Joint working at the interface

Early Intervention in Psychosis and specialist Child and Adolescent Mental Health Services
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Information about organisations involved

IRIS is a national network of regional clinical leads with expertise in early intervention in psychosis established by the National Early Intervention in Psychosis (EIP) Development Programme (2004-10) under the National Institute for Mental Health in England (NIMHE) and Rethink. The programme co-ordinated EIP development to improve the access of young people to local services offering a three year evidence based treatment package. This national network of regional EIP leads continues to function as IRIS via www.iris-initiative.org.uk

The National CAMHS Support Service (NCSS) is the national child and adolescent improvement programme commissioned by the Department of Health to work with regional and local partners in health and local authorities. It supports those agencies to improve outcomes for children and young people’s emotional health and wellbeing and mental health through: strengthening commissioning processes; workforce development; user participation and delivery of mental health services in universal, targeted and specialist settings. The NCSS was funded from 2003 to March 2011 and the programme closed at the end of that month. Its legacy resource can be found on www.chimat.org.uk/camhs

The National Mental Health Development Unit (NMHDU) was launched in April 2009, consisting of a small central team and a range of programmes funded by both the Department of Health and the NHS to provide national support for implementing mental health policy by advising on national and international best practice to improve mental health and mental health services. NMHDU closed on the 31st March 2011, however all the publications and resources produced remain available on www.nmhdu.org.uk

Rethink, the leading national mental health membership charity, works to help everyone affected by severe mental illness recover a better quality of life. We help over 52,000 people each year through our services and support groups and by providing information on mental health problems. Our website receives over 500,000 visitors every year. Our aim is to make a practical and positive difference by providing hope and empowerment through effective services and support to all those who need us. We actively campaign for change through greater awareness and understanding and we are dedicated to creating a world where prejudice and discrimination are eliminated. www.rethink.org
Foreword

This status report is launched at a time where on the one hand we have extensive change across the mental health system, including the disbanding of our two report partners National Mental Health Development Unit (NMHDU) and National CAMHS Support Service (NCSS), and on the other, opportunities for reform.

One of the most positive developments is a renewed focus on supporting mental health across the life cycle, including an emphasis on developing youth focused mental health services stretching from childhood well into early adulthood. Another is the emphasis on the voice of young people focused-care, developed in response to feedback from young people and their families.

We know that managing transitions between services at significant age breaks is a key challenge for mental health services across the world. Staff working at the interface, as well as young people and their families in England, tell us how unsatisfactory the current system is at supporting the children to adult service transition pathway. Research evidence supports this as well. With few positive examples to draw on Rethink, NMHDU and NCSS collaborated to undertake an audit to create this report.

We hope you find it a useful reference document and Rethink will be working with the Children and Young People’s Mental Health Coalition to take forward our recommendations.

Paul Jenkins
CEO, Rethink
Foreword from Young People

We really support the case for early intervention and joint working between services. It can be very difficult to manage the move from one service to another. There is often not a consistent person involved to help, which can make things feel much worse again even when they were starting to feel better. If services don’t work together when young people are discharged or have to move to a different service at the age of 18 (or before), then it can feel like you’ve been abandoned and just left with nothing.

Services designed specifically for young people are a really good idea because it is much easier to talk about difficult things in a comfortable and relaxed environment. It helps a lot to have other young people around who might have similar experiences and staff who really understand the issues that affect young people. It is also really important as young people to be involved in planning our own care so that we know what to expect and what is going to happen, that we feel part of the process.

We found this report an interesting read – we hope you do too. We hope you take something from the progress being made and that it inspires you and the people you work with to continue the early intervention focus. We like the idea of having services for children and young people until the age of 25. More joint working ‘at the interface’ between Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS) would give young people the support that they need to make sure that later on in life they have the skills to cope.

Laura Hamilton and Charlotte Hopper
(Chair and Vice-Chair)
Rethink Young People’s Panel
Introduction

This report summarises progress made by specialist Child And Adolescent Mental Health Services (CAMHS) and Early Intervention in Psychosis (EIP) and Adult Mental Health Services (AMHS) in working together to support young people aged 18 and under with psychosis.

The join up between CAMHS and EIP/AMHS is the main focus, although broader issues of supporting young people in transition between services and the interface with AMHS are also considered.

The aim is to review progress towards creating a better and more person-centred youth mental health system and to suggest recommendations to improve the experiences of vulnerable young people ‘in transition’.

The report is structured in several sections, drawing upon material from the following sources:

• Firstly, the context for considering quality of care at the interface is reviewed. We describe key policy drivers, good practice guidance and present review data that have structured work to improve and develop a more ‘joined up’ CAMHS – EIP/AMHS interface over the last few years.

• Secondly, we carried out an online survey of all specialist Tier 3 CAMHS teams and EIP/AMHS teams in England in October 2009. These findings are summarised.

• CAMHS and EIP/AMHS development sessions were held in the West Midlands in 2010 attended by practitioners from children and adult services. Key learning points are described.

• Finally we have collated some case studies of CAMHS and EIP/AMHS collaborative working to provide ideas and possible solutions to service interface challenges.

The importance of ensuring joined up support at the CAMHS-EIP/AMHS interface:

The YoungMinds 2006 Stressed Out and Struggling project reported that, on average, it took a young person experiencing psychosis 18 months to receive help; high rates of admission under the Mental Health Act were noted1.

In a Care Services Improvement Partnership (CSIP) 2007 report on early detection and intervention, the risks of suicide within the first five years following a diagnosis of psychosis are highlighted. The risk of suicide is greatest around the time of first diagnosis, with young females having a 150 times higher risk, and young males a 300-fold higher risk, than the general population2.

A 2007 study by Boeing and colleagues found that 80% of first admissions for young people with psychosis were to adult acute psychiatric wards, and that only 20% were to specialist adolescent facilities. The researchers noted that ‘the reality of community care for many young people with psychotic illnesses falls short of guidelines for standards of provision... There is also substantial underprovision of adequate inpatient facilities for this group of patients, including secure beds1,3
Where we are today: a summary

The organisation of mental health care for young people with emerging psychosis is a problem because the illness often presents in late teenage and early adulthood when responsibility for service provision changes from CAMHS to AMHS.

7,500 people and their families deal with emerging psychosis each year in the UK. 75% of all severe and chronic mental illnesses emerge between the ages of 15 and 25, with research highlighting that the majority of adolescents experiencing first episode psychosis have a poor prognosis, with recurrent illness and impaired social functioning.

We know that early identification and the engagement and support of young people in appropriate care and treatment is vital for long term outcomes, but that services can really struggle with provision “at the interface”. Studies indicate that the shorter the duration of untreated psychosis (DUP), the better the long-term outcome.

Overall, the data presented in this report indicate that there has been considerable progress in many areas over the last few years “at the interface”. For example, shared clinical posts, specific recruitment protocols that require EIP/AMHS staff to have CAMHS experience, the co-location of some services, joint referral meetings and protocols for a psychosis pathway for younger people are all more common. Findings from the online survey also indicate that where CAMHS and EIP/AMHS are now closely aligned, there appear to be more developed arrangements for supporting young people in crisis out of hours and more services with CAMHS to EIP/AMHS transition protocols in place.

However, alongside these developments are frequently reported problems of long waiting times, high entry thresholds and of continued poor understanding amongst EIP/AMHS of CAMHS and vice versa.

Services also have different philosophical approaches which translate into problems of unclear criteria for referrals, confusion and variability in processes for gaining parental consent when needed, and limited communication between services. The end result being far too often a poor experience for a young person and their family. As one young person sharing their views about service transitions with the CAMHS National Advisory Council (NAC) noted:

“Services work against what they are trying to achieve. The way that some young people are treated by services can make them feel worse rather than better.”

The challenge now, as we enter a period of increased resource constraints and pressures on the workforce, will be to hold onto the progress that has been made in developing more collaborative working between CAMHS and EIP/AMHS, whilst continuing to seek solutions to these interface difficulties.
The national policy context

“An ongoing and major area of concern for users of children’s mental health services is the difficulty they face when they need to access adult mental health services.” (DCSF and DH 2010)

Prominent in a number of key documents are themes relating to transition challenges and inappropriate care placements for young people.8,9

• There has been a considerable focus on addressing deficits in the provision of services for 16- and 17-year olds, including access difficulties.

• Attention has been drawn to the problems of young people under the age of 18 being admitted to adult inpatient wards, with inadequate co-ordinated planning to ensure that their care is returned to CAMHS at the earliest opportunity (including where appropriate, a transfer to a bed in a Tier 4 CAMHS unit) and a widespread lack of post-discharge support.

• The poor treatment and care experiences of young people moving between mental health services are highlighted.

A number of mental health policies have attempted to tackle transition issues for young people including the National Service Framework (NSF) for Mental Health. The National Service Framework for Children, Young People and Maternity Services also expressly covers the mental health and psychological well-being of children and young people in Standard 9.

A major dilemma, however, has been that national or local funding sources have often been different between services. This can influence resource decisions to under 18s with psychosis who are often viewed as a very small group with a specific, and often complex, set of needs. The recent review by Professor Sir Ian Kennedy concerning cultural barriers in the NHS, noted that transition problems were a ‘phenomenon created by the system’. The review recommended that services think creatively around funding streams to ensure that there is greater flexibility around transition pathways because the rewards will be reaped in later adulthood for the individual.

With the formation of a new Coalition Government in 2010, mental health policy changed direction and emphasis. A new mental healthy strategy was launched and as part of the consultation process, in November 2010, young people from a number of mental health charities (Rethink, YoungMinds and Beat) met with members of the CAMHS National Advisory Council. They shared their views as to what they thought the new strategy should focus on – and one of the areas they highlighted as of greatest concern to young people and needing careful consideration in forthcoming policy, was improving the process of transition for young people needing to move on from CAMHS, including to AMHS.

Suggestions for improving the situation included clearer protocols so that young people are not left without support; planning well in advance of transitions actually happening; stepped down discharge arrangements, and crucially, young people, parents and carers not being the ones left to negotiate the pathways into services:

“We know about the difficulties between CAMHS and adult mental health services, but we want them to work out how they can work together to better support us.”

In No health without mental health from the Department of Health (2011), early intervention across all ages is identified as a priority and a prominent theme of the strategy is of joined up approaches and the best use of resources across all age ranges. This includes government reviews, with local action being supported by a sustained cross-government approach. Activity to address interface difficulties and improve transitions from CAMHS to adult services, whilst not expressly mentioned, clearly fits well within this national agenda.
Research overview: supporting young people in transition through mental health services

There is a growing body of research literature and practice learning about what is needed to support young people in transition. These include solutions to the difficulties surrounding transition from Tier 4 inpatient provision to community mental health services and the development of transition protocols, policies and procedures.

At an international level, there has been considerable interest in developing youth mental health services, often spanning the 15-25 age range, in recognition that often the gap in support is widest at the critical point when young people have to make the transition from childhood to adulthood. This inconsistency is well summed up by McGorry, when arguing for better integration of services: “the surge of new morbidity between the ages of 15 and 25 is paired with the worst access to services, the system is weakest where it needs to be strongest.”

In a project led by the National Children's Bureau (NCB) exploring effective transitional support the following were identified:

• The need for flexible services
• The need for, and frequent lack of, integration and cross-agency planning
• The need for clear cross service operational procedures and funding
• The need for discharge planning – which must start from a much earlier stage and encompass a range of different services.

A key theme of this work is the importance of involving young people and their families in the transition process. The NCB toolkit highlights that young people require the professionals supporting them to be able to communicate effectively with them and to be well informed about generic teenage health issues. This echoes the recommendation also made in the Department of Health’s guidance on transition.

The Royal College of Psychiatrists have identified a number of risk factors for adolescents in transition; these include becoming lost in the system and having nobody to support attendance. Having a trusted adult who takes on the key role of link worker and who acts as the sole point of contact for the young person in transition, preparation for transition, case management and joint management of care, are all identified as promoting effective transition. There is also a need for strong therapeutic relationships and flexibility regarding the point of transfer and again, the full involvement and participation of the young person in these processes is emphasised. The Royal College recommends a number of practical ways to improve transition, in the absence of significant new resources:

• Setting up a local forum to take things forward
• Accepting that neither CAMHS or AMHS have all the expertise but together they can provide a more comprehensive package of support
• Establishing partnerships with a range of statutory and non-statutory agencies
• Identifying interested clinicians in CAMHS and AMHS willing to take on a link role
• Developing joint CAMHS and AMHS training opportunities and possibilities for joint working.

Findings from a recent large scale research programme – known as the TRACK study (Transition from CAMHS to Adult Mental Health Services) – by Singh and colleagues at the University of Warwick indicate the scale of work still to be done if young people are to be effectively supported at transition. For example, TRACK reported that almost 40% of young people with ongoing mental health needs are never referred to AMHS, even when CAMHS thought they were suitable for referral; that a fifth of referrals from CAMHS accepted by AMHS were subsequently discharged without being seen and that:

“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 three months following transition.”

TRACK also identified specific groups most likely to fall through the transition gap: those with neuro-developmental disorders (ADHD and ASD), those with emotional/neurotic disorders and those with emerging personality disorder.
Development of the CAMHS-EIP/AMHS interface

Calls for information through national surveys and case studies by the Royal College of Psychiatrists and CAMHS Regional Development Workers (RDWs) provide a contextual background as to how the CAMHS and EIP/AMHS interface has developed over the last decade.

Three national unpublished surveys give the following audit results for specialist CAMHS teams for older adolescents in England:

- 1999 – 14 teams (Not known how many linked into EIP/AMHS teams)
- 2001 – 19 teams (12 linking into EIP/AMHS teams)
- 2005 – 31 teams (all 31 linking into EIP/AMHS teams).

Some of the early key issues impeding the development of this area of provision included the capacity of specialist CAMHS at Tier 2 and 3 and the national shortage of CAMHS inpatient services (Tier 4). Marked philosophical differences between CAMHS and adult services were also apparent, reflected in differences in the style of interventions. Eligibility criteria and entry thresholds were often a source of dispute, with the general pressure of workloads resulting in few opportunities for joint training or for CAMHS and EIP/AMHS practitioners to work together in a flexible, user led way.

By 2005, although the national survey still found a lack of appropriate day services and inpatient beds, progress was reported in a number of areas including the development of transition mental health teams for young people leaving care and multi-agency commissioning of services. In terms of 24 hour crisis arrangements for young people with psychosis, the following arrangements were identified:

- For those under 16, often management was via local arrangements between Crisis Resolution/ Home Treatment, EIP/AMHS and CAMHS
- For those aged 16 and over, management was typically by the Adult Mental Health Crisis Resolution/Home Treatment Team.

Feedback from services to CAMHS RDWs in 2009 noted that good links were being forged with positive practice being developed in a number of areas:

- EIP/AMHS using Child and Adolescent Psychiatrists for young people aged below 16 and many for young people aged below 18
- Designated Child Psychiatrist sessions into EIP/AMHS and shared CPN resource for CAMHS/EIP/AMHS
- Input into CAMHS by non-psychiatrist members of EIP/AMHS.

Examples of the development of a more ‘joined up’ interface included:

- Appointments of Family Therapists, to work across CAMHS and EIP/AMHS
- Joint assessment, consultation, liaison and working
- Members of EIP/AMHS team attending the CAMHS team meetings on a regular basis
- EIP/AMHS providing continuity of psychiatry input for young people aged 18 years as they move from CAMHS to adult services
- Some EIP/AMHS extending their provision beyond psychosis to become more generic youth mental health services.
Established in 2006, Team C is a distinct part of Central Norfolk Early Intervention Service. It offers support and intervention to those individuals within the service who are aged between 14 and 18 years who present with a first-episode of psychotic symptoms, or attenuated psychotic symptoms and complex social circumstances, behavioural disturbance, substance misuse, or high levels of distress from either the individual or family.

The team is multi-disciplinary, with input including occupational therapy, clinical psychology, nurse therapy and psychiatry. The Responsible Medical Officer (RMO) role for clients remains within CAMHS, while case managers within the team manage the role of care co-ordination, linking in with the RMO within CAMHS. The team maintain the care co-ordination role during the clients transition from CAMHS to adult services, ensuring continuity of care between services.

The team offers an intensive outreach model of treatment that does not depend on clients’ attendance at clinic or office-based appointments. Instead, individuals are seen in the most natural settings possible, and there is an emphasis on seeing clients in youth-friendly and non-stigmatising venues. With a focus on engagement with the young person, including a flexible approach towards appointment times and missed appointments, the team has shown to be successful at maintaining engagement with young people who present with complex and often co-morbid mental health difficulties, who have traditionally been considered a ‘difficult to engage’ client group.

The team also does in-reach to clients placed in out of area adolescent residential units, maintaining the clients links to their local support networks and taking a proactive role in discharge planning and supporting the young person in their transition back to their local area and home. Interventions include: a combination of Cognitive Behavioural Therapy (CBT); assertive case management; support work and family work. There is a focus on promoting social activity and engagement with existing sources of educational and vocational activity, and peer and family support.

Clients who present to the team typically have a broad range of complex needs, and the team works comprehensively to support individuals, ensuring a holistic approach where the focus is not solely on mental health needs. Typically the team will work with the individual, their families and the support system around them (e.g. school), using the common assessment framework where appropriate. Outcome data for the team show reductions in not only psychotic symptoms after 12 months of service, but also decreases in co-morbid anxiety and depression, as well as improvements in social recovery.
A qualitative study undertaken by England and colleagues involving 20 Primary Care Trusts (PCT) and three Strategic Health Authorities (SHA) provides valuable findings about what helps to support the interface between CAMHS and EIP/AMHS. The researchers note the following:

“A lack of understanding between the CAMHS and early-intervention services often appeared to impede working together. However, CAMHS and early-intervention service team members who had participated in joint training and educational initiatives described how an improved awareness of each other’s priorities, philosophy of care, and ways of working had helped in breaking down some of these barriers.”

It is also highlighted that:

“One of the most important facilitators at the interface between early-intervention services and CAMHS was senior support either from an individual, such as a senior PCT or SHA executive, or through the involvement of an individual who had greater expertise in the area of mental health and early-intervention service development. Such persons appeared to facilitate the exchange of information and resources and to help those involved at the interface to negotiate past any difficulties that arose.”

The study concluded that poor communication and a lack of strategic planning have hampered many areas of service development. Another conclusion was the gap that exists between CAMHS and AMHS is also present in the interface between CAMHS and EIP/AMHS. This is an important observation since one of the underlying premises of EIP/AMHS was to strengthen the collaboration with CAMHS.

What the study termed as some “optimistic findings” were that joint training, educational initiatives and the development of a youth-focused model of working, can all help to improve the CAMHS and EIP/AMHS interface. Leadership, an “interface facilitator” and working in a participatory way are other important features in encouraging CAMHS and EIP/AMHS cooperation and collaborative working.

Case study: an integrated service model in Newcastle and North Tyneside

Newcastle and North Tyneside EIP/AMHS and Newcastle CAMHS have established excellent links and built an integrated service model. As early as 2004, EIP/AMHS teams were actively recruiting care coordinators with CAMHS experience. In 2006, a Consultant Adolescent Psychiatrist became a formally integrated team member, with two sessions funded out of the EIP/AMHS budget although workloads in real terms generated six sessions of demand.

Over the course of time, it was agreed with the four CAMHS teams in North Tyneside that all young people suffering a potential psychotic illness across the whole of Newcastle and North Tyneside would be seen by the EIP/AMHS team in liaison with the Consultant Adolescent Psychiatrist. This was the preferred model as it was felt that the Care Coordinators might experience conflicts of opinion if they were discussing cases in more than one multi-disciplinary team.

Staff feedback suggests that this model has helped to develop a more joined up service interface in a number of ways:

- Having a CAMHS psychiatrist within the EIP/AMHS team allows the development of a shared philosophy of practice including multiple models of biopsychosocial care and prescribing practices in line with contemporary EIP/AMHS work.

- A CAMHS perspective has proved helpful to practitioners less familiar with the developmental perspectives of working with adults and clients with children.

- To minimise transition issues, the adolescent psychiatrist will remain involved in the young person’s care up to 23 years of age rather than transferring 18 or 19 year olds to the adult psychiatrist in the team.

In order to retain expertise within the different multi-disciplinary teams in CAMHS, there is teaching and updates on psychosis in young people available across the area.
Practice learning from the West Midlands

In early 2010, a regional audit was undertaken by NHS West Midlands to capture the current development of EIP/AMHS. In the final report the main concerns of EIP/AMHS managers were summarised. These indicate that:

- Relationships with CAMHS teams were variable
- There was a lack of understanding of each others’ services
- There was a lack of formal joint working and protocols/practices in place, especially around transition.

The issues identified as impacting on joint working between CAMHS and EIP/AMHS, or causing tensions or blockages in the care pathway for young people with psychosis in the West Midlands mirror other findings, namely that there is often a lack of communication between services, inconsistencies in service criteria and thresholds and a lack of clarity about assessment pathways and about managing those with an ‘at risk’ status. Other problems included young people being reluctant to use services due to stigma, illness denial, and also cultural barriers. Again the lack of appropriate inpatient provision for young people was identified as a problem.

At a procedural level, it was noted that there was no agreed policy for managing non-compliance and DNAs (missed appointments), no agreement as to what to do with young people with substance misuse problems; procedures for obtaining parental consent were also described as unclear or variable. At a practical level, CAMHS in West Midlands are unable to refer directly to EIP/AMHS; there can be delays in referrals being seen and there is different referral documentation between CAMHS and EIP/AMHS, including for CPA. All of which are further compounded by no computer database compatible and accessible to both services.

Working in locality clusters over a two-day period, staff from CAMHS and EIP/AMHS joined together to gain an understanding of their different services and to develop future plans. Staff wanted to attend each others’ referral meetings and to develop shared resources. Some of the ideas and suggestions for addressing these barriers to an effective, seamless CAMHS and EIP/AMHS interface were as follows:

- Developing a “Champion care co-ordinator”
- Flexible working hours and working to reduce duplication
- Joint risk assessments from the outset
- Training for staff in adult mental health services about CAMHS
- Development of family and service user support groups
- Shadowing of each others’ teams and development of peer discussion sessions
- Named links between CAMHS and EIP; more dedicated CAMHS/EIP/AMHS workers
- Quarterly managers meetings.

Case study: Cross agency workers in the West Midlands

In Sandwell, Worcester, Birmingham and Dudley, workers have been recruited to work across CAMHS and EIP/AMHS teams specifically to engage with younger people and to assist with the transition and joint working arrangements that arise when young people aged under 18 present with psychosis. The posts are jointly commissioned by Children’s and Adult Mental Health Service commissioners.

During the recent development workshops held in the West Midlands, the workers highlighted how their roles smoothed the pathways between CAMHS and AMHS for the young people. They had increased knowledge and understanding within the different teams working with young people, thereby also increasing the confidence of the workers.

Young people supported by these cross agency workers appeared to engage with services and it is felt that these roles have helped to increase the element of choice around service provision.

In another area of the region, Coventry, the EIP/AMHS team have a worker who champions work with the younger age group and who is well known within the local specialist CAMHS. This provides staff in both CAMHS and EIP/AMHS with a local practitioner who they can contact for advice who is familiar with the working processes and protocols in both settings.
The 2010 CAMHS-EIP/AMHS transition audit

NMHDU, NCSS and Rethink collaborated in 2010 to undertake an audit of services focused specifically on the care and treatment of 14-18 year olds. An online survey tool was developed and promoted across the country to all specialist CAMHS and EIP/AMHS teams.

In total, 122 services submitted a completed questionnaire, drawn from all regions of England. It was filled in by a team manager and the overall response rate was poor – 50.8% for EIP/AMHS and 26.5% for CAMHS. In 25 services (20%) the respondent filled in data for both their EIP/AMHS and CAMHS provision, which we have taken be to an indication of a level of ‘joined up’ working.

There are several problems with the audit. The response rate is low and many returns contained missing information and therefore the data provides a description of a proportion of services – not all of them. Several respondents commented that the data asked for was unavailable. Despite the limitations some important feedback was provided.

Variability in provision for young people

Services were asked:

- If they were working with young people aged under 18 with psychosis: 71% of EIP/AMHS and 43% of CAMHS reported this to be the case.
- If they thought these numbers had increased over the past five years: Just over half, 57% of respondents indicated yes.
- If their Mental Health Trust had a clear written policy for working with young people with psychosis: Overall (CAMHS and EIP/AMHS) 65% said yes. Broken down by service, 58% of CAMHS and 66% of EIP/AMHS replied yes.
- If they had a specialist transition protocol with CAMHS locally: Asked of EIP/AMHS teams, 58% of responding teams (response rate of 41%) have a protocol with CAMHS. If we include teams that provided no response, only 24% EIP/AMHS teams indicated they have a protocol.
- Where provision is closely aligned and data in the returns was provided jointly, 83% of services reported having a protocol.
- If they had a specialist transition protocol with EIP/AMHS locally: Asked of CAMHS teams, 54% of CAMHS teams responding (response rate of 32%) have a protocol with EIP/AMHS. If we include teams that provided no response, only 18% CAMHS teams indicated they have a protocol.
- Where provision is closely aligned and data in the returns was provided jointly, 86% of services reported having a protocol.
- If they had a protocol covering administration of anti-psychotic medication to under 18s: Asked of EIP/AMHS teams only, 42% of responding services reported that they did have a medication protocol (response rate 55%).
Identification of young people with psychosis

Possibly one of the most important areas of the online survey explored practitioner views as to whether young people with first episode psychosis, or at risk of developing psychosis, are being identified, and if not, their suggestions were sought as to why this remains a problem. We asked:

- If they felt that young people at risk were being properly identified: Less than half of the respondents, 43% of all services replied yes, with 57% responding no.

The most commonly reported explanations were:

- Interface problems and role confusion between teams
- Capacity limitations within team to do outreach work into the community
- Staff with inadequate training and a lack of resources to support early detection work to identify signs of early onset of psychosis, particularly in primary care or substance misuse services
- Young people are not engaging, related social exclusion of many and stigma
- GPs not referring.

A key problem which appears to be affecting the identification of young people is the funding of services to work with ‘at risk mental states’. This was reported in a number of the returned online questionnaires, with one EIP/AMHS team noting:

“We currently don’t provide an assessment services for ‘at risk mental states’ so very early detection is not implemented. We are not commissioned to do ‘Watch and Wait’ and have since stopped doing this work as the service is commissioned and funded to meet First Episode targets only.”

Another EIP/AMHS team reported:

“Lack of clarity around ‘at risk mental states’ within CAMHS and CMHT; GPs not referring on and more time needed to do health promotion work. In this area we have very good links with Connexions which does address some young people that would fall into this group. Stigma is also an issue around this.”

From a CAMHS perspective, it was noted that:

“There are difficulties in the way that EIP/AMHS and CAMHS work together as the capacity to join from EIP/AMHS to CAMHS early is limited due to resources and therefore their involvement does not come in early enough, i.e. that there is a strong suggestion of psychosis.”

Another suggested:

“Conflicting demands on services. High demand on CAMHS restricts access to medical staff and impacts on early treatment philosophy.”

Suggested solutions to this problem emphasised the importance of inter-team relationships and cross team training, also joint working of cases causing concerns. One EIP/AMHS team also wrote (about the non-identification or referral of young people):

“This maybe due to the fact that professionals are not sure where to place young people presenting with certain problems.”

“More education to primary health care professionals especially schools where most young people are seen, with challenging behaviours.”

Training of EIP/AMHS staff to work with young people

Staff working in EIP/AMHS were asked if they had received any training to work with young people aged 18 and under. The responses were as follows:

- 91% of respondents reported their staff had not received training to work with young people aged under 14
- 67% of respondents reported their staff had not received training to work with 14-16 year olds
- 64% of respondents reported their staff had not received training to work with 16-18 year olds.

In terms of what training was offered, in-house training appeared to be used most and the need for more joint training was noted and illustrated by the following comment:
“Would be useful to have some formal training in working with under 18s. We have a non-medical prescriber in the team and training in use of anti-psychotic medication in younger people would be an advantage.”

Linked to the lack of joint training is the problem of very different treatment approaches persisting between CAMHS and EIP/AMHS, for example:

“In some parts of the country the adult philosophy of treating people with severe and enduring mental illness is very, very different from the CAMHS preventive model.”

Funding restraints and boundary issues were also identified as playing a role:

“We have a positive relationship with CAMHS as we have a number of CAMHS staff who we have recruited. We also had a CAMHS consultant psychiatrist post which has now also become the adult post. There has to be a recognition that CAMHS services do things differently from adult services and that we can learn from each other. There are financial restraints in that we don’t take on under 14s and that we aren’t always able to train CAMHS staff in early recognition due to the staff turnover in CAMHS and boundary issues as we are funded by adult services.”

Access to inpatient facilities and crisis out of hours resources for young people

A number of questions in the online questionnaire explored practitioners’ access to inpatient resources and also sought their views on how this impacted on their ability to support young people.

- If they had access to age appropriate beds in the local area for young people aged under 14: The response rate to this question was 73%. Of those responding, 51% indicated that they had access to appropriate local beds. However definitions of ‘local’ do vary.
- If they had access to appropriate beds for 14-16 year olds: The response rate to this question was 60%. Of those responding, 47% indicated that they had access to appropriate local beds.
- If they had access to appropriate beds for 16-18 year olds: The response rate to this question 57%. Of those responding, 40% indicated that they had access to appropriate local beds.
- Whether young people can access out of hours crisis and home treatment support: Yes, particularly through local CAMHS crisis provision.

Of the 58% of teams responding to this question, 30% indicated that under 14s can access help out of hours; 41% reported that 14-16 year olds can access out of hours support and 82% reported that 16-18 year olds could access out of hours support.

Where CAMHS and EIP/AMHS are closely aligned access to out of hours provision was reported by 44% of teams for under 14s, 6% of teams for 14-16s and 88% of teams for 16-18s.

One concern apparent from the data is the variation across teams. Out of area placements (both age appropriate and inappropriate) were reported by 54 teams for young people, with an average distance of 24 miles and a range of 5 to 100 miles.

In some cases this was for secure provision alone, but mostly, it was because for 26% of teams, there is no local adolescent inpatient provision.

When asked what the average distance all young people travelled for age appropriate care across 68 teams the average was 27 miles. The furthest distance travelled was 65 miles.

Several respondents noted new units inpatient were due to open in 2010 so this situation may improve, however, in the meantime, the lack of local resources cause considerable difficulties for all concerned – young people who run the risk of losing contact with their local area; parents, carers and friends who may struggle to visit them and practitioners trying to support them. The following illustrate these difficulties:

“This is not local, it is 70 miles away. It makes for lots of problems in case management and for families seeing their young people” (CAMHS team)

And:

“Local provision not specifically for psychosis We have often had a small number of younger people admitted to private hospitals 100s of miles from home” (EIP/AMHS team)
The future

The findings from the online survey, alongside the other data presented in the report, indicate that progress has been made to improve the CAMHS-EIP/AMHS interface via a variety of mechanisms.

Despite these positive developments however, some serious concerns persist:

• Data collection about the 14-18 age group with first episode psychosis is still limited in many services, including hospital admission data.

• It is apparent that rates of identification of young people at risk are poor with, perhaps not surprisingly, numbers of young people on current caseloads not matching the expected prevalence for this age group.

• Access to appropriate inpatient resources remains an ongoing problem, with young people often travelling considerable distances and thereby becoming easily disconnected from their family, friends and peers, local educational system and community. Such circumstances exacerbate the isolation experienced by many young people with mental health problems and have important adverse social and educational consequences.

• Worryingly, in terms of building workforce capacity, the amount of training reported by staff in EIP/AMHS about working with young people aged 18 and under is extremely low.

Young people with first episode psychosis are a highly vulnerable group, at a significantly heightened risk of suicide around the time of first diagnosis and where a failure to identify and effectively support them can result in a wide range of life-long problems (with associated economic implications). Such problems include: struggling to complete education, gain qualifications or a job, have a home and maintain relationships.

At the same time, as McGorry and others point out, an inverse care law seems to be at work across many countries, not just in England, wherein service provision is weakest just at the points where it is most needed leaving those in greatest need without help. Such a situation is only compounded by a lack of good quality up-to-date data about both the numbers of young people needing help and the range of needs presented.

At the time of writing, a process of considerable reorganisation is underway across the NHS. Significant changes are planned for commissioning arrangements and the need to make savings and optimise the use of existing resources is high on the national policy agenda.

Within this challenging environment, it will be crucial for CAMHS and EIP/AMHS services to collaborate effectively. This includes collecting more detailed and better quality information about the numbers of young people with first episode psychosis they are working with, in order to justify ongoing investment in this area of mental health provision.

Alongside this, ensuring the effective involvement of young people, their families and carers in planning their care, and in ensuring that what is offered is age-appropriate and relevant to their needs, will be vital.

In some areas, joined up working is extending to service redesign with youth mental health services emerging to cover the transition gap providing child to aged 25 provision thus shifting transition away from adolescent. We await with interest research detailing the impact of these initiatives from young people, their families and routine service outcome data.
Recommendations

1. At a strategic level, there should be clearly agreed processes for gathering comprehensive data about young people with psychosis across CAMHS and EIP/AMHS.

2. Services should consider developing and aligning their outcomes indicators across CAMHS and EIP/AMHS, or having outcome specific to the client group of young people with psychosis, in order to assess any progress made in developing quality patient pathways and greater consistency of thresholds between services.

3. All services should develop an agreed protocol for managing young people aged under 18 with psychosis; this should be embedded within everyday practice and based on cross-agency agreement of threshold criteria.

4. The practice learning from the many CAMHS and EIP/AMHS teams who have become more closely aligned, including those with cross-agency workers, integrated models of provision and joint protocols, should be considered by those services still struggling to join up and develop a more ‘seamless’ service interface.

5. Opportunities for training between CAMHS and EIP/AMHS should be built into all local workforce development and training strategies. Joint training is noted in the literature as playing a key role in breaking down the cultural differences and lack of understanding that so significantly affects the CAMHS-EIP/AMHS service interface; it should include training for CAMHS in early detection work, and training for EIP/AMHS in the developmental needs of young people and skills for working with the 14-18 age group.

6. The availability of local age-appropriate inpatient provision requires ongoing monitoring at a national level since it is apparent that there are still significant gaps and geographic inequities. Young people also continue to be placed some considerable distance from home, which isolates them from key sources of emotional support (their family and friends) and disrupts their education, thus greatly increasing the risk of poor educational outcomes in the longer-term.

7. The growing body of evidence about alternatives to inpatient provision that can maintain young people with complex needs within their local community, or which can help to minimise lengths of inpatient stay, should also be drawn on to ensure that there is as little disruption to young people’s lives as possible.

8. Those working in CAMHS and EIP/AMHS should consider how youth mental health services can evolve and how their practice might contribute to this. Possibilities include the co-location of services, more ‘one-stop shop’ models and greater flexibility around the age at which transition between services takes place.
References


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Joint working at the interface

Working together to help everyone affected by severe mental illness recover a better quality of life

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