# A systematic review of mental health services for emerging adults; moulding a precipice in to a smooth passage.

Joanna Anderson, Tamsin Newlove-Delgado and Tamsin Ford

# ABSTRACT

**Background:** The transition between child and adult services should aim to support young people into the next stage of their life in a way that optimises their function. Yet financial, organisational and procedural barriers to continuity of care often hamper smooth transition between child and adult services.

**Aim and method:** We reviewed studies of transition from child to adult mental health services, focusing on: (i) rates of referrals and referral acceptance; (ii) barriers and facilitators of successful transition; (iii) continuity of care during and post-transition; and (iv) service users' experience of transition. Studies were identified through systematic searches of electronic databases: PsychINFO, Medline, Embase and Child Development and Adolescent Studies.

**Findings:** 47 papers describing 43 unique studies met inclusion criteria. Service provision is influenced by previous history and funding processes, and the presence or absence of strong primary care, specialist centres of excellence, and coordination between specialist and primary care. Provision varies between and within countries, particularly in whether services are restricted to "core" mental health or broader needs. Unsupportive organisational culture, fragmentation of resources, skills and knowledge-base undermine the collaborative working essential to optimise transition. Stigma and young people's concerns about peers' evaluation often prompts disengagement and discontinuation of care during transition, leading to worsening of symptoms and later, to service re-entry. Qualitative studies reveal that young people and families find the transition process frustrating and difficult, mainly because of lack of advanced planning and inadequate preparation.

**Conclusion:** Despite increasing research interest over the last decade transition remains "poorly planned, executed and experienced". Closer collaboration between child and adult services is needed to improve the quality of provision for this vulnerable group at this sensitive period of development.

# **KEY POINTS**

- Despite considerable continuity of mental health conditions, mental health services in many countries are commissioned and delivered separately for young people and adults. The discontinuity of service provision falls at the time of peak incidence of depression and the onset of severe and enduring mental disorders.
- Young people and their families find the transition process frustrating and difficult, mainly because of lack of advanced planning and inadequate preparation. Stigma and social concerns as well as misconceptions, particularly salient for young people with neurodevelopmental disorders, can lead to disengagement during the transition period.
- There is a clear need to develop and evaluate different models of care or interventions and particularly for economic evaluation. The latter must take a broad societal perspective, including the costs to young people and carers in order to demonstrate the true costs and benefits of improved transition.
- Given the joint responsibility highlighted in NICE Guidance (2016), CAMHS should monitor the outcomes of those who graduate from their service, while AMHS should carefully monitor acceptance of referrals and attendance in order to improve the quality of provision for this vulnerable group at this sensitive period of development.

#### BACKGROUND

Late adolescence and emerging adulthood is a period of life where actions, decisions and developing habits profoundly influence a young person's future life chances, including their health (Sawyer et al., 2012). During this period many simultaneous transitions occur; which include starting to live and work or study independently (Cleverley, Rowland, Bennett, Jeffs, & Gore, 2020). Young people with poor mental health during these key life transitions risk paying a particularly heavy developmental price in terms of the impact of poor functioning at such a critical developmental period (Costello & Maughan, 2015). Yet despite considerable continuity of mental health conditions, mental health services in many countries are commissioned and delivered separately for young people and adults, which installs financial, organisational and procedural barriers to continuity of care at this critical stage of development (Signorini et al., 2018). Furthermore, the discontinuity of service provision falls at the time of peak incidence of depression and for some, the onset of severe and enduring mental disorders, such as schizophrenia, bipolar disorder and eating disorders (McGorry, Bates, & Birchwood, 2013).

Change, even if positive, requires adaptation. The change from trusted healthcare while struggling with poor mental health needs careful management, particularly given the other simultaneous adjustments that most emerging adults face (Signorini et al., 2018). Within the context of healthcare, there is consensus that transition between child and adult services should aim to support young people into the next stage of their life in a way that optimises their function rather than the simply undertaking an administrative transfer of clinical responsibility (Beresford, 2004). At a minimum, professional consensus suggests that successful transition requires planning and information transfer between the referring and receiving teams; is aided by joint working and should result in continuity of care (NICE, 2016; Royal College of Paediatrics and Child Health, 2003).

In the UK, formal guidance from the National Institute of Clinical and Social Care excellence (NICE) emphasises that transition is the responsibility of *both* child and adult services but should also

involve the young person and their parents or carers (NICE, 2016). This guidance suggests that planning for transition should start early as well as offering developmentally appropriate support before, during and after transition, while the process should be strengths-based and person centred. A systematic review of transitions for teenagers with long term physical health conditions recommended that preparation should start as young as 14 years, with a gradual transition process that ideally completes around the age of 18 (Yassaee, Hale, Armitage, & Viner, 2019). Mental health practitioners could benefit from the experience of their paediatric colleagues who recognised the need to adapt their practice to support transition earlier because of the change in caseload from primarily episodic infectious diseases to long term conditions, such as diabetes (Crowley, Wolfe, & McKee, 2013). Arguably, CAMHS provision is modelled on the management of episodes of care for what for many young people turn out to be long-term conditions. A shift in perspective to support service users to live with a long term, relapsing condition might be helpful, particularly for this transitional age group.

The following barriers emerged from a systematic review of transition from paediatric to adult care across varied conditions in the United States of America (USA); changing relationships, accessing adult practitioners, gaining funding, negative beliefs about adult care, lack of knowledge about the transition process and lack of self-management skills (Gray, Schaefer, Resmini-Rawlinson, & Wagoner, 2018). Similarly, a UK-based follow up study of young people with diabetes, cerebral palsy, or autistic spectrum conditions found appropriate parent involvement, promotion of health selfefficacy and meeting the adult team\_before transfer were strongly associated with better outcomes (S. Gray et al., 2018).

Over three quarters of young adults accessing specialist mental health services experience their first difficulties during childhood or adolescence while only a quarter of children experiencing poor mental health will be functioning without impairment relation to health, occupation and relationships as adults (Costello & Maughan, 2015; Kim-Cohen et al., 2003). Given the urgent need

to improve transitional care to avoid unnecessary distress and difficulty functioning, we systematically reviewed the literature on transition from child to adult mental health services, augmented by non-systematic searches of qualitative studies of the experience of transition. We cover the severe and enduring psychiatric disorders such as psychotic, bipolar, personality and eating disorders that may first emerge in adolescence and conditions such as anxiety and depression that are common across the lifespan as well as neurodevelopmental disorders, which commonly develop in childhood but often persist into adulthood.

Our aim was to review the depth and strength of the evidence on transition from child to adult mental health services in relation to different types of mental health disorder. We specifically focus on: (i) rates of referrals to adult services and referral acceptance; (ii) barriers and facilitators of successful transition; (iii) continuity of care during and post-transition; and (iv) service users' experience of transition. We also wanted to highlight the gaps where further evidence is needed to inform service development. We anticipate that findings from this review of research could guide evidence-based service improvement so that practitioners and young people with poor mental health can better navigate the obstacles to continuity of care. Improved access to care for young people with mental health difficulties is likely to improve their short- and long-term mental health outcomes, and improve their quality of life (Patel, Flisher, Hetrick, & McGorry, 2007).

# METHODS

#### Search strategy and selection criteria

Studies were identified through systematic searches of four electronic databases: PsychINFO, Medline, Embase and Child Development and Adolescent Studies. All searches were conducted on 30/06/2020 and updated on 28/06/2021 using variation of words and phrases related to transition, mental health and neurodevelopmental disorders, children, and adult mental health services. Supplemental search methods included backward and forward citation searching of key studies and reviews in the field and contacted experts in relation to specific disorders. The full search strategy for each database is available in the on-line Supplement.

We included empirical studies of young people with mental health conditions, attending Child and Adolescent Mental Health Services (CAMHS) and requiring transition into Adult Mental Health Services (AMHS). Included study designs included randomised controlled trials, cross sectional surveys, cohort, quasi-experimental studies and qualitative studies. Studies conducted in any healthcare setting providing mental health care, published in English were included, and there was no limitation on publication date. We excluded non-empirical publications such as commentaries, editorials, and opinion pieces, as well as case studies and articles published in languages other than English. Inclusion/exclusion criteria are available in the on-line Supplement.

The main focus was on what happens at the upper age-boundary of CAMHS, particularly regarding continuity of care. We excluded opinion pieces, editorials, case descriptions or case series, or studies that only studied young people attending paediatric/secondary health care provide primarily for physical health. To supplement searches, we contacted experts in the field, which revealed one unpublished PhD thesis (Appleton, 2021).

#### Study selection

Search results were managed using CADIMA (https://www.cadima.info/index.php). One author (JKA) screened all titles and abstracts, and subsequently all full texts. Second reviewer (TND) independently rated 10% of the papers at both screening stages. All disagreements were resolved by discussion between the three authors. Interrater agreement levels in both stages were high with kappa values 0.79 and 0.91 at abstract and full text screening stages respectively.

# Data extraction

Data from included studies were extracted into a spreadsheet developed specifically for this review. Extraction tables included the following information: Reference, Country of origin, Condition(s)

studied, Study aims, Study design, Description of participants, Description of an intervention (if any), Outcomes studied, Method of data collection, Findings. A sample of extracted studies (10%) was checked by the second reviewer (TND) with inter-rater agreement (kappa) at 0.86.

#### Quality appraisal

Included studies were appraised using the Effective Public Health Project Practice (EPHPP) Quality Assessment Tool for Quantitative Studies (Armijo-Olivo et al. 2012). The EPHPP tool assesses six domains: (1) selection bias; (2) study design; (3) confounders; (4) blinding; (5) data collection method; and (6) withdrawals/dropouts. Each domain can be rated as strong, moderate or weak. Scores are averaged to provide the total score that indicates a study's quality rating. The quality of qualitative studies was appraised using the Critical Appraisal Skills Programme (CASP) qualitative checklist (Long, French, & Brooks, 2020), which appraises the validity, quality of results based on methodological aspects of a study, and the value of the results in terms of contribution to existing knowledge base and transferability. One reviewer (JKA) appraised the quality of papers and 50% was checked by the second reviewer (TND).

Due to high heterogeneity of study designs, interventions, and outcome measures, it was not appropriate to conduct meta-analysis, so we have provided a narrative summary of existing evidence.

# RESULTS

#### Study characteristics

Forty nine papers describing 44 unique studies met all inclusion criteria (see Figure 1). Most were conducted in the past five-year period (n=30), based in the UK (n=29) and either did not differentiate between types of mental health conditions (n=24) or focused on ADHD (n=16); see Table 1. The most commonly applied methodology was retrospective case note review (n=25), and notably we only retrieved one randomised controlled trial (Singh SP, 2021).

# Table 1: Characteristics of included studies

Criterion	Characteristic	Number of publications	
		(n=49)	
Year	2008 - 2010	3	
	2011 - 2015	15	
	2016 - 2020	23	
	2021	7	
Country	Australia	1	
	Canada	1	
	Ireland	2	
	Italy	3	
	Spain	3	
	UK	29	
	USA	8	
	Multiple countries	1	
Study design	Cross sectional	4	
	Retrospective case note review	25	
	Prospective case note review	6	
	Longitudinal study	5	
	Cohort study	2	
	Prospective longitudinal cohort	1	
	Randomised controlled trial	1	
	Qualitative study	3	
Condition	Any MH diagnosis	24	
	ADHD	16	
	Other neurodevelopmental conditions	9	

# Figure 1: PRISMA flow diagram indicating the studies retrieved from searches, the final number

# selected and reasons for exclusion



# Participants

The number of participants ranged from 10 to 8239. In 25 studies, data were collected from patient records without researchers interacting with participants. In all but one study, samples included young people who either required a transition from CAMHS to AMHS or recently completed a transition, whether successful or not. One study additionally included parents of young people (A. Price et al., 2019), and one both parents and child psychiatrists (Reale & Bonati, 2015).

# Interventions

Only four studies evaluated interventions designed to facilitate transition and ensure continuity of care for young people transitioning from CAMHS to AMHS (Cappelli et al., 2016; Maslow, 2016; Moosa & Sandhu, 2015; Singh SP, 2021). These included an evaluation of a quality improvement project focused on transition and continuity of care for young people with ADHD (Moosa & Sandhu, 2015), and an assessment of the utility of a transition clinic established to keep young people with psychiatric conditions in contact with services while awaiting intake into AMHS (Maslow, 2016). The Youth Transition Project (Cappelli et al., 2016) aimed to help young people and families to develop an individualised transitional care plan. Young people and families participating in the programme received support from a transition coordinator who helped prepare them for transition and ensured continuity of care (Cappelli et al., 2016).

The recently completed cluster randomised controlled trial, the MILESTONE study, tested the effectiveness of a complex managed transition process in eight European countries (Singh SP, 2021). The intervention involved the systematic identification of those approaching the transition age boundary, with a structured assessment of needs to facilitate transition planning and information transfer, if required. Practitioners working in CAMHS allocated to the intervention were offered a single training session on how to optimise transition and fed back the structured assessment (Santosh et al., 2020) to discuss with the family and adult services (Young et al., 2016).

# Quality of included studies (see Tables 2 and 3)

The quality of included quantitative studies (n=37) was mostly weak (23 studies) according the Effective Public Health Practice Project (EPHPP) tool (Armijo-Olivo, Stiles, Hagen, Biondo, & Cummings, 2012); only twelve studies were rated as moderate and one randomised controlled trial was rated as strong (Singh SP, 2021). Most studies were case note reviews, and all but two were retrospective. Case-note reviews, particularly those that select cases and follow them prospectively over the transition boundary, are arguably one of the most efficient and reliable methodological approaches to study transition outcomes. Case-note reviews are less prone to selection bias by loss to follow up, which is a common issue in studies with young people experiencing mental health difficulties, and particularly common among this age group. Regardless, most quality assessment tools, including the EPHPP, consider this design weak. Other aspects of these same studies scored higher.

In contrast, both qualitative studies were rated as strong using the CASP tool (Long et al., 2020). The trial and cohort study related to the MILESTONE project in particular are robust, given the direct and prospective follow up of young people across the transition boundary. The MILESTONE cohort is also the only study to our knowledge to report directly on those who do not transition (Singh SP, 2021).

Another common methodological weakness was the failure of most studies to report on losses to follow up, and whether these were withdrawals or dropouts. Moreover, only one included study reported whether participants' consent was sought and how many of those approached agreed to participate, which is important to consider in relation to the generalisability of findings. Since most case review studies used anonymised data from patient records, it is likely that researchers were not required to seek patient consent, while the advent of electronic health records means that case records are less likely to be unavailable in studies that could access them. The completeness of follow up remains important to report.

Most included studies used data extraction and coding tools specifically designed for the purpose of the study. Eight studies reported assessing their tool for reliability or using a tool with proven psychometric properties, however, none reported any psychometric values (Appleton, 2021; Asl, 2014; Livanou, Lane, D'Souza, & Singh, 2020; McNicholas et al., 2015; McNicholas & Singh, 2015; Reale, Costantino, Sequi, & Bonati, 2018; S. Singh, 2013, 2014, 2015; S. P. Singh, 2012; S. P. Singh et al., 2010; Singh SP, 2021; Tatlow-Golden et al., 2018).

Reference	Selection	Design	Confounders	Blinding	Data	Withdrawals	Global
	bias		*	*	collection	and dropouts	rating
Any mental health diagnosis							
Adamopoulus,	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
2021							
Appleton, 2021	Strong	Weak	N/A	N/A	Strong	Moderate	Moderate
Appleton et al,	Strong	Weak	N/A	N/A	Strong	Moderate	Moderate
2021							
Bond et al, 2019	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
Capelli et al,	Strong	Weak	N/A	N/A	Moderate	N/A	Moderate
2015							
Cohen et al,	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
2020							
Garcia et al,	Weak	Weak	N/A	N/A	Weak	N/A	Weak
2019							
Islam et al, 2016	Strong	Weak	N/A	N/A	Weak	N/A	Weak
Leavey et al,	Strong	Weak	N/A	N/A	Moderate	N/A	Moderate
2018 & 2019							
Leeb et al, 2020	Strong	Weak	N/A	N/A	Moderate	N/A	Moderate
Livanou et al,	Moderate	Weak	N/A	N/A	Moderate	N/A	Moderate
2020							
Malkov et al,	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
2021							
Maslow, 2016	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
McNicholas et	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
al, 2015							
Paul et al, 2013	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
Perera et al,	Moderate	Weak	N/A	N/A	Moderate	N/A	Moderate
2015							
Pottick et al,	Strong	Weak	N/A	N/A	Moderate	N/A	Moderate
2008							
Reneses et al,	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
2018							
Saour,	Weak	Weak	N/A	N/A	Weak	N/A	Weak

# Table 2: Quality of included studies (EPHPP tool)

2021							
Singh et al,	Moderate	Weak	N/A	N/A	Moderate	N/A	Moderate
2010; 2012;							
2013; 2014;							
2015							
Singh et al,	Strong	Strong	Strong	Strong	Strong	Moderate	Strong
2021							
Stagi et al, 2015	Strong	Weak	N/A	N/A	Weak	N/A	Weak
ADHD							
Ayyash et al,	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
2018							
Eke et al, 2019	Moderate	Weak	N/A	N/A	Weak	Strong	Weak
Eke, Ford, 2018	Moderate	Weak	N/A	N/A	Weak	Strong	Weak
Heron et al,	Strong	Weak	N/A	N/A	Weak	Strong	Weak
2020							
Janssen et al,	Moderate	Weak	N/A	N/A	Moderate	N/A	Moderate
2020							
Magon et al,	Moderate	Weak	N/A	N/A	Weak	Moderate	Weak
2015							
McCarthy et al,	Weak	Weak	N/A	N/A	Weak	N/A	Weak
2009							
McNicholas,	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
2015							
Moosa, Sandhu,	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
2015							
Ogundele, 2014	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
Ogundele,	Weak	Weak	N/A	N/A	Weak	N/A	Weak
Omenaka, 2012							
Reale et al,	Moderate	Weak	N/A	N/A	Strong	N/A	Moderate
2018							
Tatlow-Golden	Weak	Weak	N/A	N/A	Weak	N/A	Weak
et al, 2016							
Neurodevelopme	ntal condition	s					
Asl, 2014	Moderate	Weak	N/A	N/A	Strong	N/A	Moderate
Blasco-	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
Fonticiella et al,							
2012							
Laxman et al,	Moderate	Weak	N/A	N/A	Moderate	Moderate	Moderate
2019							
Maslow, 2016	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
Merrick et al,	Moderate	Weak	N/A	N/A	Strong	Moderate	Moderate
2020							
Patwardhan,	Weak	Weak	N/A	N/A	Weak	N/A	Weak
Singh, 2019							
Sharif, 2021	Moderate	Weak	N/A	N/A	Weak	N/A	Weak
Tunesi et al,	Moderate	Modera	N/A	N/A	Strong	N/A	Moderate
2019		te					

\* Due to studies' design and applied methodology, only one quantitative study were appraised for

confounders and blinding

# Table 3: Quality appraisal of qualitative studies (CASP tool)

Criteria	Appleton et al,	Price et al,	Reale et al,
	2021	2019	2015
Clear aims?	Yes	Yes	Yes
Qualitative methodology appropriate?	Yes	Yes	Yes
Research design appropriate to address aims?	Yes	Yes	Yes
Appropriate recruitment strategy?	Yes	Yes	Yes
Data collection appropriate?	Yes	Yes	Yes
Relationship between researcher and participants	Unclear	Unclear	Unclear
considered?			
Ethic issues considered?	Yes	Yes	Yes
Data analysis sufficiently rigorous?	Yes	Yes	Unclear
Clear statement of findings?	Yes	Yes	Yes
Valuable research?	Yes	Yes	Yes

# Transition from child to adult mental health services for young people with varied mental health disorder.

We identified 24 papers describing 19 unique studies that focused on the transition of young people to AMHS regardless of their specific mental health condition. Twelve studies included participants with any MH diagnoses without further specification, (Adamopoulos & Samuel, 2021; Cohen, Klodnick, Kramer, Strakowski, & Baker, 2020; Garcia, Boix, Vegue, & De Angel, 2019; Islam et al., 2016; Leeb et al., 2020; Livanou et al., 2020; McNicholas et al., 2015; Paul et al., 2013; Pottick, Bilder, Vander Stoep, Warner, & Alvarez, 2008; Reneses et al., 2018; Saour, 2021; S. P. Singh et al., 2010; Singh SP, 2021; Stagi, Galeotti, Mimmi, Starace, & Castagnini, 2015). One study focused on "serious" mental health disorders and provided the following example:, schizophrenia spectrum, bipolar, and major depressive disorders (Cohen et al., 2020). Maslow included young people with a range of physical and MH conditions including psychosis, bipolar disorders and major depression (Maslow, 2016), and we found a single study that included only young people with personality disorders (Malkov et al., 2021). In addition, Appleton (2021) in a secondary analysis of data from the MILESTONE study (Singh SP, 2021) selected a cohort of a young people with anxiety, depression, neurodevelopmental and emerging personality disorders as prior work suggested that such young people were particularly likely to drop through gaps in services (Appleton, 2021). The wider MILESTONE cohort study included young people with any diagnosis (Singh SP, 2021).

There were several studies of transition among young people with neurodevelopmental conditions, particularly ADHD, which are therefore grouped and discussed separately below. Interestingly, no studies solely focused on psychosis, which may reflect the move over the last two decades or more towards early intervention in psychosis services with more flexible lower age boundaries in the UK and across other higher income countries (McGorry et al., 2013).

The 19 studies of "any mental disorder" included between 25 and 8239 young people, to give a total number of participants of 21,625. The mean age of participants (if reported) was 18-19 years, which would fit with the commonest reported transition boundary (Eke et al., 2019; Signorini et al., 2018). Most samples included an even percentage of males and females and were ethnically diverse; there was only one study in which nearly all participants identified as Caucasian, which reflects the context in which it was conducted (McNicholas et al., 2015).

All but two studies focused on transition process and outcomes. Transition outcomes varied, including discharges and referrals (including non-referrals, referral acceptance and uptake), availability of appropriate services, continuity of care and waiting times, overall mental health and quality of life. One study additionally explored young people's experience of transition mental health, quality of life and number and costs of service contact, as well as mental health service providers' views of current and future needs of their clients (Appleton, Elahi, Tuomainen, Canaway, & Singh, 2021). Only one study quantitatively assessed mental health post transition (Appleton, 2021).

# Likelihood of referral

Several studies found that CAMHS providers only refer a proportion of their patients to adult services when they reach transition age. For example, the TRACK study (S. P. Singh et al., 2010) reported that nearly 60% of young people received a referral to AMHS, which dropped to only 41% among those who failed to make the transition but were deemed to have ongoing needs. Leavey and colleagues (Leavey et al., 2018; Leavey et al., 2019) reported higher referral rates (72% of young people with ongoing poor mental health); the strongest predictor of referral was having a prescription for anti-psychotic medications (Leavey et al., 2018; Leavey et al., 2019). Perera at al (2015) found that young people with schizophrenia-related disorders, behavioural disorders and trauma were more likely to be referred to AMHS (79% chance) compared with young people diagnosed with neurotic or mood disorders (58% and 54% chance respectively) (Perera, Rogers, Edwards, Hudman, & Malone, 2017). Living with both parents or independently, and longer length of stay in CAMHS also increased the likelihood of receiving a referral to AMHS (Perera et al., 2017). Referral rates were slightly lower for young people with depression and anxiety; in this group only about of half of patients were referred to AMHS (S. Singh, 2014). Similarly, a replication of TRACK in Ireland reported that 32% of young people with ongoing MH needs were referred to AMHS (Islam et al., 2016; McNicholas et al., 2015). A more recent service evaluation conducted in the UK showed that fewer than 30% of young people were successfully referred from CAMHS to AMHS (Saour, 2021). Interviews with young people and parents suggested that those judged as not ill enough to access ongoing care were not referred (Appleton et al., 2021). Being in crisis at transition point facilitated referral, while previous crisis, including suicide attempts, was not considered sufficient reason to warrant continuous access to care (Appleton et al., 2021).

# Barriers and facilitators of successful transition

The most common barriers to transition reported by clinicians was young person's or parents' refusal to consider referral to AMHS, followed by failure to meet adult services criteria leading to its

rejection, as well as a lack of appropriate services to meet young person's needs (Islam et al., 2016; Leavey et al., 2018; Leavey et al., 2019; McNicholas et al., 2015).

The type of mental health condition as well as the severity of the young person's difficulties influenced the likelihood of successful transition. Young people with serious and enduring mental disorders including psychosis (McNicholas et al., 2015) were most likely to be referred, whilst those with emerging personality, neurodevelopmental and emotional disorders were the least likely to transition successfully in several studies (Malkov et al., 2021; S. P. Singh et al., 2010). Leeb et al (2020) examined the factors affecting whether the care of young people with mental health, behavioural and developmental disorders included key elements of optimum transition using a 'transition measure' (Leeb et al., 2020). The transition measure focused on how providers work with young people to prepare them for transition, including three specific aspects of young people's interactions with clinicians: (i) spending time alone with the provider at a last preventive visit; (ii) working with the provider to gain health management skills or understand healthcare changes occurring at age 18 years; (iii) discussing the shift to an adult provider. Young people who were most likely to have experienced the input recorded via the transition measure were White, female and diagnosed with depression (Leeb et al., 2020). Patients with developmental disorders and ASD were the least likely to meet the criteria for optimum transition, regardless of the severity of their conditions and comorbidities (Leeb et al., 2020).

Bond et al. (2019) showed that attending outpatient adolescent mental health services significantly increased the likelihood of being discharged to primary care, while being admitted as inpatients increased chances of transition to AMHS (Bond et al., 2019), which echoed the findings of TRACK (Singh et al., 2010). The authors examined care pathways in an independent mental health service in Ireland when young people reach the age of 18 (Bond et al., 2019); those discharged to public services were more likely to have diagnoses of eating disorders (34.6%) and borderline personality disorders (19.2%). Those who remained with independent services more often had anxiety disorders (41.3%) or ADHD (19.6%). Most young people with two or more admissions were discharged to

public mental health services (63.6%); 36.4% to CAMHS and 27.3% to AMHS, and 36.4% to independent AMHS (Bond et al., 2019).

#### Continuity of care

Being referred from CAMHS or community paediatrics does not necessarily translate into smooth transition into adult services; one of the commonest reasons for failing to transition was low acceptance rates of referrals (Islam et al., 2016; Leavey et al., 2018; Leavey et al., 2019; McNicholas et al., 2015; S. Singh, 2014). For example, the TRACK study reported that a fifth of the young people with emotional disorders who were referred to AMHS were discharged without ever being seen (S. Singh, 2014). In a more detailed analysis of TRACK data, Islam et al (2016) showed that out of twelve referrals made, seven were not accepted by AMHS (Islam et al., 2016). Three young people rejected by adult services were offered alternatives including crisis support and referral to other community services, while the remaining four were discharged from CAMHS to their GP. The remaining five out of 12 referrals made were still pending when data collection was completed; of the three still open, one was offered additional 46 weeks of care in CAMHS and one was discharged without any subsequent care (Islam et al., 2016). Further, Adamopoulus and Samuel (2021) reported that 30% of cases discharged from CAMHS did not reengage with AMHS (Adamopoulos & Samuel, 2021), particularly if the young people described their experience of transition as suboptimal; of those 66% did not engage with AMHS beyond three months post-transfer (Adamopoulos & Samuel, 2021).

We can draw some reassurance that severity predicted transition in Appleton's quantitative analysis of a cohort of young people with depression, anxiety disorder, neurodevelopmental disorder or emerging personality disorder who were prospectively followed across the transition boundary in seven European countries (Appleton, 2021). As country independently predicted transition, it suggests that service organisation also plays a significant role. Notably, young people living in Italy, the Netherlands and the UK were least likely to transition to adult services compared to other participating countries (Appleton, 2021). Similarly, a UK-based study showed transition was more successful among young people in forensic medium secure services, which is likely to be related to severity and complexity of the young people's presentation (Livanou et al., 2020). All 32 patients eligible for transition were referred within 10 weeks before their 18<sup>th</sup> birthday, and the average time between referral and transition was 6 months. Nearly 40% of young people transitioned to Early Intervention Services, 25% to adult medium secure hospitals, and the remaining individuals to secure units of different levels, prison, rehabilitation or educational services and psychiatric hospital (Livanou et al., 2020).

Non-attendance was another common reason for discontinuity of care (Cohen et al., 2020; Garcia et al., 2019; Maslow, 2016; Reneses et al., 2018). Garcia et al (2019) reported that 23% of Spanish young people referred from CAMHS to AMHS did not attend their first appointment, and a further 14% dropped out before their fifth visit (Garcia et al., 2019). Similarly, Reneses et al (2018) found that nearly 60% of young people dropped out without discharge even before transition, and out of those offered access to AMHS, 27% did not attend their first appointment (Reneses et al., 2018). A Canadian study reported that out of 127 young people referred to AMHS, 47 (21.8%) cancelled services, including 31 (14.4%) immediately after the referral was made (Cappelli et al., 2016). Similarly, an USA-based study found that over 50% of nearly 1,500 patients dropped out soon after turning 18 (Maslow, 2016). Another USA-based study demonstrated that the outpatient service attendance rates among both pre-transition and post-transition young people was 20% higher than the rates among those in the transition-age range. But by the end of the transition-age period (24-and 25-year-olds), there were a third fewer patients (34%) who received mental health services compared to the 16-to-17-year-olds (Pottick et al., 2008).

Failure to attend may be compounded by long waiting lists for AMHS. Leavey et al found that out of 175 referrals accepted by UK AMHS (out of 289 made), 60 young people waited for their first appointment for longer than 100 days (Leavey et al., 2018; Leavey et al., 2019). Similarly, the mean time to transition in a Canadian study, defined as the gap between last CAMHS and first AMHS

appointment, was 110 days (Cappelli et al., 2016). Given that change is unsettling and requires adaption, this would seem unhelpful; future studies should explore the reasons for failure to engage to understand which relate to potentially tractable factors.

Three studies, conducted in Spain and the USA, examined the characteristics of young people who were more likely to continue with AMHS after transition (Cohen et al., 2020; Garcia et al., 2019; Reneses et al., 2018). Young people with continuity of care were more likely to have a primary diagnosis of schizophrenia or major depression (Cohen et al., 2020), anxiety, adaptive or affective disorders (Garcia et al., 2019), or eating disorders (Reneses et al., 2018), compared to those who did not attend their first appointment or disengaged. Pharmacological treatment (Reneses et al., 2018) and more service contact in the year leading to transition were (Cohen et al., 2020) also positively associated with continuation. However, neither of the studies found association between socio-demographic characteristics and continuation (Cohen et al., 2020; Reneses et al., 2018).

The MILESTONE cohort systematically followed young people with emotional disorders, neurodevelopmental disorders and emerging personality disorder across the transition boundary to compare service use and costs between those who did and did not transition to AMHS (Appleton, 2021; Singh SP, 2021). Findings suggest no difference in mental health or quality of life between these groups, and worse functioning among those who transitioned, which would suggest this group had worse mental health. Contrary to expectations, those who were discharged at the transition boundary attended primary health care or Accident and Emergency services no more frequently than their peers who successfully transitioned. Service use dropped substantially in both groups, so the similar outcomes could reflect failings in AMHS and unmet need in both groups. To our knowledge, this is only economic evaluation to be conducted related to transition outcomes. A broader analytic perspective, particularly if it focuses on the costs to young people and parents, might reveal that failure to transition is associated with significant economic costs, as a related qualitative study revealed huge levels of family support required by young people who did not transition (Appleton, 2021; Appleton et al., 2021).

# Experience of transition

The TRACK study outlined four criteria for optimal transition, which have been applied to many subsequent projects: continuity of care (operationalised as engagement with AMHS three months after transition or an appropriate discharge); a period of parallel or joint care from CAMHS and AMHS, having at least one transition planning meeting and successful information transfer (Paul et al., 2013). Among 90 referrals accepted by AMHS the element of optimal transition most often met was continuity of care (70%, n= 63), followed by having had at least one transition planning meeting (40%, n= 36), good information transfer (27%, n= 24) and a period of parallel care (24%, n= 22). No criterion for optimal transition were experienced in 13 (14%) cases and all criteria in only 4 (4%) cases. This multi-method study examined the experience of transition from young people's perspective (S. Singh, 2015; S. P. Singh, 2012; S. P. Singh et al., 2010). Optimal transition was reported by fewer than 5% of participants. Those who transitioned successfully reported improved MH outcomes, but these were not assessed quantitatively, which contrasts with Appleton's' findings described above (Appleton, 2021). Qualitative exploration of experience of young people who did not transition revealed that many struggled with their mental health and felt unsupported. The authors describe two main themes; systematic barriers to continuity of care, and not being 'ill enough' for AMHS. Many of the young people who participated in their study did not feel prepared for CAMHS care to end (Appleton et al., 2021). Poor transition planning and lack of options about available care options meant they felt lost and abandoned, which compounded their mental health difficulties. Some struggled to manage without continued care, in particular lacking support with managing medication, and sometimes even having to stop their treatment (Appleton et al., 2021).

#### Transition for those with neurodevelopmental disorders

Twenty five papers, each reporting on a separate study, focussed on neurodevelopmental disorders, although four papers relate to the constituent studies in CATChuS (Eke et al., 2019; Eke, Janssens, & Ford, 2018; Janssens et al., 2020; A. Price et al., 2019). Three studies included young people with ASD (Laxman, Taylor, DaWalt, Greenberg, & Mailick, 2019; Merrick et al., 2020; Tunesi, Bosio, & Russo, 2019), four included young people with any neurodevelopmental condition (Asl, 2014; Maslow, 2016; Patwardhan, Singh, & Kanster, 2019; Singh SP, 2021), one focused on learning disabilities (Sharif, 2021), one on hyperkinetic disorder (Blasco-Fontecilla et al., 2012), and the remainder focussed on ADHD (Ayyash et al., 2018; Eke et al., 2019; Eke, Janssens, & Ford, 2018; Heron et al., 2020; Janssens et al., 2020; Magon, Latheesh, & Muller, 2015; McCarthy et al., 2009; McNicholas & Singh, 2015; Moosa & Sandhu, 2015; Ogundele, 2013; Ogundele & Omenaka, 2012; A. Price et al., 2019; Reale et al., 2018; Reale, Frassica, Gollner, & Bonati, 2015; Tatlow-Golden et al., 2018). However, most studies included young people with comorbidity, including those with comorbid ADHD/ASD. The number of young people included in the studies ranged from 20 to 2274.

Most of these studies focussed on the process and outcomes of transition for young people with neurodevelopmental disorders, and on the views of young people, parents/carers and clinicians. One project (CATCh-uSs: Children and Adolescents with ADHD in Transition between Children's and Adult Services) used prospective surveillance to estimate the incidence of need for transition in young people with ADHD, and the incidence of successful transition via the Child and Adolescent Psychiatry Surveillance System (CAPSS) and the British Paediatric Surveillance Unit (BPSU) in the UK and Ireland at population level (Eke et al., 2019). Over twelve months, clinicians were asked to report ADHD patients who were approaching the transition age boundary, prescribed ADHD medication, and who were judged in need of transition to adult services due to ongoing need for medication. The study estimated the incident rate of need for transition to be 202–511 per 100 000 people aged 17–19 per year. Incidence of successful transition was much lower as discussed below.

# Likelihood of referral

A number of included studies noted the high proportion of young people with ADHD who disengaged from child services before reaching the transition age boundary or before reaching the point of onward referral. For example, Ogundele (Ogundele, 2013) reported that more than half (65%) of young people from the paediatric ADHD service voluntarily stopped medication or stopped attending before reaching transition age. This may have potentially life changing consequences; Scandinavian registry studies suggest substantially reduced levels of suicidal behaviour (Chen et al., 2014), depression (Chang, D'Onofrio, Quinn, Lichtenstein, & Larsson, 2016), substance misuse (Chang et al., 2014), road traffic accidents (Chang et al., 2017), convictions and violent reoffending (Lichtenstein et al., 2012) among young adults who continued ADHD medication compared to those who stopped taking it.

The proportion of young people with ADHD referred to adult mental health services varied from 2% to 95% (Blasco-Fontecilla et al., 2012; Eke et al., 2019; Moosa & Sandhu, 2015; Ogundele, 2013; Reale et al., 2018; Tatlow-Golden et al., 2018). The highest figure comes from a study of a quality improvement process in a UK community CAMH service, where nearly all of those in need of transition were referred following the introduction of transition clinics (Moosa & Sandhu, 2015). In the Irish TRACK sample of 20 cases (McNicholas et al., 2015), there was not a single referral to 'public' AMHS, and only two to 'private' AMHS (10%). Notably a third refused referral, and in Reale's study in Lombardy, only one referral to adult services was made from 52 patients (Reale et al., 2018).

The UK TRACK study reported that 20% of those with neurodevelopmental disorders (including ADHD and ASD) were referred, but the breakdown by condition was not given (S. P. Singh et al., 2010). Similarly, in a Wales transition clinic sample of young people with neurodevelopmental conditions, 16% were referred to adult mental health services, but again there was no breakdown by

diagnosis (28). The most recent study of referral patterns came from the 2015/16 CatCh-uS surveillance study, where 77% were referred to a general or specialist AMHS (Eke et al., 2019). This variation in the proportion referred may relate to different health systems, changes over time, and to inclusion criteria. Predictors of referral and acceptance into adult services identified included female gender, comorbidity, and pharmacological or combined treatment of ADHD (Merrick et al., 2020).

# Continuity of care

Only a minority of young people with ADHD or ASD who would be eligible for, or were defined as requiring, transition to adult services, experienced continuity of care by completing transition to an adult service. The proportion of participants transitioning to AMHS was again highly variable between studies (from 0% to 55%).

Magon's UK study reported that 64% of cases known to CAMHS with established ADHD did not transfer to an adult service (Magon et al., 2015). In most cases, the reason for failed transition was unknown, but where case note review found reasons, these included receiving treatment from abroad, patient decision to discontinue medication, and patient difficulty tolerating medication. In CATCh-uS, although 64% of AMHS referrals were accepted, only 22% attended a first appointment (Eke et al., 2019). Similarly, Ogundele's study in one English region found that 73 per cent of those with ADHD eligible for transfer to adult services were either discharged or lost to follow-up (Ogundele, 2013). Of those transferred to AMHS, 19% were discharged within two years. In general, the rates reported of continuity of care are lower than the rate of continuity of impairing difficulties from epidemiological data in clinical samples, which also suggest a higher rate of continuity of impairing difficulties among a clinical sample (Faraone, Biederman, & Mick, 2006).

In studies outside the UK, continuation of ADHD medication in primary care seemed a more common outcome. A study tracking patients seen in Italian Regional ADHD Paediatric Centres (RAPC) reported that of those turning 18, just over 60% were discharged to be monitored in primary care,

15% continued with the RAPC, and 6% were transferred to an adult mental health service (Reale et al., 2018). In Tatlow-Golden's Irish cohort there were no young people directly transferred to public AMHS. Instead, nearly half remained in CAMHS for an average of over a year and the remainder were discharged to the GP for further medication management or disengaged from services.

(Tatlow-Golden et al., 2018)

We found a single UK study following up young people seen in CAMHS for ASD and an additional mental health problem (Merrick et al., 2020). Of 118 young people, 25 transferred to adult mental health services (28%), 48 to primary care and 20 remained with CAMHS. Laxman's USA study of service use patterns reported that all individuals with ASD experienced reduced levels of service use at transition age, but those without intellectual disabilities experienced a far steeper decline in service use prior to high school exit, which suggested discharge or disengagement prior to the age of transition (Laxman et al., 2019). Tunesi studied health service utilisation in a cohort (n=331) of transition aged young people with ASD drawn from the Italian Administrative Healthcare Database (Tunesi et al., 2019). Over the transition period, there was a drop in the use of services categorised as psychological or rehabilitative and in the percentage of patients having a 'neuropsychiatric consultation'. However, the use of community mental health services (both child and adult) increased, defined as psychiatry visits, residential facilities, pharmacological interventions and family support in psychiatric setting.

# Experiences of transition/Barriers and facilitators of successful transition

Two qualitative studies focussed on experiences of transition and continuity of care in ADHD and ASD (A. Price et al., 2019; Reale et al., 2015). Reale and colleagues used a questionnaire based approach with thematic analysis of data, and Price et al. undertook qualitative interviews analysed using Braun and Clarke's thematic analysis approach within a Framework method (Braun & Clarke, 2006; Gale, Heath, Cameron, Rashid, & Redwood, 2013). Commonly reported barriers to continuity of care included clinicians' perceptions and limited understanding of ADHD and ASD as a condition

that affects adults, lack of expertise with these conditions in AMHS, referrals rejected, long waiting lists, lack of information and support for young people and parents, and disengagement of young people either at, or prior to the service age boundary, as well as with disengagement once referred to AMHS. A number of studies included audit against NICE guidelines on transition, in general finding that many of these 'transition elements' such as joint meetings, were not widely implemented (Eke et al., 2019; Patwardhan et al., 2019; Reale et al., 2018).

The CATCh-uS project highlighted interlinked factors influencing transition success in ADHD, including how prepared a patient and parent were for transition, the quality of patient information handover, accessibility of adult services and the fit of patient needs with the remit of adult services available. Given the nature of ADHD, the role of the parent in seeking, navigating and translating information appeared to be particularly crucial in navigating the transition from child to adult services; and young people without an actively involved parent were seen as more likely to disengage (A. Price et al., 2019).

Moosa and Sandhu describe a quality improvement process to overcome barriers to successful transition for young people with ADHD (Moosa & Sandhu, 2015). This involved the development of a single database accessible by both CAMHS and AMHS, setting up a CAMHS transition team, and instituting joint transition clinics. They reported a reduction in the numbers of young people staying in CAMHS beyond transition age boundary, an increase in referrals to AMHS from 67% to 95%, and a reduction in the waiting time for transfer of care from 12 to four months. Rates of successful handovers increased, although the proportion of those disengaging or self-discharging remained the same at 20%. The authors also noted that the non-attendance rate at the transition clinic, already high, increased from 26% to 34%, again highlighting barriers touched on above; including the letters being sent to the young people, hence parents could not support and remind, and the limited times available at the transition clinic which were not convenient to the young people.

# DISCUSSION

#### Depth and strength of the evidence-base

Our systematic searches revealed a small but growing literature on transition to AMHS, although many studies were rated as weak methodologically; we detected one randomised control trial of an intervention to support transition (Singh SP, 2021). Design alone does not ensure the quality of a study, so this does not mean that we should disregard the findings of retrieved studies. Young people with poorer mental health are more likely to drop out of research than many other groups, and conducting a trial that alters process in hard pressed mental health services has many barriers to implementation with fidelity (Wolke et al., 2009). Randomised controlled trials are also expensive to conduct well, and participation by atypical services may undermine the generalisability of findings to routine services (Yeh et al., 2018). Electronic health records provide the opportunity of more complete follow up, particularly if conducted on regional or national scales (Huguet et al., 2020; Wood et al., 2021). Although there will always be constraints in terms of the quality and completeness of the data, while the delivery and recording of health care is heterogeneous even within one health care organization (Chan, Fowles, & Weiner, 2010). Similarly, service evaluations and service improvement methods may allow innovations to be developed and tested at lower cost (Morris et al., 2021).

#### Continuity of care and experience of transition

The evidence suggests that many young people in need of additional support in adulthood do not make the transition from child to adult services, which is seems to be a 'leaky pipeline', with some young people disengaging prior to transition, others refusing or reluctant to be referred onwards. In other cases, referrals are not made, or not accepted by AMHS. Finally, a significant proportion of those accepted do not 'land' safely in AMHS in terms of engagement and attendance, possibly influenced by lack of preparation for AMHS, long waiting lists and cultural differences between services. There is some reassurance from several studies that those with most severe problems as indicated by the type of mental health condition (Perera et al., 2017), length of CAMHS contact (Islam et al., 2016; McNicholas et al., 2015), and a history of inpatient admission (Bond et al., 2019), detention under the mental health act (Livanou et al., 2020), and medication (Leavey et al., 2018; Leavey et al., 2019), are most likely to transition. Equally, there is clearly a significant amount of unmet need (McGorry et al., 2013; Signorini et al., 2018).

The provision of services for young adults in any given context is influenced by the previous history of provision plus clinical interests and funding processes (Crowley et al., 2013), as well as by the presence or absence of strong primary care, highly specialist centres of excellence, and how specialist and primary care are coordinated. Huge variation exists in provision between and within countries, and in particular in whether services are restricted to "core" mental health or broader needs (Cetrano et al., 2020). The outcomes of young people in the transitional age-range are also influenced by the extent to which health care is integrated with social and special educational services that many children with long term conditions need (Crowley et al., 2013). Knowledge and cultural gaps combine with fragmentation of organisation, resources, skills and knowledge-base to undermine the collaborative working essential to optimise transition (Coghill, 2017; Cortese & Barbui, 2017; Janssens et al., 2020). For example, training pathways for practitioners for CAMHS and AMHS diverge early while paediatrics, CAMHS and AMHS are rarely financed and administered within the same organisation (Russet et al., 2019; Signorini et al., 2018).

In terms of young people's perspectives and needs, the stigma related to AMHS may deter some young adults from transition (Young et al., 2016). Social concerns about peers' evaluations may be particularly acute for adolescents, and prompt disengagement (Buitelaar, 2017). This may be particularly salient for those with neurodevelopmental disorders who were initially treated within paediatrics. Indeed, a lower proportion of young people transferred successfully from paediatric services than from CAMHS in the CATCh-uS surveillance study (Eke et al., 2019).

Difficulties and frustration arising from navigation of the gap between CAMHS and AMHS deter young people and families, and hamper successful transition. Different severity thresholds for referral acceptance in CAMHS and AMHS, inadequate provision, fragmentation of services (Appleton et al., 2021), long waiting lists, little or no communication from providers (Butterworth et al., 2017), and the need repeat young person's story multiple times and to establish new relationships (Lindgren, Söderberg, & Skär, 2014; Lockertsen et al., 2020a, 2020b; Street, Walker, & Tuffrey, 2018) left young people stressed and frustrated, and feeling as if they had to "prove" that they needed mental health care (Lindgren et al., 2014; Lockertsen et al., 2020a, 2020b; Street et al., 2018).

Fragmentation of services is particularly evident in the UK where some young people's difficulties are considered too severe for Increasing Access to Psychological Therapy but not severe or complex enough for Community Mental Health Teams. Some of these young people are signposted to Accident and Emergency or the criminal justice system, or directed back to primary care where they often feel unsupported (Appleton et al., 2021). Primary care clinicians are frequently unaware that their patient was leaving child services, and complain of the lack of an ongoing management plan (Newlove-Delgado, Blake, Ford, & Janssens, 2019).Young people with complex mental health difficulties facing all these barriers, as well as an expectation to take more responsibility for their care (Lockertsen et al., 2020b) often end up feeling overwhelmed, while their families felt excluded and unable to offer practical support (Janssens et al. 2020). This is likely to explain why many disengage from services around the time of transition (Appleton, 2021; Janssens et al., 2020). Those who need to re-enter later as adults and are again being faced with similar challenges including a lack of information about where to go and how to negotiate the process (Janssens et al., 2020).

Across high income countries, there have been attempts to address many of the barriers described, both in terms of improving the transitional mental health care for young people, as well as provision of services for adolescents with long term conditions in general (Crowley et al., 2013; McGorry et al., 2013). Some of these services have also attempted to address young people's concerns about AMHS through using alternative models and settings of provision. "Headspace" centres in Australia augment traditional primary care for young people aged 12-25 years with easily accessible mental and physical health care, drug and alcohol services and access to vocational or educational advice (McGorry et al., 2013). Headspace centres also link to AMHS who focus on supporting young people with emerging severe mental illness and personality disorder. The "Forward Thinking Birmingham" programme is one of several similar UK-based youth services that provide specialist mental health care for young adults up to the age of 25; it includes a dedicated team for transition and specific consideration of ADHD (McGorry et al., 2013). However, while moving the upper age boundary to 25 avoids a break in provision at the maximal incidence of depression, psychosis, eating disorders and personality disorder, it may merely postpone difficulties with transition for those with neurodevelopmental disorders, if the capacity of AMHS to work with these conditions remains very low.

# **Research gaps**

Despite an increasing number of publications examining transition in recent years, we lack robust evidence on which to base practice, and we have no data from Lower and Middle Income Countries, where the lack of CAMHS is likely to mean a smaller cohort of young people requiring transition to AMHS (Patel et al., 2018). There is a clear need to develop different models or interventions and to evaluate their effectiveness in supporting continuity of care for those who need it, and for economic evaluation. The latter must take a broad societal perspective, including the costs to young people and carers in order to demonstrate the true costs and benefits of improved transition. Research is accumulating for transition for neurodevelopmental disorders, early intervention in psychosis and youth services, but there remains a significant gap in our understanding of the needs of those with emotional, eating and emerging personality disorders in this transitional age group. We are hampered by our lack of knowledge of the natural trajectory of mental health conditions across the lifespan and predictors of persistence or relapse in planning interventions and services to tackle those most in need. Finally, we urgently need more data about the outcomes for those who do not transition.

#### Clinical and practice implications

The emerging literature on transition between child and adult mental health services suggests that despite increasing research interest over the last decade, that transition remains "poorly planned, poorly executed and poorly experienced" (S. P. Singh et al., 2010). We could add poorly researched to this list. If transition is not discussed with a young person, disengagement is likely to occur even before the upper age-boundary for the service is reached. This lack of preparation for transition often stems from little differentiation in the approach to young children or adolescents and poor awareness of adult provision (Buitelaar, 2017; Price, Janssens, Woodley, Allwood, & Ford, 2019). Indeed poor quality care whether in relation to transition or experienced within CAMHS and AMHS have cited by many young people and their carers who did not transition to AMHS (Appleton et al., 2021).

Ultimately, we need a variety of low-cost designs to select promising interventions that could then be evaluated. These interventions should aim to address the barriers identified in the literature to date and scaffold clinicians from CAMHS and AMHS in the provision of the elements of high quality transition. That is they should encourage re-evaluation of needs and thinking with the young person about managing their condition (or relapse as appropriate) as a long term condition, co-produce a care plan to travel with the young person if they are referred on and ideally include joint planning and joint working during the transition period (Morris et al., 2021).

In terms of models that current services could consider, observational data from the Republic of Ireland demonstrated extremely high rates of referral to AMHS via a transition clinic, while the employment of a transition practitioner to work between CAMHS and AMHS is another simple

model worth exploration (Bond et al., 2019) The MILESTONE study co-produced a systematic method to track and re-assess young people's needs at the transition boundary that provides a structure for planning with the young person and their carers, as well as information transfer between child and adult services (Santosh et al., 2020; Singh SP, 2021). Although complex in terms of having several components, it involves very little training and would be relatively cheap to deliver (Singh SP, 2021).

In the meantime, the scoping review by Cleverley and colleagues (2018) identified six essential components to transitional mental health service provision that we should consider incorporating into practice; specified transition policy or protocol, tracking and monitoring of young people approaching the transition age-boundary, transition readiness, transition planning, transfer of care and continuity of care (Cleverley et al., 2020). Qualitative studies suggest that clear information about the process with frank discussion of stigma and what to expect from AMHS might avoid disengagement, while those who decline referral or are discharged should be provided information about to how to return to services should they need to; such a contingency plan should also be shared with their General Practitioner. Given the joint responsibility highlighted in NICE Guidance (2016), CAMHS should monitor the outcome of those who graduate from their service, while AMHS should carefully monitor acceptance of referrals and attendance in order to improve the quality of provision for this vulnerable group at this sensitive period of development (NICE, 2016). Ultimately, we need a variety of low cost designs to select promising interventions that could then be evaluated via randomised controlled trials. These interventions should aim to address the barriers identified in the literature to date.

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