb, C. and Murphy, M. (2013) 'The divide between child and adult mental health services: points for debate', *British Journal of Psychiatry* [online], British Journal of Psychiatry website

Lamb C, Hall D, Kelvin R, and Van Beinum, M. (2008) *Working at the CAMHS/Adult Interface: Good practice guidance for the provision of psychiatric services to adolescents/young adults.* A joint paper from the Interfaculty working group of the Child and Adolescent Faculty and the General and Community Faculty of the Royal College of Psychiatrists, May 2008.

Leavey, G., McGrellis, S., Forbes, T., Fullerton, D., Davidson, G., Hughes, L., Thampi, A., Bunting, B., Toal, A., Divin, N., Paul, M.and Singh, S. (2018) *Improving Mental Health Pathways and Care for Adolescents in Transition to Adult Services in Northern Ireland (IMPACT},* Ulster University.

Ludvigsson, J. F., Agreus, L., Ciacci, C., Crowe, S. E., Geller, M. G., Green, P. H. R., Hill, I., Hungin, A. P., Koletzko, S., Koltai, T., Lundin, K. E. A., Mearin, M. L., Murray, J. A., Reilly, N., Walker, M. M., Sanders, D. S., Shamir, R., Troncone, R. and Husby, S. (2016) 'Transition from childhood to adulthood in coeliac disease: the Prague consensus report', *Gut* 65(8), pp.1242-1251.

McDonagh, J.E. (2006) *Growing up ready for emerging adulthood: an evidence base for professionals involved in transitional care for young people with chronic illness and/or disabilities.* [online] Council for Disabled Children website

McGorry, P. (2007) 'The specialist youth mental health model: strengthening the weakest link in the public mental health system', *Medical Journal of Australia (supplement)* 187: s53-s56.

McGorry P, Bates T, Birchwood M (2013) Designing youth mental health services for the 21st century: examples from Australia, Ireland and the UK. *British Journal of Psychiatry*, 202: 30–5.

National Assembly for Wales (2001) *Child and Adolescent Mental Health Services. Everybody's Business. Strategy Document,* The National Assembly of Wales, [online], National Health Service website

National Assembly for Wales (2014) *Inquiry into Child and Adolescent Mental Health Services, National Assembly for Wales* [online], National Assembly for Wales website

National Assembly for Wales (2018) *Mind over Matter: A report on the step change needed in emotional and mental health support for children and young people in Wales,* Cardiff, National Assembly for Wales [online], National Assembly for Wales website

NHS Digital (2018) *Mental Health of Children and Young People in England, 2017,* NHS. [online], National Health Service Website

NHS Wales (n.d.). 'Together For Children And Young People' Framework For Action, Accessed online at: National Health Service website

NICE (2016) *Transition from children's to adults' services for young people using health or social care service,* [online], National Institute for Health and Care Excellence website

NICE (2018) *Developing NICE guidelines: the manual,* NICE, [online], National Institute for Health and Care Excellence website

Norfolk & Waveney Children and Young People's Mental Health Commission (2019). A Better Future Together [online] Norfolk & Waveney Children and Young People's Mental Health Commission website

O'Keeffe, L., O'Reilly, A., O'Brien, G., Buckley, R. and Illback, R. (2015) "Description and outcome evaluation of Jigsaw: an emergent Irish mental health early intervention programme for young people," Irish Journal of Psychological Medicine, Cambridge University Press, 32(1), pp. 71–77.

Plaistow, J., Masson, K., Koch, D., Wilson, J., Stark, R.M., Jones, P.B., Lennox, B.R. (2014) 'Young people's views of UK mental health services', *Early Intervention in Psychiatry, 2014* 8(1), 12-23.

Price, C.S., Corbett, S., Lewis-Barned, N., Morgan, J., Oliver, L.E. and Dovey-Pearce, G. (2011) 'Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes', *Child: care, health and development* 37(6), pp.852-860.

Public Health Wales (2016) *Together for Children and Young People Programme Child and Adolescent Mental Health Needs Assessment*, Public Health Wales [online], Good Practice Wales Website

Royal College of Psychiatrists (2017) *Good mental health services for young people*, [online] Royal College of Psychiatrists website

Royal College of Psychiatrists (2019) [online],] Royal College of Psychiatrists website

Royal College of Psychiatrists (n.d.). *Young people's experiences of health transition,* [online], Royal College of Psychiatrists website

Sebastian, S., Jenkins, H., McCartney, S., Ahmad, T., Arnott, I., Croft, N., Russell, R. and Lindsay, J.O. (2012) 'The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: differing perceptions from a survey of adult and paediatric gastroenterologists', *Journal of Crohn's and Colitis* 6(8), pp.830-844.

Singh, S.P., Paul, M., Islam, Z., Weaver, T., Kramer, T., McLaren, S., Belling, R., Ford, T., White, S., Hovish, K. and Harley, K. (2010) *Transition from CAMHS to AMHS (TRACK): a study of service organisation, policies, process and user and carer perspectives.* Report for the National Institute for Health Research Service Delivery and Organisation Programme, London

Sloper, P., Beecham, J., Clarke, S., Franklin, A., Moran, N. and Cusworth, L. (2010) *Models of Multiagency Services for Transition to Adult Services for Disabled Young People and those with Complex Health Needs: Impact and Costs*, Report to the Department of Health.

Southwark Council and Southwark National Health Service Clinical Commissioning Group (2018) *Review of Child and Adolescent Mental Health and Emotional Wellbeing Services in Southwark*. [Online] Southwark Council and Southwark National Health Service Clinical Commissioning Group

Street, C. (2019) *Improving transition from Child and Adolescent Mental Health Service to Adult Mental Services - an overview of the issues,* University of Warwick. [online], Young People's Health website

Swift, K.D., Hall, C.L., Marimuttu, V., Redstone, L., Sayal, K. and Hollis, C. (2013) 'Transition to AMHS for young people with Attention Deficit/Hyperactivity Disorder (ADHD): a qualitative analysis of their experiences', *BMC Psychiatry* 13(1), p.74.

Together for Children And Young People (n.d.) *Good Transition Guidance: A Seamless Transition From Child And Adolescent To Adult Mental Health Services*, [online], Good Practice Wales website

Welsh Government (2012a) *The Costs and Benefits of Transition Key Working: an analysis of five pilot projects Final Report,* Welsh Government, [online], Welsh Government website

Welsh Government (2012b) Together for Mental Health A Strategy for Mental Health and Wellbeing in Wales, [online], Welsh Government website

Welsh Government (2016) *Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan*, [online], Welsh Government website

Welsh Government (2019) *Scoping Study for the Alignment and Development of Autism and Neurodevelopmental Service,* [online], Welsh Government website

Wilson, J., Clarke, T., Lower, R., Ugochukwu, U., Maxwell, S., Hodgekins, J., Wheeler, K. and Goff, A., Mack, R., Horne, R. and Fowler, D. (2017) 'Creating an innovative youth mental health service in the United Kingdom: The Norfolk Youth Service *Early Intervention in Psychiatry.* 12. 10.1111, [online], National Library of Medicine website

Wolpert, M., Harris, R., Hodges, S., Fuggle, P., James, R., Wiener, A., McKenna, C., Law, D., York, A., Jones, M., Fonagy, P., Fleming, I., and Munk, S..(2016) *Thrive Elaborated,* Anna Freud National Centre for Children and Families, [online], Anna Freud website

Wolpert, M. and Martin, P. (2015) *THRIVE & PR: Emerging thinking on a new organisational and payment system for CAMHS,* [online], Square Space website

Appendix: list of items included in the review

1. Foster, H. E., Minden, K., Clemente, D., Leon, L., McDonagh, J. E., Kamphuis, S., Berggren, K., van Pelt, P., Wouters, C., Waite-Jones, J., Tattersall, R., Wyllie, R., Stones, S. R., Martini, A., Constantin, T., Schalm, S., Fidanci, B., Erer, B., Dermikaya., Ozen, S., & Carmona, L. 2017. EULAR/PReS standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases. *Annals of the Rheumatic Diseases*, *76*(4), pp.639-646.
2. Kolehmainen, N., McCafferty, S., Maniatopoulos, G., Vale, L., Le-Couteur, A. S., & Colver, A. 2017. What constitutes successful commissioning of transition from children's to adults' services for young people with long-term conditions and what are the challenges? An interview study. *BMJ paediatrics open*, *1*(1) pp.1-8.
3. Ludvigsson, J. F., Agreus, L., Ciacci, C., Crowe, S. E., Geller, M. G., Green, P. H. R., Hill, I., Hungin, A. P., Koletzko, S., Koltai, T., Lundin, K. E. A., Mearin, M. L., Murray, J. A., Reilly, N., Walker, M. M., Sanders, D. S., Shamir, R., Troncone, R. & Husby, S. 2016. Transition from childhood to adulthood in coeliac disease: the Prague consensus report. *Gut*, *65*(8), pp.1242-1251.
4. Prüfe, J., Dierks, M. L., Bethe, D., Oldhafer, M., Müther, S., Thumfart, J., Feldkötter, M., Büscher, A., Sauerstein, K., Hansen, M., Pohl, M., Drube, J., Thiel, F., Rieger, S.,John, U., Taylan, C., Dittrich, K., Hollenbach, S., Klaus, G., Fehrenbach, H., Kranz, B., Montoya, C., Lange-Sperandio, B., Ruckenbrod, B., Billing, H., Staude, H., Brunkhorst, R., Rusai, K., Pape, L. & Kreuzer, M. 2017. Transition structures and timing of transfer from paediatric to adult-based care after kidney transplantation in Germany: a qualitative study. *British Medical Journal open*, *7*(6), pp.1-9.
5. Appleton, R., Connell, C., Fairclough, E., Tuomainen, H., & Singh, S. P. 2019. Outcomes of young people who reach the transition boundary of child and adolescent mental health services: a systematic review. *European child & adolescent psychiatry*, pp.1-16.
6. Chance, L. 2016. *The transition to AMHS from a secure inpatient environment: An Interpretative Phenomenological Analysis of the experiences of nursing staff* (Doctoral dissertation, Department of Neuroscience, Psychology and Behaviour).

7. Fusar-Poli, P. 2019. Integrated Mental Health Services for the Developmental Period (0 to 25 Years): A Critical Review of the Evidence. *Frontiers in psychiatry*, 10 (355), pp.1-17.
8. Hill, A., Wilde, S., & Tickle, A. 2019. Transition from Child and Adolescent Mental Health Services (CAMHS) to AMHS (AMHS): a meta-synthesis of parental and professional perspectives. *Child and Adolescent Mental Health*, pp.1-12
9. HSIB (Healthcare Safety Investigation Branch. 2018. Investigation into the transition from child and adolescent mental health services to AMHS [Online], Healthcare Safety Investigation Branch website (Accessed: 22nd August 2019).
10. Leavey., G. McGrellis, S., Forbes, T., Fullerton, D., Davidson, G., Hughes, L., Thampi, A., Bunting, B., Toal, A., Divin, N., Paul, M., & Singh, S. 2018. *Improving Mental Health Pathways and Care for Adolescents in Transition to Adult Services in Northern Ireland (IMPACT)*. Ulster University.
11. Southwark Council. 2018. *Review of Child and Adolescent Mental Health and Emotional Wellbeing Services in Southwark*. NHS Southwark Clinical Commissioning Group.
12. Norfolk City Council. 2017. *Child and Adolescent Mental Health Services – a needs assessment for the Norfolk and Waveney Local Transformation Plan October 2017*. Norfolk City Council.
13. Tatlow-Golden, M., Blanaid, G., McNamara, N., Singh, S., Ford, T., Paul, M., Cullen, W. & McNicholas, F. 2017. Transitioning from child and adolescent mental health services with attention deficit hyperactivity disorder in Ireland: Case note review. *Early Intervention in Psychiatry*, 12(3) pp. 505–512.
14. Campbell, F., Biggs, K., Aldiss, S. K., O'Neill, P. M., Clowes, M., McDonagh, J., While, A. & Gibson, F. 2016. Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database of Systematic Reviews*, (4), pp.1-64.
15. Clemente, D., Leon, L., Foster, H., Carmona, L., & Minden, K. 2017. Transitional care for rheumatic conditions in Europe: current clinical practice and available resources. *Pediatric Rheumatology*, *15*(1), 49.
16. Colver, A., Pearse, R., Watson, R. M., Fay, M., Rapley, T., Mann, K. D., Le Couteur, A., Parr, J. R. & McConachie, H. 2018. How well do services for young people with

long term conditions deliver features proposed to improve transition?. *BMC health services research*, *18*(1), 337.

17. Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2019). 'Something needs to change': Mental health experiences of young autistic adults in England. *Autism*, 23(2), pp.477-493.
18. Dunn, V. 2017. Young people, mental health practitioners and researchers co-produce a Transition Preparation Programme to improve outcomes and experience for young people leaving Child and Adolescent Mental Health Services (CAMHS). *BMC health services research*, *17*(1), 293.
19. Eklund, H., Cadman, T., Findon, J., Hayward, H., Howley, D., Beecham, J., Xenitidis, K., Murphy, D., Asherson, P. and Glaser, K., 2016. Clinical service use as people with Attention Deficit Hyperactivity Disorder transition into adolescence and adulthood: a prospective longitudinal study. *BMC health services research*, *16*(1), p.248.
20. Heath, G., Farre, A. and Shaw, K., 2017. Parenting a child with chronic illness as they transition into adulthood: a systematic review and thematic synthesis of parents' experiences. *Patient Education and Counseling*, *100*(1), pp.76-92.
21. Hodgekins, J., Clarke, T., Cole, H., Markides, C., Ugochukwu, U., Cairns, P., Lower, R., Fowler, D. and Wilson, J., 2017. Pathways to care of young people accessing a pilot specialist youth mental health service in Norfolk, United Kingdom. *Early intervention in psychiatry*, *11*(5), pp.436-443.
22. Hokken-Koelega, A., van der Lely, A.J., Hauffa, B., Häusler, G., Johannsson, G., Maghnie, M., Argente, J., DeSchepper, J., Gleeson, H., Gregory, J.W. and Höybye, C., 2016. Bridging the gap: metabolic and endocrine care of patients during transition. *Endocrine connections*, *5*(6), pp.R44-R54.
23. Hughes, G.C., O'Hanrahan, S., Kavanagh, G. and McNicholas, F., 2017. Review of international clinical guidelines for adolescents on transition to AMHS and adults with attention-deficit hyperactivity disorder and their application to an Irish context. *Irish journal of psychological medicine*, *34*(1), pp.59-73.
24. Islam, Z., Ford, T., Kramer, T., Paul, M., Parsons, H., Harley, K., Weaver, T., McLaren, S. and Singh, S.P., 2016. Mind how you cross the gap! Outcomes for young people who failed to make the transition from child to adult services: the TRACK study. *BJPsych bulletin*, *40*(3), pp.142-148.

25. McNamara, N., Coyne, I., Ford, T., Paul, M., Singh, S. and McNicholas, F., 2017. Exploring social identity change during mental healthcare transition. *European Journal of Social Psychology*, *47*(7), pp.889-903.
26. Sayal, K., Prasad, V., Daley, D., Ford, T. and Coghill, D., 2018. ADHD in children and young people: prevalence, care pathways, and service provision. *The Lancet Psychiatry*, *5*(2), pp.175-186.
27. Signorini, G., Singh, S.P., Marsanic, V.B., Dieleman, G., Dodig-Ćurković, K., Franic, T., Gerritsen, S.E., Griffin, J., Maras, A., McNicholas, F. and O'Hara, L., 2018. The interface between child/adolescent and AMHS: results from a European 28-country survey. *European child & adolescent psychiatry*, *27*(4), pp.501-511.
28. Singh, S.P., Tuomainen, H., De Girolamo, G., Maras, A., Santosh, P., McNicholas, F., Schulze, U., Purper-Ouakil, D., Tremmery, S., Franić, T. and Madan, J., 2017. Protocol for a cohort study of adolescent mental health service users with a nested cluster randomised controlled trial to assess the clinical and cost-effectiveness of managed transition in improving transitions from child to AMHS (the MILESTONE study). *BMJ open*, *7*(10)
29. Young-Southward, G., Philo, C. and Cooper, S.A., 2017. What effect does transition have on health and well-being in young people with intellectual disabilities? A systematic review. *Journal of Applied Research in Intellectual Disabilities*, *30*(5), pp.805-823.
30. NICE. 2016. Transition from children's to adults' services for young people using health or social care services. NICE.
31. Day, P., Turner, J., & Hollows, A. 2007 Bridging the gap: transitioning from child 2 to adult services. *British Journal of School Nursing* 2(146).
32. Mills, J., Cutajar, P., Jones, J. and Bagelkote, D., 2013. Ensuring the successful transition of adolescents to adult services. *Learning Disability Practice*, *16*(6).
33. Paul, M., Street, C., Wheeler, N. and Singh, S.P., 2014. Transition to adult services for young people with mental health needs: a systematic review. *Clinical child psychology and psychiatry*, *20*(3), pp.436-457.
34. Singh, S.P., Paul, M., Islam, Z., Weaver, T., Kramer, T., McLaren, S., Belling, R., Ford, T., White, S., Hovish, K. and Harley, K., 2010. *Transition from CAMHS to AMHS (TRACK): a study of service organisation, policies, process and user and*

carer perspectives. Report for the National Institute for Health Research Service Delivery and Organisation Programme: London.

35. Sloper, P., Beecham, J., Clarke, S., Franklin, A., Moran, N. and Cusworth, L., 2011. *Models of Multi-agency Services for Transition to Adult Services for Disabled Young People and those with Complex Health Needs: Impact and Costs*. Report to the Department of Health.
36. Swift, K.D., Hall, C.L., Marimuttu, V., Redstone, L., Sayal, K. and Hollis, C., 2013a. Transition to AMHS for young people with Attention Deficit/Hyperactivity Disorder (ADHD): a qualitative analysis of their experiences. *BMC psychiatry*, *13*(1), p.74.
37. Swift, K.D., Sayal, K. and Hollis, C., 2013b. ADHD and transitions to AMHS: a scoping review. *Child: care, health and development*, *40*(6), pp.775-786.
38. Allen, D., Cohen, D., Hood, K., Robling, M., Atwell, C., Lane, C., Lowes, L., Channon, S., Gillespie, D., Groves, S. and Harvey, J., 2012. Continuity of care in the transition from child to adult diabetes services: a realistic evaluation study. *Journal of Health Services Research & Policy*, *17*(3), pp.140-148.
39. Beresford, B. and Stuttard, L., 2014. Young adults as users of adult healthcare: experiences of young adults with complex or life-limiting conditions. *Clinical Medicine*, *14*(4), pp.404-408.
40. Binks, J.A., Barden, W.S., Burke, T.A. and Young, N.L., 2007. What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Archives of physical medicine and rehabilitation*, *88*(8), pp.1064-1073.
41. Cadario, F., Prodam, F., Bellone, S., Trada, M., Binotti, M., Trada, M., Allochis, G., Baldelli, R., Esposito, S., Bona, G. and Aimaretti, G. 2009. Transition process of patients with type 1 diabetes (T1DM) from paediatric to the adult health care service: a hospital-based approach. *Clinical endocrinology*, *71*(3), pp.346-350.
42. Care Quality Commission. 2014. *From the pond into the sea: children's transition to adult health services*. London: CQC.
43. Cobb, R.B. and Alwell, M., 2009. Transition planning/coordinating interventions for youth with disabilities: A systematic review. *Career Development for Exceptional Individuals*, *32*(2), pp.70-81.

44. Commission for Social Care Inspection (2007) *Growing up matters: better 18 transition planning for young people with complex needs*. London: 19 Commission for Social Care Inspection.
45. Crowley, R., Wolfe, I., Lock, K. and McKee, M., 2011. Improving the transition between paediatric and adult healthcare: a systematic review. *Archives of disease in childhood*, *96*(6), pp.548-553.
46. Doug, M., Adi, Y., Williams, J., Paul, M., Kelly, D., Petchey, R. and Carter, Y.H., 2011. Transition to adult services for children and young people with palliative care needs: a systematic review. *BMJ supportive & palliative care*, *1*(2), pp.167-173.
47. Kime, N.H., Bagnall, A. and Day, R., 2013. *Systematic review of transition models for young people with long-term conditions: A report for NHS Diabetes*. NHS Yorkshire and Humber.
48. Kingsnorth, S., Lindsay, S., Maxwell, J., Tsybina, I., Seo, H., Macarthur, C. and Bayley, M. 2010. Implementation of the LIFEspan model of transition care for youth with childhood onset disabilities. *Int J Child & Adolescent Health*, *3*, pp.547-561.
49. Prestidge, C., Romann, A., Djurdjev, O. and Matsuda-Abedini, M., 2012. Utility and cost of a renal transplant transition clinic. *Pediatric Nephrology*, *27*(2), pp.295-302.
50. Price, C.S., Corbett, S., Lewis-Barned, N., Morgan, J., Oliver, L.E. and Dovey-Pearce, G., 2011. Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes. *Child: care, health and development*, *37*(6), pp.852-860.
51. Sebastian, S., Jenkins, H., McCartney, S., Ahmad, T., Arnott, I., Croft, N., Russell, R. and Lindsay, J.O., 2012. The requirements and barriers to successful transition of adolescents with inflammatory bowel disease: differing perceptions from a survey of adult and paediatric gastroenterologists. *Journal of Crohn's and Colitis*, *6*(8), pp.830-844.