

Transition from CAMHS to Adult Mental Health Services (TRACK): A study of service organisation, policies, process and user and carer perspectives

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Executive Summary

Background

Many young people with mental health problems experience transfer of care (transition) from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS). Problems in transition disrupt continuity of care. There are currently no UK studies that have specifically explored the process of transition from either a service or a user/carer perspective.

Aims

The TRACK study aimed to:

- (a) identify factors that facilitate or impede effective transition of patients from CAMHS to AMHS and
 - (b) make recommendations about the configuration and delivery of services that will promote good continuity of care.
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About this study

Stage 1: Mapping CAMHS services and auditing transition policies in six trusts in Greater London and West Midlands.

Stage 2: Tracking the pathways and outcomes of all users who crossed transition boundary in a given year.

Stage 3: Diagnostic analysis across health services and voluntary sector using semi-structured interviews

Stage 4: Qualitative interviews with a sub-sample of service-users, carers and care co-ordinators.

Key findings

Stage 1

There were 14 active protocols in the study areas (13 in Greater London, 1 in West Midlands).

Age-based transition boundaries varied from 16 years to 21 and over, 18 being modal value.

Protocols were based on policy documents, but differed on practical aspects of transition.

Most protocols identified the service users as central to the transition process; none specified ways of preparing them for transition.

Three-quarters of the protocols had no provision for ensuring continuity of care for cases not accepted by AMHS.

Stage 2

Of the 154 cases who crossed the transition boundary, 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.

Over four fifths of the entire group were thought suitable by CAMHS for transition to AMHS. However, a third (n=52) were not referred at all to AMHS.

AMHS accepted 93% of all referrals from CAMHS, despite a widespread CAMHS perception that AMHS do not accept referrals.

Those with neurodevelopmental disorders (ADHD, autistic spectrum disorder), emotional/neurotic disorder or emerging personality disorder were most likely to fall through the CAMHS-AMHS gap.

A fifth of cases accepted by AMHS were discharged without being seen.

Those with a severe and enduring mental illness, a hospital admission and on medication were most likely to make a transition to AMHS.

Actual referrals were significantly more likely to have attended CAMHS with their parents.

Less than 4% of those accepted by AMHS experienced an optimal transition as defined by at least one transition planning meeting, a period of joint working between CAMHS and AMHS, good information transfer and being engaged with AMHS 3 months following transition.

Stage 3

Perceptions of CAMHS and AMHS differed; the former were described as more person-centred, holistic and family-oriented; the latter medication-focussed and crisis-oriented.

Facilitators for transition were dedicated transition posts, joint working, early communication and greater involvement of carers.

Barriers for transition were variability in eligibility criteria and thresholds between AMHS & CAMHS, communication problems, lack of confidence among AMHS staff on managing young people, lack of understanding and clarity about services, high staff caseloads, lengthy waiting lists, lack of inpatient facilities and limited services for neurodevelopmental disorders.

Stage 4

Participants described three preparatory mechanisms for transition: transfer planning meetings, joint working and good information transfer. Few users

had experienced these in practice, and those that had viewed these as positive.

Most young people preferred not having their parents involved in their care with AMHS, while parents wanted greater involvement.

Following transition to AMHS, most users stayed engaged and reported improvement in their mental health.

Key methodological issues:

Recruitment was difficult at all sites. Clinicians, even while appearing enthusiastic, did not participate as expected.

IT systems were poor quality and unable to provide reliable clinical information.

Conclusions

For the vast majority of service users, transition from CAMHS to AMHS is poorly planned, poorly executed and poorly experienced.

Mutual misperceptions among clinicians contribute to pre-existing ideological, practical and structural barriers between CAMHS and AMHS.

Even where protocols exist, there is a policy-practice gap.

Many young people with ongoing mental health need fall through the gap between CAMHS & AMHS; especially those with neurodevelopmental, emotional or personality disorders. 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.

Even among those who cross the gap, very few experience optimal transition. Basic principles of good practice appear not to be implemented.

Early and substantial service improvement is needed, much of which can occur by improved liaison, collaboration, communication and joint working between CAMHS and AMHS.

Dedicated youth mental health services can overcome traditional CAMHS-AMHS barriers but require substantial new resources.

Future research should evaluate different models of transitional care.

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme, and managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO), based at the London School of Hygiene & Tropical Medicine.

The management of the SDO programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Although NETSCC, SDO has conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.