SERVICES FOR CHILDREN AND ADOLESCENTS WITH LEARNING DISABILITIES AND MENTAL HEALTH PROBLEMS

A MANAGED CARE APPROACH

Summary

October 2005
INTRODUCTION

This summary is taken from a report commissioned by the Foundation for People with Learning Disabilities (FPLD) to look at ways of improving access to Child and Adolescent Mental Health Services (CAMHS) for children and young people with learning disabilities who also have mental health problems. The report was researched and written by Tina Jackson. The aim of the scoping report was to review current service models as well as look at the feasibility of adopting managed care approaches to better coordinate CAMHS for children with learning disabilities.

The rationale behind this piece of work were a number of policy initiatives driving change for young people with learning disabilities, namely Valuing People (2001), National Service Framework 2004 and the Public Service Agreement (PSA) Target 2005 introduced relating directly to children and young people with learning disabilities and mental health problems. The PSA Target means that commissioners of CAMHS Services will now be measured against this target using the following question and detailed definition:

The availability of a full range of CAMHS for children and adolescents who also have a learning disability. Services should be provided by staff that have the necessary training and competencies to deal with children who are experiencing learning disabilities. Children and young people with learning disabilities should receive equal access to CAMHS, including:

- Mental health promotion and early intervention (including attention to attachment and parenting issues);
- Training and support to front line professionals, in particular in the recognition of normal development and developmental delay;
- Adequately resourced Tiers 2 and 3 learning disability specialist CAMHS with staff with the necessary competencies to address mental health difficulties in children and young people with learning disabilities or pervasive development disorders; and
- Access to Tier 4 services providing in-patient, day-patient and outreach units for children and adolescents with learning disabilities and severe and complex neuro-psychiatric symptomatology.

There were two major objectives to be achieved from the scoping study:
- To find out the range of service configuration used by CAMHS who accept referrals from children with learning disabilities at present.
- To find out what can be learned from current ‘managed care approaches’, to inform evolving models for CAMHS overall.

REVIEWING EXISTING CAMHS MODELS

The NSF 2004 states that one third of NHS specialist CAMHS provide specific services to children and adolescents with learning disabilities. Services are
also provided from within life-span learning disability services and in child health services.

A small service mapping exercise was undertaken as part of this study, using a questionnaire (appendix 1) sent to 48 CAMHS who were known to provide services for children with learning disabilities from the CAMHS mapping exercise. A total of twenty services responded (17% response rate) to the questionnaire. One learning disability team sent in two responses, one from psychiatry the other from a nursing perspective. These, interestingly, had slightly different perceptions specifically around the skill levels and confidence of staff to work with children and young people with mental health problems.

THE MODELS
The responses were ‘grouped’ to identify different approaches to service development. The five broad types of service provision identified were –

No provision (4)
Each of these services highlighted that services for children and adolescents with a mental health problem and learning disability were excluded from their Service Level Agreements. There were no Child Psychiatry posts based in Learning Disability Services and staff were attempting to deal with mental health problems without adequate training.

Patchy provision (3)
These respondents, although providing a level of service, usually with children and young people with a mild learning disability, highlighted that there were no clear pathways or agreements in place to meet the needs of this group. This resulted in children and young people to falling through the net and a reliance on Social Services ‘to do it’.

CAMHS/LD Psychiatrist based in Learning Disability Team (7)
These services had generally identified the mental health needs of children and young people with a learning disability and responded by employing a Psychiatrist (mostly dual trained CAMHS/LD) within the Learning Disability Service. There was limited resources (staffing) in these services and the children do not have access to the range of therapies generally seen in mainstream CAMHS Services.

Distinct CAMHS/LD team based within mainstream CAMHS Services (5)
These services in the main appeared to be more recent developments. The benefits of a single entry system (into mental health service provision) allows for greater flexibility between specialist areas, and greater access to the full range of mainstream CAMHS service provision.

Integrated Service (1)
This service works with children and young people with mental health problems regardless of whether they have a learning disability. There are three specialist psychologists within the Tier 2 team and other staff who do not have any experience of learning disabilities work under supervision.
Key areas highlighted by the respondents:

**Joint Commissioning and Planning**
Many of the respondents highlighted the lack of joint commissioning of services for this group of children and young people. In some instances it was unclear where the strategic planning would take place for learning disability/mental health and in a couple of instances it appeared that services were having to ‘battle it out’ over specific cases rather than having a strategic approach.

**Access Criteria**
Most of the respondents defined access to learning disability as ‘being in specialist education’ although, during telephone discussions, this was highlighted as problematic given the education inclusion agenda. The community team at Prudoe Hospital have developed a proposed care pathway to determine whether the referral is better suited to mainstream CAMHS or LD service.

**Single point of entry for referral**
Three services did provide a single entry point for referral. In the main there did appear to be a clearer pathway where the service was based within mainstream CAMHS services or where there is an inclusive approach to service provision.

In some cases where there were no clear planning arrangements for this group of children, inappropriate referrals were sent back to the referrer suggesting ‘the other service’ be sent the referral.

**Benchmarking**
In an average health district of 300,000 people, at any one time there will be in the region of 120 young people with learning disabilities who have substantial psychiatric problems. (Royal College of Psychiatrists, 2004).

Information gleaned from the questionnaire (appendix 2) regarding benchmarking should be viewed with caution but can perhaps be seen to highlight the disparity in service provision for this group of children and young people, given also the high level of propensity to mental health problems within this population.

**Involvement of young people and carers**
Two areas had started involving users but in the main, services who responded highlighted there had been ‘consultation’ with parents and carers as opposed to ‘involvement’ in service developments. One respondent summed this up succinctly by commenting –

**Workforce Development and Training**
The training needs of staff both in CAMHS and LD services were raised as an issue in many of the responses. This was either in relation to mental health training for LD staff or training in LD for CAMHS staff to feel totally comfortable in working with this group of children and young people. Much of...
the ‘mental health’ expertise for example lay with Psychiatry and to some extent Psychology in LD services. Whilst specific training in LD in CAMHS services was also patchy, some also highlighted a lack of ‘interest’ in some CAMHS staff to work with children and young people with learning disabilities.

There were also positive examples of where the skill mix had been appropriately balanced to address these issues, for example the new team in Camden.

**PSA Target 2005 - Current challenges facing CAMHS**

In order to gain a ‘snapshot’ of the main challenges facing CAMHS services in meeting the new PSA Target 4 in relation to children and young people with learning disability and mental health problems, a random selection of services were contacted and asked what are the key challenges in implementing the new PSA Target.

The most frequent comments were:
- Workforce skill mix and training
- Links with other agencies to provide a comprehensive service
- Comprehensive care pathways for all children
- Capacity
- Targeted money to recruit people to this area of work
- Joint posts with adult LD services

**MANAGED CARE APPROACHES**

Running alongside these expectations for the development of a comprehensive CAMHS/LD service there has also been a growing interest in the use of care pathways and managed networks to improve services for children and young people especially where their needs are complex or cross over organisational boundaries. This report seeks to examine the development of managed care approaches, looking in particular at key success factors, identify models of current service provision for children and young people with learning disabilities and mental health problems.

Simon Lenton (April, 2005) has conducted a range of studies looking at the benefits of a managed care approach stating that “Networks can be used as a means of improving services through better commissioning and delivery, especially for families who require care across a range of professional and organisational boundaries. Managed networks are increasingly seen as a key tool which will help Children’s Trusts or equivalent structures rise to the challenges in Every Child Matters, the NHS Plan and the NSF”

Managed (clinical) networks (MCN’s) have been defined as:

“**Linked group of health professionals and organisations from primary, secondary and tertiary care, and social care and other services working together in a co-ordinated manner, with clear governance and**
Managed networks can be an effective way of delivering service provision particularly where an individual’s care requires intervention from more than one agency. They can also ensure that the provision of a full range of service is available from health promotion through to specialist in-patient care if required.

Such approaches have also seen to be beneficial over a wide geographical area to deliver appropriate care at a local level but with clear routes to specialist care should that be necessary.

By following the patient’s journey managed care approaches can help to improve the outcomes for users of the services and ensure that they get the right help at the right time from the right person.

Existing networks

Several networks were identified and contacted as part of this work. None were found focussing specifically on children with learning disabilities and mental health problems, although one is due to be launched in Camden in December which will include this group. There are however, many similarities in what learning can be drawn from the ‘networks’ as discussed below.

Camden CAMHS – Single Point of Intake
Camden is described as a ‘complicated borough’ with lots of different CAMHS providers. A new managed care approach has been developed to link the service providers together to form ‘Camden CAMHS’ and provide a ‘Single Point of Intake’. ‘Camden CAMHS’ links together The Tavistock, Royal Free Hospital, the Anna Freud Centre, Camden PCT and the voluntary sector. A new Learning Disability CAMHS has been developed with 5 whole time equivalent staff (40,000 children in the borough).

All referrals will go to the single point of entry where an experienced CAMHS administrator and clinician will forward on to the correct organisation. Referral pathways have been developed which link ‘presenting problems’ to ‘service providers’. Where there are multiple or complex presentations these cases will be discussed by a panel to assess most appropriate provider.

The network is to be launched in November. Commissioners were key to the development along with senior managers and clinicians and the overall network is managed by the PCT.

West Midlands Regional Transition Network
The Transition Pathway in West Midlands provides accessible guidance and tools that can be used by anyone with an interest in supporting young disabled people (aged 13 – 25) in the transition to adult life. It provides a firm foundation to person-centred transition planning.
It consists of four key tools which all link together:

- The Transition Pathway – Guidance and Tools
- The Big Picture – Information booklet for young people
- ‘My Life, My Future’ Template for individual transition planning workbooks
- CD containing all tools and templates.

The above pathway has been developed over the last three years and piloted for two of those. It is supported by the Valuing People Support Team. The Transition network has also been meeting over that period to increase awareness of resources across the West Midlands and provide a forum for consultation on new initiatives.

There are over 100 young people and family carers involved in testing out and developing the Transition Pathway. They are also involved in the Transition network. Listening to their stories has influenced the development of the pathway. The pilot has been evaluated and is being amended in line with feedback from service users and professionals. Agreement has been reached to use the pathway across agencies and has improved joint working.

The initiative has received funding from Learning Skills Council, Birmingham SSD and PCT’s and has a full time project director. The partnership has also developed three other pathways for adults with learning disabilities. They are for hearing, challenging behaviours and epilepsy.

**Children with Disabilities Pilot Scheme – Andover**

This scheme has been developed to deliver better outcomes for children and young people with severe learning disabilities by combing resources and working together to reduce assessments for families. The scheme includes statutory and voluntary agencies and aims to steer them more quickly to the right services. It has been piloted at a school for children and young people with learning disabilities.

The development was agreed at a strategic level and local implementation teams including Primary Care Trusts, Social Services Departments and Education were formed in 2004. The team identified a resource from the Department for Education and Skill’s Early Support programme, an initiative to improve services for disabled children under three and their families. Although the package is intended for children under three, the team have utilised the family file (which is sent to the family for free by the DfES) for the broader age range and are seeking to evaluate its use.

**Integrated pathway for children with Autistic Spectrum Disorders and their families in the Scottish Highlands**

The aim of the pathway is to identify children with autism as early as possible, equipping the staff with the appropriate skills to do that, and providing information about signposting to the correct service at a local level.
Prior to the development and implementation of the pathway all children went to a central clinic to get a diagnosis, which led to bottlenecks in the system. Highland has a population of 300,000 over a vast area with many outlying areas with limited access to local specialist services. There was also an absence of key practitioners in particular areas. The development of local assessment clinics (virtual teams) has improved access with the least complex cases being treated locally. The central team now deals with the more complex cases, severe autism or where is co-morbidity.

A co-ordinator was appointed on a two year secondment to develop the approach. A multi-agency group of senior managers was set up as a steering committee as well as a project management team of operational staff. One of the key elements of the success of the network was the training given to staff.

West Midlands Alternative and Augmentative Communication (AAC) Care Pathway
This project is funded by all the Commissioners in the West Midlands and was signed up to by all the Speech and Language managers in the area. The network was set the task of drawing up a care pathway to ensure a more equitable service across the whole of the area. The main aim was to improve services to this client group, both at a local level and at the regional centre. The Care Pathway aims to provide support for services that have less expertise and to encourage teams to carry out assessments locally without immediately referring to the regional service.

A project assistant was appointed for the duration of the project and was able to carry out user interviews to get their views on the development. Common themes were lack of co-ordination and a desire for continued information about the process. The project is also seeking to appoint a training officer to train the local services in the use of the pathway, but also how to assess and provide intervention on this area.

The regional service has also changed its models of service delivery from assessment and review to consultancy, outreach, assessment, helpline and training. The waiting lists have been reduced significantly.

Dementia North
This collaborative was established in the North East of England in July 2002 to improve services across the region for people with dementia and their carers. The main aim of establishing the network was to improve service provision by working across organisations. The collaborative covers 5 Strategic Health Authorities and includes 60 organisations. It has been in existence for 34 months.

The key aims of the Dementia Services Collaborative are:

- To increase recognition of dementia, thus aiding earlier diagnosis and improving care management.
- To improve the provision of information given to people with dementia and their carers.
To help ensure that dementia services are person centred
To improve systems to explore patient and carer experience
To help co-ordinate services between agencies

The Collaborative has a Steering Committee whose membership includes managers at Chief Executive level, Clinicians and a full time Project Co-ordinator. The project team comprises of the Co-ordinator, Clinical Lead (1 day per week), management lead, administrator, half time user involvement lead, and half time researcher.

Thirty nine project leads were identified across the region to work with multi-disciplinary teams (virtual) in each locality. The regional project team are responsible for providing support to the locality leads by measuring progress, collating information and providing comparative data. They also organise ongoing learning events, develop local networks and have developed a newsletter and website.

The Collaborative has placed major importance on training the project leads in the methodology as well as emphasising that involving users and carers is central to its success. Data collection and evaluation are also key factors.

IMPLEMENTING THE MANAGED CARE APPROACH

As previously discussed mental health provision for children and young people with learning disabilities are provided by a range of services and in a range of settings. The potential for service users then to either ‘fall through the net’, not have their needs identified, assessed or treated appropriately is a significant issue. A system that allows for a single point of entry prior to assessment and treatment would simplify the process and ensure that services are provided at the most appropriate level.

The following conditions for success have been drawn from both literature and the personal experiences of those who have participated in the creation of managed approaches across a range of service areas as outlined above:

Strategic commitment
Involvement of commissioners
Strategic level steering group/management board
User involvement
Dedicated time/post
Dedicated administrative support
Project team
Patient journey mapping
Methodology
Clinical governance, accountability and quality assurance
Communication and consultation
Workforce – training and development
CONCLUSIONS

This review of the literature and current service models emphasises the potential benefits of a ‘managed care approach’ in delivering services to children and young people with mental health problems and learning disabilities.

On a local level the review found different service configurations. The most common being services delivered within specialist CAMHS services (either dedicated provision or integrated) and services provided by Learning Disability Services. The former model seems to provide added value in that once in the CAMHS system, children and young people with learning disabilities have equal access to the full range of therapeutic interventions provided by the specialist mental health services.

Camden, for example, through its creation of an LD team within specialist CAMHS and its Single Point of Intake model, ensures that children and young people with mental health problems receive an appropriate service regardless of level of ability. They are also able to move within the overall system much more fluidly without additional administration and delay and once again have access to the full range of therapeutic interventions to meet their assessed needs.

Where service provision is currently provided by learning disability services located outside of specialist child mental health services, it may be more useful to look at the development of care pathways linking CAMHS and LD services where appropriate. This use of pathways, along with further workforce development and recruitment of staff, will allow these services to broaden the current range of interventions available for learning disabled children. This will best be achieved by strategic agreement across the services with a view to ensuring that the PSA Target relating to comprehensive CAMHS for children and young people with learning disabilities is fully met.

A structured approach such as managed networks might be more appropriate with regards to Tier 4 specialist provision perhaps on a ‘regional’ basis. Some of the networks examined found that the development of pathways and managed networks ensured that the service was delivered at the most appropriate level locally, with the central services developing consultation and outreach models.

The importance of training was also emphasised along with the recruitment of suitably experienced and qualified staff with the skills to work across organisational boundaries. The development of pathways would also help to identify where the gaps in knowledge, skills and experience lie within the separate organisations and ensure that the individuals involved receive the appropriate level of training.

The provision of a comprehensive CAMHS service for children and young people will be difficult to achieve through the adoption of any ‘single’ model or
service. It will require strategic planning and commitment to address those needs at national, regional and local levels. The use of managed care approaches, workforce planning and development of cross organisational pathways, although all potentially time consuming and costly, could help to ensure that children and young people with mental health problems have equity of access to a range of service provision including specialist Tier 4 provision, regardless of level of ability or where they live in the country.
Appendix 1.

SERVICE IMPROVEMENT QUESTIONNAIRE FOR CHILDREN AND YOUNG PEOPLE WITH LEARNING DISABILITIES.

1. Could you briefly please describe the current pathway route, for a referral for a young person with learning disabilities who has a mental health problem, in terms of accessing services?

2. What specific interventions are in place for children and young people with learning disabilities who have mental health problems (please comment on evidence base also if possible)?

3. To what extent are services for this group of young people jointly commissioned and planned via health, social services, education and the voluntary sector (please make reference to any such provision being informed by a service needs assessment)?

4. To what extent have young people and carers been involved in such service development and what methods were used?

5. Could you please make some comment as to the number of clinicians per 100,000 populations (adult population) in general CAMHS and in any specific CAMHS LD service provision?

6. Please comment on training and workforce development issues (with NSF Standard 9 and PSA Target standard 4 in mind) with regards to services being provided by staff who have the necessary training and competencies for children and young people who have a learning disability and mental health problems (particularly with regards to Tiers 2 and 3).

7. With regards to mapping and pathways, which people or services might get involved with each of the brief case studies below?
   a. Paula is someone with a severe learning disability. She can communicate verbally, and has always been considered compliant and easy. During adolescence, starts to show signs of anxiety, depression or maybe even psychosis.
   b. Srikant has had episodes of depression or anxiety throughout his childhood. He has a learning disability, but has been to mainstream school. He has received services from CAMHS, and saw a consultant psychiatrist when he was a child.
   c. Sue has a history of behavioural challenges. She communicates largely non-verbally, and can become very distressed when she is not understood. She has been diagnosed as having an autistic spectrum disorder.

8. Please describe how an ‘urgent’ referral to service would be dealt with (young person with learning disability and mental health problem) particularly with regards to a case where the onward pathway was not so clear?

9. If it was felt that your services were not appropriate, to what extent would a young person with a learning disability and mental health problem (or their carer) be helped to access the right service?

10. Please list and comment upon any barriers to good practice for this group of young people in relation to pathways, interventions, training and joint planning and commissioning of services?

11. Please comment upon any examples of good practice regarding staff networking and sharing of good practice (locally or elsewhere) sometimes referred to as ‘managed clinical networks’ or ‘care managed approach’.
### Appendix 2.

#### Benchmarking findings from questionnaire

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<thead>
<tr>
<th>Service Type</th>
<th>Population</th>
<th>WTE CAMHS</th>
<th>WTE CAMHS/LD</th>
<th>WTE LD</th>
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<tr>
<td>Integrated Service</td>
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<td>Tier 2-6.7 WTE Tier 3 – 14 WTE</td>
<td>As per CAMHS</td>
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<td>Included in WTE LD</td>
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<td>CAMHS team offering limited service – no joint approach</td>
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<td>CAMHS SLA excludes LD</td>
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<td>CAMHS SLA excludes LD</td>
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