



University of Warwick institutional repository: <http://go.warwick.ac.uk/wrap>

This paper is made available online in accordance with publisher policies. Please scroll down to view the document itself. Please refer to the repository record for this item and our policy information available from the repository home page for further information.

To see the final version of this paper please visit the publisher's website. Access to the published version may require a subscription.

Author(s): Swaran P. Singh, Moli Paul, Tamsin Ford, Tami Kramer, Tim Weaver, Susan McLaren, Kimberly Hovish, Zoebia Islam, Ruth Belling and Sarah White

Article Title: Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study

Year of publication: 2010

Link to published article:

<http://dx.doi.org/10.1192/bjp.bp.109.075135>

Publisher statement: This is an author-produced electronic version of an article accepted for publication in the British Journal of Psychiatry. The definitive publisher-authenticated version is available online at <http://bjp.rcpsych.org>

## **Process, Outcome and Experience of Transition from Child to Adult Mental Health Care: Multi-perspective study**

Correspondence to [S.P.Singh@warwick.ac.uk](mailto:S.P.Singh@warwick.ac.uk)

### **Acknowledgments:**

The TRACK study is funded by the National Institute of Health Research (NIHR) Service Delivery and Organisation (SDO) programme. [www.sdo.nihr.ac.uk](http://www.sdo.nihr.ac.uk)

The TRACK Study team included Professor Swaran Singh , Dr Ruth Belling, Dr Jenny Dale, Dr Navina Evans, Dr Tamsin Ford, Dr Nicole Fung, Ms Katherine Harley, Dr Daniel Hayes, Ms Kimberly Hovish, Dr Zobia Islam, Dr Bob Jezzard, Dr Tami Kramer, Professor Susan McLaren, Dr Moli Paul, Dr Anne Rourke, Dr Tim Weaver, & Dr Sarah White.

**Conflict of interests:** none declared

## **Abstract**

*Background:* Many adolescents with mental health problems experience transition of care from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS).

*Aims:* To evaluate the process, outcomes and user and care experience of transition from CAMHS to AMHS.

*Method:* We identified a cohort of service users crossing the CAMHS-AMHS boundary over one year across six mental health Trusts in England; tracked their journey to determine predictors of optimal transition and; conducted qualitative interviews with a subsample of users, their carers and clinicians on how transition was experienced.

*Results:* Of 154 cases who crossed the transition boundary in one year, 90 were actual referrals i.e. they made a transition to AMHS, and 64 were potential referrals i.e. were either not referred to AMHS or not accepted by AMHS. Individuals with a history of severe mental illness, being on medication or having been admitted were more likely to make a transition than those with neurodevelopmental disorders, emotional/neurotic disorders and emerging personality disorder. Optimal transition, defined as adequate transition planning, good information transfer across teams, joint working between teams and continuity of care following transition, was experienced by less than 5% of those who made a transition. Following transition most users stayed engaged with AMHS and reported improvement in their mental health.

*Conclusions:* For the vast majority of service users, transition from CAMHS to AMHS is poorly planned, poorly executed and poorly experienced. The transition process accentuates pre-existing barriers between CAMHS & AMHS.

*What I was really hanging around for, I was trying to feel some kind of a good-by. I mean I've left schools and places I didn't even know I was leaving them. I hate that. I don't care if it's a sad good-by or a bad good-by, but when I leave a place I like to know I'm leaving it. If you don't, you feel even worse. J.D. Salinger, *The Catcher in the Rye**

## Introduction

Young people with mental health problems can get 'lost' during transition of care from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) [1-3]. Disruption of care during transition adversely affects the health, wellbeing and potential of this vulnerable group [2-9]. Ideally transition should be a planned, orderly and purposeful process of change from child-oriented to adult models of care, taking into account both developmental and illness-specific needs [1, 10-12]. If the process is seen simply as an administrative event between CAMHS and AMHS, many health and social care needs may remain unmet [13].

Transition is often discussed but rarely studied. UK national policy emphasises the need for smooth transition from CAMHS to AMHS [2, 14, 15] [16] [17] but there is no published evidence on the process, models and outcomes of transition. A systematic review of 126 papers on transition found only one on a mental health population and only within the US context [5]. Transition is a critical aspect of continuity of care, yet we know little about who makes such transition, what are the predictors and outcomes of the process, and how it affects users and their carers. Without such evidence, mental health services cannot develop and evaluate efficient models that promote successful transition or plan the future development and training programmes to improve transitional care. The TRACK study was designed to answer some of these questions in the UK context.

## Aims

The overall aims of the TRACK study were to:

- (1) conduct an audit of the policies and procedures relating to transition within six mental health trusts in London and the West Midlands (three trusts in each region) (Stage 1);
- (2) evaluate the process of transition by a case note survey identifying all actual and potential referrals (see definitions below) from CAMHS to AMHS in the preceding year, 'track' their journey and outcomes in terms of referral and engagement with adult services, and determine the predictors of successful transition (Stage 2);
- (3) conduct qualitative interviews across organisational boundaries and services within health and social care agencies to identify specific organisational factors which constitute barriers and facilitators to transition and continuity of care (Stage 3); and
- (4) explore the views of service users, carers and mental health professionals on the process of transition experience by a sub-sample of service users (Stage 4).

In this paper we present findings from stages 2 and 4. A paper from stage 1 has already been published [18]. The TRACK report including stage 3 findings is available in full at [www.sdo.nihr.ac.uk/projdetails.php?ref=08-1613-117](http://www.sdo.nihr.ac.uk/projdetails.php?ref=08-1613-117).

The study received ethical approval from Wandsworth Local Research Ethics Committee (LREC).

## Definitions

**Actual referrals** were all cases that crossed the transition boundary and were accepted by AMHS. **Potential referrals** included cases that crossed the transition boundary but did not complete transition to AMHS, regardless of the reasons for non-transition.

Transition pathways were categorised as 'optimal' or 'sub-optimal'. **Optimal transition** criteria were developed from an audit of CAMHS transition protocols [18] and literature on good practice in relation to continuity of care [19]. These criteria included:

*Information transfer (information continuity):* evidence that a referral letter, summary of CAMHS care, or CAMHS case notes were transferred to AMHS along with a contemporaneous risk assessment

*Period of Parallel care (relational continuity):* a period of joint working between CAMHS and AMHS during transition

*Transition planning (cross boundary and team continuity):* at least one meeting involving the service user and/or carer and a key professional from both CAMHS and AMHS prior to transfer of care

*Continuity of care (long-term continuity)* - either engaged with AMHS three months post-transition or appropriately discharged by AMHS following transition;

**Sub-optimal transitions** were cases that failed to meet one or more of the above criteria.

## **Design**

The study was undertaken in six mental health Trusts (service provider organisations within the National Health Service), three in Greater London and three in the West Midlands, covering a population of 8.1 million with wide socio-economic, ethnic and urban-rural heterogeneity. All CAMHS teams that managed young people until the age of transition were included. Highly specialised and tertiary services (such as a national eating disorder service) were excluded because of the atypical population served and the logistical problems of tracking cases from services which accept referrals from across the country.

### *Case Ascertainment*

Cases were ascertained in a two stage process. First, central databases of all included CAMHS were searched for open cases who had reached age X or above (where X = age boundary for transition to AMHS). Since the age boundary for different services (X) varied, for each service, X was specifically defined as per that service's transition protocol [18]. In the next stage, all CAMHS clinicians within included services were contacted by letter and email explaining the study and requesting details of actual and potential referrals during the study period. Initial contacts were followed up by further emails and phone calls during the study period until all clinicians had submitted cases or provided a nil response. For the qualitative study, young people identified for inclusion were contacted through their care coordinators to explain the study and seek informed consent.

### *TRACKING Tool*

Two data extraction tools, one each for actual and potential referrals were devised and piloted for reliability. Data were collected on sociodemographic and clinical variables, transition pathways and transition outcomes (for actual referrals) and reasons for non-transition in potential referrals. Inter-rater reliability was checked by two researchers independently extracting data from the tools from five actual referrals from a site unrelated to the project. Comparing 491 non-text variables for each of the 5 cases, an error rate of less than 2% was found. Study tools are available in the online report.

### *Ascertaining Diagnoses*

Since CAMHS case notes vary in recorded diagnoses, we categorised presenting problems into seven diagnostic groups: i) Serious and enduring mental disorders: including schizophrenia, psychotic disorders, bipolar affective disorder, depression with psychosis; ii)

Emotional/neurotic disorders: including anxiety, depression (without psychosis), post-traumatic stress disorder, obsessive-compulsive disorder; iii) Eating disorders: anorexia nervosa, bulimia nervosa, atypical eating disorder; iv) Conduct disorders: including behavioural disorders; v) Neurodevelopmental disorders: including Autism spectrum disorders, learning disabilities; vi) Substance misuse disorders: alcohol and/or drug misuse and; vii) Emerging personality disorder. Data on presenting problems were discussed with three CAMHS clinicians (MP, TF, TK) to assign a diagnostic group. Comorbidity was defined as the presence of more than one diagnostic category from the seven above.

### ***Predictors of Transition***

In the absence of previous evidence, we could not develop a prediction model for transition. Instead a two-stage analysis was conducted with initial identification of independent variables with an association ( $p < 0.05$ ) with the dependent variable using Pearson  $\chi^2$  tests (Fishers exact tests where necessary) for categorical variables and unpaired t-tests for continuous variables. Prior to logistic regression significant independent variables that were highly associated with each other were recoded into a composite variable to reduce co-linearity. Two logistic regression analyses were planned: first to determine predictors of achieving transition (being an actual rather than a potential referral) and second to determine predictors of optimal transition. However the small numbers of cases identified in the study who experienced optimal transition precluded the second regression analysis (see results below). It was felt inappropriate to conduct a multi-level analysis as the study did not aim to determine the impact of Trust level variables on transition outcomes. With only six Trusts in the sample, there would be insufficient variation in Trust level data for such an analysis. However, to account for possible clustering within Trusts, i.e. to patients within Trusts being less variable than patients between Trusts, the logistic regression was repeated and

standard errors (and therefore 95% CIs and p-values) adjusted for cluster effects (see results below). This analysis was conducted using Stata version 9.

### *Qualitative Case Studies*

Semi-structured qualitative interviews were conducted with a subsample of service users who had completed transition, and where possible their carers and CAMHS and AMHS care-coordinators. A purposive sample of service users (n=20) was initially identified comprising 10 service users, each in two groups: those who did or did not remain engaged with AMHS 3 months post-transition. Within each group we sampled cases with or without evidence of joint working between CAMHS and AMHS. Within this primary sampling frame we sought to achieve range and diversity in terms of study site, diagnosis, gender, ethnicity and whether or not the service user was an age outlier at time of transition. Service users who declined to participate or who were deemed clinically unsuitable for inclusion were substituted with a matched case. Interviews were conducted by two researchers (KH, ZI) using topic guides developed by the project team and amended to incorporate emergent themes from all study components. The main focus was on preparation for transition, transition experiences, transition outcomes and factors identifiable as related to positive or negative transition outcomes.

### *Qualitative analysis*

Interviews were recorded, transcribed and entered onto NVivo software. KH led the development and application of a coding frame with input from ZI and the qualitative study lead (TW). Use of NVivo facilitated investigator checking of coding. Qualitative analysis was undertaken using the Constant Comparative Method within the Framework Approach

described by Ritchie and Spencer [20]. This approach was particularly appropriate for integrating a thematic analysis built upon multi-perspective data.

## **Results**

### **Quantitative Study Results**

We encountered major difficulties when searching the central CAMHS databases and these could not be interrogated using the study criteria (see full report for details). We therefore relied primarily on clinician recall to identify cases. A total of 154 cases were thus identified (London n=12; West Midlands n=41). The rate of actual and potential referrals per 100,000 population in the London sites were 2.68 and 1.49 respectively and in the West Midlands sites 2.23 and 2.97 respectively. The service boundary for transition from CAMHS to AMHS (X) ranged from 16-21 years (mode 18).

#### *Transition Pathways*

Of the 154 cases, 90 (58%) were accepted by AMHS (i.e. actual referrals). Sixty-four (42%) were potential referrals, i.e. those who crossed the transition boundary during the study period but did not make a transition to AMHS. Transition pathways for the entire cohort are shown in Figure 1.

**Fig 1 here**

#### *Sample description*

The total sample consisted of 78 (51%) males and 76 females with a mean age of 18.12 (SD 0.82). A third (31%) were White and 23% Black but ethnicity was not recorded in a large proportion (27%). The majority (71%) lived with their parents and nearly two thirds were

either in employment or education (60%). Diagnostically, half (n=78) had emotional/neurotic disorders, a quarter (n=38) had neurodevelopmental disorders and 22% (n=34) had serious and enduring mental disorders. Other disorders included substance misuse (n=14, 9%), conduct disorders (n=6, 4%), eating disorders (n=6, 4%), and emerging personality disorder (n=4, 3%). In five cases (3%) the presenting problem was not recorded. Almost a fifth (n=29, 19%) had comorbid mental health disorders.

### *Sociodemographic and clinical variables*

Table 1 shows sociodemographic and clinical details of actual and potential referrals. Actual referrals were more likely to have been living with parents, having attended CAMHS with their parents, to be involved with a child protection agency or be a 'Looked After Child', been admitted to a psychiatric hospital, to have been detained under the Mental Health Act (MHA), to have a serious and enduring mental disorder, substance misuse, an emerging personality disorder or more than one category of presenting problem (comorbidity) but less likely to have an eating disorder. To reduce the number of variables to enter into the logistic regression a known broader social risks score variable was created that equalled the sum of the following: 'Looked After Child', child protection involvement, Youth Offending Team involvement, special educational needs or refugee/asylum seeker.

### **Table 1 here**

### *Predictors of transition*

Table 2 shows the results of the logistic regression conducted twice, with the second analysis controlling for clustering within Trusts. Having a severe and enduring mental illness and

being on medication at the time of transition predicted transition in both analyses. The effect of clustering among Trusts was evident in two predictor variables: having 'known broader social risks' and having been admitted for inpatient care.

### **Table 2 here**

#### *Optimal transitions*

Based on our four criteria, only 4/90 actual referrals experienced optimal transition. They were 2 males and 2 females, all from ethnic minority backgrounds. Three had a serious and enduring mental disorder and had been admitted to hospital, two under the MHA. All four were on medication and were from London. Three were referred from an adolescent service.

We were unable to explore predictors of optimal transition given how few cases had experienced it. We therefore determined predictors of one of the key criterion of optimal transition - continuity of care. This was defined as 'still engaged with AMHS or appropriately discharged 3-months post-transition'. Logistic regression revealed that cases with emotional/neurotic disorder were a third less likely to experience optimal continuity of care (OR 0.34, 95% CI: 0.12, 0.96, p=0.04). There was no association of continuity of care with any clinical, demographic or process variables.

#### **Qualitative study results:**

Of the planned 20 service user participants, we could only interview 11 cases. The most common reason for failing to recruit was no response from the service users to our requests for participation (25%). The second commonest reason was that a clinician felt that the

service user was too ill to participate (18%). A total of 27 interviews were conducted with 11 service users, 6 parents, 3 CAMHS clinicians and 6 AMHS clinicians.

## Emergent themes

Emergent themes are reviewed briefly below with some illustrative quotes set out in table 3.

### *Preparation for transition*

Participants described three preparatory mechanisms for transition: transfer planning meetings, joint working and good information transfer. About half (54%) of young people interviewed reported attending at least one transition planning meeting, usually in the weeks preceding transition, with key-workers from both CAMHS and AMHS and at least one parent. Service users and carers who did not have transition planning meetings thought that these would have been helpful. CAMHS and AMHS clinicians attributed lack of time as a barrier to such meetings. Two service users were told only at their last CAMHS appointment that they were going to be moved to AMHS.

### *Joint working*

CAMHS were generally seen by AMHS colleagues as being in favour of joint working. AMHS key workers appreciated the benefits of joint working (getting to know the service user, being *in the best interest of the client*) but expressed concern about *responsibility for someone on your caseload, should something go wrong*.

### *Parental involvement*

Parents tended to be less involved with AMHS than with CAMHS. While young people preferred not having their parents involved in their care any more, parents wanted to be more involved with adult services, in order to be able to express concerns or because they felt *left*

*in the dark.* One parent stated: *I know he is now eighteen but he is still my son and I worry about him.*

### *Outcomes of transition*

Eight of the eleven young people were still engaged with AMHS at the time of the interview. In most cases (n=7), young people felt that their mental health had improved since the transition to AMHS but did not necessarily attribute this improvement to transition to adult services. Key-worker flexibility and persistence in the face of missed appointments helped with engagement although this was more likely to happen when there was evidence of deteriorating mental health or emerging crises. Of the three young people no longer engaged with AMHS, one was discharged as his symptoms had resolved, one did not want to be seen and one was discharged due to non-attendance.

### *Other transitions:*

A number of young people experienced other transitions, such as change of accommodation or educational status, becoming pregnant, or becoming involved with other agencies. Only two young people were still living with parents after transition. One young person was living with her partner and their child and another was homeless and living in his car. Of the five young women interviewed, three had unplanned pregnancies during the transition period. Four young people had physical health problems closely linked to their mental health and of these, two experienced parallel health service transitions from paediatric to adult care. Five young people had involvement with other services, including Social Services, Health Visitors, a Homeless Persons Unit, the Probation Service, school/education support services, counselling services and an autism support service.

## **Discussion**

It is a paradox that while treatment for mental disorders in young people have improved substantially in the past two decades, health system responses to young people with mental disorders have been inadequate [21]. Although adolescence is a risk period for the emergence of serious mental disorders, substance misuse, other risk taking behaviours, and poor engagement with health services, mental health provision is often patchy during this period [21, 22]. By following a paediatric-adult split, mental health services introduce discontinuities in care provision where the system should be most robust.

To the best of our knowledge, TRACK the first study in international literature of transition process, outcome and experience in a systematically identified cohort of young people who cross the boundary from CAMHS to AMHS. Our biggest methodological challenge was case ascertainment and we were hampered by the poor quality of CAMHS databases. Recall bias among clinicians is likely and our transition rates are certainly underestimates. Additionally, case notes may not accurately reflect the quality and content of services delivered. However our qualitative results appear to complement the quantitative findings of inadequate transitional care. The ethical requirement that we seek service user consent through care coordinators meant that we could not interview cases from the non-referred population (potential referrals) who were invariably out of contact with services. Our catchment was large and diverse, making our findings generalisable to other services in the UK. Internationally there has been concern about adolescent mental health services in general [21, 22] and about transition in particular [3, 23, 24]. Our findings are likely to reflect similar problems across the developed world.

TRACK findings can be summarised as follows: while most users who crossed the CAMHS transition boundary needed transfer to AMHS, a significant proportion (a third in this study) were not referred to AMHS. Those with neurodevelopmental disorders, emotional/neurotic disorders or emerging personality disorder were most likely to fall through the CAMHS-AMHS

gap. Those with a severe and enduring mental illness, a hospital admission and on medication were more likely to make a transition to AMHS but many (a fifth of all actual referrals in this study) were discharged from AMHS care without being seen. Having social risks also predicted transition of care when clustering at Trust level was taken into account. This might reflect a greater likelihood of the London sample experiencing such risks. Less than 4% of those accepted by AMHS experienced optimal transition. While we cannot conclude that optimal transition equates with good clinical outcomes, it certainly equates with good patient experience, a key marker of service quality. In the TRACK cohort, basic principles of good practice identified in transition protocols [18] were not implemented. For the majority of service users, transition from CAMHS to AMHS was therefore poorly planned, poorly executed and poorly experienced. Transition process appeared to accentuate all the pre-existing barriers between CAMHS & AMHS [3, 25].

*Aligning referral thresholds:*

We cannot say why young people with emotional/neurotic, neurodevelopmental or emerging personality disorders are not being referred to AMHS. CAMHS may be adjusting their referral thresholds on knowledge and prior experience of local AMHS. If so this obscures inadequacies in current provision. Where services exist, all young people with ongoing needs should be referred. Where services do not exist, notably those for young people with neurodevelopmental disorders, unmet user needs should be systematically documented and made clear to AMHS providers and commissioners. Currently neither CAMHS nor AMHS appear to accept responsibility for the health and welfare of this group. Their outcomes are not known and should be a serious cause for concern.

### *Transition boundary*

Transition policies in the Trusts recommend about flexibility around transition boundary based on user need [18]. Our study found little evidence of such flexibility. Perhaps services should use 'age windows' to decide optimal time for transition rather than a strict age cut-off. A crisis should be a relative contra-indication to transition; transitions should only be planned and proceed at times of relative stability. There may be situations where transition can only occur during or immediately following a crisis, or where the transition process itself precipitates a crisis, but these occurrences should be relatively rare.

### *Transition preparation*

Since most transitions can be long anticipated, there should be an adequate period of planning and preparing the service user and their carer for transition. Information about adult services, what to expect, differences in service provision, issues around confidentiality and parental involvement should all form a package of information that CAMHS share with service users and carers prior to transition. The completion of a 'transition logbook' would be a cheap and simple intervention to help structure the transition process. It would be jointly completed by the service user and their care-coordinator and contain relevant details such as contact names and numbers, the dates and number of appointments with each agency, the final transition date and user views on the experience. Such a tool can be easily evaluated on its impact on the process, outcomes and user experience.

### *Improving information transfer*

We found that current IT systems, particularly in CAMHS, did not allow clinicians and managers to access high quality information on case loads. Information transfer was also hampered by a lack of understanding of each other's services, inconsistent documentation, different systems used for transfer of electronic information and transfer of referrals to

lengthy waiting lists during which professional dialogue was reduced. Inadequate IT systems in mental health services clearly hinder informational continuity [26]. The recent National CAMHS Review [27] notes the frustrations that arise as a result of separate, incompatible IT systems across different agencies and the need for systems reform and resource support. We recommend that protocols for transition should explicitly specify information that should be transferred between agencies. Where possible, case-notes should follow the young person and detailed referral letters, including risk assessments, should be sent to AMHS to facilitate planning. Introduction of electronic records offers an opportunity to facilitate standardisation across services and trusts.

### *Managing multiple transitions*

Many young people had multiple transitions between AMHS teams, amongst care coordinators and in personal circumstances, the cumulative effect of which was complex and unsettling for many service users. From our data we can not tell whether services were unaware of these multiple transitions or unequipped to deal with them. Mental health services, however, must pay attention to these multiple transitions through multi-agency involvement, in order to address the complex needs of this vulnerable group [2, 7, 28].

### *Improving liaison between CAMHS and AMHS*

Maitra and Jolley [29] have described a model where child and adult psychiatrists regularly attend each other's clinical meetings at which they jointly address the mental health needs of parents and children within families. Another approach is the development of designated transition workers with posts split between AMHS and CAMHS [4, 30, 31]. Such innovations have several benefits, including a higher profile for children and young people within adult services, shaping of the process of referrals across services, improved scope for

preventative work, possibilities of joint working and the availability of a forum for formal and informal discussions.

These strategies require closer collaboration between services and agencies, which is demanding of both time and personnel. In periods of fiscal austerity, it is difficult to make a case for enhancing existing services, creating new transition workers posts, or developing specialist clinics such as for adults with ADHD. The CAMHS-AMHS divide is also mirrored in the differing commissioning arrangements in the UK, where CAMHS are often commissioned by acute care or children's services while AMHS is firmly within mental health commissioning. Research evidence such as TRACK, therefore is the best way for academics and clinicians to influence policy and shape service provision. We believe that joint commissioning between mental health services for children and adults, and shared commissioning approaches at a regional level are the best ways to improve transitional care.

Box 1 outlines the overall recommendations of the TRACK project. Further recommendations can be found in the full report.

### **Box 1 here**

#### *Bridging the divide*

There are two contrasting approaches for improving care for young people undergoing transition from CAMHS to AMHS. We can improve the interface between services as these currently exist, or we can develop a completely new and innovative service model of integrated youth mental health services. Each has its advantages, limitations and resource implications. Common to both approaches is the need for services to pay attention to the developmental needs of this age group in areas beyond healthcare transition such as changes in educational and vocational domains, independent living and social and legal status of young people. While we call for further research into ways of improving transitional

care, TRACK findings by themselves demand early and substantial service improvement, some of which can occur without new resources and by simply improving liaison, planning and joint working between CAMHS and AMHS.

In their review of youth mental health services across the world, Patel *et al* [21] concluded: 'our single most important recommendation is the need to integrate youth mental health programmes, including those in the health sector (such as reproductive and sexual health) and outside this sector (such as education)'. TRACK findings highlight how far away we are from such integration, given the problems of transition revealed at the interface of CAMHS and AMHS. Even though we do not as yet know how to achieve best transitional care, the *status quo* of existing service barriers should not be acceptable. We certainly need evidence for any models of transitional care that we test in the future. The search for that evidence should be a goal, rather than a pre-requisite for service change. We need to ensure that the vital need for improving youth mental health is not ignored for fear of dismantling long-standing and yet unhelpful service barriers.

## References

1. Royal College of Paediatrics and Child Health. *Bridging the gaps: health care for adolescents*. 2003 [11 October 2007]; Available from: [www.rcpch.ac.uk](http://www.rcpch.ac.uk).
2. Lamb, C., et al., *Working at the CAMHS/Adult Interface: Good practice guidance for the provision of psychiatric services to adolescents/young adults. A joint paper from the Interfaculty working group of the Child and Adolescent Faculty and the General and Community Faculty of the Royal College of Psychiatrists, May 2008*, C. Lamb, Editor. 2008.
3. Singh, S.P., *Transition of care from child to adult mental health services: the great divide*. *Current Opinion in Psychiatry*, 2009. **22**(4): p. 386-390.
4. Forbes, A., et al. *A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability*. Report for the National Coordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO) 2002; Available from: [www.sdo.lshtm.ac.uk](http://www.sdo.lshtm.ac.uk).
5. While, A., et al., *Good practices that address continuity during transition from child to adult care: synthesis of the evidence*. *Child: Care, Health and Development*, 2004. **30**(5): p. 439-452.
6. Kennedy, A., et al., *Young people with chronic illness: the approach to transition*. *Internal Medicine Journal*, 2007. **37**(8): p. 555 - 560.
7. Department for Children Schools and Families and Department of Health, *Transition: moving on well. A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability*. 2008, Department of Health: London.
8. Department of Health, *Good transitions for good people*. 2006, Department of Health: London.
9. American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine, *A consensus statement on health care transitions for young adults with special health care needs*. *Pediatrics*, 2002. **110**: p. 1304-1306.
10. Blum, R., et al., *Transition from child-centered to adult health-care systems for adolescents with chronic conditions: a position paper for the Society of Adolescent Medicine*. *Journal of Adolescent Health*, 1993. **14**: p. 570-576.
11. McDonagh, J.E. and D.A. Kelly, *Transiting care of the pediatric recipient to adult care givers*. *Pediatric Clinic of North America*, 2003. **50**: p. 1561-1583.
12. Royal College of Nursing, *Adolescent transition care*. 2004, London: RCN Publications.
13. Vostanis, P., *Patients as parents and young people approaching adulthood: how should we manage the interface between mental health services for young people and adults?* *Current Opinion in Psychiatry*, 2005. **18**(4): p. 449-454.
14. Commission for Health Improvement. *Transition of care between CAMHS and adult services*. 2003; Available from: [www.chi.nhs.uk](http://www.chi.nhs.uk).
15. Department of Health, *Getting the right start: national service framework for children: emerging findings*. 2003, Department of Health: London.
16. Department for Education and Skills, *Every child matters: change for children*. 2004, Department for Education and Skills: London.

17. Department of Health and Department for Education and Skills, *National service framework for children, young people and maternity services*. 2004, Department of Health, Department for Education and Skills: London.
18. Singh, S.P., et al., *Transitions of care from child and adolescent mental health services to adult mental health services (TRACK study): a study of protocols in Greater London*. BMC Health Services Research, 2008. **8**(135): p. 1-7.
19. Freeman, G., et al., *Promoting continuity of care for people with severe mental illness whose needs span primary, secondary and social care: a multi-method investigation of relevant mechanisms and contexts*. 2002, NCCSDO: London.
20. Ritchie, J. and J. Lewis, *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. 2003, London: Sage.
21. Patel, V., et al., *Mental health of young people: a global public-health challenge*. The Lancet, 2007. **369**: p. 1302-1313.
22. McGorry, P., *The specialist youth mental health model: strengthening the weakest link in the public mental health system*. Medical Journal of Australia (supplement), 2007. **187**(7): p. s53-s56.
23. Cosgrave, E.M., et al., *Met and unmet need in youth mental health*. Journal of Mental Health, 2008. **17**(6): p. 618-628.
24. Davis, M., J.L. Geller, and B. Hunt, *Within-state availability of transition-to-adulthood services for youths with serious mental health conditions*. Psychiatr Serv, 2006. **57**(11): p. 1594-9.
25. Singh, S.P., et al., *Mind the gap: the interface between child and adult mental health services*. Psychiatric Bulletin, 2005. **29**(8): p. 292-294.
26. Burns, T., et al., *Experiences of continuity of care and health and social outcomes: the ECHO study*. 2007, National Coordinating Centre for Service Delivery and Organisation: London.
27. National CAMHS Review, *Children and young people in mind: the final report of the National CAMHS Review*. 2008, Department for Children, Schools and Families and Department of Health.
28. Department for Education and Skills and Department of Health, *Report on the implementation of standard 9 of the national service framework for children, young people and maternity services*. 2006, Department of Health: London.
29. Maitra, B. and A. Jolley, *Liaison between child and adult psychiatric services*, in *Family Matters: Interface Between Child and Adult Mental Health*, P. Reder, M. McClure, and A. Jolley, Editors. 2000, Routledge: London. p. 285-302.
30. HASCAS, *CAMHS to adult transition: a literature review for informed practice*. n.d., Health and Social Care Advisory Service (HASCAS) Tools for Transition, Department of Health: London.
31. Social Exclusion Unit, *Transitions: young adults with complex needs*. 2005, Office of the Deputy Prime Minister: London.

**Table 1: Demographic variables comparing actual and potential referrals**

Variable	Actual referrals n=90 n (%) or mean (sd)	Potential referrals n=54 n (%)	Chi-Square	P value
Male	49 (54.4)	29 (45.3)	1.24	0.26
Age at first referral to any CAMHS	13.34 (3.9)	14.29 (2.9)	1.69	0.09
English as first language	82 (91.1)	54 (84.4)	1.64	0.200
Living with parent	58 (64.4)	52 (81.3)	6.99	0.03
Educational attainment GCSEs and below	43 (47.8)	27 (42.2)	1.35	0.51
Parent attended CAMHS	34 (37.8)	20 (31.3)	11.64	0.003
Positive family history of mental health problems	51 (56.7)	22 (34.4)	3.64	0.06
Looked after child whilst attending CAMHS	24 (26.7)	8 (12.5)	4.56	0.03
Evidence of special educational needs	19 (21.1)	10 (15.6)	0.74	0.39
Evidence of Child Protection involvement	12 (13.3)	1 (1.6)	6.70	0.01
Evidence of Youth Offending Team involvement	7 (7.8)	7 (10.9)	0.45	0.5
Refugee or asylum seeker status	10 (11.1)	9 (14.1)	0.02	0.96
Serious and enduring mental illness	32 (35.6)	2 (3.1)	22.87	<0.0001
Emotional/neurotic disorder	43 (47.8)	35 (54.7)	0.71	0.4
Eating disorder	1 (1.1)	5 (7.8)	4.49	0.03
Conduct disorder	3 (3.3)	3 (4.7)	0.81	0.67
Substance misuse	12 (13.3)	2 (3.1)	4.76	0.03
Emerging personality disorder	4 (4.4)	0	2.92	(0.09)
Comorbidity (2 or more disorders)	23 (25.6)	6 (9.4)	6.41	0.01
Admitted to hospital while attending CAMHS	31 (34.4)	3 (4.7)	19.25	<.0001
Detained under Mental Health Act	15 (16.7)	1 (1.6)	9.16	0.002
Risk of self-harm at transition	5 (5.6)	6(9.4)	1.50	0.22
On medication at time of transition	69 (76)	29 (45)	15.89	<0.0001

Table 2 Results of logistic regression: factors predicting actual transition with clustered results accounting for Trust level data

<b>Independent variable</b>	<b>OR</b>	<b>95% CI</b>	<b>p-value</b>	<b>95% CI clustered</b>	<b>p-value clustered</b>
Known broader social risk (score)	1.38	0.9, 2.1	0.14	1.1, 1.8	0.02
English as first language	0.76	0.3, 2.3	0.62	0.4, 1.3	0.30
Parents attend CAMHS	0.56	0.2, 1.3	0.19	0.2, 1.3	0.16
Admitted as psychiatric inpatient	5.05	1.0, 26.8	0.05	0.2, 147.3	0.34
Admitted under section	5.0	0.5, 48.3	0.165	1.6, 15.5	0.01
Eating disorder	0.24	0.0, 2.4	0.22	0.0, 3.4	0.29
Substance misuse	1.66	0.3, 11.0	0.59	0.3, 8.7	0.55
Comorbidity	2.82	0.9, 9.4	0.09	0.8, 9.6	0.01
Serious and enduring illness	7.85	1.6, 37.8	0.01	1.5, 40.9	0.01
On medication at the time of transition	2.36	1.1, 5.3	0.04	1.7, 3.4	<0.01

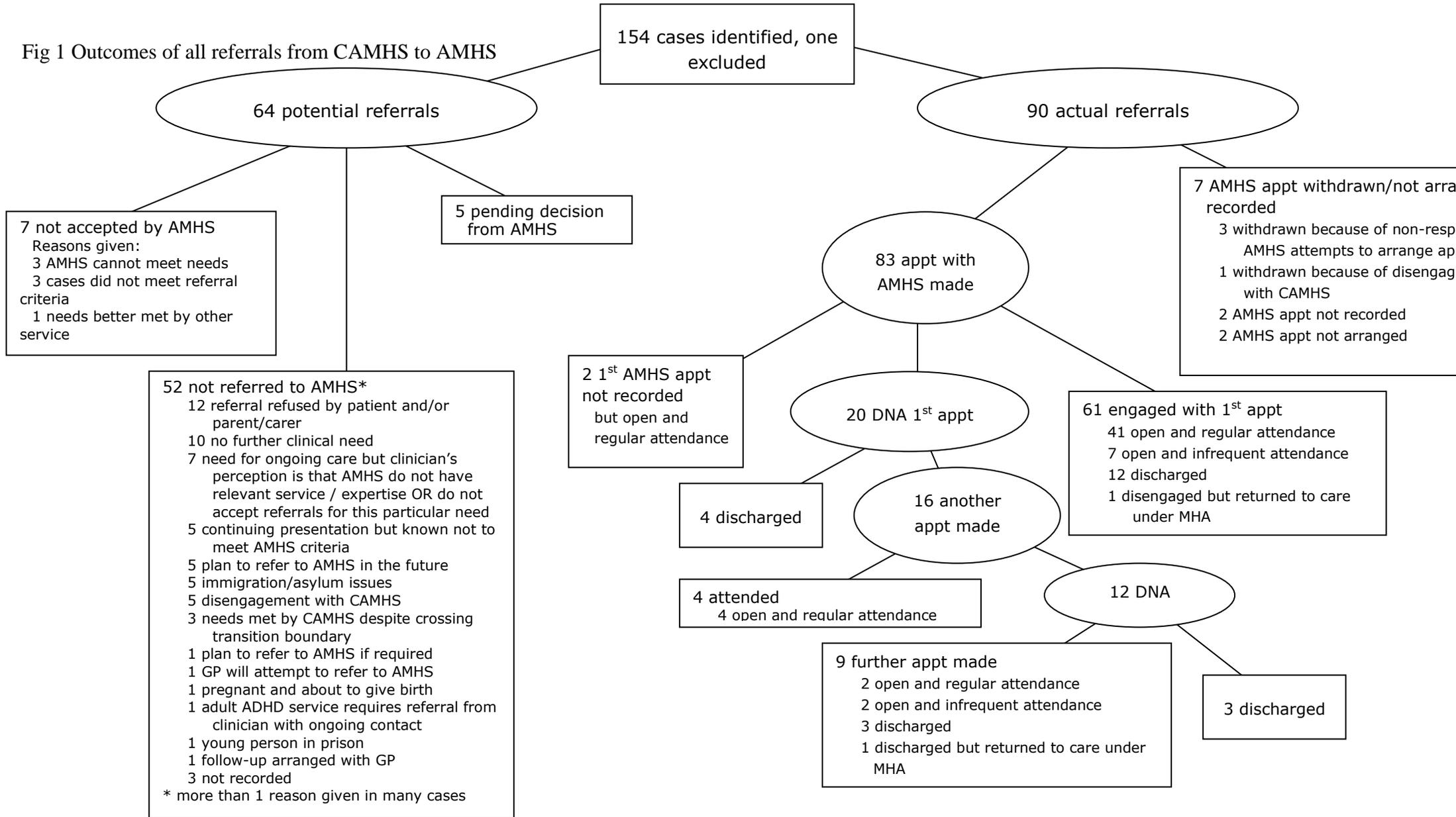
Table 3: Emergent themes from qualitative interviews with illustrative quotes

Preparation for transition	
Service user accounts of planning meetings:	<p><i>'... I just thought it was another meeting...I just didn't see the point of that lady from CAMHS being there, she didn't know me, she didn't know anything about me, all she knew was what was on my file, she'd never met me and yeah, [AMHS key-worker] is really nice, the psychiatrist didn't really say much, I didn't really see any point in their being there really.'</i> 'I was told about the transfer and I would be meeting the new care co-ordinator and the transfer would happen slowly...they explained how different it would be...'</p>
A service user account of a transition with joint working:	<p><i>'gradually just slowly, slowly I moved up to the adult services when I was ready...I think it was a good transition, I don't really know what could be any different. I didn't notice it too much. I thought it was good'</i>.</p>
AMHS key-worker perspective on the problems of joint working:	<p><i>'...I like the idea of joint working for a couple of months because I think it's definitely in the best interest of the client and it's helpful for the worker who's taking on the case but I do think there's this issue of, you know, if someone's on your caseload and something goes wrong you're responsible for it.....in discussions that have come up with other CAMHS cases and I've said it would be really useful to, to co-work the case for a couple of months people have been really, really unwilling to do that for that reason ... (it) isn't at all in the best interest of the client but I think it does happen, definitely. Yeah, so that's probably one of the biggest issues I think.'</i></p>
Service user accounts of transition outcome	<p><i>'Being with the adult mental health service is quite pressuring I find to be honest because there's too much transfers.'</i> <i>'...I just think that it was a complete waste of time going there and maybe these services, like GPs, mental health teams, all sort of thing, they should be a bit more in the loop together, you know? Not like so separate they don't know what's going on, the service providers, not really, I just think they should be a bit more knowledgeable of each others and what they offer and stuff like that and they should talk more, like what would be more beneficial to the patient because like I wouldn't like anyone else to like go through that really, you know, like, just go to one and then be passed on to the next one when you're eighteen. That's what it was like, it's like, oh, you're eighteen now, you gotta go...'</i> (The transition) <i>'... was just all of a sudden...I didn't really like it.'</i></p>

*AMHS clinician account of poor engagement*

*'I haven't seen [service user] for awhile but reading into him not coming to the appointments more recently I think he's probably found the different approach [between CAMHS and AMHS] difficult'. '...it was, very frustrating and difficult because I wanted to engage him and I knew how important it would be to, to try and make the transition to adult services as painless as possible so I, you know, I tried to word letters and speak to him in a way which, you know, would make him feel comfortable and stuff but I just, I couldn't find a way of really engaging him.'*

Fig 1 Outcomes of all referrals from CAMHS to AMHS



## Box 1. Overall recommendations from TRACK study

1. The needs of the service user should be central to protocol and service development regarding transition.
2. Trusts should have regular updated mapping of local CAMHS, AMHS and voluntary services, identifying scope of operation, communication networks and key contacts.
3. Protocols should be developed and implemented in collaboration with all relevant agencies and young people and their carers.
4. Multi-disciplinary training should be planned and delivered about transition, including local service structures, protocols, and working with young people. This training should be linked to the appraisal process and skills and competency frameworks.
5. Protocols should specify the time-frame, lines of responsibility and who should be involved, how the young person should be prepared and what should happen if AMHS are unable to accept the referral.
6. Protocols should stress flexibility in the age range to accommodate a range of needs and developmental stages, and have explicit referral criteria and service provision.
7. Transition should occur at times of stability where possible; young people should not have to relapse in order to access a service.
8. Agencies should try to avoid multiple simultaneous transitions.
9. Improved information transfer between CAMHS / AMHS with the standardisation of record keeping or, where this is impossible, clear indication of what information should be made available. A referral letter summarising past contact, current state and risks is a bare minimum. If all records cannot be transferred, copies of all correspondence and contact summaries should be.
10. Transition process should include collaborative working between CAMHS and AMHS, with cross agency working or periods of parallel care.
11. Carers' needs and wishes should be respected in the transition process and carer involvement in adult services should be sensitively negotiated between clinicians, service users and their carers.
12. Services need to develop for young people with emotional/neurotic, emerging personality and neurodevelopmental disorders wherever there is gap in such provision.
13. Active involvement by AMHS is required before CAMHS can discharge a case; transfer onto a long waiting list is unacceptable.
14. Changes should be evidence-based. Prospective research is required on the clinical course, service needs, health and social cost implications for the young people receiving little service provision after leaving CAMHS