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# Transition to adult services for young people with mental health needs: A systematic review

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## Abstract

**Background:** Young people's transition from child and adolescent (CAMHS) to adult mental health services (AMHS).

**Objectives:** To systematically review evidence on the effectiveness of different models of CAMHS–AMHS transitional care, service user and staff perspectives, and facilitators of/barriers to effective CAMHS–AMHS transition.

**Data sources:** A systematic search in May 2012 of Medline, PsycINFO, CINAHL, EMBASE, AMED, Health Business Elite, HMIC, Cochrane Database, Web of Science and ASSIA; ancestral searches; and consultation with experts in the field.

**Study selection:** Qualitative, quantitative and mixed-methods primary research on the CAMHS–AMHS health-care transition of young people (aged 16–21 years) with mental health problems.

**Data extraction:** Two reviewers independently completed a standardised data extraction form and critically evaluated identified documents using a validated appraisal tool for empirical studies with varied methodologies.

**Results:** A total of 19 studies of variable quality were identified. None were randomised or case-controlled trials. Studies incorporating service user/carer perspectives highlighted the need to tackle stigma and provide accessible, age-appropriate services. Parents/carers wanted more involvement with AMHS. Transitional care provision was considered patchy and often not prioritised within mental health services. There was no clear evidence of superior effectiveness of any particular model.

**Conclusions:** High-quality evidence of transitional care models is lacking. Data broadly support the development of programmes that address the broader transitional care needs of 'emerging adults' and their mental health needs but further evaluation is necessary. Developing robust transitional mental health care will require the policy–practice gap to be addressed and development of accessible, acceptable, responsive, age-appropriate provision.

## Keywords

Transition, adolescent, young people, mental health, health services

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## Introduction

Transitional care refers to the co-ordination and continuity of care between different health-care locations or levels of care within the same location, regardless of the age of the patient (Coleman & Berenson, 2004). Used in this way, transition refers to the process that starts with preparing a patient to leave a health-care setting and finishes when the patient is 'received in the next setting' (Coleman & Berenson, 2004, p. 533). Transition planning and management is therefore a key element in the organisation and delivery of health services (American Academy of Child and Adolescent Psychiatry, 2007; National Mental Health Development Unit, 2011; Reiss & Gibson, 2002).

Unfortunately, for many young people with mental health problems, transition is poorly planned, lacks co-ordination and results in discontinuity of care (Singh, 2009). Most mental illnesses of adult life begin in late adolescence, affecting young people just when they require transition to adult services. The current child–adult split in mental health services creates systematic weakness when need is most pressing (McGorry, Purcell, Hickie, & Jorm, 2007; Singh, 2009). The split parallels similar discontinuities between paediatric and adult services for young people with chronic physical and complex care problems.

Transitions literature includes systematic reviews of paediatric to adult health care (Crowley, Wolfe, Lock, & McKee, 2011; Doug et al., 2011), but to our knowledge, there are no systematic reviews of mental health transitions research. Despite numerous reviews of the broader literature (Davis, 2003; Muñoz-Solomando, Townley, & Williams, 2010; National Mental Health Development Unit & YoungMinds, 2011; Pottick, Bilder, Vander Stoep, Warner, & Alvarez, 2008; Singh, 2009; Social Care Institute for Excellence, 2011; Vloet, Davidson, & Capelli, 2011), there is little primary research, especially on the effectiveness of different models of mental health transitional care.

The objective of this systematic review was to critically appraise primary research on young people's health-care transitions between Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS). Our research questions were as follows:

1. Are different models of transitional mental health care for young people effective in achieving transfer of care and improving the quality of transitional care? (Paul et al., 2013)
2. What do young people and their parents/carers (hereafter called parents) report about their experience of transition?
3. What do professionals working within mental health services report on the adequacy of provision of facilitators of and barriers to effective CAMHS–AMHS transition?

## Methods

### *Search strategy and data management*

Ten databases were systematically searched (Medline, PsychINFO, CINAHL, EMBASE, AMED, Health Business Elite, HMIC, Cochrane Database, Web of Science and ASSIA). Keywords, their truncations and relevant database-specific subject headings and MeSH terms were used, targeting three subject areas:

- *Transition*: including transition*, interface*, transfer, 'continuity of care', 'CAMHS to AMHS', 'child and adolescent mental health services to adult mental health services', becom* adult.

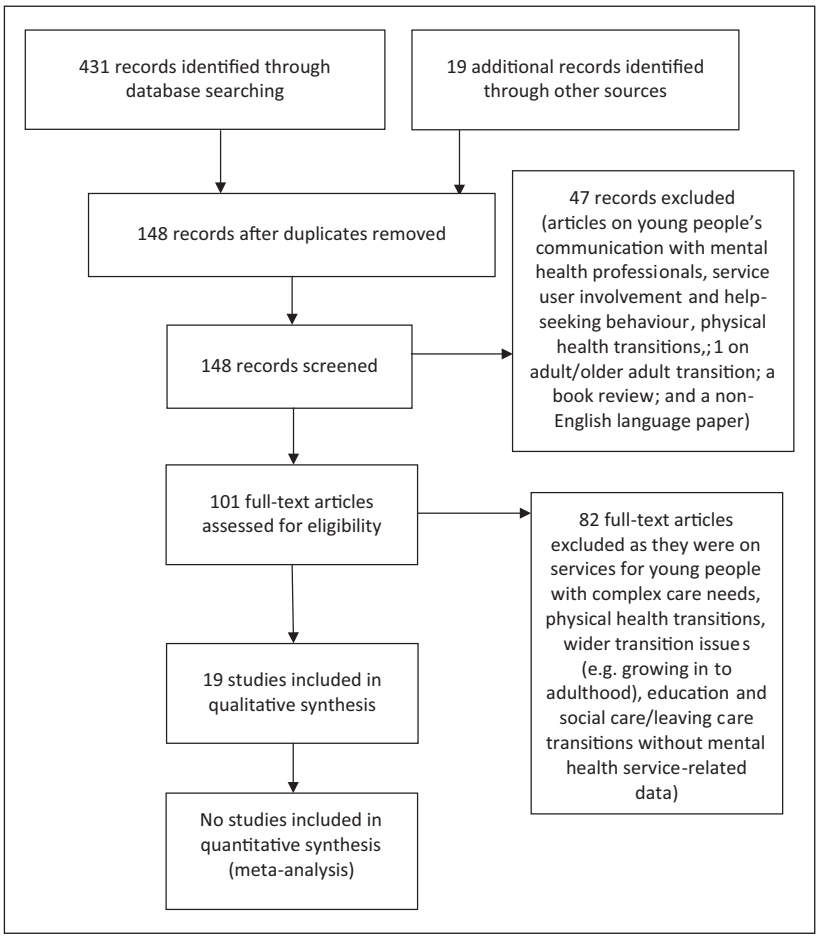


**Figure 1.** Flowchart for systematic review (Moher, Liberati, Tetzlaff, & Altman; The PRISMA Group, 2009). PRISMA: Preferred Reporting Items for Systematic reviews and Meta-Analyses.

- *Age*: including young, youth*, teen*, adolesce*, CAMHS, 'child and adolescent mental health service' or age-group criteria (e.g. 'adolescence' (13–17 years and 'young adulthood' (18–29 years) in Medline).
- *Mental health*: including CAMHS, child and adolescent mental health service*, psychiatr*, mental health, youth service.

The search was undertaken in May 2012. C.S. and N.W. checked titles and abstracts to assess whether articles fulfilled inclusion/exclusion criteria and remove duplicates. Any doubts about meeting inclusion criteria were resolved through retrieval of full articles and team discussion. Full versions of the yield were read by a researcher (either C.S. or N.W.) to check against inclusion and exclusion criteria, to identify systematic reviews, reviews and primary research. Uncertainty was resolved through review of each paper by two others from the reviewing group (C.S., N.W. and M.P.). Ancestral searches of the references of reviews and identified studies were undertaken (C.S., M.P.) and repeated recurrently. Experts in the field were consulted about additional reviews and primary research (see Figure 1).

**Table 1.** Summary of quality scores ($n$ = 19).

| | Good 4 | Fair 3 | Poor 2 | Very poor 1 |
|---|---|---|---|---|
| 1. Abstract and title | 8 | 6 | 5 | |
| 2. Introduction and aims | | 18 | 1 | |
| 3. Method and data | 10 | 6 | 3 | |
| 4. Sampling | 3 | 7 | 8 | 1 |
| 5. Data analysis | 8 | 6 | 5 | |
| 6. Ethics and bias | | 3 | 7 | 9 |
| 7. Findings/results | 12 | 7 | | |
| 8. Transferability/ generalisability | 2 | 8 | 9 | |
| 9. Implications and usefulness | 9 | 10 | | |
| Total | 22×3; 24×3; 25×2; 27×2; 28×3; 29×2; 30×1; 31×3. | | | |

## *Inclusion and exclusion criteria*

Searching was restricted to English language papers published since 2000 (an arbitrary but necessary time limit, given that older studies are not generalisable to current health systems). Studies on the transitions of young people with learning difficulties, physical disorders and those addressing psycho-social transitions to adulthood without addressing mental health service use were excluded.

## *Quality assessment*

The initial scoping exercise did not identify any randomised controlled trials (RCT) or case-controlled trials and indicated that relevant studies had used wide-ranging qualitative, quantitative and mixed methodologies. The appropriateness of a mixed studies review methodology therefore led to selection of a validated critical appraisal tool (Hawker, Payne, Kerr, Hardey, & Powell, 2002), previously used in another systematic review of transitions research (Doug et al., 2011). The scoring system covered nine components of critical appraisal, including those likely to create bias (Appendix 1). Each study was given a quality score of 1 (very poor), 2 (poor), 3 (fair) or 4 (good) on each component, generating a maximum potential score of 36 (Table 1). We amended the criteria for appraising 'introduction and aims': the 'fair' score criteria were changed to include 'aim OR objectives OR research questions' rather than requiring more than one.

## *Data extraction*

Two reviewers (M.P., C.S.) independently completed a standardised data extraction form (Appendix 2) for each included full text paper. If either reviewer had been a co-author, she was substituted by a third (N.W.). Discrepancies were resolved by consensus.

## *Data analysis*

Descriptive statistics were generated with regard to critical appraisal criteria. Given the heterogeneity of studies and limited use of measures of effectiveness/outcomes, meta-analysis was not feasible. Characteristics and main findings of identified documents were summarised, tabulated (Table 2) and synthesised into a narrative.

## Results

Figure 1 describes the paper selection process using the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) flow diagram (Moher, Liberati, Tetzlaff, & Altman; The PRISMA Group, 2009). The initial searches yielded the following numbers of articles: Medline 282, PsychINFO 45, CINAHL 0 (some on physical health but none on mental health), EMBASE 31, AMED 119, Health Business Elite 2, HMIC 10, Cochrane Database 0, Web of Science 25 and ASSIA 17. Removal of duplicates produced 129 unique results. Screening of titles and abstracts lead to removal of articles on young people's communication with mental health professionals, service user involvement and help-seeking behaviour, leaving 90 references. Reading of the full articles identified 15 reviews (no systematic reviews) and 8 primary research papers. Papers discarded were on services for young people with complex care needs, physical health transitions, wider transition issues (e.g. growing into adulthood), education and social care/leaving care transitions papers without mental health service-related data.

Ancestral searches of the research papers and reviews indicated another 10 possible papers, of which 8 were discarded (1 education, 1 wider transition, 3 physical health, 1 older adults, 1 book review and 1 not in English).

Consultation with experts in the field and on-going ancestral searches produced a final total of 19 papers, reports or policy documents integrating primary data: 12 from the United States of America; 7 from the United Kingdom. No RCTs were identified. Five studies used mixed methods, seven used quantitative methods and seven used qualitative methods (two to gather quantitative data) (see Table 2 for details of study designs).

### *Quality of included studies*

Quality scores ranged between 22 and 31 (maximum score = 36; median = 27.5; no clear mode; mean = 26.7). 'Good' scores were most frequently for 'findings and results' (12/19). The worst aspect of the critical appraisal was 'ethics and bias' with 7/19 scoring 'poor' and 9/19 'very poor', that is, no mention of ethics. 'Sampling' was the next poorest category, with no sample size calculations in any paper and frequently unclear sampling strategies (see Table 1 for score frequencies and Table 2 for the overall quality scores of each study), which had implications for the transferability/generalisability score. Aims and objectives were often inferred rather than specified and research questions were rarely stated. Certain limitations in the scoring criteria also affected the scores – for example, it was not possible to give high scores for the very brief abstracts required by some journals and some of the reports did not include an abstract.

### *The effectiveness of different models of transitional care*

Three US intervention studies were identified. Styron et al. (2006) evaluated a Young Adult Service (YAS): a comprehensive service including clinical, residential, case-management and planned step-up/step-down care into more/less intensive services, across a variety of life domains. YAS aimed to help young people develop viable and durable social support systems, achieve educational/vocational success and learn pro-social, adaptive behaviours and independent living skills. A randomly selected sample ($n = 60$) of high-risk young adults (18 years plus) had moderate/severe mental illness. Treatment planning variables were significantly correlated with positive outcomes: the strengths-focussed treatment planning (SFTP) and community-focussed treatment planning (CFTP). They lead to fewer symptoms, less loneliness, fewer mental health problems, higher functioning and greater satisfaction with services. SFTP contributed significantly to greater quality of

**Table 2.** Characteristics of empirical papers with quality scores.

| Study | Aim | Methods | Participants | Intervention | Quality score/36 |
|---|---|---|---|---|---|
| United States | | | | | |
| Davis and Butler (2002) | To ascertain parents' views of the quality of general transition support their child had received from various service systems, barriers to services, system components they thought were important and policy considerations | Quantitative: Survey | 115 members of the Federation for Families for Children's Mental Health (parents of youth aged 16–25 years with severe emotional or behavioural difficulties (SED)). 66% of youth had received out-patient therapy, 58% pharmacotherapy and 31% adult mental health services | n/a | 29 |
| Davis and Sondheimer (2005) | To describe transition services provided/efforts made by State mental health systems to serve youth with severe emotional and behavioural disorders; populations served by/eligibility criteria for CAMHS and AMHS; efforts to link CAMHS and AMHS to provide transitional support; interagency efforts to address transition need that included child mental health systems | Semi-structured interview schedules used in interviews, transcribed data then coded into categories and summarised in an aggregate form using descriptive statistics. Essentially a qualitative method used to establish quantitative survey data | One member of the Children, Youth and Families Division of the National Association of State Mental Health Programme Director per state ($n$ = 50) and the District of Columbia | n/a | 22 |
| Davis and Hunt (2005) | To describe the efforts that State adult mental health systems were making to address the needs of young adults | Mixed methods: Semi-structured interviews collecting quantitative and qualitative data | 50 adult services members from the National Association of State Mental Health Program Directors | n/a | 24 |
| Davis et al. (2005) | To focus attention on specific, structural, systemic impediments that are likely to exist at many sites and to stimulate discussion of how to eliminate or minimise their impact on appropriate transition support systems | Qualitative: Key informant interviews, Social Network Analysis | 103 key informants, one each from organisations providing services in the Clark County Transition Network including case-management approaches, counselling and wrap-around services, to support young adults aged 14–25 years with serious mental health conditions. Clark County was one of five sites given a *Partnerships for Youth Transition* grant | n/a | 29 |

**Table 2.** (Continued)

| Study | Aim | Methods | Participants | Intervention | Quality score/36 |
|---|---|---|---|---|---|
| Davis, Geller, and Hunt (2006) | To describe the existence and nature of services within state child and adult mental health systems that support the transition from adolescence to adulthood | Semi-structured interviews, used to produce descriptive statistics. Essentially a qualitative method used to establish quantitative survey data | State child and adult mental health administrators from 41 states (with the exception of one state (Michigan) where no Adult Services member was interviewed) | n/a | 28 |
| Styron et al. (2006) | To evaluate a YAS across a variety of life domains | Mixed-methods intervention study: Structured face-to-face interviews, including administration of standardised measures of mental health symptoms, functioning and quality of life. Face-to-face qualitative interviews with sub-sample of participants. Survey of clinicians and case file review of treatment plans. Quantitative analysis: bivariate correlation matrix, logistic regression; qualitative thematic analysis using the constant comparative method | Young adults (18 years plus) with moderate/severe mental illness 'aging out' of children and families services; 95% with history of early, severe neglect, physical and/or sexual abuse; three main groups (juvenile sex offenders, young adults with pervasive developmental disorders and high-risk behaviours, young adults with behavioural needs) receiving services from the YAS. $N = 60$ random sample for quantitative study and $n = 12$ for qualitative study. No control group | YAS is a comprehensive service including clinical, residential, case-management and planned step-up/step-down care into more/less intensive services, across a variety of life domains. YAS aimed to help young people develop viable and durable social support systems, achieve educational/vocational success and learn pro-social, adaptive behaviours and independent living skills | 27 |
| Haber, Karpur, Deschenes, and Clark (2008) | To describe rates of improvement, of young people attending PYT services, on indicators of transition progress (in education and employment) and transitional challenges (e.g. criminal justice involvement, interference with daily activities because of mental health and substance misuse problems) | Quantitative intervention study: Application of the Transitions to Adulthood Assessment Protocol (demographic and historical assessment information and indicators of transition-related progress and challenges Analysis of data from first four quarters (out of eight) of the programme (as *n* decreased); imputation of missing data, attrition analyses and outcome trajectories | 193/562 young people aged 14–21 years enrolled in a multi-site demonstration of five transition support programmes No control group | PYT was an initiative to develop programmes offering comprehensive transition supports (including mental health care) for adolescents with serious mental health conditions | 22 |

*(Continued)*

**Table 2.** (Continued)

| Study | Aim | Methods | Participants | Intervention | Quality score/36 |
|---|---|---|---|---|---|
| Manteuffel, Stephens, Sondheimer, and Fisher (2008) | To examine the characteristics, service use and clinical and functional outcomes of TAY receiving services for SED and SMI, in systems of care, using data from a national evaluation of the Children's Mental Health Initiative | Quantitative studies: a cross-sectional descriptive study and a longitudinal child and family outcome study. Measures included standardised instruments such as the Descriptive Information Questionnaire; the Multi-Sector Service Contacts Form; the Child Behaviour Checklist, Restrictiveness of Living Environments Scale Revised, Behavioural and Emotional Rating Scale and the Child and Adolescent Functional Assessment Scale. An education questionnaire, delinquency survey<br>Analysis included descriptive statistics and, for the sub-sample enrolled in the outcomes study, the Reliable Change Index' was used to compare outcome data. | TAY, aged 14–15, 16–17 and 18+ years, enrolled in 45 Federally-funded systems of care, in 36 US States between 1997 and 2006.<br>*N* = 8484 in the descriptive study and 3613 in the outcome study | n/a | 25 |
| Jivanjee, Kruzich, and Gordon (2009) | To explore family perspectives on the transition to adulthood with a focus on young people's experiences of community integration | Qualitative study using participatory research (researchers who had been service users and carers) Focus groups. Thematic analysis | Family members supporting their children with mental health difficulties in the transition years. A total of 42 family members (in eight groups) of young people, aged 16–24 years, using mental health services. Opportunistic sampling | n/a | 31 |

**Table 2.** (Continued)

| Study | Aim | Methods | Participants | Intervention | Quality score/36 |
|---|---|---|---|---|---|
| Jivanjee and Kruzich (2011) | To explore TAY and their parents' experiences and perceptions of receiving formal mental health services and family/peer support | Qualitative study undertaking 20 focus groups (12 with TAY and 8 with parents) with a sub-sample of pairs of TAY and their parents. Constant comparative analysis | Young people aged 17–23 years (mean 19.4), with mental health difficulties, and their parents recruited through mental health agencies, youth advocacy/support groups, colleges, alternative schools and youth employment organisations. Opportunistic sampling. Participants mainly support group-related participants and mother–son dyads | n/a | 25 |
| Gilmer et al. (2012) | To examine changes in service use associated with provision of age-specific services to youth in their transitional years | Quantitative, intervention study: Quasi-experimental, difference-in-difference design with propensity score weighting within logistic regression modelling. Demographic and clinical characteristics compared using chi-square tests | Intervention group: 931 18–24-year-old youth, enrolled in an out-patient programme specifically for TAY in San Diego County, USA<br>Control group: 1574 youth enrolled in parallel standard, adult, out-patient programmes | Out-patient programme, within AMHS, tailored for transition-age young people | 28 |
| United Kingdom | | | | | |
| Richards and Vostanis (2004) | To establish themes of mental health needs of young people aged 16–19 years, as perceived by professionals from all agencies involved in their care | Qualitative: Semi-structured interviews, thematic content analysis based on Grounded Theory | A total of 39 managers and practitioners from mental health, social care, education and voluntary agencies.<br>Opportunistic sampling from local services | n/a | 31 |
| Marcer, Finlay, and Baverstock (2008) | To find out about the experiences of community paediatricians when transferring patients with ADHD to adult care | Quantitative: Questionnaire survey (not stated if postal or otherwise) | 78/100 community paediatricians in the United Kingdom | n/a | 24 |
| Singh, Paul, Ford, Kramer, and Weaver (2008) | To identify existing transition protocols in Greater London, to conduct a content analysis of protocols and identify annual transition rates | Mixed methods: Questionnaire survey and content analysis of protocols | 42 CAMHS in Greater London | n/a | 30 |

*(Continued)*

**Table 2.** (Continued)

| Study | Aim | Methods | Participants | Intervention | Quality score/36 |
|---|---|---|---|---|---|
| Taylor, Fauset, and Harpin (2010) | To identify on-going service needs of young people with ADHD | Quantitative: Case note review. Descriptive statistics | Cross-sectional sample of 139 14–16 year olds with ADHD attending a paediatric neurodisability clinic | n/a | 24 |
| Singh et al. (2010) | To evaluate the process, outcomes and user and carer experiences of transition from CAMHS to AMHS | Mixed methods: 1. retrospective case note survey 2. qualitative interviews with service users, carers and clinicians Analysis for 1 involved descriptive statistics, chi-square tests, unpaired T-tests and logistic regression analyses. Analysis for 2 involved the constant comparative method within the Framework Approach, integrating a thematic analysis | 1. Case notes of 154 young people in six English Trusts who crossed the transition boundary between CAMHS and AMHS in a calendar year 2. 11 CAMHS service users, 6 parents, 6 CAMHS and 3 AMHS clinicians | n/a | 28 |
| Thomas, Pilgrim, Street, and Larsen (2012) | To review progress towards creating a better and more person-centred youth mental health system and to make recommendations to improve the experiences of vulnerable young people in transition | Online survey; case studies of CAMHS and EIP/AMHS collaborative working. Descriptive statistics used to present findings. Qualitative comments clustered by key themes. | 122 specialist CAMHS and EIP/AMHS in England opportunistic sampling | n/a | 22 |
| Hovish, Weaver, Islam, Paul, and Singh (2012) | To understand the experiences of service users, their parents and CAMHS/AMHS clinicians of transition between CAMHS and AMHS | Qualitative: Semi-structured interviews, compilation of multi-perspective case dossiers, thematic analysis | 11 CAMHS service users, 6 parents, 6 CAMHS and 3 AMHS clinicians | n/a | 31 |
| Paul et al. (2013) | To separate and evaluate concepts of transfer and transition between CAMHS and AMHS | Quantitative: Retrospective case note surveys | Case notes of 154 young people reaching the upper age boundary of six English CAMHS in a calendar year | n/a | 27 |

CAMHS: Child and Adolescent Mental Health Services; AMHS: Adult Mental Health Services; YAS: young adult service; PYT: Partnerships for Youth Transition; SED: serious emotional disturbance; SMI: severe mental illness; TAY: transition-aged youth; ADHD: attention deficit hyperactivity disorder; EIP: Early Intervention in Psychosis.

life and CFTP to fewer arrests. Clients using YAS longer were more likely to have used SFTP or SFTP+CFTP.

Haber, Karpur, Deschenes, and Clark (2008) studied 193/562 young people aged 14–21 years, enrolled in five Partnerships for Youth Transition (PYT) services. PYT was an initiative to develop programmes offering comprehensive transition supports for adolescents with serious mental health conditions. Limitations arose from missing data and variations in sample characteristics for each site. Programme tenure was significantly associated with increased educational advancement, employment and productivity and decreased criminal justice involvement, mental health symptom interference and substance abuse interference. Those aged 19 years and over did better than those aged 18 years and under. Those with mood/learning disorders had better outcomes than those with disruptive behaviour disorders.

Gilmer et al. (2012) evaluated an out-patient programme, within AMHS, tailored for transition-age young people (18–24 year olds) ($n$ = 931) and compared it with standard out-patient AMHS (1574). Mean out-patient visits were 12.2% (significantly) greater within the tailored service. Clients in youth-specific services were less often female and more often African American/Asian and with Medicaid coverage. Neither diagnosis, co-morbid drug use, in-patient admissions, use of emergency services nor jail service days differed between groups.

### *Service user perspectives on the experience of transition*

The experience of transition is difficult for many young people and their families. In Davis and Butler's (2002) survey of 115 members of the Federation for Families for Children's Mental Health (parents of youth aged 16–25 years with severe emotional or behavioural difficulties), few parents reported service systems to be helpful during transition. Stigma of accessing mental health care prevented many young people from engaging with services. AMHS, generally serving an older, chronically unwell clientele, typically did not address accommodation/employment needs, provide information on available services or sufficiently include parents. Parents also highlighted the importance of peer advocacy support.

Jivanjee, Kruzich, and Gordon (2009) explored the experiences of 42 families of young people aged 16–24 years, using mental health services. Parents wanted their children to be better integrated into their local community, able to achieve goals, gain a sense of accomplishment and healthy peer relationships. Parents worried about young people's lack of preparedness for adult life, lack of community resources to meet their mental health, vocational and social needs and for dealing with stigmatising attitudes, social anxiety and isolation. Identified supports were specific mentoring relationships and flexible, individualised wrap-around services. A general view was that transition planning started too late in the care journey to adult services.

In Jivanjee and Kruzich's (2011) study of 16 young people and 18 parents, both young people and parents appreciated helpful, responsive, wrap-around services. Parents emphasised practical supports, the provision of respite support and providers' willingness to communicate with them. They highlighted difficulties caused by restrictive eligibility criteria and the loss of services when a young person turned 18 years, sometimes as a result of insurance cover being stopped. Young people highlighted difficulties finding age-appropriate and accessible services; some ended up in juvenile justice systems.

### *Staff perspectives*

Studies of managers' and clinicians' views of service provision for transition-aged youth (TAY) with mental health problems illustrate the complexity of providing transitional care and pressures

besetting this service sector. Richards and Vostanis' (2004) study of mental health, social care, education and voluntary agency professionals indicated that older adolescents have multi-faceted needs; statutory mental health services were not geared towards the 16–19 years age group; communication between services was variable; and there were no formal transfer arrangements between child and adult services. Davis and colleagues (Davis, Geller, & Hunt, 2006; Davis & Hunt, 2005; Davis & Sondheimer, 2005) found that, overall, a quarter of child State mental health systems and half their adult equivalents offered no transition services addressing the needs of 'emerging adults' (Arnett & Tanner, 2006) (i.e. young people facing multiple life changes as they move from adolescence into adulthood, often including multiple transitions across education, social and health agencies) with mental health problems. Few states provided more than one kind of transition service (e.g. age-specialised case management, transition protocols, peer support, comprehensive system-building, supervised or supported housing, wrap-around approaches, vocational support, independent living preparation and assertive community treatment or dual diagnosis services), at any site (<8% of adult systems and <22% of child systems). The type of service offered by the largest number of States was supported/supervised housing; however, this was only available state-wide in one state. Wrap-around approaches were also common. Continuity of services was hampered by generally separate child and adult mental health systems with differing referral criteria, lack of clarity about procedures to access AMHS and lack of shared client planning between child and adult systems. Although limited fiscal resources often impeded the development of services for young adults, the main barriers were system fragmentation, lack of leadership and prioritisation of this age group.

## *Facilitators and barriers to effective transition*

The multi-stage, multi-method UK TRACK study focused on the development and implementation of transition policies, protocols and reciprocal working arrangements between CAMHS and AMHS. Transition policies across services vary (Singh, Paul, Ford, Kramer, & Weaver, 2008), for example, age boundaries vary from 16 to 21 years (18 years was the mode); sometimes this depended upon whether the young person was in education or not; some young people remained with CAMHS beyond the transition boundary. Although stated aims of transitional care were very similar across protocols, often using the language of government policy documents, procedures differed, for example, whether a period of joint care between CAMHS and AMHS was required, whether protocols were shared at locality or health-care provider organisation level. The centrality of service users to the process was frequently stressed but no protocols specified how the service user should be prepared for transition. A major omission was lack of follow through if service users were not accepted by AMHS.

The TRACK case note review (Singh et al., 2010) explored how policies were put into practice, what proportions of young people made the transfer from CAMHS to AMHS and the quality of transitional care. Of the 154 young people who crossed the transition boundary in six CAMHS over a year, 58% were accepted by AMHS. The main reasons for a lack of transfer were service user refusal to accept referral to adult services, CAMHS professionals not making a referral and no on-going need. Having a severe mental illness, being on medication and having had an admission to a mental health hospital was associated with greater likelihood of making a transfer to AMHS. Young people with neurodevelopmental disorders, emotional/neurotic disorders and emerging personality disorder were least likely to be transferred to AMHS. Optimal transition (good information transfer, a period of joint working, at least one joint transition meeting and continuity of care) was experienced by less than 5% of young people. Following transfer to AMHS, most young people stayed engaged and reported an improvement in their mental health.

Generally, however, young people's transitions between CAMHS and AMHS were 'poorly planned, poorly executed and poorly experienced'. A re-analysis of the data indicated that transfer and transition were overlapping but separate concepts: transfer was common but good transitional care was rare (Paul et al., 2013).

TRACK qualitative output (Hovish, Weaver, Islam, Paul, & Singh, 2012; Singh et al., 2010) indicated that informal and gradual preparation, transition planning meetings, periods of parallel care and consistency of key worker promoted positive experiences of transition. Transfers between AMHS, changes of key worker and waiting lists (of up to 6 months) were viewed negatively. Like a number of the other studies reviewed, young people highlighted the importance of other, often multiple, life transitions including changes in housing, pregnancy and physical illness.

### *Addressing the inadequacy of provision for young people in transition*

A number of the above studies and three others, related to the US (Professional Yoga Therapy) PYT program (Davis et al., 2006; Davis et al., 2005; Manteuffel, Stephens, Sondheimer, & Fisher, 2008), highlight the need to expand capacity to provide transition services. Davis et al. (2005) found that no PYT-related sites offered all their services continuously to 14–25 year olds, prior to implementation of the programme. Davis et al.'s (2006) interviews with State mental health administrators found that 50% of the adult service administrators reported no transition services anywhere in their state. Manteuffel et al.'s (2008) study of the characteristics, service use and clinical and functional outcomes of TAY receiving services for serious emotional disturbance and severe mental illness found that less than 10% of 16–17 year olds received transition support.

Three disorder-specific UK studies indicate important gaps in service provision for young adults with attention deficit hyperactivity disorder (ADHD) (Marcer, Finlay, & Baverstock, 2008; Taylor, Fauset, & Harpin, 2010) and psychosis (Thomas, Pilgrim, Street, & Larsen, 2012). Marcer et al.'s (2008) questionnaire survey of paediatricians ($n = 78$) found that only a fifth were aware of dedicated local adult ADHD clinics, although 90% perceived a need for them. In contrast, Taylor et al.'s (2010) case note survey of 14- to 16-year-olds ($n = 139$) attending a paediatric neurodisability clinic found that 50% of their sample had well-controlled ADHD: only 37% were thought to need transition to AMHS. Clinical nurse specialists were promoted as a support to general practitioners (family physicians) or AMHS professionals in managing young adults with ADHD.

Rethink, a voluntary sector organisation in UK, focussed on problems at the interface between CAMHS and Early Intervention in Psychosis (EIP) services (Thomas et al., 2012). Their online survey of 122 specialist CAMHS and EIP/AMHS in England reviewed progress towards creating a better and more person-centred youth mental health system for youth with psychosis. Over half the respondents indicated existing transition protocols between their local CAMHS and EIP. Problems at the interface included identifying young people with psychosis; role confusion between teams; limited capacity to do outreach work; training gaps; young people not engaging with services because of stigma; general practitioners not referring young people; different treatment philosophies between CAMHS and EIP/AMHS; funding restraints; and boundary issues.

## Discussion

This systematic review, which we believe to be the first in the mental health service transitions literature, clearly shows a lack of adequately powered studies, RCTs or case-controlled studies that evaluate the effectiveness of different models of transitional mental health care for young people. Specific models of transitional care that have been studied include the protocol and reciprocal agreement approach, prevalent in the United Kingdom, which tends to fall foul of a policy–practice

disconnection (Singh et al., 2008; Singh et al., 2010), and transition programme models, more prevalent in the United States, which tend to be difficult to roll out state-wide and have not been attempted nation-wide (Gilmer et al., 2012; Haber et al., 2008; Styron et al., 2006). There have been no studies of a third type of model (Vloet et al., 2011), the shared management framework interventions, such as transition teams/co-ordinators, employed by CAMHS to direct transitional care, assist with training CAMHS and AMHS staff, evaluate and manage transition clinics staffed by CAMHS and AMHS, among other things.

The 19 studies identified varied in methodology and quality; however, their findings consistently indicate significant gaps in the provision of transitional care in the mental health arena. These include a general lack of services (Davis et al., 2006; Davis et al., 2005; Manteuffel et al., 2008), especially acceptable, age-appropriate and responsive adult services, which limits the uptake of AMHS care by young people (Davis and Butler, 2002; Thomas et al., 2012) beyond the upper age limits for CAMHS; gaps in provision of adult services for young people with specific disorders such as ADHD (Marcer et al., 2008; Singh et al., 2010; Taylor et al., 2010) and emotional/neurotic disorders (Singh et al., 2010), both resulting in reduced transfer rates between CAMHS and AMHS. While the need to specifically improve transitional care is long established (Davis et al., 2006; Davis & Hunt, 2005; Davis & Sondheimer, 2005; Richards & Vostanis, 2004), the quality of transitional care can remain very low (Singh et al., 2010).

## *Policy and practice implications*

Provision of transitional care is complex and often sparse and patchy, especially if it includes holistic, wrap-around approaches and assertive community treatment. Although lack of fiscal resources often impedes development of services for young adults, the main impediments are separation of child and adult mental health systems, a lack of leadership and a lack of prioritisation of this age group, often the result of disconnected commissioning structures whereby services for children and young people, which are often relatively small in size, 'lose out' against a larger and more numerous range of services for adults.

Managers and clinicians highlight poor communication between CAMHS and AMHS and a lack of understanding of each other's services, role confusion between teams and training gaps, problems in identifying and referring young people needing care, young people not engaging with services because of stigma, and different treatment philosophies and working practices between CAMHS and AMHS, issues also highlighted in a study exploring the influence of organisational cultures on transition from child to adult mental health services (McLaren et al., 2013). Young people, and their parents and carers, also note the deterrent effect of mental health stigma, as well as reporting a general paucity of information about services. A need to provide adult mental health services that young people would choose to use, that are responsive, accessible and holistic in their approach, is emphasised in much of the data collected about their perspectives on transitional care.

All of these issues pose policy and practice implications including how mental health services are organised, how to integrate different areas of provision and how services are commissioned and funded. There are also training and workforce development implications, not least how to foster a better understanding between professionals working in services for children and young people and services for adults, of each other's roles and the treatment approaches used.

Despite better transitional care being promoted by policy-makers and health professionals, generally, mental health services have not prioritised the needs of TAY. Allocation of significant extra funding is unlikely during the current economic downturn; however, no- or low-cost approaches may still be possible and these warrant further attention. Rationalising fragmented services, providing more information about what AMHS actually do and about alternative services, notably in

the voluntary sector whose role as a significant provider of services to some of the most vulnerable young people is often unacknowledged (Rees & Anderson, 2012), is likely to promote better access to and engagement by young people in services. Likewise, making adult services more youth-friendly, clarifying referral pathways and criteria and promoting self-referral wherever possible are likely to help us move away from the distressing and costly situation of many young people disengaging from services, only to re-present at some later time in crisis.

When transitional services are delivered, commissioners and providers of services should build in service evaluation, measuring rates of transfer and the quality of good transitional care. Many studies show that young people in transition have multi-faceted needs, including those arising from a number of possible contemporaneous, social, educational and status-related transitions, for example, from parental home or Local Authority Care into independent living; from school into employment/apprenticeship, unemployment or college/university; moving into romantic partnerships; and changing from being a minor to an adult. While holistic services prioritising helping TAY make more comfortable and successful moves into adult life, more recent studies indicate the need not to lose sight of services that prevent and treat symptoms of mental health problems and disorders.

In recently published guidance from the Royal College of Psychiatrists (*Building and Sustaining Specialist CAMHS to Improve Outcomes for* Children *and Young People*, November 2013), a number of specific recommendations are made for improving transition from CAMHS including the development of clearly defined care pathways, the forging of effective collaborative links with primary care and other agencies working with young people and the development and implementation of joint transition protocols between CAMHS and adult services. These are not new ideas; however, what may help to address what appears to be almost a situation of 'service stalemate' are the College's suggestions that new resources and different commissioning structures will be required. Mention is also made of drawing on the learning from EIP services and from the 'youth mental health services' which are emerging in some parts of the country and which cross traditional age boundaries in order to provide comprehensive services for adolescents and young adults.

Other possible drivers for change include national health policy initiatives to promote routine outcomes monitoring, and work within National Health Service (NHS) England to develop a generic service specification for children and young people's transition to adult services. Both may help in realising the aims of measuring rates of transfer and the quality of transitional care. Within the CYP's Improving Access to Psychological Therapies (IAPT) programme, the gathering of outcomes data and the active participation of children and young people are central to all activities and underpin the work to transform CAMHS and improve its accessibility – with young people consulted about CYP IAPT identifying transition as one of the priority areas for improvement.

With regard to the issue of addressing the multi-faceted needs of young people, many of the local partnerships involved in CYP IAPT include CAMHS, social care and voluntary sector agencies working collaboratively. Furthermore, and potentially addressing the cultural barriers and different belief systems that can exist between services, all of the CYP IAPT training (in evidence-based therapies and including a leadership course) is provided on multi-disciplinary, cross-agency basis. As highlighted in the paper by McLaren et al. (2013), shared education and training, standardised approaches to record keeping and information transfer (also promoted within CYP IAPT) and management strategies which evaluate the achievement of outcomes are likely to help in breaking down the mutual misperceptions, differences in attitudes and beliefs that can exist between services, thereby promoting a more integrated approach. Breaking down the practical differences in referral criteria for AMHS and CAMHS, that is, the former being more focussed on people with severe and enduring mental illness, while the latter accept children and young people with emotional and behavioural difficulties as well as those with mental illness, will remain an issue to be

tackled by commissioners and policy-makers as well as service provider organisations, whether statutory or voluntary.

## *Strengths and limitations of this systematic review, quality of evidence found and implications for future research*

The mix of qualitative, quantitative and mixed-methods studies and lack of RCTs and case-controlled trials vindicate the choice of a mixed studies review methodology (Hawker et al., 2002). The quality of all studies identified, however, would be considered low, if using more regularly used schedules prioritising RCTs.

The search strategy used was rigorous, but it is surprising that only papers from the United States and United Kingdom were identified. This may be in part due to limiting the search to English language publications. It is also likely, as this systematic review specifically targeted CAMHS/AMHS transitions, that research on youth services, such as those pioneered in Australia (Cosgrave et al., 2008; Muir et al., 2009), have been excluded. Although youth services could be said to fall under the transitions programme category, they practically create two transitions (CAMHS/youth service and youth service/AMHS). No articles on the shared management transition model were found. Future systematic reviews could specifically search for and include research on youth mental health services and shared management components, such as transition workers. The variability of policy and service provision contexts limits the generalisability of this systematic review.

Only three intervention studies were found. More such studies should be undertaken, especially those comparing different models of transitional care, for example, disorder-specific services versus extended referral criteria for AMHS, separate youth mental health services versus CAMHS staff embedded in AMHS and holistic transition programmes addressing mental health needs of emerging adults (Arnett & Tanner, 2006) versus mental health service-based transition programmes. As traditional, statutory mental health services seem unacceptable to many TAY, further evaluation of more acceptable voluntary sector-provided programmes, especially those working in partnership with statutory agencies, would also be useful.

Only a handful of studies used standardised outcome measures. Future research, whether in mental health, physical health or complex care contexts, should use standardised measures of health and other socio-economic outcomes of relevance to those emerging into adulthood, measures of service user satisfaction and quality of transition. The latter measures need to be standardised and validated in a number of countries if meta-analysis of transitions research is to be possible in the future. Transfer should be investigated alongside transition. Proof that good transitional care improves mental health outcomes remains to be established and will require longitudinal studies.

The limited findings of this systematic review confirm the need for good quality primary research on the effectiveness of different models of mental health transitional care. We have long known that transition is important and the studies we found often re-affirm barriers to transfer and good quality transitional care noted in policy review documents and previous reviews. In the UK NHS, a lot of transition services are started under the banner of ‘innovation’; publically funded research money is sometimes available to evaluate such innovation but unfortunately this is not considered ‘portfolio research’ and hence does not merit the support of the Mental Health Research Network (MHRN) or the Comprehensive Local Research Networks (CLRN). This makes good quality research on innovative services, such as a recent evaluation of whether or not adding a Transition Worker to a transition protocol-driven model improves transitional care (the Bridge Project) difficult to administer, with negative repercussions for case identification and recruitment,

resulting in poor sample sizes and hence a lack of statistically significant quantitative results. Such difficulties are exacerbated by the current research governance rules that stop researchers administering case identification and recruitment. Having more portfolio studies on transition would be an improvement as they could be supported administratively by the MHRN and CLRN (or their new manifestations). Research is still not embedded in many NHS Trusts in terms of being seen as core business; hence, support for evaluation of innovation is often undermined by databases that are not fit for research purposes and inconsistent or poor administrative support (which is often dependent on middle management support for evaluations), however robust the methodology. The pressure of clinical work, especially in the current climate of service cuts, is acknowledged but the need to support good quality research should not be seen as of less importance if we really live in a culture of evidence-based practice and service delivery.

## Conclusion

Evidence on mental health transitional care is generated from a context of patchy provision of services and studies using a range of methodologies. The quality of studies is very variable and no RCTs or case-controlled studies inform the evidence base. There should, therefore, be an emphasis on delivering high-quality research in this field, especially comparing different models of transitional care. To achieve this, transition research must be included in 'portfolio research', thereby meriting the support of the research networks that facilitate case identification and improve recruitment, rather than the current situation whereby funding, typically smaller in scale and short term, comes under the banner of 'innovation'.

Policy-makers have been active in trying to improve mental health care for TAY but policy–practice gaps prevail: mental health service commissioners and providers should prioritise young adults with mental health problems, both because of the people they are and the people they will become. The development of a national generic service specification for children and young people's transition to adult services and of transition-specific outcomes indicators are thus both warranted in addressing this longstanding area of concern. At a practice level, the importance of leadership by senior staff who understand the challenges of effective transition is crucial.

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## Author biographies

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Cathy Street is an independent mental health researcher and trainer. She has lead research studies focused on children and young people with complex mental health problems for the last 15 years, including studies that have looked at the particular problems of accessing services faced by those aged 16-25 years.

Nicola Wheeler is now a trainee clinical psychologist at the University of Plymouth, UK. Working as an assistant clinical and research psychologist in the NHS her main research area was dementia care but her clinical interests include service development and innovation and working with looked after children.

Swaran P Singh is Head of the Division of Mental Health and Wellbeing at the University of Warwick and consultant psychiatrist for the Birmingham Early Intervention Service. He is also a Commissioner for Equality and Human Rights Commission, UK (www.equalityhumanrights.com). His research interests include ethnicity in mental health, early intervention in psychosis, transition from child to adult care, youth mental health, mental health law and medical education.

## Appendix 1

### *Modified critical appraisal criteria (from Hawker et al., 2002)*

1. Abstract and title: Did they provide a clear description of the study?
   i. Good Structured abstract with full information and clear title.
   ii. Fair Abstract with most of the information.
   iii. Poor Inadequate abstract.
   iv. Very Poor No abstract.

2. Introduction and aims: Was there a good background and clear statement of the aims of the research?
   i. Good Full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge. Clear statement of aim OR objectives OR research questions.
   ii. Fair Some background and literature review. Research questions outlined.
   iii. Poor Some background but no aim OR objectives OR questions, OR aims/objectives/research questions but inadequate background.
   iv. Very Poor No mention of aims/objectives. No background or literature review.

3. Method and data: Is the method appropriate and clearly explained?
   i. Good Method is appropriate and described clearly (e.g. questionnaires included). Clear details of the data collection and recording.
   ii. Fair Method appropriate, description could be better. Data described.
   iii. Poor Questionable whether method is appropriate. Method described inadequately. Little description of data.
   iv. Very Poor No mention of method, AND/OR Method inappropriate, AND/OR No details of data.

4. Sampling: Was the sampling strategy appropriate to address the aims?
   i. Good Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained.
   ii. Fair Sample size justified. Most information given, but some missing.
   iii. Poor Sampling mentioned but few descriptive details.
   iv. Very Poor No details of sample.

5. Data analysis: Was the description of the data analysis sufficiently rigorous?
   i. Good Clear description of how analysis was done. Qualitative studies: Description of how themes derived/respondent validation or triangulation. Quantitative studies: Reasons for tests selected hypothesis driven/numbers add up/statistical significance discussed.
   ii. Fair Qualitative: Descriptive discussion of analysis. Quantitative.
   iii. Poor Minimal details about analysis.
   iv. Very Poor No discussion of analysis.

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?
   i. Good Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed. Bias: Researcher was reflexive and/or aware of own bias.
   ii. Fair Lip service was paid to above (i.e. these issues were acknowledged).
   iii. Poor Brief mention of issues.
   iv. Very Poor No mention of issues.
7. Results: Is there a clear statement of the findings?
   i. Good Findings explicit, easy to understand and in logical progression. Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.
   ii. Fair Findings mentioned but more explanation could be given. Data presented relate directly to results.
   iii. Poor Findings presented haphazardly, not explained, and do not progress logically from results.
   iv. Very Poor Findings not mentioned or do not relate to aims.
8. Transferability or generalisability: Are the findings of this study transferable (generalisable) to a wider population?
   i. Good Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
   ii. Fair Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.
   iii. Poor Minimal description of context/setting.
   iv. Very Poor No description of context/setting.
9. Implications and usefulness: How important are these findings to policy and practice?
   i. Good Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice.
   ii. Fair Two of the above (state what is missing in comments).
   iii. Poor Only one of the above.
   iv. Very Poor None of the above.

## Appendix 2

### *Data extraction/assessment form (from Hawker et al., 2002)*

Author(s):

Date of Publication:

Abbreviated Title:

Assessor:

Date Assessed:

Study Design [ ] Quantitative [ ] Qualitative [ ] Combination

Location of Study:

Sample – Description:

Sample – Size:

Aim:

Research Questions/Hypothesis (If Any):

Method and Analysis:

Intervention (If Applicable):

Results:

Conclusions, Comments, and Issues Raised:

| | Good 4 | Fair 3 | Poor 2 | Very Poor 1 | Comment |
|---|---|---|---|---|---|
| 1. Abstract and title | | | | | |
| 2. Introduction and aims | | | | | |
| 3. Method and data | | | | | |
| 4. Sampling | | | | | |
| 5. Data analysis | | | | | |
| 6. Ethics and bias | | | | | |
| 7. Findings/results | | | | | |
| 8. Transferability/ generalizability | | | | | |
| 9. Implications and usefulness | | | | | |
| Total | | | | | |