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Rapid Evidence Review Series:

Effective pathway from child to adult mental health services

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PROVIDING INTELLIGENCE FOR THE PUBLIC HEALTH

Rapid Evidence Review Series:

Effective pathway from child to adult mental health services

Contents

Summary

Liverpool Public Health Observatory (LPHO) was commissioned by the Merseyside Directors of Public Health, through the Cheshire & Merseyside Public Health Intelligence Network, to produce this rapid evidence review. The review presents the evidence of gaps in transition from child to adult mental health services and evidence of effective solutions. A rapid literature search of academic databases was conducted to examine research evidence from 2004 to 2014. As this is a rapid evidence review, not a full systematic review, the results should be regarded as provisional appraisals.

Background

Although there is evidence that young people aged 12-25 years have the highest levels of mental illness across the lifespan, access to mental health services is the poorest of all age groups (McGorry et al, 2013). At a certain age, 16, 17 or 18 depending on where the young person lives, those getting help from Child and Adolescent Mental Health Services (CAMHS) must move onto Adult Mental Health Services (AMHS). In many areas, a person may be too young to access adult mental health services, but may be either too old or not in the appropriate education to access CAMHS, leading to a period of no support (RCN, 2013).

To get any service from AMHS the threshold in terms of severity of illness is higher than CAMHS so many young people are locked out from receiving a service (YoungMinds, 2014). This often includes those with autism and ADHD, for whom there are a lack of appropriate adult services (SCIE, 2014).

Evidence of gaps

The TRACK study is a multi-site UK study aiming to explore issues around transition of care in mental health. It found that for the vast majority of service users, transition from CAMHS to AMHS is poorly planned, poorly executed and poorly experienced (Singh et al, 2008 and Singh et al, 2010b). A quarter of the cases with ongoing clinical need failed to be transferred and around one-third experienced interruption in their care (Singh et al, 2010b; JCP-MH, 2012). Only 4% of young people reported a good transition, with many disappearing from services (Singh et al, 2008; YoungMinds, 2014). The main reasons for transfers failing were young people's refusal to accept referral to adult services, and CAMHS clinicians' failure to refer. Other reasons included AMHS refusing to accept referrals or discharging young people who did not attend the first appointment offered (Paul et al, 2013).

A local study on transitional care to adult ADHD services in the Liverpool area found that as many as 73% (almost three quarters) of patients eligible for transition to adult services were either discharged or lost to follow-up (Ogundele, 2013).

Youths who disengage from services during transition have a significantly higher risk of developing more enduring mental health problems (Cappelli et al, 2014).

There is a major problem of a lack of information for young people and their parents and carers, and even staff, who often do not know what is available from other services or how to access it (SCIE, 2014).

Evidence for alternative approaches

Although it is widely recognised that transition services need to be improved, there is limited evidence on which policies can be based (Crowley et al, 2011; Swift et al, 2013a).

A transition outcomes evaluation across various countries by Cappelli et al (2014) concluded that it is necessary to have established formal transition services in place, that should be focussed on shared responsibilities to achieve effective transition.

In summary, available research would indicate that transition from CAMHS to adult services can be improved by

- planning early,
- listening to young people,
- involving the family in partnership, as they often continue in their role of advocate,
- providing appropriate and accessible information,
- providing a more holistically focussed, 'young people friendly' AMHS,
- training AMHS professionals in wider mental health issues, ADHD and ASD,
- using a transition co-ordinator and
- focusing on outcomes and joint commissioning.

(DH, 2011; SCIE, 2014; MHF, 2014; Cappelli et al, 2014; Hall et al, 2013; YoungMinds, 2014)

New joint commissioning model: The last bullet point above is the key to improving transition. Commissioners of mental health services will need to think beyond traditional models of care to approaches which view young people aged 16-25 as having distinct needs, providing holistic care to meet mental and physical health needs and support around relationships, education and employment (MHF, 2014). These services should be based on the model adopted by many UK Early Intervention in Psychosis Teams and some general mental health teams and voluntary counselling agencies, which offer a distinct service for young people up to the age of 25 (YoungMinds, 2014). As well as parts of the UK, this approach has been successfully employed in Australia and parts of Ireland (McGorry et al, 2013).

In the meantime, Paul et al (2013) suggest that CAMHS clinicians should make referrals to AMHS based on need, regardless of assumptions about whether adult services will accept them, which will help to highlight current gaps in services.

Despite their limited evidence base, it is important that new models of transitional care are implemented now, based on available good practice examples. All models should include an evaluation component, and include qualitative research involving young people, to help assess outcomes (SCIE, 2014).

Key Findings

- Young people aged 12-25 have the highest levels of mental illness, but the poorest access to services
- In many areas, a young person may be too old to access child mental health services and too young to access adult mental health services
- Many leaving CAMHS may not be accepted by AMHS, where illness levels often have to be more severe to qualify for help
- A quarter of those with ongoing clinical need may fail to be transferred, with numbers higher for those with ADHD (almost three quarters)
- Only 4% of young people report a good transition
- Young people, carers and even staff have a lack of knowledge of other services available
- Available evidence indicates that transition can be improved by:
  - planning early,
  - listening to young people and involving the family in partnership, as they often continue in their role of advocate,
  - providing appropriate and accessible information,
  - providing a more holistically focussed, 'young people friendly' AMHS,
  - training AMHS professionals in wider mental health issues, ADHD and ASD,
  - using a transition co-ordinator,
  - using joint commissioning, ideally to provide a mental health service tailored to meet the needs of young people up to the age of 25.

1. Background

Liverpool Public Health Observatory (LPHO) was commissioned by the Merseyside Directors of Public Health, through the Cheshire & Merseyside Public Health Intelligence Network, to produce this rapid evidence review. It is the fifth in a series of LPHO reviews, with previous reviews covering the topics of loneliness interventions, the cost effectiveness of monitored dosage systems, suicide prevention training and outdoor air pollution. This review presents the evidence of gaps in transition from child to adult mental health services and evidence of effective solutions.

Aim

The review will aim to identify evidence of gaps in transition and an effective pathway from child to adult mental health services. It will add to the Joint Strategic Needs Assessment (JSNA) evidence bank, supporting evidence based commissioning of services. It will inform the JSNA Clinical Commissioning Group (CCG) review of commissioned services.

The review was requested by Wirral Borough Council, who noted that anecdotal evidence suggests there is a gap in transition from child to adult mental health services including those not in contact with Child and Adolescent Mental Health Services (CAMHS). The review will be shared with partners across Merseyside to inform similar work being undertaken.

Rapid evidence reviews are used to summarise the available research within the constraints of a certain timescale, typically less than three months and in this case, three weeks. They differ from full systematic reviews due to these time constraints and therefore there are limitations on the extent and depth of the literature search. They are as comprehensive as possible, yet some compromises are made in terms of identifying all available literature. They are particularly useful to policy makers who need to make decisions quickly but should be viewed as provisional appraisals (CRD, 2009).

CAMHS transitions

CAMHS are specialist Child and Adolescent Mental Health Services. At a certain age, 16, 17 or 18 depending on where the young person lives, those getting help from CAMHS must move onto Adult Mental Health Services (AMHS), a process termed 'transition'. The Royal College of Nursing (RCN) report 'Lost in Transition' noted that in many areas, the upper threshold for accessing CAMHS can be different to the entry threshold for AMHS. A person may be too young to access adult mental health services, but may be either too old or not in the appropriate education to access CAMHS (RCN, 2013). YoungMinds (2014) described the 'postcode lottery' in access to services, with the transition from CAMHS to AMHS being subject to extreme local variation. Some young people make the transfer to adult services at 16, some at 16 if not in school or 18 if in school, and some at 18, and many not transferring at all but disappearing into a 'void' (YoungMInds, 2014). For those no longer eligible for CAMHS there is often a period of no support as they wait to access AMHS services and are put back on waiting lists (YoungMinds, 2014). For some young people this can result in never making the transition (RCN, 2013). This transition gap is not a new problem, nor one confined to mental health services (Rayment, 2014; RCN, 2013).

The recent Mental Health Foundation guide for commissioners noted that although teenagers and young adults are at a notably higher risk for the onset of mental health problems, they face barriers to accessing effective and early care. Transitions between services for children and adults tend to be poorly co-ordinated and there is a lack of age-appropriate mental health care (MHF, 2014).

In addition to those 'lost in transition', of equal concern are the greater number of young people who, around the age of 17, become ill but fail to get any help at all in many areas of the country (Rayment, 2014).

YoungMinds (2014) note that to get any service from AMHS the threshold in terms of severity of illness is higher than CAMHS so many young people are locked out from receiving a service. For some, their illness has to reach crisis point before they receive a service from AMHS with the effect that their entry to services is more traumatic and more costly to the young person, family and to services than it would have been had their needs been met earlier (RCN, 2013; DH, 2014).

The early TRACK study of transitions in London found only 4% of young people reported a good transition, with many disappearing from services (Singh et al, 2008; YoungMinds, 2014). Transfer to adult services often leads to repeated assessments and new staff to deal with. Differences between the service location and style of the two services often alienates many young people (YoungMinds, 2014).

ADHD and autism

The Social Care Institute for Excellence (SCIE, 2014) research briefing on mental health service transitions for young people noted that for some groups, long-term experiences and outcomes into adulthood are not well documented. This is especially the case for young people with learning disabilities, attention deficit hyperactivity disorder (ADHD) and autistic spectrum disorders (ASDs) (SCIE, 2014; Swift et al, 2014b). Young people with these difficulties who receive help from CAMHS are likely to need ongoing support as adults - however, there is a lack of adult services to cater for them (SCIE, 2014; Murcott et al, 2014). Adult mental health services (AMHS) tend to focus on services for people with severe and enduring illnesses such as psychosis or severe depression (JCP-MH, 2012). As a result, many young people fall into a gap between CAMHS and adult care.

National Policy

Government policy states that CAMHS should be accessible to young people until their eighteenth birthday (RCN, 2013). The Royal College of Nursing (RCN) noted that this is a current proxy measure for the public service agreement (PSA) target of a comprehensive mental health service for children and young people. The RCN point out that transitional services need to be up and running now to help young people in this age group. The Adult Mental Health National Service Framework (NSF) requires services to have a transition protocol. Again, the RCN note that such protocols should be functioning now (RCN, 2013).

The 2011 mental health outcomes strategy *'No health without mental health'* states that service transition from CAMHS to adult services can be improved by planning early, listening to young people, providing appropriate and accessible information and focusing on outcomes and joint commissioning (DH, 2011; SCIE, 2014).

A recent House of Commons Health Committee report found that there are issues with the commissioning and provision of CAMHS (HC, 2014). These issues run through the whole system from prevention and early intervention through to inpatient services for the most vulnerable young people. The Committee draws conclusions and makes recommendations for action. They reported from an NHS England statement as follows:

> *'transition from child centred to adult services is currently poorly planned, poorly executed, and poorly experienced. This can lead to the "cliff edge" where support falls away; the young person disengages, and may present as their first episode of transition acutely in crisis to an adult Emergency Department.*
>
> *To avoid this and ensure a smooth and integrated pathway to adult services, NHS England, through its transition work stream, is defining the mental health requirements for a service specification for children and adolescents in 2014. CCGs and Local Authorities*

will be able to use the specification to build best measurable person-centred services that take into account the developmental needs of the young person as well as the need for age appropriate services' (HC 2014, para 104, from NHS England [CMH0193] para 41).

The recent government mental health policy document 'Closing the Gap' states that it will end the 'cliff-edge of lost support' as children and young people with mental health needs reach the age of 18 (DH, 2014). The government plans to support the NHS England work to develop a service specification for transition from CAMHS, for use by CCGs and local authorities in commissioning high quality age appropriate services. There will be a range of quality indicators such as personalised transition plans that include joint meetings with CAMHS and adult mental health services. For those who do not need to transfer to adult services, it will include information on how to access services if they become unwell. They plan to undertake a scoping study to examine evidence for both physical and mental health services focused on the 15-24 year age group and the implications this might have for care pathways, social workers and health professionals in the UK.

For young people with autism, the adult autism strategy 'Think Autism' included transition as one of its themes. It states that *'local areas must follow statutory duties around transition for children with SEN, which will include most young people with autism. Protocols should be in place in every area for the transition of clinical mental health care for children with autism in receipt of CAMHS'* (DH, 2014a).

Under the Children and Families Act 2014, a new Code of Practice covers children and young people with special educational needs and/or disabilities (SEND) from birth to age 25. Education, Health and Care Plans (EHC plans) will now replace statements of special educational needs (SEN) and learning difficulty assessments (LDAs) (DfE, 2014). It is expected that these changes will lead to the improved integration of health and social care provision for young people up to the age of 25.

Methods

The researcher based the search strategy as closely as feasible in the permitted timescale to the CRD guidance for undertaking rapid evidence reviews (CRD, 2009).

Identification of studies

The following electronic databases were searched, initially from 2004-2014: Web of Science, Scopus, National Institute for Health and Clinical Excellence (NICE) and the NIHR Centre for Reviews and Dissemination database (CRD database). The CRD database was the first to be searched, as this includes all the main systematic reviews relevant to public health and also includes Cochrane reviews.

The researcher developed a research strategy incorporating synonyms and spelling variants, based on key papers and how they had been indexed, and were adapted to each database. Reference lists were visually scanned from relevant articles meeting the inclusion criteria.

Inclusion and exclusion criteria

The brief for this rapid review was to summarise the evidence relating to children (14-17 years) and adults. All non-clinical interventions were to be included, with clinical interventions excluded. Transitions for those with attention deficit hyperactivity disorder (ADHD) and autism were to be included.

The primary outcome measure was 'seamless transition over to adult mental health services'.

The review looked for evidence in papers published since 2004, up to 1st September 2014. Key search terms for the review included combinations of the following: child; mental; CAMHS; AMHS; transition; pathway; evidence; continuing care; shared management; early intervention psychosis team; ADHD; autism.

Initially, searches were made for key words in the title plus abstract fields. If this produced too many articles for the particular search term, then the search for that term was limited to the title only and then to more recent time periods.

2. Results

2.1 Evidence of gaps in transition

In 2004, a qualitative UK study in Leicester found that statutory mental health services were not geared towards ages 16-19 and that there were no formal transfer arrangements from child to adult services (Richards and Vostanis, 2004). Problems with transition remain and are not restricted to the UK, as indicated in a 2014 Canadian study by Cappelli et al (2014). This study documented evidence from various countries indicating that youth who are engaged with CAMHS and require continued services in AMHS are not well supported as they prepare for transition.

There is widespread evidence of youth disengagement from mental health services, including US studies that indicate that disengagement occurs in around 60% of known cases (Cappelli et al, 2014). Capelli et al point out that one of the consequences of this disengagement is crisis-driven reconnection in the future. They noted that youth who disengage from services during this transition have a significantly higher risk of developing more enduring mental health problems.

Cappelli et al (2014) noted the lack of integration and effective collaboration between CAMHS and AMHS in Canada, US, UK and Australia, as illustrated in the UK TRACK study by Singh et al (2010a). The TRACK study is a multi-site study aiming to explore issues around transition of care. It found that for the vast majority of service users, transition from CAMHS to AMHS is poorly planned, poorly executed and poorly experienced (Singh et al, 2008 and Singh et al, 2010b).

The first stage of TRACK was a study of CAMHS' transition protocols in Greater London (Singh et al, 2008). Discontinuity in care provision was found for some patients who leave

CAMHS services but are not accepted by adult services. For each CAMHS team, there were an estimated annual average of 12.3 cases considered suitable for transfer to AMHS per CAMHS team, but there were only an average of 8.3 cases per team actually accepted by AMHS. The study found that not all protocols met all requirements set out by government policy, with none specifying how users should be prepared for transition and no procedures to ensure continuity of care for those not accepted by AMHS.

A more recent analysis of TRACK data covered three mental health trusts in Greater London and three in the West Midlands. It was found that although transfer of care was common, good transitional care was rare (Paul et al, 2013), confirming the earlier TRACK finding that only 4% reported good transition (Singh et al, 2008), as mentioned on p.2. Where transfers failed, more often this was because of young people's refusal to accept referral to adult services, and CAMHS clinicians' failure to refer, rather than AMHS refusing to accept referrals or discharging young people who did not attend the first appointment offered (Paul et al, 2013). Paul et al noted that the latter two reasons have been assumed to be the main reasons in the past.

A systematic review of the literature into barriers to mental health help-seeking in young people found that stigma and embarrassment, problems recognising symptoms (poor mental health literacy), and a preference for self-reliance were perceived as the most important barriers (Gulliver et al, 2010). There is a lack of age-appropriate mental health services to support this particular group. Adult mental health services are often not designed or delivered in ways that young people wish to engage with (Right Here, undated). Gulliver et al noted that aids to help-seeking were comparatively under-researched. There was some evidence that young people perceived positive past experiences, and social support and encouragement from others as factors in encouraging help-seeking.

Murcott et al (2014) pointed out that placing limits, such as age cut-offs, on the time allowed with a service does not reflect need and strays a long way from the ethos of a person-centred service. They noted that wherever transition occurs, there is a risk of falling through this ‘gap’ and being failed by services, but this is less problematic for older ages, as young people aged 12-25 are more likely to need help (McGorry et al, 2013).

Lack of information

The SCIE research briefing noted that there is a lack of information for young people and their parents and carers, and even staff, who often do not know what is available from other services or how to access it (SCIE, 2014).

ADHD

As mentioned on p.3, there is a lack of research tracking transition from child to adult mental health services for young people with ADHD (SCIE, 2014; Swift et al, 2014b). Studies have shown that as young people with ADHD move into adulthood, prevalence of ADHD declines. However, there will still be a significant number of adults requiring appropriate services to manage their ADHD. At transition, they will often have ongoing symptoms needing

medication and co-morbid conditions; they are at increased risk of committing criminal offences (Taylor et al, 2010; Swift, 2013a; Ogundele, 2013).

In ADHD, a major challenge comes from adult services being comparatively poorly developed (Taylor et al, 2010; Crowley et al, 2011; Swift et al, 2013a). National Institute for Health and Clinical Excellence (NICE) guidelines provide an evidence base for the need to provide transition services for young people with ADHD who have continuing impairment (NICE, 2008).

In a review of transition and the current failings of services, Murcott et al (2014) similarly noted the difficulties faced by some young people who have been with CAMHS with ongoing mental health difficulties such as autism, depression or ADHD. Once they reach a certain age, clinicians may be concerned that they would not be accepted by AMHS and so they do not get referred (Murcott et al, 2014), as in the findings of the TRACK study mentioned on p.6 (Paul et al, 2013).

A study by Swift et al (2013a) involved qualitative interviews with ADHD patients accessing CAMHS clinics in Nottinghamshire. The authors found that the more 'complex presentations' with associated mental health problems that were more familiar to AMHS (e.g. self-harm, depression) were more likely to have smoother transitions to adult services. Transitions to AMHS were more difficult when ADHD was viewed as the main or sole clinical problem.

A local study on transitional care to adult ADHD services in the Liverpool area found that 21% of adolescents on the specialist ADHD database were eligible for transition to adult services and 18% were referred to CAMHS (Ogundele, 2013). The study found a high rate of discontinuation of medications, loss to follow-up and a very low rate of successful transition to locally commissioned adult ADHD services amongst those diagnosed with ADHD in childhood. As many as 73% (almost three quarters) of eligible patients were either discharged or lost to follow-up.

Autism

Young people with autism face similar challenges around transition. Recent research by the National Autistic Society (NAS) involved a survey of 455 parents of children with autism and a survey of CAMHS professionals (Read and Schofield, 2010). They found that those CAMHS services that took steps to achieve a smooth transition to adult services often found it very difficult to get adult mental health services to participate in the process (Box 1). It is hoped that the new adult autism strategy will lead to improvements (DH, 2014a, see p. 4).

Box 1

"I would start thinking about transition from 14 plus, but it is very hard to get social care and adult mental health involved at that age. In fact, it is almost impossible. …… like a complete lottery, there is almost no planning involved at all. It all seems to be done as a crisis, rather than in a planned way".*

Clinical Psychologist (in Read and Schofield, 2010)

** this was one of the recommendations in the NICE guidance (NICE, 2013)*

2.2 Evidence for alternative approaches and examples of good practice

It has been noted that although many agree that adolescent transition services for physical and mental health need to be improved, there is little empirical data on which policies can be based (Crowley et al, 2011; Swift et al, 2013a).

2.2.1 TRACK study

The UK TRACK study (see p.5) found that a quarter of the cases with ongoing clinical need failed to be transferred. One of the two main reasons for this was CAMHS clinicians thinking that AMHS would reject the referral or would not have appropriate services (Paul et al, 2013). Paul et al suggest that making referrals based on need, regardless of assumptions about whether adult services will accept them, may highlight the types of adult service that are inadequate or non-existent. This should aid the development of appropriate services for young adults.

The second main reason for failure to transfer was the young person's refusal to be referred to AMHS.

SCIE (2014) summarised the TRACK findings on the features of the best transitional services as follows:

- effective information transfer (e.g. referral letters and case notes, and written information for the young person)
- a period of parallel care and joint working between CAMHS and AMHS or other services
- transition planning with at least one meeting including the young person, parent/carer, CAMHS, AMHS and other services
- continuity of care (from AMHS or elsewhere) at least three months after transition.

2.2.2 Canadian shared management project

Cappelli et al (2014) carried out an evaluation of a youth transition project in Canada, based on the 'shared management' model of managing transition. This involved a flexible collaborative approach to promoting coordination and continuity of care between CAMHS and AMHS. A key feature of the project was an advisory committee of hospitals and all other agencies involved. The other key feature was the transition co-ordinator, who helped prepare and see the youth and families through the transition period.

The evaluation study found that of 215 youths who were assessed by the transitions youth coordinator, there was successful transition for the 127 (59%) who went on to be seen by an AMHS provider. Although levels of disengagement were much less than suggested by national studies (60% - see p.6 above), there were still 47 (22%) who cancelled services and 41 (19%) who remained on the waiting list. Those on the waiting list were found to have more behavioural disorders and those who cancelled, more anti-social behaviour and anxiety disorders than youths who remained in the programme. Those remaining in the

programme and undergoing transition were more likely to suffer from psychological distress (Cappelli et al, 2014).

There was success in reducing transition waiting times significantly over the study period, from an average of 134 days when the project began in 2011 to 69 days in 2013.

The authors concluded that although the project failed to address waiting lists, overall, the model had been successful in promoting continuity of care by transitioning youth seamlessly from youth to adult services. However, they point out that qualitative research with young people undergoing transition is needed, to determine whether they would regard their transition to AMHS a success. Success at an administrative level is not necessarily success at a personal level. The SCIE (2014) research briefing similarly noted that even when young people are successfully referred to adult services, the move may not go well, as practice is frequently inconsistent and often poor.

Cappelli et al (2014) suggest that the waiting list problem illustrates the need for a clinical transition team to provide essential services that can bridge waiting times in order for youth to continue their services without interruption. They note that existing CAMHS providers could also attempt to continue providing services as youth await placement with AMHS (Cappelli et al, 2014).

To reduce the rate of disengagement during transitions in care, according to Capelli et al, (2014), research indicates that it is necessary to have established formal transition services from child to adult systems of care in place and that transitional models of care should be focused on shared responsibilities to achieve effective transition.

2.2.3 Young adults service up to age 25

It has been suggested that if commissioners across youth and adult services are willing to consider the joint commissioning of services for 16-25 year olds, then they can build local capacity to meet the distinct needs of this age group (Rayment, 2014; Murcott et al, 2014; Lamb et al, 2013).

Although there is evidence that young people aged 12-25 years have the highest levels of mental illness across the lifespan, access to mental health services is the poorest of all age groups (McGorry et al, 2013). This is becoming an increasing problem, as McGorry et al note the changing experience of the developmental transition from childhood to adulthood in the 21st century, with emerging adulthood becoming a more prolonged and unstable developmental stage, with increased risks of mental ill-health. At present, it is felt that the mental health system is weakest where it needs to be strongest (Box 2) (McGorry et al, 2013; Paul et al, 2013).

The review by Murcott et al (2014) of transition and the current failings of services noted the potential of aligning services around young adults aged under 25 years, a strategy which has been well received in Australia and is being considered in parts of the UK and Ireland.

Box 2

'If we were to set about designing mental health services now, we would not include a transition point at age 16-18 years; indeed this is the point likely to do most harm'.

McGorry et al, 2013

Australia

In Australia, Headspace is an expanding primary care level model of youth mental healthcare, operating nationally across the country. It provides early intervention for people aged 12-25 with mental ill-health. It is run through highly accessible youth friendly centres that operate as a 'one-stop-shop', covering all young people's physical and health needs. Initial evaluation shows that clinicians and young people reported how useful it was to have medical and counselling services co-located (McGorry et al, 2013).
The early intervention for psychosis programme, largely focused on young people aged 15-24, is being scaled up across Australia and will be linked where possible to the expanding Headspace network. This will provide a backup for the young people in Headspace who need a more specialist service with a youth-friendly culture (McGorry et al, 2013).

In Melbourne, south east Australia, a comprehensive service for the under 25s is already in place. The Orygen Youth Health programme provides a second tier back up system to Headspace, for those aged 15-25 with complex or severe conditions who need more specialist mental health services. There are four specialised clinics and one in-patient facility, covering different mental health needs. There is a focus on vocational interventions and groups that focus on assisting clients with school, study and work goals and functioning (McGorry et al, 2013).

Ireland

In Ireland, Jigsaw is a public-private funded initiative providing additional early intervention support to young people up to age 25, largely operating to co-ordinate existing provisions (McGorry et al, 2013).

Birmingham

In the UK, Youthspace in Birmingham has provided improved youth access and care through the redesign of existing secondary mental healthcare provision. In partnership with the Prince's Trust, Youthspace was created by the Birmingham and Solihull Mental Health Foundation Trust to jointly deliver mental health services to young people under 26 years old in Birmingham, placing social inclusion and employment at its heart. Young people are assessed within one week of referral and are seen in low-stigma sites of the young person's choice, including primary care or Prince's Trust facilities. Youthspace also operates across Birmingham providing mental awareness and interventions to promote resilience in young people in schools or targeted groups. Evaluation of Youthspace is in progress (McGorry et al, 2013).

Paul et al (2013) note that there are some who would debate whether separate youth mental health services are preferable. They suggest there might be an argument for generic adolescent health services rather than condition-specific (e.g. psychosis-specific) or youth mental health services.

Norfolk

Lower et al (2014) describe how Central Norfolk Early Intervention Team (CNEIT) offers support to individuals aged between 14 and 35 years who are experiencing their first episode of psychotic symptoms. Within this service, a specialist youth team operates to support individuals who come into the service aged between 14 and 17 years. The youth team will work with young people who present with attenuated psychotic symptoms and complex social circumstances, behavioural disturbance, substance misuse or high levels of distress. Young people in this age group can receive a five year service rather than a usual three year service in order to reduce the need for unnecessary transition between services and make smoother transfers to Adult Mental Health Services (AMHS) or back into primary care (SCIE, undated; Lower et al, 2014).
The team offers an intensive outreach model of treatment, where young people are seen in youth-friendly, non-stigmatizing venues rather than clinic or office-based appointments, with faster access to services. Appointment times are flexible, and missed appointments do not exclude the client from the service. The team accepts referrals from all agencies (voluntary and statutory), as well as self-referrals and referrals from family members (Lower et al, 2014).

Lower et al (2014) note that this early intervention in psychosis model has been instrumental in overcoming some of the weaknesses in service provision at the transition point between CAMHS and AMHS. Data on outcomes of the CNEIT is being gathered and early indications are that the 'did not attend' (DNA) rates are very low (2009/10). Of those who DNA, 74% are now showing good engagement with the team, whereas previously CAMHS would have excluded them after 3 missed appointments (SCIE, undated). Feedback from young people using the service has been positive, e.g.:

> *'[Staff] didn't just ask me about my mental health and all the weird stuff, but helped me sort out all the things that were stressing me out; college, getting a safe place to live, helping smooth out arguments in my family.' (SCIE, undated).*

Lower et al (2014) note that it has been suggested that this model could be successfully broadened to young people with other emerging, potentially severe or complex disorders (by McGorry, 2007; McGorry et al, 2007; and Singh 2010).

Norfolk and Suffolk NHS Foundation Trust has built on the success of its youth early intervention team and innovatively redesigned its services in line with this model by developing a specific youth mental health service. This service is designed to meet the needs of young people aged between 14 and 25 years with emerging severe mental health difficulties, thereby reducing the problems of transition between CAMHS and AMHS. The service has been developed to be more age appropriate for adolescents and young people than traditional child or adult services, and young people have been consulted throughout the design of the service. The pilot of this service was launched in April 2012 (Lower et al, 2014).

Leeds

The Leeds Transition Service increased the age of CAMHS service users from 17 to 18. CAMHS and AMHS managers and clinicians meet regularly to review their transition protocols and practice. The two dedicated transition workers are primarily involved with young people aged 17.5 to 18.5 years during the service transition period, with robust transition planning taking about six months for most young people. They also work jointly across services, for example attending team meetings of community mental health teams in AMHS (SCI, 2014).

Mental Health Foundation and 'Right Here project

A guide for commissioners of mental health services for young people has been produced by the Mental Health Foundation (MHF, 2014). The guide is based on a pioneering five-year programme run by the Mental Health Foundation and Paul Hamlyn Foundation at four sites across the UK, known as 'Right Here'. It notes that adult mental health services are often not designed or delivered in ways that young people wish to engage with, and the fear of being stigmatised for having a mental health problem is a major factor in young people's decisions not to access help from mainstream, traditional services. The guide suggests that *'commissioners will be required to think beyond traditional models of care and look towards innovative, and even radical, service models and approaches – approaches which view young people aged 16–25 as having distinct needs, and which place mental health support within the wider context of their lives, including their physical health, relationships, education and employment'* (MHF, 2014).

Suggestions for commissioners include the following:

- Joint Strategic Needs Assessment (JSNAs) should include a specific focus on 16-25s in their assessment of mental health needs. It is not appropriate to amalgamate young people and children in needs assessments, as the needs of a 20-year old are considerably different from a 12 year old (MHF, 2014).
- Pathways of care should be commissioned that cross age barriers, for example with early intervention in psychosis services. Providers should commission interventions that promote mental wellbeing and early intervention for the 16-25 year age group, for example in sixth forms and colleges and universities.
- There are various ways in which services can be made more 'young people friendly', for example by engaging with young people where they are, rather than expecting young people to come to them. There are links to resources and further guides to encourage this (http://www.righthere.org.uk/resource-centre/).
- To fully understand how effective young-people focused commissioning has been, it will be necessary to complete the feedback loop and ask the young people involved what difference it has made to them and their peers.

(MHF, 2014)

The 'Right Here' project has adopted these approaches and reported improvements including greater service uptake by young people and improved mental health and wellbeing of young people using services (MHF, 2014; Right Here, undated).

The Joint Commissioning Panel for Mental Health (JCP-MH) produced earlier guidance for commissioners on transitions for young people (JCP-MH, 2012). Their document is based on the guidance *'Planning Mental Health Services for Young Adults – Improving Transition: a Resource for Health and Social Care Commissioners'* (NCSS, 2011). The guide suggests that there is no prescribed 'best practice' model to meet the needs of young people in transition. Many different models can be found across the UK (JCP-MH, 2012). The guide includes examples of these models, including the Wirral 16-19 Transition Service and the City and Hackney extended CAMHS service for young people aged 18–25 years (p.8-9, JCP-MH, 2012).

Voluntary sector

Key points of transition often occurring in adolescence include leaving education; change and breakdown in family and other relationships; leaving or living away from home; entering work or training. Rayment (2014) notes that these transition points often occur at the very time (i.e. in late adolescence and early adulthood) when many statutory services are the least sensitive to their needs. In contrast, youth counselling services are often available to young people up to 25 years. These and other voluntary services are able to sustain help to young people through adolescence and into young adulthood, assisting with transitions (Rayment, 2014). Unlike many statutory mental health services, many Youth Information, Advice, Counselling and Support Services (YIACS) have the capacity to address a range of problems alongside offering help with mental health problems. This was also a feature of the Norfolk CNEIT service mentioned above (p.10).

Lamb et al similarly noted that it might be possible to achieve improved access and a broader range of interventions for young adults by working more closely with YIACS and with GP-Led primary care services such as the Young People's Clinic in Herne Hill, South London (Lamb et al, 2013).

2.2.4 Parental involvement

A Nottinghamshire study (Swift et al, 2013a) found the need for continued parental support was openly accepted by the majority of young people with ADHD during transition. Similarly, a study by Gerten and Hensley (2014) into the transition of children with mental illness noted the importance of working in partnership with parents of transition-age clients. The authors point out that this recognises the fact that parents often continue in the roles of advocate, coordinator of care, and medication manager, as well as being a nurturer and caretaker during the transition stage.

2.2.5 ADHD and autism

Taylor et al note that continuing support in adulthood for those with ADHD could be provided by trained professionals including general practitioners, adult mental health teams and specialist adult ADHD nurses (Taylor et al, 2010).

A more recent study of ADHD transitions in the East Midlands called 'Mind the Gap' involved a survey of 96 healthcare professionals working in CAMHS and adult mental health services (Hall et al, 2013). The authors concluded that there is a need for an increase in ADHD-specific training for clinicians in adult services, the development of specialist adult ADHD clinics and greater involvement of primary care to support the work of generic adult mental health services in adult ADHD management.

In his Liverpool study, Ogundele (2013) formulated a multi-disciplinary local transitional care pathway to adult services for young people with complex health needs and learning difficulties (see Figure A1 in Appendix). He noted that establishing a formal transitional process early from the age of 13 amongst those with childhood ADHD, with a multi-disciplinary team approach providing holistic care, may improve the rate of follow up and successful transition. Ogundele concluded that adult ADHD services should be carefully planned to be able to accept referral from a wide range of healthcare professionals, including young people diagnosed with ADHD in childhood but lost to follow-up, and those not diagnosed in childhood but with recognisable symptoms.

Ogundele et al (2013) noted the evidence in the literature of the benefits of smooth transitions. This included how effective multi-disciplinary coordination and planning of transitional care leads to reductions in medication errors, decreased Emergency Department and hospital admissions, decreased readmissions, increased outpatient follow-up and medication compliance in adolescents with complex medical care needs. Conversely, poor transition can lead to disengagement with potentially serious outcomes and additional health service costs (Ogundele, 2013).

2.2.6 Reviews and recommendations for models of transitional care

The authors of the Leicester study (see above p.5, Richards and Vostanis, 2004) outlined possible models for the development of transitional mental health services for those aged 16-19. One possibility was a designated service for those aged 16-19, but they noted that this would have the drawback of adding yet another transfer point. Other suggestions included designated staff trained in working with older adolescents being placed within adult mental health teams. Richards and Vostanis point out that in all cases, mental health professionals need to incorporate the involvement of social workers, educationalists and youth workers. They note the need for further debate and evaluation.

In 2005, Tantum noted that if the age-limit for CAMHS was universally accepted as 18 years of age, this would help to deal with the transition problems between CAMHS and adult mental health services. However, he pointed out that philosophies of care traditions between the two services are so different that a barrier will continue to exist. Tantum concluded that some degree of joint working will be the best way forward (Tantum, 2005).

Crowley et al (2011) undertook a systematic review of transitional care programmes in physical and mental health in an attempt to identify their successful components. They noted that there has been little high quality evaluation published. Although their search strategy included all chronic physical and mental conditions and disabilities, they found it striking that the only condition for which any evaluated transition programme achieved successful

outcomes was diabetes mellitus. The review concluded that existing evidence supports the use of educational programmes, joint paediatric/adult clinics and specific young adult clinics.

SCIE transitions briefing

The SCIE (2014) research briefing on mental health service transitions for young people set out how effective transitions could be supported, based on research evidence and practice, summarised as follows:

> • Start early: at least six months before transition *(preferably age 14, as suggested for autism and ADHD in NICE, 2013 and Ogundele 2013)*
>
> • Involve the family
>
> • Give timely and accurate information and be sensitive to feelings, keeping the young person informed
>
> • Assess needs and make multi-agency plans which give the young person a more central role in deciding their care plan
>
> • Ensure that assessments are co-ordinated
>
> • Use care planning models that involve and empower the young person
>
> • Think about the different professionals who might need to be involved and establish links with them
>
> • Develop flexible ways of working as much as possible

(SCIE, 2014)

YoungMinds (2014) and the National Advisory Council (NAC, 2009) added:

> • Young people need to receive a continuity of care with no delay in receiving services. They note that there are already examples of services in England which combine the expertise of CAMHS and AMHS to work together to support young people and their families. Many Early Intervention Psychosis Teams have successfully combined CAMHS and AMHS, with both disciplines learning from each other
>
> • Whatever age is chosen to move young people into Adult Services, the transfer should be negotiated and supported to make sure that the young person does not leave services only to experience great difficulty in another aspect of their life and, for example, end up in the criminal justice system, or turn their back on services altogether
>
> • AMHS budgets need to shift to focus more on the 16-19 age group, which YoungMinds suggest is an 'invest to save' argument

• The style of service needs to change within AMHS so it is more holistically focused, as in the CAMHS model

(YoungMinds, 2014 and NAC, 2009)

As detailed on p. 11 above, the Mental Health Foundation guide for commissioners included the following:

• Joint Strategic Needs Assessment (JSNAs) should include a specific focus on 16-25s in their assessment of mental health needs

• Pathways of care should be commissioned that cross age barriers

(MHF, 2014).

Good practice examples in the SCIE research briefing include a website for staff, young people and families being developed in Liverpool, bringing together information on transitions and services (SCIE, 2014).

CQC and NICE

The recent CQC review (CQC, 2014) and proposed NICE guidance on transition from children's to adult services focused on young people with physical needs and did not consider mental health services. They suggested there should be distinct young people's services for people aged 14 to 25, which they commented is a credible approach that works well in some mental health services for example. No further details were given.

Autism

NICE guidance on autism recommends that individuals are reassessed at around age 14 to establish the need for continuing treatment into adulthood. It states that *'for young people aged 16 or older whose needs are complex or severe, use the care programme approach (CPA) in England, or care and treatment plans in Wales, as an aid to transfer between services'* (NICE, 2013).

3. Discussion

Starting with a clean slate, the design of mental health services would not include a transition point at the age when it is likely to do the most harm, as is the case now, as pointed out by McGorry et al (2013). They suggest that the aim of youth mental health and wellbeing services should be to reduce the need for transition into adult services (McGorry et al, 2013).

Joint commissioning between CAMHS and AMHS to provide a service for young people up to the age of 25 would appear to be a promising approach. McGorry et al (2013) point out that new initiatives are usually asked to prove themselves, whereas this is not always the case for those supporting the status quo. They argue that the status quo tends to privilege the needs of professionals and managers over those needing the service.

Despite their limited evidence base, it is important that models of transitional care are implemented now, based on available good practice examples. All models should include an evaluation component.

Key Findings

- Young people aged 12-25 have the highest levels of mental illness, but the poorest access to services
- In many areas, a young person may be too old to access child mental health services and too young to access adult mental health services
- Many leaving CAMHS may not be accepted by AMHS, where illness levels often have to be more severe to qualify for help
- A quarter of those with ongoing clinical need may fail to be transferred, with numbers higher for those with ADHD (almost three quarters)
- Only 4% of young people report a good transition
- Young people, carers and even staff have a lack of knowledge of other services available
- Available evidence indicates that transition can be improved by:
  - planning early,
  - listening to young people and involving the family in partnership, as they often continue in their role of advocate,
  - providing appropriate and accessible information,
  - providing a more holistically focussed, 'young people friendly' AMHS,
  - training AMHS professionals in wider mental health issues, ADHD and ASD,
  - using a transition co-ordinator,
  - using joint commissioning, ideally to provide a mental health service tailored to meet the needs of young people up to the age of 25.

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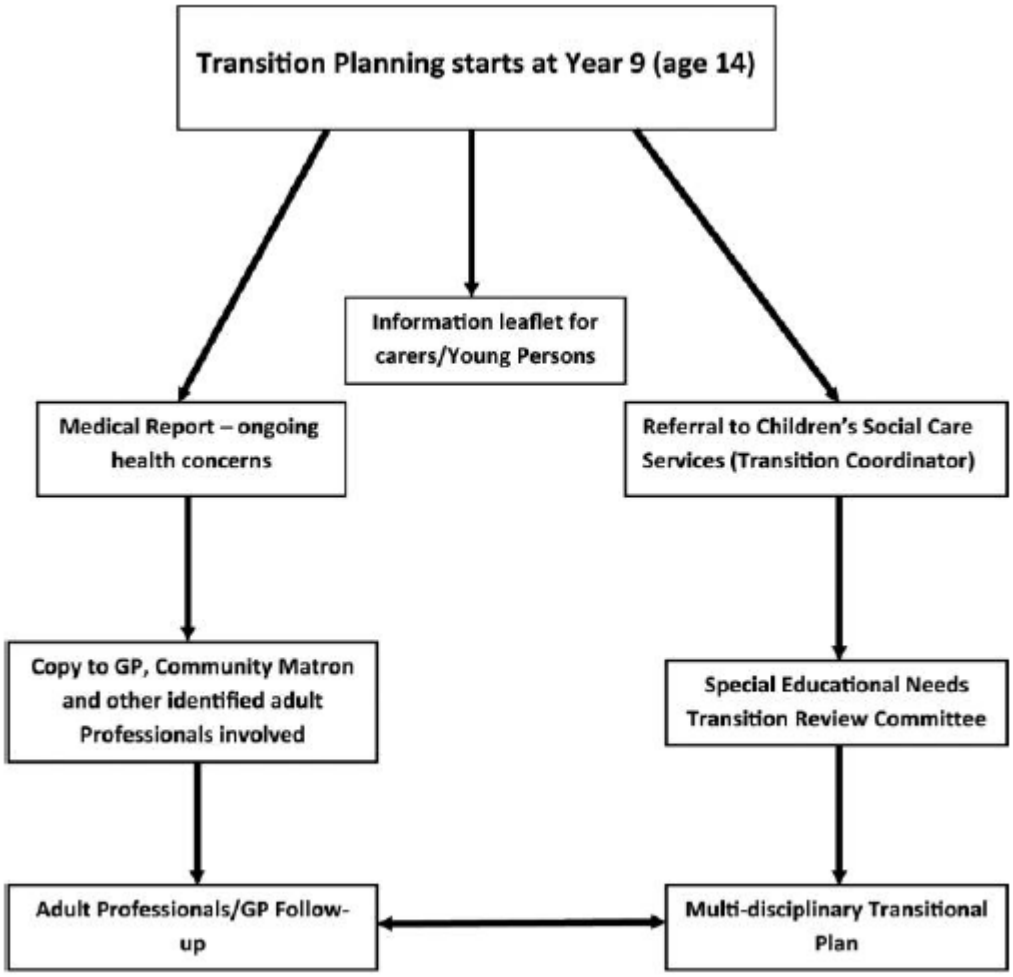
Appendix

Care pathway diagram

Figure A1.
Proposed care pathway for transitional care to adult services for young people with complex health needs and learning difficulties.

(Reproduced from Ogundele, 2013, p. 215)



Key: GP – General Practitioner (Family Doctor)

Further resources

Transitions in mental health care: a guide for professionals. Published by 'Young Minds', this guide includes a chapter using case studies to illustrate how some of the issues around transition can be addressed.
http://www.youngminds.org.uk/assets/0000/1331/YM_Prof_Transitions_Guide_email_version.pdf

The national framework for NHS continuing healthcare and NHS-funded nursing care (Department of Health, July 2009 (revised):
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103162

The National Framework for Children and Young People's Continuing Care:
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114784

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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 (Department of Health, 19 March 2008):
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083592

Guidelines on the discharge from hospital of children and young people with high support needs (Council for Disabled Children, 2010) available at:
www.ncb.org.uk/cdc/Guidelines_on_the_discharge_from_hospital_of_children_and_young_people_with_high_support_needs.pdf

Power to the Youth: Commissioning Better Services for Young People
Transitions between services for children and adults tend to be poorly co-ordinated and there is a lack of age-appropriate mental health care. This commissioners' guide is drawn from young people's own experiences making it fresh and practical, helping to overcome barriers and support the commissioning of innovative services.
http://www.mentalhealth.org.uk/our-news/news-archive/2014/14-10-28-power-to-youth/

'Right Here' guide to making services 'young people friendly':
http://www.righthere.org.uk/resource-centre/.

Working at the CAMHS/Adult Interface: Good practice guidance for the provision of psychiatric services to adolescents/young adults.
https://www.rcpsych.ac.uk/pdf/Transition_2008.pdf

Further resources are listed on p.15 of the JCP guidance (JCP-MH, 2012):
https://www.rcpsych.ac.uk/pdf/JCP-MH%20CAMHS%20transitions%20(March%202012).pdf

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Liverpool
Public Health
Observatory

Liverpool Public Health Observatory (LPHO) is a research and intelligence centre, commissioned by the Merseyside and Cheshire Directors of Public Health, through champs, the public health collaborative service, to provide public health research and intelligence to local authorities.

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