

The Children's Consultancy  
Network

**DEVELOPMENT OF A SERVICE MODEL AND  
CARE PATHWAY FOR CHILDREN AND  
YOUNG PEOPLE WITH LEARNING  
DISABILITIES AND MENTAL HEALTH NEEDS  
IN BRISTOL.**

**MARCH 2008**

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## Executive Summary

Research indicates that children with a learning disability are at high risk of developing mental health problems. Nationally 40% have a significant problem compared with 10% of all children and young people. Service development for these young people has been identified as a priority both nationally and locally.

The Bristol CAMHS Commissioners identified a number of issues to be addressed regarding the service model and care pathway for these young people. The Children's Consultancy Network (CCN) was commissioned to assist with this work and produce a report recommending a Bristol - wide service model and care pathway with clear links to other agencies who work with these young people.

CCN have interviewed 40 professionals, and 16 parents as well as 11 young people with a learning disability and additional emotional, behavioural or mental health difficulties in Bristol. We have also reviewed local reports and data, national policy and good practice exemplars. We have met with representatives of 4 neighbouring local services. The findings were brought to a Stakeholder Event on March 3rd before production of this report.

There was agreement that these young people are known to a number of services and that support to them cannot be confined to one group of people. A whole system response is needed. Proposals are made to enhance the capacity and confidence of staff in universal services to identify early the onset of these difficulties and with support to offer assistance in some situations. However proposals are also made to enhance the support to these staff by the development of a consultation model which will enable any professional to bring situations for discussion and advice. Nationally this type of model has improved outcomes for young people and halved the referral rate to specialist services.

We propose that all the specialist staff working in the two existing Health Trusts be brought together into a Bristol wide specialist team with a sufficient critical mass to offer a comprehensive service to this group of young people in concert with the CAMHS Service. They will work in close cooperation with parents, voluntary organisations and other health, education and social care colleagues. Ideally the team will have additions to its membership to make it multi disciplinary and they will

be co - located with a number of other children's services staff. It is crucial to this model that the team operates as a hub and spoke and has agreed processes for relating to other key personnel through regular and clear contact.

A Care Pathway is proposed that follows the model laid out in 'A mental health care pathway for children and young people with learning disabilities' by Pote and Goodban which was developed after extensive consultation as part of a national Do Once and Share Project. A number of proposals are made covering the five stages- pre -referral, referral, assessment, intervention, and what happens next.

The intention is that the proposed changes will improve the experience for the young people and their families and produce a clearer and more equitable service.

## Background to the Project

### Introduction

Historically the services to meet the needs of children and young people with learning disabilities and additional mental health or emotional difficulties have been patchy nationally. There has not been a national blueprint for service delivery and very often this group of young people have not had their needs met.

However in the last few years there has been a raft of legislation and guidance that has drawn attention to this group and made it clear that they now should receive the full range of services that are their entitlement.

Work by the Bristol CAMHS Commissioners on this area identified a number of issues to be addressed including:

- The current NHS service is scattered in different Trusts
- Care Pathways could be smoother and clearer

In addition to the national impetus for improvement of these services Bristol has identified a good opportunity to redesign services for learning disabled children with mental health needs through the Contestability Exercise which is currently being undertaken. This aims to secure a single provider of child and adolescent mental health services in addition to a similar exercise for provision of a single provider of community children's health services for Bristol.

The publication in 2007 of "A mental health care pathway for children and young people with learning disabilities" by Pote and Goodban, which was developed after extensive consultation with a wide range of stakeholders as part of a 'Do Once and Share' Project led by Professor Panos Vostanis was also seen as providing a tool for the management of change (hereafter referred to as Pote and Goodban).

The Children's Consultancy Network (CCN) was commissioned to assist with this work and produce a report recommending a Bristol-wide service model and local care pathways with clear connection points to other agencies for children and young people with learning disabilities and mental health problems. These will:

- Have been developed with clear reference to the views of relevant young people and their parents and carers.
- Meet national good practice standards (Pote and Goodban).
- Include effective, clear consistent links to services for relevant children and young people in Children and Young People's Services (CYPS).
- Evidence improvement in the estimated time taken for children and young people to move through the referral and assessment system and access treatment.

## Methodology

A Clinical Reference Group was established to steer the work of this project. This was chaired by the CAMHS and Joint Commissioning Development Officer to whom the Senior Consultant from CCN also reported on a regular basis.

A team of three consultants from CCN interviewed staff involved with this group of young people including Commissioners, Managers, NHS Clinicians, CYPS Staff and Schools. A list of interviewees appears in Appendix One. In addition a number of people attended the Stakeholder Event who had not been seen individually.

Parents' views were gained by meeting with two voluntary parent groups, and one Special School consulted parents on our behalf (using our question guide) when they declined to meet with us individually. A total of 16 parents contributed.

Two young people were interviewed with their families and another group of young people contributed to the discussion in their Special School. A total of 11 young people between 13-17 years contributed.

Relevant local reports and data were read.

National policy and guidance was reviewed to ensure that the recommendations are consistent with best practice and the developing agenda for children and young people.

Contact was made with other providers of similar services across the country to establish best practice and learn from their experiences. In addition meetings also took place with representatives of local services in Swindon, Somerset, Gloucester and Bath.

The project findings and proposals were put to a multi agency stakeholder event on 3.3.08 for discussion. Some of the points raised there have been included in this report.

## Parameters given for this work

There was no new money available for service redesign with the exception of the Local Development Plan bid for a full time Children's LD Psychiatrist which was agreed towards the end of the project.

The project was to focus on the health provision to this group though there were to be links to services for relevant children and young people in CYPS. At the Stakeholder Event it was raised that it would be helpful to have a whole overview of LD services and resources across the board as many agencies have involvement with this group of young people.

## Limitations

The Contestability Exercise placed some limitations on this piece of work. Staff who were involved in this were under considerable time pressure and there was difficulty in meeting with some staff. Several potential contributors felt unable to discuss their views on service redesign as this was seen as commercially sensitive information.

Shortage of time also meant that the Joint Planning Workshop model as outlined by Pote and Goodban which involved a considerable amount of preparatory work by Service Providers, Commissioners and Additional Stakeholders could not be implemented. The Clinical Reference Group steering the project agreed that this would be carried out where possible by the Children's Consultancy Network but accepted that this would only be partial within the time allocated.

There are no established mechanisms in Bristol for seeking the views of children and young people with learning disabilities and mental health needs or their families and so inevitably collection of their views has been somewhat ad hoc.

## Terminology

CLDT – Community Learning Disability Team is used generically in this report to refer to the current services provided in the North and South of Bristol for children and young people with a learning disability and additional emotional, behavioural or mental health needs.

CCLDT – Community Children’s Learning Disability Team is used to refer to the proposed specialist team for the whole of Bristol.

Specialist Services –This refers to Tier 3 services provided by CAMHS and the CCLDT. It is implicit that expertise is also found in many other individuals and services.

These are ‘working titles’ for these teams and are not proposals. We recommend that a user-friendly name be adopted after consultation with young people, parents and staff especially as it is believed that the people who use the services would not like the term ‘Mental Health’ in the team name.

## **Demand for the service**

The following information is extracted from the original specification provided by Bristol at the time of tendering and no further work on this area has been conducted by CCN. Due to the lack of precise information on the number of children and young people in Bristol with a learning disability and additional emotional, behavioural and mental health difficulties, and lack of reporting of those with these difficulties currently seen in existing services, this report is not going to try to draw any further conclusions about the likely number of children requiring intervention from the service. It requires much more work than we have been able to do in the time allowed. However, the following indicators are a useful starting point and numbers accessing the service will need to be carefully monitored along with the introduction of systematic data recording within existing services around this client group.

### **Estimating the number of children and young people with learning disability and mental health needs in Bristol.**

Research indicates that children with learning disability are at a high risk of developing mental health problems (Count Us In, 2002). Nationally 40% of children and young people with LD have significant mental health problems (as compared with 10% of all children and young people). Particular risks are emotional difficulties (anxiety, depression) and challenging behaviour (or conduct disorders).

Estimates of the number of children with learning disability in Bristol vary.

700 0 -19 year olds in Bristol were receiving Disability Living Allowance under the category of 'Learning Disabilities' in November 2005.

The total Bristol population of children and young people less than 19 years in 2005 was estimated by the Office of National Statistics to be 92,100.

The generally accepted DOH definition of LD includes people below IQ 70 with functional impairment. It is estimated that 2.5% of children have a mild to moderate learning disability, and 0.6% of children are likely to have a severe or profound learning disability (Valuing People, DoH, 2001).

Nationally, 40% of children with Learning Disability are estimated to have mental health problems.

Applying these general estimates to the Bristol figures, there are likely to be:

- 2302 0-19s with mild/ moderate learning disability in Bristol.
- 552 0-19s with a severe or profound learning disability in Bristol (this group is rising through the effect of improved neonatal care).
- 920 0-19s with mild/ moderate learning disability and mental health problems in Bristol.
- 220 0-19s with severe/profound learning disability and mental health problems in Bristol.

In terms of planning specialist services, the combination of mild and moderate learning disability categories is not particularly helpful in terms of Bristol's mental health services, as young people with mild learning disabilities are seen in mainstream CAMHS, with specialist services reserved for those with moderate to severe learning disabilities.

Bristol's Educational Statementing figures for 2007 indicate that 1,026 children were statemented under learning disabilities primary needs categories:

Profound and multiple learning disability-	59
Severe learning disability –	174
Moderate learning disability –	793
<b>TOTAL</b>	<b>1026</b>

In addition, 171 children had a primary need category of Autistic Spectrum Disorder. Some of these will not have learning disabilities. The number of those in Special LD or funded independent schools, ie 98, is a very rough guide (likely to be underestimate) to those likely to also have moderate to severe learning disabilities. Adding this to the figure above gives a total of **1124**.

Applying 40% incidence to the statementing figures would indicate that there are likely to be at least 450 statemented children with learning disability and mental health problems in Bristol (this group will not include very young children with developmental delay).

## **Mapping of existing services and resources**

Appendix Two contains two documents which were produced by Bristol as part of the mapping work in preparation for the CCN project. They were provided with the caveat that there may be a small number of inaccuracies within them.

## National Policy and Good Practice

### National policy drivers

The following section is extracted from Pote and Goodban and sets out the key national policy drivers for CAMHS Learning Disability service development:

**Public Service Agreement (PSA)** between Treasury and Department of Health. It states that all areas must have comprehensive CAMHS. This is 'measured' by 3 proxies:

- 24/7 access
- CAMHS available for 16 and 17 year olds
- Complete range of services available for children with learning disabilities

[www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4055830.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4055830.pdf)

### **Disability Discrimination Act 2005**

Disability equality duty proposes that listed bodies, including local authorities, PCTs, health trusts etc:

- will publish a Disability Equality Scheme to demonstrate appropriate outcomes achieved
- must report on their progress
- must review within 3 years and implement changes

Specified secretaries of state must report on progress.

[www.opsi.gov.uk/ACTS/acts2005/20050013.htm](http://www.opsi.gov.uk/ACTS/acts2005/20050013.htm)

### **Local Delivery Plans: CAMHS for children and young people with learning disabilities**

Local Delivery Plans are performance returns for PCTs, drawn up by the Department of Health. They aim to ensure that there is a full range of mental health services (for children and young people who also have a learning disability) explicitly commissioned by or on behalf of PCTs.

Aims include that 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 provided to frontline 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 developmental disorders.
- Access to tier 4 services providing in-patient, day-patient and outreach units for children and young people with learning disabilities and severe and complex neuro-psychiatric symptomatology.

### **CF/A70 Component 1: CAMHS for children and young people with learning disabilities**

The CF/A70, a performance indicator for local authorities, also aims to ensure that a full range of CAMHS for children and young people with learning disabilities have been commissioned for the council area.

Aims include that:

- Partnership working and protocols are in place to ensure that co-ordinated and integrated packages of care are available for children and young people to meet their health, education and social needs. These include links between CAMHS and other services for children with LD including SEN services and children with disabilities services.
- Commissioners ensure that joint agency planning and commissioning takes place between health, children's services (including social care and education) and the voluntary sector for children and young people with LD who have severe, enduring and complex needs.

[www.childhealthmapping.org.uk/help/guidance/2006\\_LA\\_Rating.pdf](http://www.childhealthmapping.org.uk/help/guidance/2006_LA_Rating.pdf)

### **CAMHS Partnership Self Assessment Matrix (SAM)**

The CAMHS Self Assessment Matrix was developed by the Health and Social Care Advisory Service for the National CAMHS Support Service. It is used by most CAMHS partnerships to help review and plan their priorities, investment and services. This matrix is now available as a web based tool.

Section 6 of the CAMHS SAM states that young people with learning disabilities and mental health needs should be able to receive a full service, with access to specialist services with expertise in both areas. Some children with mild learning disabilities are

best served within community CAMHS, whilst others with more severe disabilities require specialist LD provision. Joint protocols and planning between CAMHS and LD services ensure no child fails to get a service.

[www.childhealthmapping.org.uk/self.assessment/guidance.php](http://www.childhealthmapping.org.uk/self.assessment/guidance.php)

## **Every Child Matters/NSF**

### **Standard 8**

Local authorities, primary care trusts, and CAMHS ensure that:

- Disabled children have equal access to child and adolescent mental health services.
- Appropriate mental health services are available for:
  - disabled children suffering from traumatic accidental injury
  - children and young people with complex health needs and life-limiting illnesses, and the siblings of disabled children
- Assessments and services for children and young people with learning disability and mental health needs are provided by professionals with expertise in learning disability and children and young people's mental health.
- Services are planned and commissioned on a multi-agency basis.
- Local child and adolescent mental health service development strategies include plans for improvement in services for children with a learning disability across all four tiers of provision.

### **Standard 9**

Marker of good practice no. 6

'All children and young people with both a learning disability and a mental health disorder have access to appropriate child and adolescent mental health services'.

[www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4114364&chk=ebDqj9](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4114364&chk=ebDqj9)

## **Lessons from other services**

During this and other projects we have contacted the following services which are at various stages of development and a number of which are known for their good practice :

Bath, Camden, Darlington, Gloucester, Leicestershire, Nottingham, Somerset, Sheffield, Sunderland, Swindon, and Wirral.

There are some learning points that were shared and can be applied to service development in Bristol.

- A number of these services had made the mental health needs of children with a learning disability a priority for service development. Most had a senior manager or management group that were championing these children's rights to an equitable service. In identifying and articulating the Human Rights issues and discrimination issues senior managers felt empowered to ensure service development for this group remained a priority. The clinical lead in Camden in particular was a powerful advocate for this approach and would be a useful and receptive professional to contact.
- Most of these areas run specialist services for young people with moderate to severe learning disabilities and emotional, behavioural and/or mental health difficulties. The degree or nature of these difficulties was not usually specified.
- Most of the services were under the CAMHS umbrella. The mainstream CAMHS services usually work with young people with mild learning disabilities but believe that a specialist service or specialist skills within a service was needed for the most complex cases.
- Links to other services in education, social care, health and voluntary services are vital and must be clearly and formally established.
- Specialist teams need a range of skills. There was universal commitment to multi disciplinary working.
- Most services had a manager or coordinator.
- In a couple of areas this service is to be included in a Children's Trust for Disabled Children. One area described their service as a mini-children's trust within the wider children's services and the workers saw themselves as having 'dual citizenship.'
- Most areas have built in a consultation element to their services and encourage initial consultation as the preferred method for accessing the specialist services.
- The provision of training to other professionals was considered to be good practice and helped other professionals identify mental health difficulties and not assume that behaviours were always part of a learning disability.
- Services should be needs led rather than diagnosis driven.

- The services have access to a range of therapies that need to be tailored to individual needs. This and active support in behavioural approaches with families have been found to be the most effective.
- Medication assessment and review must be part of a service.
- Clear benefits of operating a time-limited service approach to avoid very long waiting lists. Most of the teams we consulted were applying this principle and had found it to be effective. This approach is supported by research carried out on the Leicester model where it was found that over time clinicians and case workers have become more confident about giving clear messages about the effectiveness of the service and the ability to bring about change in a shorter period of time.
- Re-referral should not be necessary. An 'open door' policy to the service is essential, within set parameters.
- Services should be supported by provision of specialist parenting courses that parents can be referred to.
- These teams have reduced out of area placements in the long term.
- Clear commitment to involving service users and carers in service planning and monitoring.

## **The guiding principles underpinning the development of LD/MH services**

The Care Pathway is underpinned by the following guiding principles as identified in Pote and Goodban:

### **Holistic**

The needs of the child with learning disability and mental health difficulties are central to any service planning and delivery. The full range of emotional, physical, social, educational and practical needs should be considered in the context of the family, with special attention paid to parents' carers' and siblings' needs.

### **Child-centred planning**

Service development and delivery should have the child's welfare as paramount (Children Act, 1989). There should be recognition that 'children are children first', regardless of the level of their learning disability and mental health difficulties. The intention should be to develop intervention plans to meet the child's needs rather than reflect service needs. In addition, as in any work with children, their welfare

should be paramount. In this regard one must acknowledge that children may have complex needs that require support from other agencies that may not be readily available in CAMHS, such as speech and language therapy, physiotherapy, occupational therapy, specialist teachers, psychiatric social workers, learning disability specialist support, good access to primary care and child healthcare.

Moreover, careful attention should be paid to child protection issues. Children with learning disabilities are at a greater risk of experiencing all forms of abuse and neglect. It is essential that strong links are established between children's services child protection teams and CAMHS LD services. CAMHS LD should also address issues within their own service pathways, clinical governance and policies.

### **Developmental Framework**

Throughout assessment and intervention, the difficulties presented by the child should be considered within a developmental framework. This should pay attention to both the child's chronological age and developmental level. Children with learning disabilities often show more variable developmental profiles than those without learning disabilities. For example, their verbal skills and emotional understanding may be above what might be expected given their cognitive developmental level.

### **Multi-agency commissioning and consideration of referrals**

For care to be effective, it should be provided across health, social, educational and voluntary agencies in a comprehensive and integrated manner. Avoiding duplication of service provision and ensuring effective communication between agencies is essential in offering care which is responsive to the child's and family's needs.

### **Inclusion and equality of access**

Children with a learning disability and their families should have equal access to the full range of services that children without learning disabilities have in respect to all areas of health, social and educational support. They should be offered appropriate support to access ordinary services where possible, and specialist alternatives where inclusion into ordinary services is not indicated.

### **Pro-active and problem-solving**

Services and individual professionals should take a pro-active and problem-solving approach in addressing the needs of children and their families. They should seek to

equip themselves with any necessary knowledge base or skills to meet the needs of the child. Working pro-actively will require services to be flexible in several regards:

- Referrals on to other services should be treated as requests for service provision. Responsibility for care or liaison with new services should be retained by the referring service until it is appropriate to transfer responsibility to another service. Where possible the presence of a keyworker or lead professional can contribute to the successful delivery of integrated frontline services across agencies.
- It is important to follow up with vigour those families who find it difficult to engage with services, recognising that families may be involved with several services at the same time and may find attending appointments difficult. Appointments, wherever possible, should be offered in places which are familiar and readily accessible to children and their families, for example school or home, given the particular challenges of new situations and change, and of using public transport.
- Clinicians should draw upon other resources and support the co-ordination of care in circumstances where they cannot directly meet the child's needs.

### **Collaborative practice and consent**

Service development and delivery should be committed to collaborative practice which empowers children, their families and advocates to overcome their difficulties and get the support they need from service providers. Children's views should be actively sought throughout the care process, and information should be provided in a child-friendly manner to enable children to be informed about their care and participate in decision-making. One might also consider the potential impact of individualised budgets. This would shift thinking to emphasise service responsibilities towards empowering families and young people to find their own solutions, maybe within a given budget.

### **Co-operative information sharing and communication**

Issues of consent, confidentiality and information sharing require careful consideration for children with complex inter-agency involvement. Information should be shared between service providers to meet the needs of the child, but this should be done collaboratively with children and families. Particular attention will need to be paid to information which may be 'sensitive' which might only be shared to protect the wellbeing of the child. Further guidance is available from the

Information Sharing Guidelines (2006) produced by the Department for Education and Skills, with the Department of Health and others, as part of the Every Child Matters Programme.

See [www.everychildmatters.gov.uk/resources-and-practice/IG00065/](http://www.everychildmatters.gov.uk/resources-and-practice/IG00065/)

### **Encompassing diversity**

Professionals should encompass diversity in their planning of services, and within service delivery and evaluation. Diversity relates to the child's level of disability, as well as any cultural or gender issues. Children from minority ethnic groups who have a learning disability may be more likely to face double discrimination in relation to service access.

### **Therapeutic and quality services**

The pathway should enable children to access the best available local service to meet their needs. Such services should be timely, of high quality and therapeutic for the child and family, and offer both comprehensive assessments and interventions. It is recognised that services for children with learning disabilities and emotional/behavioural difficulties are currently undergoing considerable development. In developing services, one should be mindful of the above guiding principles, and should apply them in the monitoring of service quality.

## **Bristol Stakeholder Views**

The following views emerged from the interviews with professionals.

### **What works well**

- High quality and committed staff.
- Some good informal relationships between staff on the ground in different agencies and teams.
- Some good initiatives and services.
- Staff work well together in a crisis to find solutions for individual children.
- Widespread support for 'joined-up working' and being based together.
- Young people and families seen in the most appropriate environment – often school or home.
- When parents received a service they were generally very positive about it.
- Joint Commissioning developing.
- Shared electronic index for young people across Health/Education/Social Care.

### **What works less well**

- Lack of a clear agreed vision both within agencies and across agencies. 'No overall vision for everyone but everyone has an overall vision.' There was a strong feeling that there should be a clear vision for Children's Services and that Joint Commissioners should commission an agreed comprehensive service strategically. This would result in clarity of direction that would enable clearer communication and joint working at an operational level. This would lead to a better experience for children and families.
- Considerable unmet need reported.
- Universal services (Tier 1) staff report:
  - They are not sufficiently trained or skilled to recognise or deal with some of the difficulties that present.
  - They are not sure which of the number of professionals they have contact with to approach for help.
  - They have little understanding of the eligibility criteria for Tier3 specialist mental health services and the process for accessing it.

- They do not understand the differences between CAMHS and the CLDTs.
- There are different area demarcations and some services are accessed by reference to postcode and others to schools attended.
- They do not understand how the Health, Education, and Social Care services fit together.
- The specialist services for children with learning disabilities and emotional, behavioural and mental health needs are delivered by two separate Trusts. There are a number of issues about the way they operate which make it difficult for the referrer e. g:
  - One operates as a team which allocates referrals through a meeting.
  - The other operates as a service and referrals are made to individual professionals.
  - One is based in Community Child Health.
  - The other is based in CAMHS.
  - There is no management structure to consult.
  - There are no shared assessment, planning or review mechanisms used. (The Common Assessment Framework (CAF) is not used systematically).
  - Psychiatry has been insufficient and has not been embedded in either service.
  - No use of Lead Professional/Keyworker role.
  - No clear protocols for accessing therapies which are located in different services.
  - Waiting lists are variable and in one area are lengthy.
- Trust budgets are aligned to professions. This limits opportunities to appoint to a team the role/skill mix needed. Budgets are not aligned to match population needs.
- The services provided by Health and CYPS were seen as very fragmented. There is limited understanding in both agencies of the priorities of the other. Liaison happens around individual cases (often in crisis) but there is little systematic joint working or sense that talk of more joined-up working is being operationalised. There is seen to be a need for a strategic plan across the whole area.
- There are a number of meetings and panels that have multi-professional attendance but a number of interviewees reported that they did not know

how these meetings fitted into the scheme of things or indeed how the meeting was called or the agenda set. Consultation between agencies is based on informal networks rather than clear pathways. People felt they were 'calling in favours'.

- A difficult financial situation leads to reactive working rather than proactive and preventative work. It was particularly thought that an 'Invest to Save' approach could avoid some of the costly Out of Area Placements. Pooled budgets would help this approach and improve outcomes for young people.
- Lack of local inpatient beds for this group and insufficient respite beds was seen as costly in human terms as well as financial.
- There are no systematic methods for incorporating service user/carer views from service planning through to evaluation.
- There are no agreed outcome measures used.
- Lack of data seen as unhelpful when planning services.
- Strong feeling that the needs of BME communities are not fully met through any of the services but no data is collected to ascertain facts.
- There is a lot of change and uncertainty for staff.

### What the service should look like

- The service offered to learning disabled children and young people should recognise that they have the same rights and need to achieve the five outcomes documented in 'Every Child Matters' as any other child.
- Learning disabled young people should be able to access mainstream services and universal services wherever possible.
- If this is not in their interests they should have a comparable service provided by people trained and skilled to provide it. There was wide recognition that there is a specific skill set needed for working with some learning disabled young people but also that many 'mainstream' professionals have skills that are transferable for working with this group and that their confidence and expertise needed to be enhanced.
- Bristol needs a city-wide specialist LD/MH Team which operates consistently with a clear pathway mapped out for those it serves. It should be multi-professional and have psychiatry embedded within it.
- Most people thought that it should be co-located with the other key children's professionals – CYPS disability staff and health staff – notably

paediatricians and CAMHS staff. There was great store placed on the importance of this easy and informal contact.

- People had difficulty in visualising an alternative scenario. Those who did express a view thought that it should be part of the CAMHS service as a 'team within a team' but with very clear links to the other learning disabled children's professionals. There were one or two advocates for maintaining the current co-location with child health colleagues as they had good experience of this. No one wanted it to become another 'silo'.
- Most people suggested that it should be one specialist team though someone floated the idea of two teams that worked to the same operational policy etc.
- People wanted there to be clear management arrangements for all the relevant children's services and thought this might come out of Contestability changes.
- There was a lot of empathy with the child and family's perspective and staff wanted there to be recognition of how the service was experienced by the child and family. There was considerable support for the creation of the Care Pathway on Pote and Goodban's model and improvement to be made on all the key steps:
  - Pre-Referral
  - Referral
  - Assessment
  - Intervention
  - What Next?and a number of suggestions are incorporated in the proposals.
- People liked the notion of the 'Team Around the Child' and this should include links across the statutory and voluntary sectors and with the families. This should, where appropriate, facilitate transition into Adult Services in an effective way.
- There should be more support to universal services – those that have the most contact with the young person – to enable them to offer help and to signpost and refer appropriately. There should be more emphasis on Early Intervention.
- Training was seen as crucial at all tiers to enhance knowledge, skills, and confidence.

- There should be more support and respite for families out of hours to avoid the need for Out of Area placements.
- Staff need to be encouraged to be creative. They need systems in place to support them in this – good administration, data collection, electronic systems, and budget management.

## The views of parents and carers

During the course of the project 10 parents were consulted, either individually or in groups, and a further 6 contributed their views through staff in special schools. Some parents have direct experience of CAMHS or CLDT, and some are in the process of trying to gain support for their children. All of the children concerned are either learning disabled or on the autistic continuum.

The following views emerged from the interviews with young people and their families.

Parents who had received a service were very appreciative of the support offered to themselves and their child, and the skill and expertise of a number of staff were greatly valued. One parent said she had received 'fantastic' support, and another commented that such support had held her family together.

This very positive picture was painted by a small number of parents.

The majority of parents consulted had encountered many problems in trying to secure support for their child – one commenting 'you have to fight for absolutely everything'.

There were issues with endless assessments rarely producing practical support, conflicting advice from professionals, a high staff turnover, a lack of expertise around learning disabled children with mental health needs and inadequate communication- both between professionals and between professionals and parents.

Parents felt that the difficulties in accessing appropriate, timely support had a significant adverse impact on their children, including an increase in anxiety, withdrawal from daily life, depression, heightened aggression and talk of self harm.

There is a sense that resources are limited and that services are offered to the parents who 'shout loudest'.

Several parents were particularly concerned about what they perceive as a significant lack of professional expertise and conflicting advice around the mental health needs of children with autistic spectrum disorders.

Parents and carers would like to see:

- Better communication between professionals
- A directory of 'who does what'
- Readily accessible family therapy
- Support for siblings
- More staff with expertise in the mental health needs of learning disabled children
- More support at times of transition, eg. between schools, from school to FE and to Adult Services
- Their views being sought, recorded and respected
- Someone to help their journey through the system
- The opportunity to meet with other parents for mutual support

## The views of young people

Eleven young people aged between 13 –17 years were consulted, either individually or in groups. All of the consultees have, or have had emotional or behavioural issues and some have received a service through CAMHS or CLDT.

Rather than focus on individual experiences, which we considered would have been inappropriate in a short meeting with a stranger, we asked the young people to tell us what support they would like if they felt angry, upset, anxious or depressed.

The young people gave their opinions freely, answered thoughtfully and showed considerable insight.

Some did draw on their own experiences to demonstrate particular points.

They suggested that a good service would include:

- Time and opportunity to talk things over with someone of your own choosing
- People who are good listeners and value what you have to say

- People who are trustworthy, and who don't tell everyone your business
- An invitation to come back if your problems start up again
- Mainstream school staff who have time to listen (it was generally agreed that special school staff had more time to listen)
- More school mentors and counsellors
- Treating young people as adults, and not talking down to them like children
- Not having to talk to strangers - do they really care about us?
- Asking the young person if its okay to share information with parents
- Giving the young person the notes about them, or reading the notes to them if necessary
- People who understand that autism is very complex
- People who know not to try and talk to you when you're very angry, but give you time to calm down
- A listener just for the young person. If a mum or dad needs support too, they should have a different listener
- A quiet room in schools where young people can take themselves to calm down
- Proper help - not adults who say 'don't worry' because they can't think of anything else to say.

The above views of children and young people should be considered during the reshaping of services. These views are, however, simply a snapshot and we would recommend that a Bristol - wide consultation tool is developed to facilitate the routine involvement of children and young people in decisions about their assessment and treatment.

## Proposed Service Model

The following service model has been designed with reference to national policy, best practice and the views of the range of stakeholders interviewed to address the unmet need and issues identified in Bristol

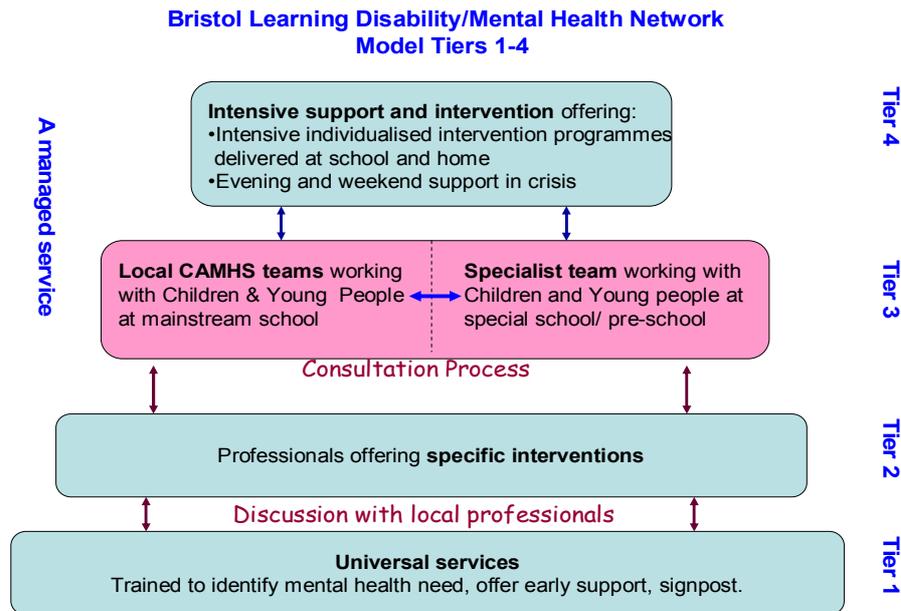
It is important to develop a response to this need that is not all focussed on direct work by a few individuals. The four tier model of mental health services acknowledges that there are various levels at which these difficulties can be addressed:

- Tier 1 Universal Services – e. g schools, GPs
- Tier 2 Targeted Services – single professionals working in networks
- Tier 3 Specialised Services – multi-disciplinary mental health teams offering specialised services
- Tier 4 Highly Specialised Services – e. g day units, inpatient beds  
(see Pote and Goodban pp52-53).

This model recognises that there are skills available at all tiers and that it is important to utilise these effectively. Broadly the less serious difficulties can be dealt with in the lower tiers and the more serious require specialist help provided higher up the tiers. But help will frequently be provided across the tiers. They are rarely self contained entities but rather face each other and overlap. Nothing in this report implies that relevant skills are uniquely confined to specialist workers in the mental health field.

It is important that there is a whole system approach to the needs of this group of children and young people. It must not feel that the lower tiers are left alone to cope with swathes of difficulties that are perceived to be less serious (and sometimes are not) whilst only a few of the most serious cases are taken at the highest level by a service with stringent eligibility criteria.

Diagram One demonstrates the interrelation of all the tiers of the mental health service and the need for a close working relationship between all professionals involved with these young people.



## Universal Services

Capacity needs to be built at Tier 1 by recognising that staff in universal services – particularly schools – have skills and relationships with the young people which can be enhanced and utilised to meet some of the needs identified. They already deal with many situations in the course of their work but sometimes reach a point where they feel they need further help.

There are a number of professionals who go into schools to offer advice and support e. g:

- Educational Psychologists
- Primary Mental Health Specialists
- NSPCC School Counsellors
- School Nurses
- Paediatricians
- COSI Team Members
- Bristol Collaborative Service
- School Improvement Officer
- CLD Team Members
- Social Workers for individual children
- Bristol Intensive Response Team for individual children

But whilst individual contributions are valued it is not felt that there is a whole system response to their needs. At the Stakeholder Event the view was expressed that there was need for more professionals working preventatively (e.g. Primary Mental Health Specialists ) with young people with challenging behaviour that puts them at risk of exclusion.

## **Recommendations**

We recommend that a short life working group be set up with representatives from a number of these services, parents, voluntary organisations, and schools to share information about their roles and to put together some proposals on how this work in schools could be more co-ordinated and effective. The Stakeholder Event emphasised the importance of professionals forging relationships with people in universal services.

At the same time a training needs analysis should be undertaken in one special school and one mainstream school initially to identify areas where staff consider they would benefit from further training. Further detail on training is provided in the section of the report on Quality Standards.

Following this initial work by the working group on service co-ordination and training needs a standing group should be established to steer the continuation of a co-ordinated response to supporting universal services in their work with these children and young people. The initial phase of the work outlined is with schools but this will need to be rolled out to other services as time and resources permit.

## **Specialist Services**

### **Consultation Service - support to Tiers 1 and 2**

The proposed model for building capacity within and support to universal services should ensure that an effective consultation service is offered by existing professionals working in a more co-ordinated fashion.

However there will be situations that require a more specialist intervention than can be offered by Tier 1 and Tier 2 professionals. In urgent situations referrals can obviously be made directly to Tier 3 services – either the CAMHS service for mainstream children or the CCLDT for preschool and special school children. But an

ideal model would be where professionals bring situations for discussion to the consultation meeting prior to referral.

The consultation model has been used to good effect in other areas, notably Sheffield, and has led to better outcomes for children and young people as well as halving the referral rate to the specialist team as consultees have been given appropriate advice to enable them to carry on working with the young people. The consultation can either be ad hoc telephone consultation, where situations are fairly urgent, with a designated CCLDT member who is on 'telephone duty', or planned consultation sessions with team representatives.

### **Recommendations**

We recommend that a regular consultation meeting is formed where any professionals can bring situations for discussion and advice. Membership should include the Consultant Psychiatrist so that medication advice and psychiatric opinion can be given in partnership with another CCLDT professional.. Attention will need to be paid to existing case discussion meetings, such as the Complex Needs Meeting, MAP and MALTS to ensure that new developments complement existing structures where they work well.

### **The Core Specialist Team - The Hub and Spoke Model**

There are some excellent Tier 3 workers and initiatives but there is not a coherent Bristol -wide service for children and young people with learning disabilities and mental health difficulties. As there are relatively few specialist workers in this field it is proposed that they are brought together either physically or virtually to make a specialist team with sufficient critical mass. This will need to be supplemented by other workers to make it multidisciplinary.

The exact configuration will depend on the outcome of the Contestability Exercise. Decisions are yet to be made about how the whole Child Health and CAMHS Service will be configured. However our view is that the following proposals should be compatible with any future developments.

#### **Team membership**

The ideal membership of the Core Team would comprise:

- Psychologists

- LD Psychiatrist
- LD Nurses
- Support Workers
- Primary Mental Health Specialist (LD)
- Social Worker
- Therapists
- Team Secretary

Some of these posts currently exist within the CLDTs or funding has been agreed as with the Psychiatrist post.

There is widespread commitment to closer working between Health and Social Care. This commitment could be demonstrated by the secondment of a social worker (ideally with both mental health and learning disability experience) to join the team. This would enhance the social care perspective in team work and also provide a clear link with CYPS.

The issue of the availability of therapies was harder for CCN to establish. Arts Therapies (Art, Drama and Music) are provided by Bristol PCT but therapies are also provided within CAMHS teams. There did not appear to be clear agreements about allocation of therapy resources. We recommend that the availability of all therapeutic resources be audited and clear access and liaison arrangements be documented (for CCLDT) if it is not possible to have individual therapists located within the CCLDT. This needs to be underpinned by clear commissioning arrangements and service level agreements.

Three representatives of Therapies were interviewed during this project – Speech and Language, Arts, and Family Therapists. There was considerable willingness to work to improve things for this client group. The Family Therapist wished to look at ways of offering a service to CCLDT clients. The Arts Therapies already specifically offer therapies to children with learning disabilities and emotional needs/mental health issues. In their impressive evaluation of their service in 2007 they identified that few of their clients were from South Bristol although it is a Bristol-wide service. They also use their own referral form rather than the SPE. Their service accepts direct referrals from parents. Speech and Language Therapists work in special schools and community health settings and clinics. There is also a small team that supports children in mainstream schools, where communication is the primary

presenting difficulty. The therapists work with many children with emotional and behavioural needs and also offer support with social skills and self esteem. Their main relationships are with school staff and clinical psychologists and they would welcome a closer involvement with CAMHS.

The team will need team clerk/secretarial time and how this can be achieved has not been discussed within this project.

### **Team Location**

In this model all the professionals named above would ideally physically share the same building. It is envisaged that the Specialist CCLDT will be a team. It may well be a 'team within a team' if the decision is made to locate it within a CAMHS or Child Health service.

There is great commitment to co-location in Bristol. Some of the staff interviewed were already located with other groups of staff and they were extremely positive about the benefits of the chance for informal contact - so called 'corridor conversations'- as well as more formal contact. Most people argued for co-location of all the key groups for learning disabled children – paediatricians and health staff, CAMHS teams, and CYPS. As Children's Trust arrangements are introduced and the Contestability changes develop this commitment to multi-agency co-location and joint working should be built on.

Alternatively it could operate as a virtual team where members would be located within various bases and would operate as members of that team base as well as being a member of the CCLDT. If the team is not based in the same building they will need to come together as a team on a very regular basis to ensure that referrals are discussed, work allocated according to the skills available to best meet the needs of the child and their family, to discuss team business matters, and to undertake team development.

Whilst it is envisaged that the team will get together for meetings, training etc the work will not be office/clinic based. The predominant style among all existing workers is to visit children and their families in their own environments whether in their home or school. This is widely believed to be the preferred working style with these families and was applauded by parents as sensitive to their needs.

## Key Relationships

Bristol Learning Disability/Mental Health Network  
Hub and Spoke Model Tiers 1-4

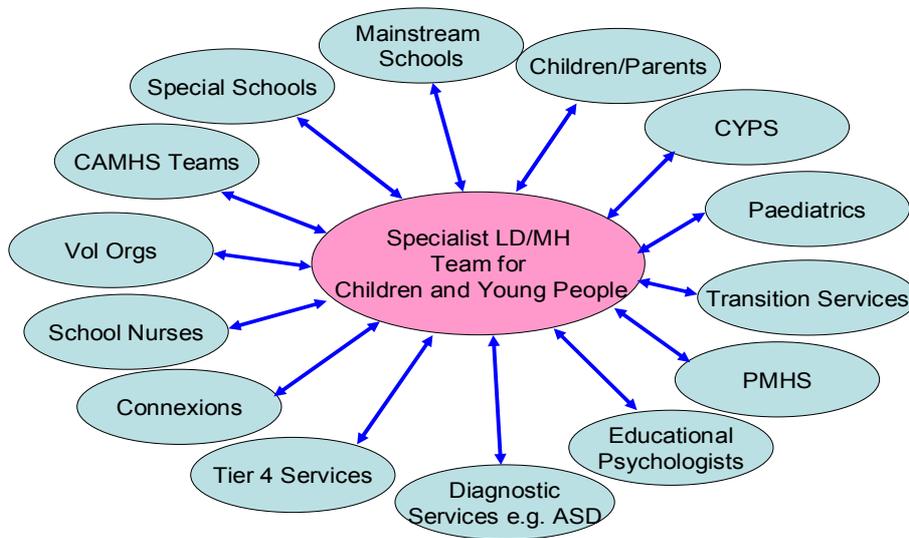


Diagram Two

The specialist team – hub – will need to ‘outreach’ to a number of others who also have significant relationships with the clients of the team. It will be important for this team to work closely with these key players and not create another silo. They are shown on diagram 2 as ‘spokes’:

- Children/Parents
- Voluntary Organisations
- CAMHS
- Paediatrics
- Children and Young People’s Services (Social Care and Education)
- Connexions
- Nurseries and Pre-Schools
- Special Schools
- Mainstream Schools
- School Nurses
- Educational Psychologists
- Transition Services
- Primary Mental Health Specialists
- Tier 4 Services
- Diagnostic Services

The team will need to designate liaison responsibilities through named individuals to build relationships that will enhance confidence and skills and arrangements for this role will need to be written down in agreed protocols .At the Stakeholder Event the term 'Designated Connectedness' was used to describe these links that are needed between specific individuals and specific services. The protocols will need to include reference to the consultation meeting described earlier.

## **Specialist Team Interventions**

### **Individual work**

It was not within the remit of this project to map or assess the types, amount, or effectiveness of the services offered to LD/MH children and young people. However the impression we gained was of a skilled group of individuals in the CLDTs who deliver effective services that were generally well regarded by families and fellow professionals. Because analysis of the interventions were not part of the project the following comments and suggestions are made as observations

There was not a sense of a holistic approach across the city. Some individuals had their own preferred styles of working – a number of these focussed on child development issues and changing behaviour .There was less reference to a psychiatric perspective of the difficulties. We expect that this perspective will be heightened by the appointment of a psychiatrist. The bringing together of all the professionals into one team should lead to a more comprehensive approach and as one interviewee said 'the whole will be greater than the sum of the parts'.

### **Co-working**

At the present time members of CLDTs occasionally work jointly within their team but not with CAMHS team members – even when they are co-located. There is potential for much greater CAMHS/CCLDT skill sharing and joint working. There is also potential for closer working with other professionals particularly in CYPS.

### **Group working**

In the South a Webster Stratton Group (LD) operates. There is no such group in the North but there are plans to develop WOW which has been running in South Glos as a support group for parents.

Feedback from the parents we interviewed was that whilst they appreciate support they do not like the implication of the term 'Parenting Groups'. They feel it can be construed that they are poor parents whereas they have often brought up a number of other children successfully, and are often 'the experts' on their own child. The approach to Parenting Groups could usefully be discussed with existing voluntary organisations to ascertain how these could be most effectively delivered.

Interviewees considered that there was potential to develop group work for parents around specific themes e. g: sleep and eating, and that groups for siblings would be valuable for the psychological well-being of brothers and sisters. Supporting parents in groups around themes may prove a good use of time. It was also suggested that therapeutic group work with young people could also be effective – e. g: support around how to make friends, coping strategies, relapse planning etc. There is also potential to work more closely with Voluntary Organisations in this area. At the Stakeholder Event a representative of the National Autistic Society outlined ways in which voluntary organisations can contribute to service development e. g expertise sharing and training particularly with staff working with higher functioning autistic young people in mainstream schools when they may not meet the thresholds for receiving a service from elsewhere. This should be explored with all relevant voluntary organisations.

#### **Intensive working –Tier 4**

Bristol like most of the country lacks inpatient beds for this group and it is generally accepted that it is usually in no-one's interests to admit them with non-disabled young people. Consequently Out of Area placements are used for young people needing hospitalisation or long term residential beds.

In addition many interviewees reported concern about the lack of respite beds and the very high thresholds for securing one. This was seen as extremely stressful for many parents, especially as there is no emergency respite or safe haven bed. Difficult and disturbed behaviour in both home and school were seen as contributing significantly to the need to purchase costly – in both human and financial terms – Out of Area placements. Most people talked of the need for 'Invest to Save' schemes to offer alternatives to Out of Area residential placements.

There are a number of developments in Bristol which were considered to be the sort of services which need to be increased and developed strategically:

Bristol Collaborative Service – a small team consisting of psychology, teaching and social care time which works mostly in Special Schools with young people with significant mental health issues who are likely to be placed Out of Area. They were not interviewed during this project but would be key players to have involved in discussion of skill development and training.

The Intensive Behavioural Intervention Programme – this is a programme working with those at risk of school exclusion and Out of Area placement. It provides very intensive individualised intervention programmes delivered at school and home to increase children’s positive skills and decrease challenging behaviours and thus prevent breakdown of home and school placements. This is operated by members of the CLD service in the North working with 3-4 children in Kingsweston School on a 2:1 ratio of staff to child. They are also funded by the PCT to do ‘inreach’ into family homes in the evenings and at weekends. The funding for this service is not ‘mainstreamed’.

Bristol Intensive Response Team (BIRT) – is an integrated health and social services Bristol-wide tertiary service for adults and children with learning disabilities and complex needs which may include severe challenging behaviour, mental health issues, and who are in crisis. It works on the principle that “people in crisis should be supported within the most positive ‘free’ environment with minimum disruption to their lives. The majority of service users and carers prefer community-based support and it has been shown that the clinical and social outcomes achieved are at least as good as those achieved in in-patient facilities” – (extract from BIRT Operational Policy 2006.) BIRT offers an office hours service for children and young people and usually has about six clients at any one time. However there is no out of hours service for children and young people – unlike the service provided for adults. The service has 20 hours allocated per week for children and young people and this is not deemed sufficient. There is a lot of support for the creation of an out of hours service for young people and their families. Whilst no-one wants to create dependence it is thought that a flexible and creative approach to this work could contribute to their improved well-being and a reduction in Out of Area placements.

## Summary recommendations

The details of the following proposals are contained within the previous sections but are summarised here:

Bring together existing specialist workers to form a Specialist CCLD Team.

Add Psychiatry, Social Work and Therapies to make it multidisciplinary.

Ideally this team will be located together and co - located with other children's services professionals.

This hub and spoke model team will outreach to a number of other individuals and organisations that have significant relationships with the team's clients. The nature of the liaison arrangements need to be written down in agreed protocols.

There are a number of observations made about Specialist CCLD Team interventions.

## Proposed Care Pathway

The sections below follow the 5 steps recommended in 'A mental health care pathway for children and young people with learning disabilities' by Helen Pote and David Goodban which was developed after extensive national consultation. It has been adapted to meet the needs of the Bristol service without losing any of the key steps as demonstrated in Diagram 3 below

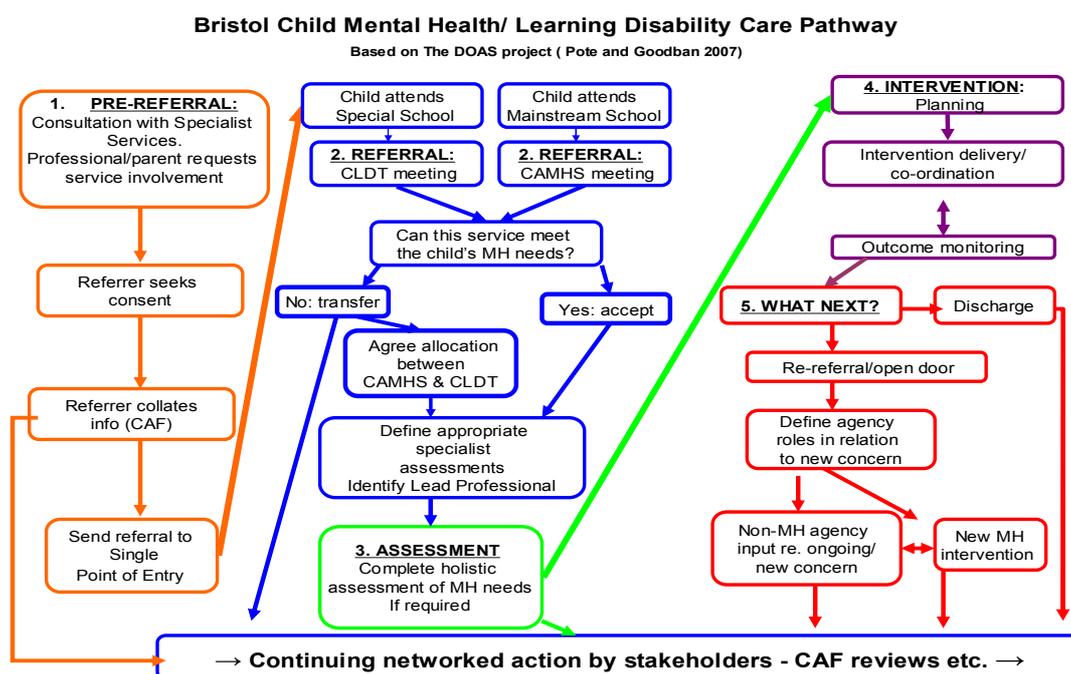


Diagram Three

Many learning disabled children and young people will already be involved with a number of other professionals prior to referral to a specialist team to assist them with emotional, behavioural, or mental health difficulties. Ideally there will be an overall care pathway for them which takes account of the fact that whilst they may need to continue on the main pathway they may also need to follow a branch off the pathway for additional services. This section of the report starts at the point when the need for help with emotional, behavioural and mental health problems are identified and they are referred on to this pathway for a specialist service.

The aim of care pathways is to ensure that the right children receive the right services at the right time and that they and their families have a good 'journey'.

It has not been possible to evidence improvement in the estimated time taken for the young people to move through the referral and assessment system and access treatment as there are so many variables and no baseline data was provided. The assumption is that the following proposals will lead to a smoother 'journey' for the young person and their family and that many of the frustrations will be removed. It is hoped that clarity about the process will bring time efficiencies as well as an improved experience. Timescales for each stage of the pathway can be built into operational policies. It is particularly important to set a timescale for the resolution of situations where allocation is not agreed. It would be appropriate to build these timescales into the commissioning document along with any national targets.

## **Step 1. Pre-Referral**

### **Quality Standards**

- Clear referral criteria and processes are agreed across provider services to ensure new cases get to the most appropriate service to meet their needs.
- Agreements are made within the overlapping agency network (e.g. CAMHS/LD-CAMHS/Challenging Behaviour Teams) about how to deal with children who do not fit current criteria or are at risk of being bounced between services.

### **Current Situation**

Lack of capacity and confidence in universal services/Tier 1 to deal with the mental health needs of young people.

Current services/roles offering support to Tier 1 are uncoordinated and not part of a strategic multi-agency approach to proactive, preventative early intervention work.

No coordinated consultation service for professionals from more specialist professionals offering advice and support that would enable decisions to be made as to whether it was appropriate for the child's needs to be met within a specialist service or whether they could be supported at Tier 1/ 2.

No shared understanding of who to refer to or what services can be delivered.

Referral information generally insufficient.

## Recommendations

Build capacity to continue working effectively with children and young people wherever possible at Tier 1/2 by:

- A review of current roles and services and reformulation into a coherent support system for staff at Tier 1.
- Provision of a pre referral consultation service for advice and discussion whether a referral would be appropriate
- Training for key Tier 1/2 staff
- Involve young people and parents and voluntary organisations in service redesign

Agree a common shared language for describing the client group. Currently the use of terms like learning disability and learning difficulty are used unsystematically. Some people refer to IQ levels and the terms mild, moderate, severe, and profound are used unspecifically. Consider using a modified version of the ISEC(A) used by Adult Community Learning Disability Teams to capture how the young people are functioning.

Encourage the use of the proposed CCLDT Consultation Service prior to referral rather than relying on a paper referral system alone.

Agree who can make referrals to the team. At present this varies between teams. A number of services across the country have open access to the CCLDT by all professionals and parents. They do not find this is problematic and this should be considered in Bristol.

Design one agreed referral form. If this is a generic Children's Services form it needs to include the possibility of referral to the CCLDT. It needs to name the school attended.

Guidance needs to be given about the format and content of referral information to ensure the quality and completeness of information. If a CAF has been completed it should always be attached. Alternatively all available assessments should be appended.

Agree an initial referral route for LD/MH referrals. One possibility would be to agree that any child who attends special school or is a preschool child will be referred directly to the CCLDT and any child who attends mainstream school will be referred directly to CAMHS. This would simplify the process for referrers and the Single Point of Entry Clerk who has to decide where to send the referral.

Informed consent should be gained in an agreed written format. Consideration should be given to adopting the 'Information Collection Form' which is being piloted in South Bristol CLDT and involves families in the making of referrals. In due course the Common Assessment Framework (CAF) could fill this role.

Information Sharing and Assessment protocols need to be agreed between all agencies (as per ISA – the central government statutory requirement based on the Children Act 2004). Children and families need to have this clearly explained to them and their agreement sought. The Stakeholder Event noted that things could be learned from the pre school system being introduced.

Written and web-based materials should be available for professionals and families on all the services available and on confidentiality and information sharing. An excellent Directory of Services for Children with Additional Needs was produced some years ago and needs to be updated and a process for the systematic issuing of it to parents be devised. Easyread and alternative formats and languages should also be available.

Ideally there will be a shared electronic system that flags up if a young person is known to any other worker in order to avoid duplication.

## **Step 2. Referral Received**

### **Quality Standards**

- Once the referral is made, it should be dealt with within the local network of services who will assume responsibility for finding the appropriate help.
- First contact is made, ideally with both caregivers and referrer, to clarify what the expectations from the referral were and what is possible (i.e. within team competencies). Ideally contact takes place at home or in a setting relevant to the child (e. g. school/short break care)

## **Current Situation**

Most referrers use the SPE forms but there are two different ones for the North and the South. One does not identify the CCLDT as a possible referral point. At least one service has its own referral form.

Some interviewees said that forms could get lost in the system.

The decision as to where referrals get passed by the SPE clerks are dependent on where the referrer requests. It is not a clinically based decision as to which service would best meet the needs of the child, or what is the best use of the skills available. In one Trust there is no Referral Meeting or team allocation process.

There is considerable potential for referrals to be 'bounced' between teams/professionals if the referral is not considered to be appropriate to themselves – families and professionals highlighted examples where this resulted in no service being offered.

Home/school-based contact is the norm for CLDTs in line with good practice. One interviewee said that this meant not always working to the Lone Working Policy.

## **Recommendations**

A clear referral route will be agreed – see proposal in the Pre-Referral Section.

Occasionally a referral will not be deemed appropriate by the receiving team. Examples of this might be where a child is in mainstream school with a moderate to severe learning disability or autism and has significant communication difficulties, or where a parent also has a learning disability and would find the CCLDT more conducive. Referrals such as these should be discussed by representatives of each team at regular liaison meetings and an agreement reached as to where the child's needs are best met. In some situations a joint initial meeting with the family will help to clarify this – as in the 'Choice and Partnership Approach' (CAPA). Failure to reach an agreement should be referred to the relevant manager for resolution.

Referrals will usually be discussed and allocated at Referral Team Meetings. They will consider all referral information provided and ideally this will have been discussed

with both the referrer and the care givers to clarify what the expectations from the referral were and what is available to offer within team competencies and obtain any additional information needed.

If the referral is not deemed appropriate for the team they must take responsibility for initiating the transfer to a more appropriate service provider.

Ideally all but the wholly inappropriate referrals will at least be seen for an initial meeting as in the CAPA model.

Letters acknowledging acceptance of a request should go to the family, copied to the referrer, GP and other agencies as appropriate.

First contact should be at a family friendly place and time and should clarify the family's expectation of the referral.

### **Step 3. Assessment**

#### **Quality Standards**

- Assessments should be holistic, considering the child's mental health needs within the context of their learning disability and their family's needs.
- Assessment for mental health difficulties should follow established protocols and good practice (eg the NICE Depression and Self Harm Guidelines etc.)

#### **Current Situation**

Clearly assessment was fundamental to much of the reported work with this group, but there was no reference to any standardised assessment tool or collation mechanisms. Individuals appeared to use their own preferred assessment formats.

CAF – Pote and Goodban (p16) states that these young people are "... children in need in terms of the Children Act 1989. If a request for mental health services is made for children and young people with learning disabilities, it is likely they will have a previous local holistic assessment of need using the Common Assessment Framework (CAF). This will nearly always be the case for children and young people referred for specialist CAMHS." This did not seem to be the case in Bristol.

No one reported the use of the Common Assessment Framework (CAF) or the Lead Professional role though interviewees were aware it was being used in other parts of the health and social care system. There was concern about how much time it would take but there was commitment to the principles underlying it. There are no plans to use CAF for this client group although Bristol Commissioners are signed up to the principles of non-repetition of core information.

Parents interviewed reiterated themes that come out of national research that there are too many assessments, too much repetition of core information, and that it is difficult to navigate their way through the support services. They would welcome the use of the CAF and the Lead Professional role. At the Stakeholder Event professionals emphasised the importance of rapport/relationship building in the assessment process.

### **Recommendations**

We would advise that as CAF should be implemented in 2008 and that as it is particularly appropriate for disabled children it be adopted for this group of children. It is a process not a form. It is also a shared assessment tool that is used across agencies by the whole children's workforce. As a result families will no longer have to tell and retell their stories to multiple practitioners with different ways of working. It helps practitioners to develop with other practitioners more of a shared understanding of a child's needs within a family context. Multi-agency holistic planning can then take place so the whole family's needs can be met. Practitioners can work jointly to meet needs more proactively rather than having to be reactive when a crisis point is reached. It includes an action plan that can be used by agencies to decide on desired outcomes and plan specific action to meet those outcomes.

If CAF is not implemented at this stage it is particularly important to adopt the QINMAC standards that underpin it, including:

- Young people receive timely mental health assessment (ie within nationally agreed 13 week timescale).
- They and their parents are fully involved and informed before the assessment.
- Assessments are co-ordinated with other agencies so they are not repeatedly asked for the same information.
- Staff have the necessary competencies and resources to conduct assessments and arrange the next steps.

- Assessments are individualised and comprehensive and take into account specific communication needs.
- Assessments are experienced as collaborative and involving.
- There is a unified clinical record to avoid repetition of information
- Young people and their parents are provided with feedback on the outcome of the assessment.

Commitment needs to be made to holistic assessments as they consider the difficulties in context, the needs of the family and pay attention to the interaction between the child's development and learning disability and the emotional and behavioural difficulties that are the concern – putting mental health presentations within this developmental framework. It does not mean that every practitioner in the team or network has to assess the child. It means that the full picture needs to be ascertained and assessment needs to be commissioned to ensure that this happens. It is also important to draw together existing assessments – e. g SEN, Paediatric, SLT, OT, and Child in Need assessments – to put together a full picture and build up a chronology of developmental history. It is important to ensure that assessments used are still up to date. At the Stakeholders Event the importance of IT solutions for bringing the various strands together was emphasised and the need for reliable protocols for multi agency assessment and care plans.

We also propose that the use of the role of the Lead Professional/Keyworker be adopted. If a CAF already exists a Lead Professional will have been identified. Where more than one service is required to meet the young person's needs a Lead Professional:

- Acts as a single point of contact for them and their family
- Supports them in making choices and navigating their way through the system
- Ensures that interventions are appropriate, timely, well planned, effectively delivered, and regularly reviewed
- Reduces overlap and inconsistency amongst practitioners
- Ensures that the results of assessments and any other information is fed back in an integrated way.

## Step 4. Intervention

### Quality Standards

- Interventions should be individually tailored to meet the mental health needs of the child and their family, taking into account their age, developmental level, and culture.
- Emotional and behavioural interventions should be available at all levels of service delivery (tiers 1-4), from a variety of psychological models (behavioural, systemic, cognitive, psychodynamic and humanistic), in a variety of formats (direct individual, group or family therapy, and consultation).
- Interventions targeted at mental health issues need to be considered within the context of other interventions (social, educational, physical) which the child is receiving. Services should develop effective inter-agency co-operation to achieve this.

### Current Situation

At Tier 1 staff did not feel that they could either deliver themselves or have access to the range of interventions that some young people needed.

At Tiers 2 and 3 skilled interventions were being delivered. However we felt that individual staff or small groups of staff delivered what they considered appropriate and what best matched their skills, training, philosophical position, and scarce resources, without recourse to a whole team intervention planning process. Some interviewees reported that they delivered what they could rather than what an ideal assessment would identify. This was particularly true regarding the availability of therapies and also the shortage of finance to create innovative solutions.

### Recommendations

The holistic assessments outlined above form the basis for a good intervention plan. This is determined by holistically formulating the mental health needs of the child and young person within the context of their:

- Age and developmental level.
- Significant relationships and culture.
- Educational, social, and physical healthcare needs.

The proposed CCLDT need to do an 'intervention audit' of their skills, techniques, and preferred styles to establish what they have available to use when they discuss

new referrals as a team. It is important to make best use of the talents available and to ensure that staff still have job satisfaction whilst ensuring that young people have a comprehensive range of interventions available to them. Any gaps need to be identified and a plan made for adding these to the team's repertoire either through training of existing team members, workforce planning that identifies the skills needed when a new post is vacant, or working collaboratively with other professionals who can offer the interventions that are needed.

At the Stakeholder Event a skills gap was identified around working with sexualised behaviour. However the group felt that there were skills available in the community particularly from the voluntary organisations, that were not known to CLDTs. The importance of practical help was also emphasised - assessments should lead to something helpful not just a label.

The proposals for developing intervention planning and delivery for Tiers1/2 are outlined earlier in the report.

## **Step 5. What Happens Next?**

### **Quality Standards**

- Discharge from mental health input should be clearly co-ordinated between agencies using existing review procedures.
- When considering re-referrals, there should be clear definition of agency roles in relation to new concerns, and an agreed inter-agency action plan.

### **The Current Situation**

Discharge planning is not always well co-ordinated. Cases were often kept open at Tier 3 because there was no one to pass them on to, especially where young people did not meet the thresholds for another service. It is also likely that some cases were kept open to continue to meet needs either related to the disability or the social circumstances rather than just a mental health need.

Some parents interviewed greatly valued support that had been ongoing over many years. However other parents reported that they had never been able to get a service at all.

## Recommendations

Work needs to be done in the CCLDT to define targeted short term work. This is already quite advanced in some parts of the service. There will be some situations that do require longer term interventions but there needs to be clarity about when this is required otherwise waiting lists will continue to build up. The principle should be that work is focussed and not open ended generally.

Discussions need to take place with colleagues in other services about discharge from the Specialist Service. A review needs to take place in order to establish that this is the correct course of action. Good transition management guidelines need to come into play here whether it is transition from children's to adult services, statutory agency to statutory agency, or statutory agency to voluntary organisation. These good working practices need to be captured in a protocol.

Re-referral: If a young person or their family wish to re-access the Specialist Service it should not be necessary to replicate the original referral pathway. We recommend that they have an 'open door' to services to prevent further deterioration. At this stage the situation will be re-assessed at the Team Referral Meeting to see what is required at this point. All previously collected assessments and reviews of earlier interventions will be revisited. Any new concerns will be identified and an action plan implemented to deal with it either through the specialist service or by ensuring that a service is provided in a more appropriate setting.

## The Quality Standards (QINMAC)

This section details a number of recommendations which will be central to any re-design of services.

The sporadic and ad hoc development of mental health services for children with learning disabilities nationally has led to a wide variety of service models. The Quality Improvement Network for Multi Agency CAMHS (QINMAC) in 2007 developed 10 Standards and a number of underpinning criteria which set out best practice for this 'multiply disadvantaged group of children'.

The standards build on national policies and on documents such as Pote and Goodban and the 'Count Us In' Inquiry report. They are designed to apply to a range of services that offer mental health provision to young people with learning disabilities focussing on those that deliver the activities of Tier 2 and Tier 3. They do not advocate one service model over another.

These standards, which can be read in full at

[www.rcpsych.ac.uk/crtu/centreforqualityimprovement/qinmaccamhs/learningdisabilitycamhs.aspx](http://www.rcpsych.ac.uk/crtu/centreforqualityimprovement/qinmaccamhs/learningdisabilitycamhs.aspx)

provide an excellent template for measuring current services and developing new services. The 10 Standards cover the following areas:

- 1: Referral and Access
- 2: Environment and Facilities
- 3: Assessment
- 4: Information, Consent and Confidentiality
- 5: Care and Intervention
- 6: Rights, Safeguarding and Child Protection
- 7: Transitions
- 8: Enabling Frontline Staff
- 9: Multi-Agency Working
- 10: Commissioning

Much of the detail contained in these standards are included in the sections of the report on proposed service models and care pathways and are not repeated here. CCN have made no recommendations that are incompatible with these standards.

Implementation of the recommendations would make Bristol compliant with many of the standards in QINMAC and the recommendations in Pote and Goodban.

We have also drawn out some overarching recommendations from these standards that would provide assistance in any restructuring of these services. Only a small number of the criteria and standards are listed here and the document needs to read in full.

### **Young people's rights (Standard 6)**

'Young people with learning disabilities are made aware of their rights and are able to express their wishes'

'Young people are afforded their rights as outlined in the UN Convention on the Rights of the Child'

'Staff recognise that young people with learning difficulties may be less aware of their rights and less able to express their wishes than others of their age'

'The specific needs of young people and parents from different ethnic, cultural or religious backgrounds are respected and responded to'

The implications for any service provider, in addition to the implication for the young person, is that there is the possibility for a legal challenge if the learning disabled young person cannot access the same range of services for their mental health difficulties as any other young person. One interviewee commented that an Equality Impact Assessment might show this to be the case.

### **Recommendations**

That the redesigned service enables young people with learning disabilities to access the full range of mental health services that are available to other young people.

### **Management structure (Standard 8)**

'There is an up to date line management structure and clear and agreed lines of responsibility and accountability'

It was reported by many interviewees that neither CAMHS nor the CLDTs had a management function within it. The management of the service was seen to be at a senior level and that day to day management was absent. Informally some of these functions were picked up well by individuals but there was no over arching

management that ensured a strategic plan, consistency across the service and resolution of difficulties. Frequently line managers were heads of professions who may not be in the same team as the worker. The Stakeholder Event endorsed the importance of management particularly in ensuring that cases were allocated and did not fall between teams.

### **Recommendations**

That the model of management that emerges from the Contestability Exercise takes account of the need for a good management structure to be put in place for the CCLDT.

Proposed reconfiguration of the team would afford the opportunity to appoint a team manager or coordinator by advertising within the team (through expressions of interest and ring fencing procedures) and appointing an existing member of staff. Alternatively when a post next becomes vacant consideration could be given to advertising a clinical post which includes a management/coordination element. Finally the management aspect could be included within the soon to be advertised LD Psychiatrist post.

### **Supervision and support mechanisms (Standard 8)**

‘All staff receive regular supervision totalling at least one hour per month’

‘Junior staff have regular supervision at least one hour per week’

‘Staff have adequate emotional support’

‘All staff, particularly professionals who work for substantial periods on their own, are well integrated within multidisciplinary teams so that they do not become isolated’

Some staff reported that they had regular supervision but others stated that they do not receive it at all and had not done so for several years. Supervision is regarded by the professional bodies of all staff groups to be fundamental to the professional and personal well being of staff. It is also generally considered to be central to the maintenance of individual professionals’ core skills and body of knowledge especially when working in multidisciplinary teams which benefit from the existence of a number of different approaches to co-working. It is also crucial at the time of significant change as is currently being experienced in Bristol.

## Recommendations

There needs to be a clear written policy for the provision of regular clinical and management supervision. These may be provided by the same individual but if two people are involved the nature of their different roles needs to be specified.

## Induction and training (Standard 8)

‘Continuing professional development is facilitated’

‘Staff have the necessary competencies and knowledge to work with young people who have learning disabilities and mental health needs .... and are provided with opportunities to develop their skills and experience’

‘Staff receive regularly updated training and education’ – 18 specific areas are identified including – evidence and value based practice, therapeutic and pharmacological interventions, risk assessment and management, specific communication needs, giving informed consent, facilitation of participation, information sharing and confidentiality, rights of young people with learning disabilities, legal frameworks, indicators of abuse, culturally sensitive practice, multi-agency working, the use of appropriate clinical outcome measures for young people with learning disabilities.

The extent of training received was not captured within this project but a number of staff in a variety of settings said that they did not feel suitably skilled and trained to work competently with this group of young people. Staff tended to feel much more competent in one area of work; some felt more proficient in the learning disability field, others in the mental health field. Tier 1 staff particularly expressed the need to learn more about the mental health needs of learning disabled young people. There was a perceived lack of budgets for meeting identified training needs.

## Recommendations

A training audit should be conducted across the various tiers of service and professions and a training programme should be devised. To make the task manageable initially the audit could be conducted in one special school and one mainstream school and a pilot programme of training be delivered to them and evaluated before further roll out. Most training could be delivered by existing staff in informal settings, often by adding a development session to existing meetings. Other means of knowledge dissemination could be considered – e. g. the use of secondments and ‘shadowing’ opportunities, group supervision, peer mentoring, and

special interest groups. These methods are valuable in themselves but particularly when there is a very limited budget. It could also be explored with the various Training Departments what relevant training already exists that does not need to be replicated. The building of knowledge, skills and confidence at all tiers is fundamental to improved service delivery to this group of young people.

## Implementation

There are a number of recommendations throughout the report which can be implemented prior to the outcome of the Contestability Exercise and others such as the location and line management which may need to await further developments. We recommend that the Clinical Reference Group develop a phased implementation plan that identifies short, medium and long term priorities for the next 2 years. Team building could begin immediately to keep up the impetus from the Stakeholder Event with a Specialist Team Away Day to exchange information about current practices and discuss how members would like to take forward the recommendations within the report. At the same time Commissioners can be drafting a Commissioning Plan and Service Specification containing specific outcomes which will improve the service for children and young people of Bristol with learning disabilities who have emotional, behavioural and mental health needs.

## Appendix One

### Interviewees

Nicola Bishop	Senior Social Worker The Transitions Team	BCC
Frances Brooke	COSI Team	BCC
Freddy Jackson Brown	Clinical Psychologist CLDT	NBT
Katherine Byron	Primary Mental Health Specialist CLDT	UBHT
Tracy Cox	Lead Nurse Specialist/Manager Bristol Intensive Response Team	Bristol PCT
Rebecca Cross	Strategy Leader	Bristol PCT/BCC
Amanda Cundy	Consultant Community Paediatrician	NBT
Justin Daddow	Consultant Psychiatrist	Bath
Susie Essex	Family Therapist CAMHS	NBT
Judy Evans	Senior Educational Psychologist	BCC
Peter Evans	Headteacher	Florence Brown School
Helen Ford	Commissioner	Glos
Chris Frost	Team Manager The Disabled Children's Service	BCC
Jane Guvenir	CLD Nurse	NBT
Diane Hall	CLD Nurse	UBHT
Ann Holmes	Senior School Health Nurse	NBT
Toni Hovey	LD Psychiatrist	BANES
Kevin Hewitt	Clinical Director for Community Child Health and CAMHS	NBT
Jonathan Hughes	Team Manager CYPS Disabled Children's Resources	BCC
David Hussey	Headteacher	Briarwood School
Viv Keast	Special School Nurse	UBHT
Alan Kellas	Consultant Adult LD Psychiatrist	Bristol PCT
Kate Lloyd and other staff	Learning Manager/Kingsweston Centre	Kingsweston School
Martin McCrea	Consultant Clinical Psychologist CLDT/CAMHS	UBHT
Jeni Mcelwee	Clinical Psychologist	UBHT
Jenny Moultrie	Head of Speech and Language Therapy	UBHT
Liz Rees	Clinical Psychologist CAMHS	NBT
Debbie Sheppard	School Counsellor	NSPCC
Philip Shoebridge	Consultant Psychiatrist CAMHS	NBT
Mark Simmonds	Team Manager CYPS LD Team	BCC

Julie Smee	Assistant Divisional Manager	UBHT
Mary Snow	SENCO	Florence Brown School
Chris Speller	Consultant LD Psychiatrist	Swindon
Sue Topalian	CAMHS/ joint commissioning officer	BCC
Jennifer Turner	Matron Children's Community Services	NBT
Richard Williams	Consultant Community Paediatrician	UBHT
Stephanie Zallik	Professional Lead for Art Therapies	Bristol PCT

Eleven young people and sixteen parents and carers took part in individual and group consultations.

## Appendix Two

### Service mapping

The following two documents were provided by Bristol as back ground to this piece of work.

Document One

#### **Services available in Bristol to meet the needs of these children**

#### **Autistic Spectrum Disorder**

Children who have both ASD and LD are included in the services below. Some children on the autistic spectrum (ASD) do not have LD (typically classified as having 'Aspergers Syndrome'). Work is currently underway to produce a Care Pathway for children with ASD.

*Children with Mild Learning Disabilities* are able to access the CAMHS Tier 2/3 teams.

Bristol PCT commissions the following specifically for children and young people with *moderate or severe learning disabilities and emotional/ behavioural/ mental health difficulties*:

#### **At Tier 1/ Preventative Specialist Services**

**Managed within NHS**  
Early Bird and Early Bird Plus

#### ***Managed within Children and Young Peoples Services***

Community and Social Interaction Teams (COSI)  
Social Services Disabled Children Teams  
Autism Project

#### ***Earlybird / Early Bird Plus Programme***

This is funded by CAMHS Commissioners to provide a parent / carer group that helps parents understand their child's autism and the impact it has on their life. The 12 week programme looks at ways of managing behaviour and uses video feedback from home visits to structure opportunities for communication to occur.

Early Bird is for children diagnosed pre school, and Early Bird is for children diagnosed after this stage.

***Community and Social Interaction Teams (COSI)  
(Learning Support Service within C&YPS)***

As a whole, COSI supports children from 2.5 to 19 years through developing communication and behaviour strategies.

There are 2 COSI teams, one for early years and one for school age. The school age team is only for children with a diagnosis and in mainstream school.

***Social Services Disabled Children Teams***

There are two Social Services Disabled Children teams, the Duty and Assessment Team and the Resource Team.

The Duty and Assessment team, based at Knowle Health Park consists of social workers and occupational therapists providing assessment intervention and planning to meet the needs of disabled children up to 18 years of age, and their carers. Some of the work undertaken by social workers contributes to the mental and emotional wellbeing of the child. If assessment indicates that additional services are needed, a report recommending this is submitted to the Resource Allocation Panel. The panel allocates resources provided by the Resources Team, such as help in the home, activity groups, and short breaks away from home according to set criteria based on the risk of family breakdown and isolation of the child. The Resources Team is based at Avonvale Road, Redfield.

Approximately 60% of referrals to the Disabled Children's Team are for those on the autistic spectrum.

***Autism Project***

This has recently been established.

2 workers work with autistic children and young people, focussing on social inclusion, and task centred work on relationships.

**At Tier 2/3**

Primary Mental Health Specialist  
Webster Stratton Groups  
Child Development Centres and Child Disability teams  
Nurses  
Psychologists  
Art Therapist  
Psychiatry

### **Primary Mental Health Specialist**

The role is to work with mainstream schools who have students statemented as MLD or SLD, to develop knowledge and skills in Tier 1, promote early identification of problems and intervention, and to improve joint working between specialist LD services and CAMHS.

(There has been one unsuccessful round of interviews for this new post, and it is now being readvertised.)

### ***Webster Stratton Groups***

UBHT provides a specialist Webster Stratton Group for parents of children with learning disabilities. In NBT, parents are referred into a mainstream Webster Stratton group.

### ***Child Development Centres and Child Disability Teams***

Both NBT and UBHT have Child Development Centres and Child Disability Teams, Westgate House at Southmead Hospital, and Tyndalls Park Children's Centre in Clifton.

Both of these centres undertake multi professional assessments of pre school children. CDT's include Community Paediatricians, other CCH therapists, attached SW's and Clinical Psychology and LD Nurses. There is great overlap with Community Child Health locality staff, though some professionals have a specialist input to the CDT.

The UBHT CDT sees children with complex motor, complex learning and complex social/communication needs. The CDT remit is from 0 to 18 though it is true that much of the CDT resource and effort is focussed on children at the time their disability is ascertained and until they make the transition into school.

### ***Nurses and Psychologists***

There are specialist Child Learning Disability Staff in NBT and UBHT. The UBHT staff are called the CLD Team, and are based at Knowle Clinic and Southwell House, and the NBT staff are part of the CDT and based at Westgate House. In NBT, the Child Learning Disability staff are not part of CAMHS, but work in liaison with the CAMHS teams. In UBHT, the Child Learning Disability Team is formally part of both CDT and CAMHS.

CLD nurses help with developmental issues, autism, toileting training, sleep issues, anger management, behaviour management, epilepsy and other allied disorders.

Most referrals to the CLD staff come from GPs, paediatricians, and special schools through the SPE. In NBT, referrals to the Single Point of Entry also come from social workers. In UBHT, the Single Point of Entry receives referrals only from Health staff, but CLDT also accepts referrals from the Disabled Children's social work team. An assessment is done to decide the priority of referral, and an initial care plan is drawn up in consultation with the child and/ or carer.

UBHT Child Learning Disability Team works explicitly with children **after** ascertainment (and therefore predominantly of school age) and the CLDT is deemed to be part of CAMHS **and** the CDT

.The UBHT team consists of:

*0.5 Clinical Psychology in CLDT*

*0.5 Clinical Psychology in CDT*

*1.6 Community LD Nurses in CLDT*

*The NBT team consists of:*

1.0 Clinical Psychology in CDT - (LD and other impairments – 0.9 spent on LD)

2.0 wte CLD Nurses in CDT

0.3 support worker

### ***Art Therapist***

Specialist Art Therapy is commissioned from Bristol PCT.

### ***Psychiatry***

Consultant psychiatrists for children with learning disabilities are based in Bristol, but managed in Bath and NE Somerset PCT. They have two sessions per week for Bristol and only see those with highest need. They attend the Complex Needs children meeting in NBT and the equivalent meeting in UBHT (School Age LD meeting) to aid communication. Most referrals come from community paediatricians and the Child Disability teams.

### **At Tier 4**

BIRT

Intensive Behavioural Intervention Programme  
Individually commissioned placements

***Bristol Intensive Response Team (BIRT)***

Bristol Intensive Response Team is an integrated Health and Social Services Team, funded by Learning Disability Development Fund Monies, Bristol City Council and Bristol PCT.

The aim of the service is to develop a centre of excellence in improving the quality of support to people of all ages with learning difficulties/disabilities and their carers by supplementing existing services in:

- Planning for preventing crisis including health and social breakdown.
- Offering flexible, intensive time linked interventions in response to crisis.
- Advising and supporting in the management of challenging behaviour and mental health needs.

All referrals are made through Adult CLDT's or Children's Complex Needs Team. Individuals may have:

- mental health needs and /or display challenging behaviour (emanating from various factors) which the professionals of the CLDT/ Children's Complex Needs Team require additional input.
- Evidence of increased vulnerability as a result of mental illness or learning difficulty/disability that cannot be addressed by the CLDT/Children's Complex Needs Team.
- Evidence of increased vulnerability to self/others.
- Support is required within the person's home as the carers/providers ability decreases because of his/her own personal circumstances (i.e. illness) or increased complex needs presented by the service user.

### ***Intensive Behavioural Intervention Programme***

This is a pilot programme for learning disabled children with mental health needs at risk of school exclusion and out of authority placement. It provides very intensive individualised intervention programmes delivered at school and home to increase children's positive skills and decrease challenging behaviours, and thus prevent breakdown of home and school placements.

### ***Individually Commissioned Placements***

Where children's needs cannot be met by NHS and City Council services in Bristol, placements are commissioned, often on a multi agency basis.

Document Two:

## **UBHT & NBT – MAPPING OF SERVICES FOR CHILDREN WITH LEARNING DISABILITY**

### **1. Name of Service and Lead Manager**

UBHT – Children’s Learning Disability Team – based in CAMHS. Also 0.5 Consultant Clinical Psychology (Disability) based in CAMHS. CAMHS is part of the Division of Women’s & Children’s Services and is managed by Assistant Divisional Manager (Julie Smee) with advice from the Senior Management Team. Clinical Psychology (Disability) and CLDT Clinicians are also informal members of the Child Disability Team, which is part of the Community Child Health Service within the Women’s & Children’s Division. The CDT has a Lead Clinician - Tom Allport. The Community Child Health Service has two Lead Clinicians – Jenny Moultrie SLT and Maria Bredow Consultant Community Paed and is managed by an ADM (Julie Smee) with advice from clinicians who attend the Business Meeting.

NBT – No formal team for children with LD. Clinical Psychology and Community Learning Disability Nurse Services are provided out of the Child Disability Team, which is part of the Child Health Service within the Women’s & Children’s Service. Some Clinical Psychology and Child Psychiatry service is also provided out of CAMHS. CD Lead Clinician is Matthew Ellis and Child Health and CAMHS are managed by Service Managers, Kevin Hewitt and Ruth Kappeluch

### **2. Overall Service Purpose**

UBHT – to provide services for the emotional, behavioural and mental health needs for children with learning disability.

NBT – As above.

### **3. Key Services Objectives.**

To provide high quality assessment and intervention services for children with learning disabilities, their families and carers. To work in partnership with other professional services and agencies in evaluating, maintaining and developing services for children with learning disabilities who experience emotional, behavioural and mental health difficulties.

To participate in initiatives to promote early detection, intervention and prevention of mental health difficulties at the level of primary care through consultation, training and support of staff in other services and agencies.

To participate in clinical governance and audit programmes within the Trust’s framework and standards.

UBHT & NBT

To provide training of students and others and to engage in continuing professional development activities to maintain high standards of evidence-based practice.

#### **4. How the Key Service Objectives are Delivered.**

- a. Direct work with children and young people, parents families and carers.
- b. Telephone contact and liaison.
- c. School visits, joint working with school staff and participation in review and other multi-professional meetings in school settings.
- d. Psycho-educational and therapeutic group work, such as Webster Stratton Parent Groups.
- e. Home visits.
- f. Clinic appointments.
- g. Provision of leaflets and written information.
- h. Involvement in the Social Communication Assessment Team for school-age children with complex social communication difficulties (UBHT)
- i. Involvement in the nursery-based assessment programme at Tyndalls Park Children's Centre (UBHT). Involvement in the cognitive assessment programme (NBT)
- j. Involvement in the Eating Difficulties Clinic for children with complex eating and swallowing difficulties and special schools.
- k. Contributing to professional student training and placement supervision.
- l. Contributing to trainee events for professionals, voluntary staff and parents and carers.

#### **5. Outcomes**

Maintenance of data on referrals (number) (attendances, non attendances, discharges) through Trust IT systems .

Individualised Clinician and Service-User evaluation.

Use of standardised outcome measures (Strengths & Difficulties Questionnaire, Honoscar, Emmerson, Goal Attainment Scale.

Service satisfaction questionnaires - UBHT Nurses

Use of standardised outcome measures for Webster Stratton Programme (IBERG, PDD) – UBHT CLDN

#### **6. Client Group**

##### UBHT.

The CLDT operates referral criteria. Children referred must have a significant learning disability. Where doubt exists about the eligibility of the child in terms of their learning disability a joint assessment may be undertaken with the general CAMHS Service and where appropriate joint work is undertaken with the CAMHS Service if necessary.

Referrals are accepted from children with a home address in the boundaries of UBHT.

No lower age limit is set for referrals, but children will only be seen after their disability has been fully ascertained by Community Child Health Disability Team. The upper age limit for referral to the Service is eighteen.

There is currently a lack of clarity about referral pathways and criteria between the CLDT and CAMHS regarding children with Autistic Spectrum difficulties. (Since this document was prepared a Care pathway for ASD has been developed

#### NBT

Children are seen with home addresses within the Trust's geographical boundaries.

Children are seen in the age range 0 – 19.

### **7. Locations of Service**

#### UBHT

CLDT Psychologists, Nurses and Primary Mental Health Specialist are based at Southwell House. Psychologist (Disability) is based at Knowle Clinic. Services are delivered at out-patient clinics in Southwell House, Knowle Clinic, Tyndalls Park Children's Centre, special schools, mainstream schools, home visits and other settings such as the Adult Community Learning Disability Team base.

#### NBT

Psychologists and Nurses are based at Westgate House. Services are delivered at out-patient appointments at Westgate House, Monks Park CAMHS base, special schools, mainstream schools, nurseries, home visits and other settings such as the Adult Community Learning Disability Team base.

### **8. Hours of Operation**

The Service operates on a 9.00.a.m. to 5.00.p.m. basis on Mondays to Fridays. When convenient to families services are also available in the early evenings.

### **9. Source of Referral and Treatment Pathway.**

Care pathways are currently being developed for children with learning disability and emotional, behavioural, mental health problems and for children with Autistic Spectrum difficulties.

#### UBHT

Referrals are accepted from Health professionals and from the Disabled Children's Social Work team, Bristol Children & Young People's Services.

All referrals are received through the Single Point of Entry system based at King Square House. The CLDT and Clinical Psychology (Disability) maintain prioritised waiting lists.

Elements of a care pathway exist currently for children with Autistic Spectrum difficulties (SCAP) and for the Social Communication Assessment Team

#### NBT

Referrals are accepted from Health and CYPs Social Work Services.

All services are received through the Single Point of Entry system at Westgate House.

Care Pathways exist for children accessing the Cognitive Assessment Programme and Motor Assessment Programme.

#### Both Trusts

Formal care bundles have not been established, but some packages of intervention are roughly standardised.

Children with Autistic Spectrum Disorder will routinely be referred to Early Bird, Early Bird plus, or HELP Programmes, the Communication & Social Interaction (COSI) Team with Education Services, Special Education, Speech & Language Therapy, National Autistic Society and the Children & Young People's Service Social Worker.

Children who do not have an Autistic Spectrum Disorder will routinely be referred to Portage Service (pre-school), the Children & Young People's Services Social Work team, Occupational Therapy and Paediatrics

Referrals will need to be made to other Services as appropriate, such as Lifetime, the Jesse May Trust, Arts Therapies (within Adult Learning Disability Services) and Psychiatry (within Adult Learning Disability Services). Note that Psychiatry Services for children with moderate to severe learning disabilities are only provided by psychiatrists within the Adult Learning Disability Service and that the Service is resourced at a minimum level. This situation is developing. An LDP bid will result in a 1.0wte Consultant post for all Bristol in mid 2008.

Referral on is made by direct written referral to the Service in question or, where appropriate, can be made at a multi-disciplinary review.

#### **10. Links.**

Overview of Services and clinical work with children and young people with complex difficulties are maintained in both Trusts by a regular Complex Needs Meeting.

Links with other Services, Agencies, professionals and networks are diverse and include CAMHS, Community Child Health Services, Bristol Intensive

Response Team, Adult Learning Disability Psychiatry, Children & Young People's Services, Voluntary Sector organisations, schools, School Nurses, Connexions, Housing Services, Acute Paediatrics, Police, Youth Offending Team, Youth & Family Justice Team, Sensory Impairment Team, Primary Healthcare Services, Adult Mental Health, Interpreters, YISP, Project X, Project Y,

## **11. Skill Mix, Staffing Levels and Specialist Skills**

### UBHT

CLDT, Clinical Psychology 0.5 wte.

Community Learning Disability Nurse 1.6 wte

Clinical Psychology (disability) 0.5 wte

Primary Mental health specialists LD – 0.5 wte (or 1.0 shared with NBT)

Admin – 0.2 wte for CLDT and further admin time for PMHS (LD) and Clinical psychology disability.

### NBT

Clinical Psychology (disability) - 1.0 wte

Community Learning Disability Nurse – 2.0 wte

Support worker – 0.6 wte

PMHS – LD – 0.5 (of 1.0 shared with UBHT)

Admin 4 hours per week for CLDN. ? for Clinical Psychology.

Access to Specialist Services includes Psychiatry, (Adult Learning Disability Services), Art Therapist (Adult Learning Disability Service), Community Child Health, CAMHS, Bristol Intensive Response Team.

There is no access to adolescent in-patient hospital assessment and treatment services, pre-adolescent day or residential unit based assessment and treatment services in the local NHS trusts. When these services are needed they are individually commissioned. Access to Family Therapy Services varies across Bristol locality CAMHS teams.

## **12. Physical Resources, Assets and Equipment**

### UBHT

The base at Southwell House is non-central and does not give easy access or parking for service users. However, services are usually local to the child and family.

There is no disabled access at Knowle Clinic.

Admin resources are judged to be satisfactory.

IT and communication resources are judged to be satisfactory.

Equipment – there is no equipment budget for continence resources, special needs software, communication materials or for other information resources such as books and leaflets.

### NBT

Westgate House has disabled access.

Admin resources are judged to be satisfactory.

IT and communication resources are judged to be satisfactory.

There is no equipment budget for other resources as with UBHT.

### **13. Response Times, Follow up Times and Waiting Times.**

*NHS policy specifies that referrals should be seen within thirteen weeks.*

### UBHT

Waiting times for Community Learning Disability Nurses are less than twelve weeks.

Waiting times for clinical psychology (disability) vary from three to five months

### NBT

Waiting times for CLDN are less than twelve weeks for assessment and approximately twelve weeks on a treatment waiting list, this could be longer depending on resources and number of referrals.

Clinical Psychology Disability – referrals are negotiated and no waiting list is kept. Accepted referrals are usually seen within twenty eight days.

### **14. Activity Measurements**

#### UBHT

Data is kept by the Trust Patient Administration System data base and manually. There is no formal system for monitoring activity.

Clinical Psychology Disability approximately thirty to forty referrals seen per year.

Community Learning Disability Nursing – ninety referrals seen per year.

#### NBT

Data is kept by the Trust ICS system and manually.

CLDN – Dec 06 – Dec 07- 70 referrals were seen