**Specialist Service for Children with moderate to severe Learning Disabilities (SSCLD)**
**Care Pathway for children and young people with complex emotional, behavioural and mental health difficulties**

**PRE REFERRAL**
- GPs, school staff, social workers, paediatricians and other community child health professionals should:
  - Try initial behavioural interventions
  - Consider accessing parent support group
  - Consult SSCLD for advice and support in delivering simple interventions at Tier 1

  **Initial interventions ineffective.**

  **Professional makes a referral:**
  - Professional working with the child and family collects information needed for referral to SSCLD:
    - Obtain consent for referral from parent/guardian and young person if appropriate
    - Consider whether safeguarding issues need addressing before or alongside referral
    - Check child meets criteria for referral to SSCLD *(Hyperlink)*
    - Complete Single Point of Entry referral form
    - On referral form outline previous interventions tried, with outcomes
    - Outline child and family’s current goals for treatment

  **Ongoing support** for child and family by GP, school staff, social workers, paediatricians and other community child health professionals

**REFERRAL RECEIVED**
- Client discussed at SSCLD team meeting. Are criteria met?
  - **No - Inappropriate referral**
    - Reason for not accepting referral explained to referrer and parent by letter
  - **Yes - Appropriate referral**
    - Unclear if meets SSCLD or CAMHS criteria
    - More information needed from referrer
  - **Maybe - Unclear referral**
    - SSCLD and CAMHS joint discussion/working as necessary with child and family then agree entry into CAMHS or SSCLD care pathway or discharge

**Enter SSCLD Care Pathway**
**Enter CAMHS Care Pathway**
**Discharge**

**Authors:** Dr Toni Hovey Consultant Child Learning Disabilities Psychiatrist and Dr Jennifer McElwee, Clinical Psychologist
ASSESSMENT and INTERVENTION

**CHOICE Appointment**
‘Choice Appointment’ (within 8 weeks of referral) with clinician/s child and family to:
- Clarify whether child and families needs can be met by SSCLD
- Identify SSCLD clinician/s to do ongoing work with the child and family
- Clarify if other services are needed and take appropriate action
- Consider Safeguarding issues

**Goals Agreed**
Clinician, child & family define goals

**Assessment**
Clinician/s and family complete holistic and collaborative assessment of needs (within 18 weeks of referral) which may include:
- Behaviour
- Emotional needs and attachment
- Development and developmental difficulties
- Communication
- Sensory needs
- Risk
- Mental health
- Physical health
- Family and relationships
- Support system difficulties
- Safeguarding issues

**Formulation**
A formulation to help understand the presenting problems and guide interventions is made by clinician/s in collaboration with the child and family

**Intervention**
Clinician/s, child and family collaborate to deliver intervention which may include interventions with:
- Child / young person
- Parents
- Family
- Wider support systems
Interventions may include:
- Individual psychological work
- Systems intervention – family/school
- Medical intervention/medication
- Developmental intervention
- Behavioural Intervention
- Parenting intervention / Webster Stratton
- Sleep Intervention
- Psycho-education

**Further Intervention**
Allied Services Include:
- BIRT
- Arts therapies
- Occupational Therapy
- Speech & Language Therapy

**WHAT NEXT?**

**Outcome Measures**
Clinician reviews goals with child and family. Has intervention been effective?
- No
- Yes

- Review assessment needs and formulation
- Adapted intervention
- Service intervention not adequate to meet needs

- From age 14 onwards consider multiagency transition plans to adult services
- Discharge from SSCLD

**Ongoing support** for child and family by GP, school staff, social workers, paediatricians and other community child health professionals

**New concern**
- Discussion at Complex Needs Group/Multiagency Group for:
  - Continuing Multi-agency input
  - Consider in-patient care as a last resort
- New assessment or intervention by SSCLD
- Other agency input

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**References:**
Referral Guidelines for the
Specialist Service for Children with Learning
Disabilities (SSCLD)

INTRODUCTION

The Specialist Service for Children with Learning Disabilities (SSCLD) is part of a wider network of health, education and social services, supporting learning disabled children and young people with complex emotional, behavioural and/or mental health difficulties.

This guidance is intended to assist referrers to know who, how and when to refer to child learning disability mental health services in Bristol and South Gloucestershire. This guidance is also designed to improve access for children and young people who need it the most, whilst concurrently, making sure that other sources and agencies of help have been tried where appropriate.

The SSCLD is comprised of a Bristol team and a South Gloucestershire team who provide a service for children living within the boundaries of the Bristol and South Gloucestershire Primary Care Trusts respectively.

The South Gloucestershire Specialist Service for Children with Learning Disabilities (SSCLD) comprises of:

- Specialist Community Learning Disability Nurses and Support Worker
- Clinical Psychologists
- Consultant Child and Adolescent Learning Disability Psychiatrist

The Bristol Specialist Service for Children with Learning Disabilities (SSCLD) comprises of:

- Specialist Community Learning Disability Nurses and Support Worker
- Clinical Psychologists
- Consultant Child and Adolescent Learning Disability Psychiatrist
- Primary Mental Health Specialist for Children with Learning Disabilities

Both teams have access to art, drama and music therapy services. The Bristol team can also access the Bristol Intensive Response Team (BIRT).

AGE RANGE

The service accepts referrals of learning disabled children and young people up to their 18th birthday. There is no lower age limit but the SSCLD would not become involved with a child until after the Community Child Health Team had completed an assessment of the child’s needs and his/her diagnostic and developmental status.
TYPES OF PROBLEM

Learning Disability Definition

Valuing People (DOH) defines ‘learning disability’ to include the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood, with a lasting effect on development.

This definition encompasses people with a broad range of disabilities.
In general, it is expected that the Specialist Service for Children with Learning Disability will work with children and young people with moderate, severe and profound learning disabilities.

Moderate, severe and profound learning disability is defined by the World Health Organisation as an IQ of 50 or less. It is important to acknowledge, however, that IQ describes only one aspect of a child or young person and does not ‘capture’ the whole child.

Services are available to learning disabled children and young people who have severe, complex and enduring developmental, emotional, behavioural or mental health difficulties, which are leading to significant distress and/or functional impairment and which have not resolved with the usual primary interventions. It is not possible to give an exhaustive list of potential referral problems but the following are some examples of difficulties which would be considered:

- Aggression / Challenging Behaviour
- Self injurious behaviour
- Sexual behaviours of risk to self or others
- Problems with sexuality or gender identity
- Severe difficulties adapting to puberty and adolescence
- Complex, severe, enduring continence problems including faecal smearing
- Severe anxiety
- Obsessive compulsive problems
- Low mood, self esteem and depression
- Feeding and dietary problems
- School refusal where mental health difficulties play a significant role
- Severe or abnormal reactions to loss and bereavement
- Severe / complex relationship difficulties leading to significant impairment of functioning or well being
- Children at risk of school exclusion and / or home / placement breakdown due to emotional and behavioural problems
- Offending behaviour where mental health difficulties play a significant role
- Psychiatric disorders including psychosis
- Medical problems significantly impacting on emotional health and well being

HOW TO REFER

Complete a Single Point of Entry form with as many details as possible (See below “What information is needed when making a Referral”) and send to the address on the form.

WHO CAN REFER

Referrals are accepted from:

- Health Service Staff
- Schools and Education Service
• Social Workers
• Voluntary Sector

HOW TO DECIDE WHAT IS AN APPROPRIATE REFERRAL

South Gloucestershire SSCLD will accept referrals for children and young people attending the following special schools: Warmley Park and New Siblands. Bristol SSCLD will accept referrals for children and young people attending the following special schools: Kingsweston, Briarwood, Claremont and New Fosseway.

For children and young people attending other special schools, or attending mainstream schools (or attached units) with a Statement of Special Educational Needs, the referral will be considered in terms of the child’s level of learning disability, the level of functional impairment and the nature and severity of the presenting problem.

A referral is appropriate if there are significant concerns about a child’s development, well being or behaviour and these are having a significant impact on the child’s functioning. If you are uncertain about a referral then please contact us to discuss the issue.

Where it is unclear whether a child has sufficiently severe learning disability to meet the criteria for SSCLD, as general guidance, if the presenting difficulties are primarily associated with the child’s developmental delay, then their needs may be best met by SSCLD. However, if the child’s presenting problems are associated with other factors and do not derive primarily from their developmental delay, then their needs may be best met by the CAMHS team. Joint working between CAMHS and SSCLD may be indicated in some cases.

Preschool children with severe, complex and enduring developmental, emotional, behavioural or mental health difficulties who attend specialist nurseries and have significant developmental delay, with functional impairment are likely to be considered for the SSCLD service once their needs have been assessed by the Community Child Health Team. Other preschool referrals will be considered in terms of the child’s level of learning disability and the nature and severity of the presenting problem.

If you are unclear if your referral is appropriate, please discuss it with a member of the team prior to referring to ensure that an appropriate referral is made.

HOW TO DECIDE WHO IS NOT AN APPROPRIATE REFERRAL

Children and young people with a mild learning disability should in the first instance be referred to the CAMHS team.

Referrals will not be accepted for “normal” responses to “normal” life events and children whose parents are in dispute within legal proceedings.

Children or young people diagnosed with an Autistic Spectrum Disorder (ASD) may also have learning disabilities. However, those with a higher level autistic spectrum disorder may be of average or above average intelligence, such as young people with Asperger’s syndrome. It is expected that for these children/young people their needs will be best met by the CAMHS team.

WHAT WORK NEEDS TO BE DONE BEFORE MAKING A REFERRAL

a. Direct assessment

The child or young person needs to have been seen in person and assessed by the referrer prior to making a referral to the service.
b. Intervention by frontline staff

It is expected that prior attempts will have been made by frontline staff (e.g. primary health care staff such as health visitors, school staff, school health nurses, CYPS staff) to resolve the child/young person’s difficulties or problems before making a referral. Many children and young people can be helped in this way and generally it is better if the problems can be resolved at this level.

We expect ongoing case-holding by referrer.

c. Consent

Formal consent needs to have been obtained from someone with legal parental responsibility for the child before a referral is made.

Young people aged 16 and above are able to consent to referral in their own right. Some young people under the age of 16 who are competent to consent to a referral can also do so. Although it is always usual to attempt to gain parental consent for a referral, the service will see young people alone, as appropriate. In such cases, the referrer should give careful consideration to any risks involved to the young person and assess the capacity of the young person to consent of the referral.

d. Attendance

We will also need to know from the referrer what, if anything, is needed to support the child and/or family to engage with the service.

Please note that any child protection concerns should already have been reported to the statutory agencies prior to referral.

WHAT INFORMATION IS NEEDED WHEN YOU MAKE A REFERRAL

You will need to complete a Community Children’s Health Partnership Single Point of Entry Referral Form, plus, if necessary, a letter outlining:

- Child and family view of current concerns/problems
- What are the reasons for seeking help at this moment in time
- How long has the problem existed, how severe it is, and how does it impact on the child/young person’s family, education, work.
- Relevant psychosocial and family issues including who is in the family or important people in the kinship system.
- Response to previous attempts to help
- Confirmation that the child, young person or family have consented to the referral
- Which other professionals are involved.
- Any other relevant information (e.g. risk factors).

ETHNICITY MONITORING

Please note that we have a legal requirement to monitor ethnicity as defined by the child or young person themselves or by a parent with legal parental responsibility in the case of a young child. This means that the ethnicity section on the referral form must be completed please.
There is an ever-increasing obligation on child and adolescent mental health services to meet the needs of children and young people with learning disabilities. This practical and concise book will help clinicians, service managers and commissioners to rapidly develop the necessary skills and knowledge in this expanding area of clinical practice. It provides a comprehensive overview of epidemiology, mental health disorders and their clinical presentations, multidisciplinary assessment and intervention, and multi-agency working. It reviews the specific roles of different medical practitioners, such as clinical psychologists and occupational therapists. Plus there are sections on working in partnership with families, and service tiers and models.

About the editors

**Sarah Bernard** is consultant psychiatrist for children and adolescents with learning disability at the Michael Rutter Centre, South London and Maudsley NHS Foundation Trust where she leads a tier 4 multidisciplinary national and specialist CAMHS-LD service. Her main clinical interests are the assessment and management of complex mental health/behavioural problems associated with learning disability. She has a particular interest in rare developmental/genetic disorders, epilepsy, offending behaviour and parents with learning disability. She is also offers advice to the Rett Society, Prader-Willi Association and Unique. She is a member of the examination subcommittee of the Royal College of Psychiatrists.

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With a foreword by **Dawn Rees**, National CAMHS Strategic Relationships and Programme Manager at the National CAMHS Support Service.

Edited by

Dr Sarah Bernard

& Professor Jeremy Turk
Developing Mental Health Services for Children and Adolescents with Learning Disabilities

A Toolkit for Clinicians
Developing Mental Health Services for Children and Adolescents with Learning Disabilities

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Edited by Dr Sarah Bernard
& Professor Jeremy Turk

RCPsych Publications
in collaboration with the National CAMHS Support Service
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We are delighted to welcome you to this practical toolkit, which, in its brief and easy-to-read format, outlines the key principles to consider when working with children and young people with a learning disability who have a mental health problem.

The National Service Framework for Children is now in its fifth year and the Public Service Agreement 12 (2007), as part of the Comprehensive Spending Review, set out the government’s vision for improving the physical, mental and emotional health of all children and re-emphasised the needs of children and young people with a learning disability. While we recognise that much progress has already been made in this field, we also know there is still a need to embed quality commissioning and provider services for all children and young people and in particular for those who have learning disabilities, in order that they have access to truly comprehensive child and adolescent mental health services which meet all their needs.

This toolkit is written by clinicians for clinicians. It emphasises the clinical, practical and theoretical perspectives which will help build a more capable workforce and deliver services that improve the life chances of this group of children.

It is a further contribution to the range of toolkits and resources which champion the needs of this group of children, such as the ‘Do Once and Share’ project and its care pathway, and which have been helpful in developing our thinking about what kind of support and developments ensure that appropriate levels of service are commissioned and provided. This toolkit adds to that body of work and extends it.

This toolkit is an _aide-mémoire_ for mental health professionals when starting out in clinical practice. It aims to support their work with children and young people with learning disabilities and covers the topic areas which are relevant to most cases. No handbook, however, can be exhaustive, so the reader will find references for further reading at the end of each chapter. Skills build over time as experience expands, and we hope that this publication will be a useful contribution to professional development for all staff working with this group of young people.
Respected clinicians and practitioners voluntarily contributed their experience to each of the chapters. Our thanks go to them. Our particular thanks go to the clinical editors, Dr Sarah Bernard and Professor Jeremy Turk, who edited the contributors’ drafts and organised the material into a coherent whole. It is typical of their unstinting commitment to improving the lives of this group of children and young people that they never turn down an opportunity to make a difference!

Dawn Rees
National CAMHS Strategic Relationships and Programme Manager.
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Preface

It is widely recognised that although young people with learning disability are at an increased risk of mental health or behavioural problems, there is a serious lack of appropriate mental health provision to meet these needs. The National Service Framework for Children states clearly that services should be available to all. Other documentation has also emphasised this need but, unfortunately, the provision of child and adolescent mental health services (CAMHS) for this group of young people remains inadequate.

This toolkit, we hope, will, along with other recent publications, help CAMHS clinicians to feel more confident in assessing and managing the basic mental health needs of these children and young people in a multidisciplinary manner. We hope that it will help abolish the discriminatory ‘IQ lottery’ of access to CAMHS provision for children with learning disability.

The term ‘learning disability’ is generally used throughout this text. Although ‘intellectual disability’ is now more commonly used internationally and in the scientific literature, ‘learning disability’ is more widespread within the context of the UK National Health Service and so is preferred here.

We would like to thank all the people who have contributed to this publication. Particular thanks go to Mary Killick, CAMHS Regional Development Worker, Care Services Improvement Partnership, for her support, enthusiasm and encouragement.

Sarah H. Bernard
Jeremy Turk
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>ADHD</td>
<td>attention-deficit hyperactivity disorder</td>
</tr>
<tr>
<td>CAMHS</td>
<td>child and adolescent mental health service</td>
</tr>
<tr>
<td>SLT</td>
<td>speech and language therapy</td>
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<tr>
<td>SSRI</td>
<td>selective serotonin reuptake inhibitor</td>
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Children and adolescents with developmental disabilities are at a greater risk of developing mental health or behavioural problems than are their non-disabled peers. This fact is supported by several epidemiological studies:

- Rutter et al (1970) studied 10- to 12-year-old children on the Isle of Wight and found that emotional and behavioural disorders were much commoner in children with learning disabilities.
- Corbett (1979) showed in a study of children with severe learning disability aged 0–15 years in south-east London that 47% of the sample had some form of psychiatric disorder.
- Gillberg et al (1986), in a study of 13- to 17-year-olds in Sweden, demonstrated increased rates of autism, language and social impairment and psychosis in those with an IQ of less than 50.
- Emerson & Hatton (2007) studied 641 children with learning disabilities and found higher rates of social disadvantage and an increased risk of all psychiatric disorders.

It is also recognised that these children are less likely to access appropriate mental health services. Even when they do, they are less likely to have their psychiatric and developmental needs recognised, understood and addressed in an evidence-based and optimally therapeutic fashion. Child and adolescent mental health services (CAMHS) are, in general, lacking in the expertise and resources required to provide comprehensive assessments and ongoing management for those with developmental disabilities. This affects the child’s mental health, and educational and social needs. Additionally, there is a negative impact on family life, with an increased likelihood of sibling and parental emotional distress, family breakdown and expensive residential placements. Research findings are consistent with a good third of children and young people with learning disability experiencing mental health problems, compared with 11% of those who have only a physical disability or chronic illness, and 8% of children and young people in the general population. In a single London borough, where the population is approximately 250000, 20% (approximately 50000) of these being children
and young people, one should expect 2–3% (approximately 1500) to have a learning disability, with approximately 250 of these having an IQ of less than 50. A good third of those with mild learning disability will have mental health problems that are diagnosable and for which help can be offered; untreated, however, these problems lead inevitably to significantly impaired quality of life and underachievement. This amounts to approximately 420 individuals. A good half of those with moderate-to-profound learning disability will have mental health problems that are both diagnosable and for which help is available, amounting to a further 125 individuals. Thus, at any time, there are approximately 550 children and young people in just one London borough who have learning disability meriting mental health evaluation and input.

Individuals with learning disability are also acknowledged as being at increased risk of autistic-spectrum disorders and attention-deficit hyperactivity disorder (ADHD). Epidemiological data suggest that in a similar population to that above there should be approximately 250 children with autistic-spectrum disorders and 2000 children and young people with ADHD, and many from both these groups will have a learning disability as well. This gives some idea of the magnitude and pressing nature of these public health issues.

Mental health disorders commonly encountered in children and adolescents with learning disability

Children and adolescents with learning disability are likely to encounter the same range of psychiatric disorders as their non-learning disabled peers, although certain disorders are more common than others.

Standardised diagnostic criteria should be considered with the understanding that symptoms and phenomena should be interpreted in the light of the child’s level of cognitive functioning and understanding. In addition, physical and sensory disabilities will influence the presentation of a psychiatric disorder, as will associated social and communication difficulties.

The account that follows is by no means comprehensive and readers should refer to the texts listed at the end of this chapter to gain further information about specific disorders.

Autism and autistic-spectrum disorders

These disorders have the following characteristics:

- they are pervasive
- they usually manifest before the child is aged 3 years
- there is abnormal functioning in all three areas of social interaction, communication and behaviour (which is restrictive and repetitive).
In children with severe learning disability, the level of cognitive functioning should be considered when considering the triad of autistic symptoms. Certain behaviours that appear autistic may, in fact, be appropriate for the child’s cognitive level. Conversely, it is quite possible, and is often the case, that a child’s level and nature of social and communicatory functioning are sufficiently out of keeping with the child’s general cognitive ability that they merit a diagnosis of autism in addition to learning disability.

The management of children with autism involves combined developmental, behavioural and educational approaches. Medication sometimes has a role but is not a first-line option and should always be used in conjunction with behavioural and other interventions.

**Hyperactivity and attention-deficit hyperactivity disorder**

Attention-deficit hyperactivity disorder (ADHD) has the following key characteristics:

- early onset – usually within the first 5 years of life
- overactive, poorly modulated behaviour with marked inattention and overactivity
- pervasiveness.

Associated abnormalities include restlessness, fidgetiness, impulsivity, distractibility, breaching of rules, social disinhibition and cognitive impairments.

ADHD is often under-diagnosed in children with developmental disabilities, because the child’s lack of attention can be interpreted as being due to the underlying cognitive impairment rather than an associated attentional disorder.

The management of children with ADHD includes a trial of psychostimulant medication, behavioural approaches to maximise attentional and associated skills, and consideration of the educational and social environments.

**Depression**

The clinical manifestations of depression include:

- low mood
- loss of interest in daily activities
- loss of energy
- tearfulness
- poor concentration and memory
- biological features, including disturbed sleep, poor appetite and diurnal mood variation
- low self-esteem and negative view of the future
• distress
• self-injury.

Distress can be mistaken for depression. Conversely, treatable depression is often missed because behavioural change is explained away as being part of the general presentation of the individual’s learning disability (this is termed ‘diagnostic overshadowing’) or is labelled as ‘challenging behaviour’.

In children and adolescents who are non-verbal, diagnosis relies largely on the biological and somatic features of depression, often as reported by others.

As in children without developmental disabilities, depression can resolve spontaneously, but the risk of relapse must be considered. Cognitive–behavioural therapies can be helpful in initial episodes of mild to moderate depression, but if unsuccessful, a cautious trial of medication should be considered, usually a selective serotonin reuptake inhibitor (SSRI) in combination with cognitive–behavioural work.

Psychosis – including schizophrenia and bipolar disorder

The clinical manifestations of psychosis include:

• thought disorder
• hallucinations
• delusions
• catatonic behaviours
• negative features, including apathy, blunting of affect and social withdrawal
• changes in behaviour.

In schizophrenia, the above symptoms are incongruent with mood, while in bipolar affective disorder they are mood congruent. Distinguishing between the two types of psychotic disorder is often problematic in children and adolescents with moderate to profound learning disability and hence treatment often needs to be pragmatic and empirical.

A diagnosis of psychosis should be made only by experienced clinicians, as once the label had been given, it will have major implications for the child’s educational placement, for access to respite services and for service provision in adulthood.

Antipsychotic medication must be supervised. The current treatments of choice are atypical neuroleptics such as risperidone, olanzepine, quetiapine and aripiprazole. In bipolar disorder, mood stabilisers have a role. Monitoring of lithium levels can pose difficulties. Thus sodium valproate or carbamazepine may, in certain instances, offer a safer alternative.

Tourette syndrome

The syndrome is characterised by:
• multiple motor tics
• one or more vocal tics often accompanied by explosive vocalisations 
• onset in childhood or adolescence.

Support and psychoeducation for parents and teachers are important. Medication such as risperidone, sulpiride, pimozide or clonidine reduces tic frequency but benefits must be balanced against the risks of side-effects. 

External stressors increase the frequency of tics. Hence cognitive–
behavioural approaches focusing on monitoring of environmental triggers, problem-solving and stress management can be useful.

**Challenging behaviour**

This is not a diagnosis. It is a descriptive term for any behaviour that poses a challenge for the individual, carers or society. Emerson (2001) defines challenging behaviour as a set of ‘behaviours of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour is likely to seriously limit or delay access to and use of ordinary community facilities’.

Any behavioural problem requires a comprehensive assessment in order to identify causative factors (antecedents); this assessment must include underlying physical or psychiatric disorders as well as possible reinforcing consequences of the behaviours.

Challenging behaviours include:

• self-injury
• aggression
• persistent spitting
• self-induced vomiting
• persistent masturbation/sexualized behaviours

Challenging behaviours are more common in individuals with learning disability and autism, their frequency and intensity increasing with the severity of these conditions.

Management involves the multidisciplinary team, the family, the school and social services. Behavioural psychotherapy is the first line of approach but cautious use of medication may be indicated. This should be tailored to individual need.

**Self-injury**

This behaviour:

• is relatively common in children and adolescents with severe learning disability and autism
• may serve a variety of functions, including attention-seeking, gaining solitude, demand avoidance, over- or under-stimulation, self-stimulation, emotional reaction to bereavement, abuse or neglect
Mental health services and learning disabilities

- may be part of a post-traumatic stress disorder
- may be a presenting feature of a specific syndrome, such as Lesch–Nyhan syndrome, Smith–Magenis syndrome, Prader–Willi syndrome, fragile-X syndrome, Cornelia de Lange syndrome.

Always consider social factors such as deprivation, disadvantage, neglect and abuse as underlying contributors. A detailed functional assessment is crucial. In the absence of environmental triggers consider using electro-encephalography (EEG) to aid diagnosis.

Management combines behavioural psychotherapy with medication such as SSRIs, atypical antipsychotics, anticonvulsants, or opioid antagonists. Medication should be tailored to individual needs and given only for as brief a period as possible, and then under highly specialist supervision.

References


Multidisciplinary mental health assessment

The aim of a multidisciplinary assessment is to undertake comprehensive and detailed evaluation of the individual from a wide range of biological, psychological, educational, developmental and social perspectives in order to achieve:

- a succinct yet informative formulation
- a set of differential diagnoses (or alternative explanations) for the nature of the presenting challenges
- a set of factors contributing to their likelihood (predisposing), occurrence (precipitating) and persistence (perpetuating)
- a profile of useful, cost-effective and evidence-based biopsychosocial interventions and supports likely to minimise the presenting challenges while maximising achievement of potential and quality of life for the individual and family.

How do mental health problems present in children with learning disability?

Mental health problems present in children with learning disability in just the same way as in children with more average intellectual functioning. The mental health worker, though, needs to beware of ‘diagnostic overshadowing’ (see p. 4). The presenting features can include:

- social, communicatory, ritualistic and obsessional impairments
- overactivity, attentional deficits
- aggression
- self-injurious behaviour
- cyclical mood and behaviour changes.

Diagnosis can be complicated by:

- frequent communication difficulties
- having to adjust for mental age.
Contributors to psychological difficulties in children and young people with learning disability

These include:
- the severity of the learning disability
- the cause of the learning disability
- the presence of autistic-spectrum disorder
- social factors –
  - abuse and neglect
  - schooling issues
  - poverty
  - parental psychiatric disorder
  - transgenerational social disadvantage
  - bereavement
  - life events, daily hassles, post-traumatic stress disorder
  - migration
  - attachment disorders.

Conditions causing, or complicating, presenting challenges

These include:
- neurodevelopmental disabilities
  - learning disability
  - autistic-spectrum disorders
  - attention-deficit disorders
- neuropsychiatric disorders
  - obsessive–compulsive disorder
  - cyclical mood disorder
  - depression
  - anxiety states
  - tics and Tourette syndrome
- psychosocial circumstances.

Types of diagnosis (and who usually makes it)

An aetiological diagnosis would be made by a paediatrician. Examples would include fragile-X syndrome, Down syndrome, foetal alcohol syndrome and congenital rubella.

A phenomenological diagnosis would be made by a mental health professional. Examples would include autism, Asperger syndrome, hyperactivity, ADHD, self-injury, ‘challenging behaviour’ and conduct disorder.
A descriptive of level of intellectual functioning would be made by an educationalist. An example would be ‘moderate learning difficulties’. A ‘diagnosis’ reflecting social factors would be made by social services, and could relate to inadequate housing or education, abuse, neglect. Similarly, a ‘diagnosis’ reflecting adverse interactions would be made by social services or a mental health professional (or both) and might relate to attachment disorder, family dysfunction or marital disharmony.

Presenting emotional and behavioural states

These presenting states may be:

- consistent with developmental level
- an understandable response to experiences (e.g. bereavement)
- the result of vulnerability produced by having learning disabilities
- indicative of a specific developmental delay (e.g. dyslexia, dyspraxia, attentional, social, communicatory)
- part of a ‘general’ genetic predisposition
- specific to particular condition –
  - gaze aversion in fragile-X syndrome
  - hyperventilation and hand-wringing in Rett syndrome
  - overeating, obesity, impulsive tantrums and skin-picking in Prader–Willi syndrome
  - profound and intractable self-injury in Lesch–Nyhan syndrome.

Multifaceted evaluation

Evaluation should cover:

- psychiatric and developmental disorders
- characteristic behavioural profiles
- intellectual functioning –
  - level, profile, meaning
  - specific learning difficulties/developmental delays
- language and communication
- family and social
- educational
- other emotional problems
- other challenging behaviours.

Multi-faceted intervention

The intervention decided upon may need to include:
Mental health services and learning disabilities

- education and information
- cognitive and behavioural psychotherapies
- family therapies
- speech and language therapy
- occupational therapy
- medication
- attention to social circumstances and social supports
- liaison and consultation
- counselling and support.

Classification of reasons for challenging behaviour:

Behaviour as part of a primary condition

Organic/biological causes

Such causes of challenging behaviour as part of a primary condition can be classified as:

- genetic (e.g. fragile-X or Down syndrome)
- toxic (e.g. foetal alcohol syndrome)
- infective (e.g. rubella)
- metabolic (e.g. phenylketonuria, hypothyroidism)
- malnutrition
- hypoxia
- physical brain trauma (e.g. from road traffic accident or child abuse).

Psychosocial causes

These include:

- profound deprivation, under-stimulation
- abuse and neglect.

Behaviour as a specific secondary consequence of the primary condition

Learning or other developmental disability may affect one or more further areas of development in such a way as to affect behaviour in a social setting:

- impaired social understanding
- impaired ability to relate socially
- impaired communication (e.g. misunderstandings, relative delay in response or failure to respond to verbal approaches from others, use of communicative behaviours which may be misinterpreted, such
as aggression ‘without reason’, literal use of language, repetitive expressive language).

**Behaviour secondary to an unrelated physical condition**

Limited communication skills can lead to pain and distress, for example, being expressed through challenging behaviour. The pain may be from, for example:

- earache
- gastro-oesophageal reflux (‘heartburn’)
- toothache
- arthritis
- intestinal blockage (constipation and faecal impaction)
- angina.

**Behaviour as non-specific secondary consequence of impact of the primary condition**

Behavioural and emotional disorders are commoner in children and young people with learning disability than in the age-matched general population.

**Behaviour related to parenting and secondary impact of disability**

The impact of the child’s disability on the emotional and mental well-being of the child’s carers and siblings needs to be considered.

**Important competences**

Learning disability specialists working on a CAMHS need to have:

- competence in the assessment of the level and profile of development (this can range from the basic, clinical–observational through the use of simple evaluation tools to comprehensive psychometric and speech and language therapy testing)
- working knowledge of key developmental milestones (motor, language, social, attentional, adaptive)
- the ability to recognise features suggestive of intellectual, social, linguistic and attentional developmental disorders which may present, or be associated, with emotional, behavioural and mental health difficulties
- an understanding of the relevance of laboratory and other biomedical investigations in the assessment process.
Referral pathways for initial assessment

Pre-school children with developmental and behavioural concerns are most likely to be referred to a child development service. School-age children with developmental, emotional and behavioural challenges are referred usually to the local CAMHS.

Following initial assessment some need referral from one team to another. A close working relationship is therefore essential between the child development team, the CAMHS, the local education authority and schools, local social services and local private and voluntary organisations. This is facilitated by a strong CAMHS presence in the multidisciplinary child development team.

Child development and warning signs of abnormal development

An individual’s developmental progress varies enormously and is determined by a complex interplay between environmental factors (maternal health antenatally, in utero conditions, the birth process, economic and social conditions facing the family) and genetic factors.

A sound knowledge of typical child development is essential for recognition of common presentations when development is abnormal in one of the following ways:

- delayed rate of development (i.e. beyond accepted range of normal variation) in one or more developmental domains (e.g. echolalia still present by 3 years)
- absolute failure to develop skills (e.g. no ‘canonical’ babble – that is, repeated strings of expressive vocalisation of well-formed syllables, such as ‘bababa’ – by 10 months)
- disordered developmental sequence (e.g. hyperlexia coexisting with delayed language – that is, precocious reading skills well in advance of understanding)
- motor asymmetry
- qualitative concerns about emerging skills and abilities
- developmental regression – that is, loss or plateauing of skills (this is a dementia if the cause is biological, or regression if the cause is psychological).

Developmental history-taking

Parents are usually best at remembering whether or not they have had past concerns and, if so, what those concerns were. However, parents’
interpretation of what their child does may reflect a wish or desire on their part rather than reality (e.g. ‘he understands everything I say’). The mental health worker should taking the history should:

- use open-ended questions, followed by requests for examples, as these elicit the best history
- follow up with a specific list of closed questions to fill gaps in history
- encourage accounts of observations of behaviour rather than interpretations of motives (e.g. ‘he will fetch his shoes only if they are visible’)
- ask for the parental view of causation
- reassure parents as to what has not caused the child’s difficulties, such as a belief that autism could be caused by the mother going out to work, or being depressed, or having agreed to immunisation with the single vaccine for measles, mumps and rubella (MMR)
- reassure parents, where appropriate, that their efforts to date have been extremely relevant, useful and productive.

Observation and interactive assessment

A suitable selection of toys should be available, covering a range of skills, interests and developmental stages and domains, such as:

- copying behaviour (bell) and understanding of cause and effect (pop-up animal toy)
- evidence of pre-verbal understanding – defining a real object by using it (cup/spoon, doll/brush) and showing symbolic understanding of the intended real-life role of play materials (doll/teddy/tea set)
- fine motor and eye–hand skills – explored with the use of coloured bricks, crayons, pencil, paper, soft ball, form boards, puzzles
- language and play (books with single pictures and stories, range of everyday toy objects, large-world and miniature-world toys).

It is helpful to have to hand toys that will appeal more to individuals at early sensory developmental stages (e.g. soft, squidgy, noisy, lighting-up) and those with obsessional/autistic tendencies (e.g. construction toys, ones with repetitive potential such as ball helter-skelter).

Most children function better when a helpful adult interacts with them, but time should be allowed for ‘free play’. This is partly because children’s ability to explore and organise the environment and generate ideas on their own is significant. The attending adult should not be too helpful, therefore.

The child may not be able to focus attention, flitting from one object to another. Alternatively, very repetitive play may be noted.

The mental health worker should observe not only at what child does, but also how the child does it. Thus quality of response needs monitoring as well as actual achievement.
Developmental domains

There are five developmental domains:
- gross motor
- visual behaviour (eye–hand coordination, problem-solving)
- language and communication
- play and social behaviour
- attentional behaviour.

Language and communication as contributors to emotional and behavioural disturbance

Children may be frustrated at their inability to communicate, understand and be understood. Behaviours may in themselves be forms of communication (e.g. throwing objects when child wishes to end an activity). Thus there is a high risk of the child’s communication strategies being mistaken for challenging behaviours, to be snuffed out.

The parents’ level of understanding of their child’s communication needs is important:
- they may not understand their child’s communicative behaviours
- they may communicate with the child at a level not commensurate with that child’s understanding.

Children with good understanding of daily family routines, and well-developed speech, often have their language comprehension overestimated by parents.

Play and social behaviour as contributors to emotional and behavioural disturbance

The mental health worker should:
- consider the child’s social development and explicitly exclude developmental disorders such as autism and hyperkinetic disorder, which may not have been considered in past assessments
- note that play, social development and attentional skills progress through developmental sequences, just as motor and language development do, and consider the child’s stage of development in relation to the overall level of learning disability
- look at pro-social behaviour, including sharing, joint attention skills, including quality of eye contact used with communicative intent, pointing and other gestures.
Attention behaviour

The development of attention, concentration span and freedom from impulsiveness and distractibility, as for other skills, passes through a succession of developmental stages as skills become increasingly sophisticated and mature. There are six stages in the development of attention:

1. extreme distractibility, with attention held momentarily by whatever is the dominant stimulus (year 1)
2. concentration on task of own choice, ignoring all other things in order to focus; extreme resistance to interference by adult (year 2)
3. adult can shift child from one task to another; attention must still be fully gained before changing focus (year 3, ‘single-channel attention’)
4. ability to control own focus of attention; gradual move towards only needing to look at adult when directions become difficult to understand (year 4, early ‘integrated attention’)
5. at school entry age, ability to perform activity while listening to teacher’s instructions (year 5, short periods of integrated attention)
6. mature stage, with attention flexible and sustainable for long periods.

Physical health and examination

The mental health worker should consider need for paediatric opinion if:

- there is the remotest possibility of physical symptoms
- self-injury or aggression is inexplicable
- there is plateauing or loss of physical, psychological or other developmental skills
- new onset of significant behavioural deterioration is not fully explained by the current diagnosis and assessment
- there are unusual skin signs
  - there are pigmented, hypo-pigmented or rough skin patches
  - there are capillary or cavernous haemangiomas (‘naevi’).

Compromised communication skills and low pain sensitivity may mask physical illness or lead to its expression through emotional and behavioural change.

Some conditions show physical signs in older childhood not present at birth or in infancy. These include:

- some forms of mucopolysaccharidoses
- adenoma sebaceum in tuberous sclerosis
- dysmorphic features – these may become more evident only in later childhood or even post-pubertally (e.g. testicular enlargement in fragile-X syndrome), or subtle signs may be missed in infancy (e.g. foetal alcohol syndrome).
Developmental diagnosis and management

The outcome of the developmental assessment will give a profile of developmental abilities and disabilities ('strengths and needs'), alongside emotional, behavioural and mental health assessments. The combined picture may indicate one or more of:

- global learning disability
- characteristic clusters of specific developmental delays or qualitative impairments (e.g. autistic-spectrum disorder, ADHD)
- specific learning difficulties (e.g. dyslexia, dyspraxia, dysarthria, dysphasia, dyscalculia, dysgraphia, sensory integration difficulties).

Laboratory investigations may be indicated to explore possible medical causes of behavioural presentations, as well as developmental disabilities and physical issues, such as:

- behavioural phenotypes (Down, fragile-X, Prader–Willi, Angelman, Lesch–Nyhan, Smith–Magenis syndromes, tuberous sclerosis, sex chromosome aneuploides and so on)
- self-injury
- aggression
- hyperkinesia and attentional deficits
- sleep disorder
- social and communicatory impairments
- epilepsy.

Further useful specialist evaluations after initial assessment include:

- speech and language therapy
- occupational therapy
- community paediatrician
- specific multidisciplinary assessment for autistic-spectrum disorder, ADHD, or psychiatric disturbances (e.g. depression, anxiety states, attachment disorder, obsessive–compulsive disorder).

Links between CAMHS and the child development services

Co-location and other strong links between teams, where possible, allows joint working, seamless services and discussion about referrals and case management.

Good care management, working together with clear and agreed multidisciplinary and multi-agency plans, named key workers and close collaboration with family and other statutory, private and voluntary agencies are necessary for the effective management of complex difficulties such as
emotional and behavioural difficulties in children and young people with learning disability.

**Important conditions**

*Foetal alcohol syndrome (alcohol-related neurodevelopmental disorder)*

- Alcohol is the toxin to which a foetus is most commonly exposed.
- The syndrome features pre- and postnatal growth deficiency.
- IQ is usually in the mild/borderline learning disability range.
- There are fine-motor and visuospatial problems, including tremulousness.
- There are problems with executive function, numeracy and abstraction.
- There are expressive and receptive language difficulties.
- Irritability is seen in infancy, hyperactivity in childhood.
- There are problems perceiving social cues.
- Family environments are often very unstable, with high rates of insecure and chaotic/disorganised attachments.

*Cerebral palsy*

- Psychiatric disorder is present in 40% of children with cerebral palsy.
- There is no gender predominance.
- Of those with hemiplegia:
  - 25% have conduct/emotional disorder
  - 10% have hyperkinetic disorder
  - 3% have an autistic disorder.
- The best predictor of behavioural problems among those with cerebral palsy is low IQ.
- Disorders manifest identically to those of psychosocial origin.

*Down syndrome*

- This is the most common identifiable genetic cause of learning disability.
- Mean IQ is in moderate–severe learning disability range.
- Those with Down syndrome have a characteristic personality and temperament.
- There are relatively low rates of autistic-spectrum disorders and attention-deficit disorders in childhood.
- There are comparatively high rates of depression.
- There are comparatively high rates of Alzheimer’s disease in adulthood.
- A major risk factor for Down syndrome is maternal older age.
Fragile-X syndrome

- This is the commonest identifiable inherited cause of learning disability.
- Mean IQ is in mild–moderate learning disability range.
- There are high rates of autistic-spectrum disorder and ADHD (inattentive type as well as overactive–impulsive and combined types).
- There are particular cognitive problems with sequential information processing, numeracy and visuospatial abilities.
- People with the syndrome are, characteristically, friendly and sociable, albeit shy and socially anxious, often with a range of autistic-like communicatory and ritualistic features, including delayed echolalia, rapid and dysrhythmic and repetitive speech, hand-flapping and gaze aversion.
- Male and female pre-mutation carriers show varying rates of the above difficulties.
- Female carriers experience premature ovarian failure.
- Male and female pre-mutation carriers experience middle-aged onset of tremor–ataxia syndrome with associated loss of cognitive skills.

Positive prognostic features for children and young people with learning disability who have mental health problems

Prognostic features include:

- level of intellectual functioning (the higher the better)
- presence of social awareness
- presence of meaningful language (expressive and receptive)
- presence of attentional skills
- warm, nurturing and structured family environment
- developmentally appropriate, focused and structured schooling
- progress to date.

Further reading


Clinical psychology

Assessment – diagnosis and degree of disability

- Clinical psychologists collaborate with other child and adolescent mental health professionals. They consider:
  - whether the child has an autistic-spectrum disorder in addition to learning disability
  - the degree and profile of learning disability
  - whether the child has ADHD.
- Differential diagnoses include specific learning difficulties, attachment disorders, language impairment and dyspraxia.
- Assessment of autistic-spectrum disorder requires home and school observation. This information is considered in conjunction with speech and language therapy and other assessments, including a thorough developmental history.
- Diagnostic decisions are aided by formal interviews (e.g. the Autism Diagnostic Interview; Lord et al, 2000), observation schedules (e.g. ADOS; Lord et al, 1994) and checklists (e.g. the Children’s Communication Checklist; Bishop, 2003).
- Assessment of ADHD requires observation in various settings. Establishing the child’s developmental level is important in order to consider whether problems are out of keeping with that developmental level.
- Establishing the child’s level and profile of cognitive functioning can help in:
  - planning appropriate education settings
  - parents and others pitching expectations correctly
  - understanding of the child’s behaviour.
- Formal cognitive assessments are complicated by attentional difficulties and many children falling below the basal level of tests. Useful assessments include:
  - Leiter–R (Roid & Miller, 1998), which can be carried out with no or limited verbal instruction
Snijders–Ooman–R (Tellegen et al., 2007), which is a short (four-item) measure of non-verbal IQ requiring no spoken language on the part of either the child or the administrator.

If direct assessment is impracticable, Vineland Adaptive Behaviour Scales (Sparrow et al., 1984), completed with parents/carers, provide useful information about developmental level in several domains.

Factors to consider in relation to behaviours that challenge

The most common emotional/behavioural problems presenting in children with developmental disabilities are:

- those that are developmentally related – for example, toileting (training, smearing, phobias), feeding (under-eating, over-eating or faddy eating habits), sleep (getting to sleep, night waking)
- those that challenge either because of harm to self or others or because they limit access to community facilities – for example, tantrums and aggression (towards adults, peers or property), self-harm (eye-poking, skin-picking, hair-pulling, face-slapping, head-banging) and sexualised behaviour (masturbation, inappropriate touching of others)
- those that relate to the child’s emotional well-being and quality of life (withdrawn, socially isolated).

Approaches are similar to those that might be adopted with children who have no learning disability. The psychologist should:

- consider the onset of the problem and recent changes or events in the child’s life, immediate triggers for the behaviour, and reinforcers for the behaviour (using ABC charts that log details of behaviour with antecedents and consequences), together with observations
- break down tasks into small steps (e.g. learning to use the toilet and learning to go to sleep alone), together with an agreed routine and reinforcers that are meaningful to the child and feasible for the family
- gather and apply existing knowledge with additions and adaptations as necessary
- take into account in the assessment three essential elements – the person, the environment, the behaviour – and interactions between these.

Factors intrinsic to the child

The psychologist should interview or play with the child and gather his or her views if possible. If this is not possible because of language and cognitive limitations, it remains important to have a sense of the child as an individual.
The psychological assessment should consider whether the child has difficulties with sensory processing. (Many children with learning disability, autistic-spectrum disorders or ADHD are hypo- or hyper-sensitive to touch, hearing, vision, smell, taste and vestibular experiences. This makes them sensation-seeking, to maintain alertness. However, they can then overload and become either difficult to calm or sensation avoidant. They may react strongly to stimuli they experience as aversive or unduly fascinating and attractive – e.g. loud noises, clothing textures, bright lights, being patted on the shoulder, strong odours, certain tastes.) Problems with sensory processing may cause behavioural difficulties. Use of the Dunn Sensory Profile (Dunn, 1999) is helpful in clarifying possible sensory issues. Interventions should be jointly planned to address challenging behaviours through therapeutic programmes to develop sensory processing abilities, or through programmes that help meet the need for sensory input in ways that do not challenge others.

There are four other points that should be considered within the psychological assessment:

- whether the child has a condition with a recognised behavioural phenotype, such as Prader–Willi syndrome (see above for further details of behavioural phenotypes)
- the child’s likes and dislikes, to identify potential reinforcers and aversive stimuli
- whether the child has a psychiatric disorder such as schizophrenia, depression, cyclical mood disorder, anxiety state or obsessive-compulsive disorder
- whether the child is responding to physical discomfort, for example resulting from constipation, toothache, mouth ulcers, gastro-oesophageal reflux (‘heartburn’) or otitis media (earache).

**Factor intrinsic to the environment**

There are three aspects of the environment to consider:

- physical environment (lighting, size, temperature, etc.)
- interpersonal environment (relationships, beliefs and values)
- organisational setting (systems in place to support the person).

The physical environment should be assessed from two points of view:

- stimulation point of view (over- or under-stimulation)
- boundary-setting and risk.

In relation to the latter, it may be more appropriate to have safety glass and door locks fitted than to increase parental stress with a behaviour programme. Is there a safe space for time-out or calm-down time? Where are keys, knives and matches kept? Can the television set, oven and other vulnerable appliances be made safe with Perspex covers, or by attaching them to the wall?
The psychological assessment should consider whether the child is engaged in activities that are over- or under-demanding. Establishing the developmental level will facilitate this. It is important to look at the rhythm of the child’s day and whether the child experiences the right mix of activities (physical, stimulating, relaxing and social).

Operant learning models provide a helpful framework for behaviours that challenge. Is the child trying to escape undesirable tasks (‘demand avoidance’)? Is the child finding a way to obtain attention (either positive or negative)? Is the child trying to escape an unpleasant stimulus (‘negative reinforcement’)?

The psychologist should consider a skills-deficit approach:

- Does the carer have unrealistic expectations of the child’s abilities, leading to mutual frustration?
- Does the child lack self-occupancy skills or communication channels?
- Does the child know the rules (e.g. where not to masturbate)?
- Does the child find it easier to process visual than auditory information?
- Does the child lack problem-solving skills?

Other points that should be included in the psychological assessment are:

- attachment issues
- abuse – children with learning disability are at significantly higher risk than other children of all forms of abuse, neglect and disadvantage (for refugee children it may be difficult to establish a clear history even though abuse/trauma is strongly suspected)
- the social environment –
  - do they have any friends?
  - are they able to have contact with them outside of school?
  - what is their level of self-esteem?
  - do they feel they can exert some control or make choices?
  - do they feel very different to their peers/siblings?
- the family environment and parental mental health – many parents are under substantial stress and suffer with anxiety or depression, or may have more significant mental health problems; and many families fragment and separate following the birth of a child with a disability, leaving single parents even more vulnerable to mental health problems and social disadvantage
- whether the school or play/respite setting is appropriate to the child’s needs.

It may be that the behaviour is the only way for the child to communicate. What supports are in place to aid more appropriate communication? If it is possible to teach more appropriate ways of communicating (e.g. using Makaton or a ‘picture exchange communication symbol’, or PECS), then the behaviour (e.g. a tantrum) may diminish. Visual timetables, communication passports and social stories are all useful techniques.
Factors intrinsic to the behaviour

Behaviours should be described in detail. The psychologist should:

- investigate the onset, severity, duration and frequency of the behaviour
- establish a baseline measure of the behaviour, so that the effectiveness of any intervention can be measured
- establish how others responded when the behaviour first appeared.

Direct observation is important, as are the observations of those in contact with the child.

Interventions

Direct work

- It can be effective to work with the child to build skills in identifying and naming different feeling states with the use of words, symbols, gestures, or pictorial representations of different feeling states, even if the child is non-verbal. Interventions should be concrete and use strategies that appeal to the child’s interests (e.g. an ‘anger volcano’ made out of clay, bicarbonate of soda and vinegar to track the feelings as they build; or a traffic light system or penalty card system).
- Communication issues will arise. It may not be possible for the mental health worker to become sufficiently accomplished in Makaton or other alternative and augmentative communication methods. However, there will usually be someone who knows the child well who is an expert on how the child is communicating and they should be asked for guidance; it may even be desirable for the CAMHS to work through that person.
- Direct work can be either home based or school based. This will need to be decided.
- Life-story work can be useful where there has been loss or change. This may take the form of an ‘All About Me’ book, with photographs of people, places and activities that form the basis for discussion and exploration of personal feelings.
- Cognitive–behavioural methods are of proven efficacy. Children’s cognitive abilities and whether they can differentiate emotions need to be considered.
- Adolescence poses new issues for the individual and family. Systemic family work can be of value.
- Transitions are particularly stressful times (e.g. starting nursery, a new school, moving home).
Risk assessment and reactive strategies

- In instances of challenging behaviour, risk should be assessed.
- Reactive strategies aim to ensure the safety of the person who is challenging and those in his or her vicinity. They are not designed to produce long-term behavioural changes. They should be used in conjunction with a broader behaviour programme and preventive strategies.
- Reactive strategies should follow the principle of least intrusiveness and least restrictiveness (e.g. ignoring behaviour, leaving the scene, distracting the child).
- Any indicators that the risky behaviour is about to occur and any patterns of escalation in behaviour need to be noted.
- Any reactive strategies that may reinforce the challenging behaviour in the longer term should be avoided.
- Where physical interventions may be necessary, these should be used as infrequently as possible. When they are used, this should be only in the best interests of the child. Restrictive physical interventions should be seen as one part of a broader strategy to address the needs of children whose behaviour poses a serious challenge to services and carers. Specialist training is essential if holding techniques are to be employed.

Problems occurring at network level

Children with disabilities quickly become the joint ‘concern’ of various people in the systems that surround them. This provides numerous opportunities for disagreement, splitting, breakdowns in communication and falling through the net. The system is complex, covering primary, secondary and tertiary levels of care in both acute and community sectors of the health service, various sections of the education department, social services, and community and voluntary agencies. Even professionals can find it hard to keep up to date with services available and current procedures, and parents need support in negotiating this system.

Professionals may play a role when the child’s school placement is under threat or has permanently broken down. Can the challenging behaviour be modified? Can the professional provide a neutral space for the parent to consider future options, including the possibility of the child going to residential school? Can the professional provide information to others in the network or to the parents that makes expectations more realistic?

Psychologists working at network level should take into account the following points:

- Work should be holistic.
- Are parental mental health issues affecting effective functioning of
the support system around the child? Can joint work with the adult mental health service promote improvements here?

- Many siblings of children with disabilities are profoundly affected. Can they be referred on for support, both practical (e.g. homework clubs, young carers’ play schemes) and therapeutic (individual and family work)?
- The impact of any lack of appropriate play, transport, medical and respite services needs to be considered. This is likely to be especially relevant where the family’s finances are stretched (many parents are unable to work because of their child’s needs).
- The effect of care provided by unskilled foster carers may need to be considered, in which case the psychologist may be able to work together with them creatively, flexibly and jointly to offer a local solution.
- Many families present at transition points in the child’s life. Families need additional support from the network to negotiate these times.
- The psychologist’s approach needs to be flexible and at times overlap with what traditionally might be the role of another professional.

How might the psychologist’s role differ from that when working with children who do not have a learning disability?

- Psychologists may do very little clinic-based work to ensure engagement and efficacy.
- There is a lot more liaison, which is essential but time-consuming.
- Negotiating confidentiality issues can be different and complex since psychologists may work in a team dedicated to children with disabilities where it is common practice to share information about both individuals and organisations.
- It is very practical.
- Psychologists need to be flexible when thinking about what their role might be.
- They may do work over the telephone, via email, in schools, homes and elsewhere to ensure accessibility and engagement.
- The work tends to be long term but it is not endless and families can come to feel empowered and skilled enough to manage with infrequent input.
- Systemic ideas (Baum & Lynggaard, 2006) are useful but not used in a purist manner. They are used to consider the system and the child’s, family’s and problem’s position within it.
- Cognitive–behavioural therapy is useful but will need to be adapted and used alongside other concrete and non-verbal techniques in one-to-one work.
• Psychologists may be limited in what they can provide because of policies, procedures or politics in the system surrounding the child and they may need to think in supervision how senior managers can take these issues up and develop a more facilitative milieu for interventions to succeed. For example, with children over 16, can senior managers negotiate the use of adult learning disability services? Can a working party be set up between the social work team, the local education authority and CAMHS to consider the needs of children excluded from school?

Further reading

Approaches to the assessment of language and communication within speech and language therapy (SLT) tend to be similar for all individuals. Intervention is based on findings from assessment which differ for each client. Some SLT contributions are specific to in-patient or out-patient settings, while others are applicable to both. An ideal speech and language therapy programme should:

- be tailored to individual needs
- have aims incorporated into all daily activities and all social situations
- be available 24 hours a day, 7 days a week, 365 days a year
- be developed, monitored and modified by speech and language therapists
- be carried out by those with most regular contact with the child, having been trained to do so by a speech and language therapist.

**Epidemiology**

- Twenty-three per cent of 5- to 8-year-olds referred to psychiatry out-patient departments have unsuspected moderate or severe language disorder (Cohen *et al.*, 1998)
- Of 17 children aged 6–12 years in a unit for children with emotional and behavioural difficulties, 16 presented with speech or language problems (or both) requiring SLT intervention (Burgess & Bransby, 1990)
- In one study, 60% of pre-adolescents in psychiatric hospital had significant speech and language problems, but only 38% had ever received SLT (Giddan & Ross, 1997).

**Nature of speech and language impairment in individuals who have learning disability**

Speech and language impairment in individuals who have learning disability may be:
• part of the general picture of developmental delay
• characteristic of a particular condition or syndrome
• a distinct additional impairment.

Assessment

• The therapist contacts community teams and SLT colleagues to collect data on communication status, previous assessments and interventions, and collates and summarises these.
• SLT assessment takes a holistic view of the individual, placing language and communication skills in a broad context. Interactions with behaviour, social skills and educational attainment are critical.
• Areas of investigation should include:
  • pragmatic skills (context, use, appropriateness, relevance, conversation, discourse)
  • semantics (meaning, vocabulary)
  • syntax (grammar, sentences)
  • speech (phonology, articulation and phonological awareness)
  • literacy (reading and spelling).
• Investigation in each area should include assessment of verbal and non-verbal:
  • input (hearing, seeing, attention, listening, looking)
  • processing (understanding, sorting, ordering, thinking, remembering)
  • output (speech, vocabulary, sentences, narrative, fluency, behaviour).
• Sources of information should include the effect of language and communication skills on emotional and behavioural functioning, and should be considered from multiple perspectives and in multiple environmental contexts.
• Standardised assessments help professionals to compare language skills against those of the ‘normal’ population and highlight areas of strength and weakness. The limitations of such instruments with this client group must be acknowledged, however.
• Observations by speech and language therapists, CAMHS staff and carers in different settings provide essential information on a person’s ability to utilise language and communication skills in different contexts (e.g. structured, educational, social).
• Questionnaires and profiles provide a structured format for gathering information and considering certain patterns of behaviour.
• The impact of level of language and communication skills should be considered in relation to:
  • functional communication (effect of language disability on daily life, including self/other awareness, organisation, interaction, learning, autonomy, choice)
- relationships
- behaviour (antecedents, communicative intent, consequences)
- higher-level language functioning (verbal reasoning, problem-solving, making predictions, inferences, etc.).

**Intervention**

- Speech and language therapists use a range of service delivery methods to suit clients’ needs and chosen intervention. These include:
  - consultation, with the multidisciplinary team, carers and other professionals
  - direct intervention with the individual in group or one-to-one settings
  - indirect intervention through another person, such as a member of the support staff or a carer
  - collaboration to identify needs, solve problems and develop interventions
  - client-centred training packages (e.g. training carers)
  - environmental change (e.g. use of visual cues, changes in language levels used).
- The intervention should:
  - acknowledge individual strengths and needs to address areas of weakness, starting at the difficulty’s source (i.e. input, processing or output)
  - take into account available time and resources.
- The therapist should:
  - advise carers and other professionals as to the appropriate language level to be used with the individual and any environmental changes required (e.g. picture cues, colour coding)
  - alert carers and other professionals to potential difficulties relating to interactions between language and behaviour
  - choose from a range of available theoretical approaches and interventions
  - closely monitor the efficacy of the intervention.
- The intervention frequently begins with development of awareness of self or others to orientate the individual to the reciprocal nature of communication, as is done with the ‘I Am Special’ (Vermeulen, 2000) and ‘Talkabout’ approaches (Kelly, 2001).
- The development of functional literacy skills is important, as it allows the child to access education and to develop vocabulary and higher-level language skills. Therapists have a role in developing phonological and language skills required for acquisition of literacy.
- Individuals benefit from learning strategies that address their own communication breakdown, and that recognise their vulnerable areas.
in both understanding and language use (Dollaghan and Kaston, 1986).

- Direct teaching of thinking skills can facilitate learning and organisation of other knowledge, as is done with ‘Mind Maps’ (Hoffman, 2001; Buzan & Buzan, 2006) and ‘Thinking Hats’ (de Bono, 2000).
- Individuals with poor understanding or expressive use of vocabulary will benefit from multi-modal and multi-sensory approaches to learning new words with large numbers of repetitions, for example using semantic links (Lewis & Speake, 1993).
- Narrative is an effective method of improving functional language and discourse skills in children and adolescents (Joffe, 2006; Stringer, 2006).
- When teaching social skills, it is essential that individuals have appropriate language modelled for them and opportunities to practise using language in a variety of contexts.
- Alternative and augmentative communication methods may be required, either as a temporary support to the development of spoken language or as a permanent means of communication. These can be high- or low-technology. Examples include:
  - signing (e.g. Makaton)
  - symbol use (e.g. Boardmaker, Blissymbols)
  - visual timetables, schedules (e.g. TEACCH)
  - talking mats
  - voice output aids.

References

Occupational therapy

The aim of occupational therapy is to help children become as independent as possible in everyday activities and to reach their maximum functional potential. Occupational therapy considers the impact of physical, emotional and social disabilities and impairments across a range of performance areas, particularly:

- self-care (e.g. dressing and personal hygiene)
- learning (e.g. school-based tasks)
- play and leisure (e.g. taking part in community activities).

Occupational therapists

Occupational therapists are concerned with enabling children and young people to master skills necessary for daily life (as above). These skills involve an interplay between personal characteristics, cultural setting and motor, sensory, cognitive and social abilities.

Paediatric occupational therapists work with children (from newborn through adolescence) whose rate of growth, development and maturation is interrupted as a result of any physical, social, emotional or learning disability, trauma, deprivation or disease.

Occupational therapists work with children and their families, focusing on the person–environment–occupation interface (Table 5.1), within all models of practice, in order to support children’s ability to fulfil their everyday occupations and roles.

Occupational therapy assessment

Different frames of reference, incorporating a range of assessment tools, may be used to determine how and why problems occur in performance and adaptive behaviour and to identify mechanisms for intervention (McElderry, 2000).
Sensory processing, including responsiveness to sensory stimulation

- There is evidence that individuals with learning disabilities, attention-deficit disorders and pervasive developmental disorders have atypical sensory processing, which may contribute to self-stimulatory or self-injurious actions in some (Tomchek & Dunn, 2007).

- Sensory modulation disorders are impairments in regulating the degree, intensity and nature of responses to sensory input, resulting in substantial problems with daily roles and routines. Some 40–80% of people with developmental disabilities have sensory modulation disorders (Baranek et al, 2002).

- Children with tactile sensitivity and poor tactile discrimination show poorer fine manipulative skills.

Sensorimotor coordination and hand function

Children with learning disabilities may have problems with balance, posture/sitting and movement control, to the detriment of their gross and fine motor abilities.

Perceptual processing

Visual spatial and visual motor abilities are associated with fine motor skills and independence in daily activities.
Problem-solving

Children with learning difficulties often have difficulties generating strategies for learning new skills and automating motor actions in the learning of a new sequence.

Psychosocial skills

- Problems with self-regulation have been associated with sensory modulation disorders.
- Children with anxiety have been shown to be at greater risk of balance and movement difficulties, and vice versa.
- There is a high incidence of coordination difficulties in children with learning and social impairments.

Occupational therapy intervention

Independence in daily activities

Community occupational therapy – through social services provision, consisting of the provision of equipment, minor and major adaptations and advice – has been shown to be effective in improving independence in children and young people.

Fine motor and functional performance

Occupational therapy for preschool children that emphasises play-based activities has been shown to improve both fine motor skills and peer interaction. Visual motor and functional outcomes are influenced by the number of sessions and percentage of sessions that specifically address self-care goals.

Sensory processing and adaptive behaviour

Occupational therapy using a sensory integration approach may be effective in improving self-regulation and adaptive behaviour and reducing self-stimulatory and self-injurious behaviour, for some young people with sensory modulation disorders.

Cognitive strategy generation for motor and social tasks

Children with mild learning disabilities or pervasive developmental disorders benefit from intervention using the ‘cognitive orientation to daily occupational performance’ (CO–OP) approach (Ward & Rodger, 2004) in terms of their ability and confidence in tasks involving motor skills.
References


As with all professions working within a CAMHS, the traditional role of a nurse is not always applicable. Most nurses will have knowledge and skills above and beyond those usually deemed to be ‘nursing’. This expanded brief is sometimes referred to as the ‘enhanced role’. Relevant skills can be grouped as:

- those generally applicable to all child and adolescent mental health learning disability clinicians
- those more specific to the nursing role:
  - general
  - child and adolescent
  - mental health
  - learning disability
- those representing interests specific to the individual:
  - family work
  - liaison and consultation
  - functional behavioural analysis and behaviour modification.

There is overlap between what nurses provide in CAMHS and what is provided by other common CAMHS clinicians, in particular psychologists, social workers and occupational therapists.

All nurses are individual and will bring with them knowledge and skills that interest them and that are needed or are not forthcoming from other team members. However, many nurses (trained in either learning disability or mental health) do not have the opportunity to work with children, particularly children with learning disability, during their training. Thus their specialist knowledge and skills are frequently acquired after registration.

Learning disability nursing

- Nurses working in child and adolescent mental health learning disability services may be qualified in mental health, learning disability or both.
• They are the only professional group to train solely to work with people who have learning disability.
• Training in learning disability nursing has a life-span approach, which is useful in terms of understanding and assisting with transition phases in people’s lives.
• Training in nursing facilitates an understanding of the physical and complex health needs of people with learning disability.
• Behavioural theory and practice are part of training for learning disability nursing.
• Learning disability nurse training and clinical practice have a bio-psychosocial approach.
• The ability to work in in-patient, out-patient and a wide range of outreach settings is integral to nursing practice within child and adolescent mental health learning disability.

Core areas of learning disability nursing practice

Nurses have a key role in each of the following areas:
• assessment of need
• health surveillance and health promotion
• developing personal competence (skill-building)
• enhanced therapeutic skills
• managing and leading teams of staff.

Learning disability nurses within a CAMHS

Within a CAMHS, nurses undertake:
• multi-modal assessments
• a bio-psychosocial approach to assessment, intervention and support
• comprehensive and detailed behavioural assessments, including functional assessment, analogue behavioural ratings, functional analysis, and construction and monitoring of behaviour modification programmes (many nurses have a good grounding in cognitive approaches as well)
• work across disciplines and across agencies
• the development, implementation and evaluation of comprehensive care plans
• the implementation of comprehensive treatment packages, particularly ones relating to challenging needs
• a hands-on approach often lacking from other disciplines
• the inclusion and involvement of clients and families in assessment and treatment.
The social work contribution

The social work report

It is important to establish the authority to write a social work report. All qualified social workers should be registered with the General Social Care Council (GSCC). The title ‘social worker’ has been protected by law in England since 1 April 2005. This law came from the Care Standards Act 2000 to ensure that only those who are properly qualified, registered and accountable for their work describe themselves as social workers.

Registration ensures that those working in social care meet rigorous registration requirements and will be held to account for their conduct by codes of practice. Qualifications, health and good character are checked as part of the registration process. Registered social workers are also required to complete post-registration training and learning activities before renewing their registration every three years. Further information can be found at http://www.gscc.org.uk.

Since 2000, social work and social work reports have been guided by the ‘framework for assessment’ (see below) and social workers have been encouraged to develop evidenced-based practice.

Framework for assessment

The key principles guiding the social work assessment (and report) are as follows (see also Fig. 9.1):

- It is child centred.
- It is rooted in child development (which includes recognition of the significance of timing in a child’s life).
- It takes an ecological approach, locating the child within the family and the wider community.
- It is based on ensuring equality of opportunity for all children and their families.
It is based on working in partnership with families and young people. It builds on the strengths in each of the three domains of the child, parents and family/environmental factors. It is a multi-agency approach model in which it is not just social care departments that are the assessors and providers of services. Assessment is seen as a process, not a single event. Action and services should be provided in parallel with assessment, according to the needs of the child and family – not awaiting the ‘completion of assessment’. It is grounded in knowledge derived from theory, research, policy and practice.

There are, however, other dimensions that need to be taken into consideration when preparing a social work report for a child with a learning disability.

**Communication**

Children may have particular needs, especially in relation to communication, which must be addressed to make any assessment meaningful. It is the responsibility of the social worker to ensure that the child has the best possible chance of communicating. This may mean: learning about each

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**Fig. 7.1** The framework for social work assessment.
individual child’s method; using interpreters or facilitators; tuning to non-verbal communication techniques; or thinking creatively about ways of listening.

**Parenting**

Where a child’s needs are complex, assessments of parenting capacity can be particularly challenging. Some children need more parenting or more skilled parenting than others; some children need intensive parenting for much longer than others. Caring for a child with a learning disability makes emotional, physical, social, time and financial demands on parents and carers that go well beyond what is expected of parents of children who have no disability. The task of caring for a child with complex needs may be more complicated, more time-consuming, less familiar, more anxiety-provoking, physically more challenging, and emotionally more difficult.

**Support networks**

Social workers should explore more widely the context in which the child lives. Supports available to most parents are often less available to parents of children with learning disabilities. Those supports that are available are often scarce, cost more and often mean joining a waiting list. The risk of family breakdown is higher, and baby-sitting, respite, leisure pursuits and other informal supports may be much harder to find.

**Equality issues**

The cultural identity of children with a learning disability needs active recognition. The situation of black and other ethnic minority children with learning disabilities requires particular attention, because the effects of racism and disablism can compound each other. Research demonstrates that families from minority ethnic groups caring for children with a disability are even more disadvantaged that white families in similar situations.
Children and young people with learning disability who have mental health problems often do not meet the diagnostic criteria for a specific psychiatric disorder. Instead, they present with behaviour suggestive of psychiatric disorder that often overlaps several diagnostic categories, fitting none of them exactly. Furthermore, indications for medications often differ from those in general CAMHS work. This chapter reviews the drugs used for ADHD, anxiety, obsessive–compulsive disorder, mood disorders, psychoses, aggression, self-injurious behaviour, sleep disorder and tics. Psychotropic medications are often not licensed for children and young people and are rarely licensed for those with learning and other developmental disabilities. This does not mean they cannot be prescribed; in fact, many are relatively safe and potentially highly beneficial when used with this patient group (Medicines Act 1968 and the EC Pharmaceutical Directive 89/341/EEC).

**Attention-deficit hyperactivity disorder**

- It is first necessary to consider whether the behaviour is compatible with the child’s developmental level; inattention and overactivity are more common in children with learning disability.
- ADHD is more common in young people with learning disability than in the general population.
- Methylphenidate (Ritalin, Equasym) is the most commonly used medication.
  - Side-effects include abdominal pain, headaches, appetite and weight loss, anxiety, agitation, insomnia, psychosis, tics, mood lability, increases in pulse rate and blood pressure, lowering of seizure threshold and reversible growth failure.
  - Height, weight, pulse and blood pressure should be monitored.
  - Long-term treatment should be anticipated if the response is good. Graded-release preparations (Concerta XL, Equasym XL, Medikinet) could be considered.
Dexamphetamine may help when methylphenidate has proved unsuccessful or when it has produced unacceptable adverse effects.

Atomoxetine, a selective noradrenaline reuptake inhibitor, is licensed in children and adults but is more expensive than methylphenidate or dexamphetamine.

- It is not used routinely as a first-line treatment except when there are clinically significant problems with psychostimulants such as low weight, very poor appetite or sleep, tics, seizures, substance misuse or parents being strongly against use of stimulants.
- Side-effects include nausea, vomiting, urinary hesitancy, rashes, weight loss, low mood, suicidal thoughts or actions (though these are rare) and hepatic failure (very rare).

Clonidine, an α-agonist, can be beneficial, does not affect appetite and if anything promotes sleep. The initial dose is 25 μg twice daily, which may, if necessary, be increased in 25 μg increments up to a maximum of 150 μg twice daily.

Neuroleptics are prescribed occasionally for ‘hyperactivity’ despite being unlicensed for this indication. Low-dose risperidone (commencing with 0.25 mg once or twice daily) can be helpful in extremis.

There is a small amount of clinically anecdotal literature supporting the use of tricyclic antidepressants and SSRIs for ADHD.

Anxiety

Most individuals with anxiety do not require pharmacological intervention. Cognitive, behavioural and social interventions are the treatments of choice.

Pharmacotherapy should be used cautiously because of side-effects.

If drugs are necessary to control acute anxiety, then short-acting benzodiazepines such as lorazepam and midazolam are recommended. Longer-acting agents such as diazepam cause more daytime sedation and hangover.

SSRIs are the pharmacological treatment of choice for refractory anxiety.

Buspirone has been used successfully in people with learning disability to reduce anxiety and related behavioural disturbance (Ratey et al, 1991).

Beta-blockers may be useful for individuals who show sympathetic overactivity when emotionally aroused.

Obsessive–compulsive disorder

- Clomipramine and other SSRIs are beneficial.
- Fluvoxamine and sertraline are licensed for children and adolescents with obsessive–compulsive disorder.
Mood disorders

- Early identification and multi-modal treatment may prevent unnecessary duration of a mood disorder and progression to refractory states.
- SSRIs should be used. Problems with concentration, continence or motor coordination may arise with the use of other antidepressants (e.g. tricyclics and monoamine oxidase inhibitors).
- Lithium is helpful for bipolar mood disorders but requires diligent monitoring for possible side-effects, including polyuria with incontinence, gastrointestinal disturbance, hypothyroidism and dermatitis. It should be discontinued if there is neurotoxicity, including seizures (not due to pre-existing epilepsy), severe tremor, vomiting, lethargy and coma.
- Anticonvulsants (carbamazepine, sodium valproate, lamotrigine) are useful for children and young people. They reduce blood sampling requirements, are relatively safe and can be beneficial for cyclical (and even not so cyclical) mood and behaviour disorders.
- Atypical antipsychotics can provide or contribute to mood stabilisation.
- The combination of an antipsychotic and a mood stabiliser can help in refractory cases.

Schizophrenia and other childhood psychoses

- The first-line treatment should be an ‘atypical’ antipsychotic agent, such as risperidone, amisulpiride, olanzapine or quetiapine.
- Their side-effects include appetite stimulation and weight gain, sedation, movement disorder and an increase prolactin level (Table 7.1).
- A history of epilepsy should always be sought. Epilepsy affects approximately a third of children and young people with moderate to

<table>
<thead>
<tr>
<th>Weight gain</th>
<th>Increased levels of prolactin</th>
<th>Sedation</th>
<th>Extrapyramidal effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clozapine</td>
<td>Risperidone</td>
<td>Quetiapine</td>
<td>Haloperidol</td>
</tr>
<tr>
<td>Olanzapine</td>
<td>Amisulpiride</td>
<td>Clozapine</td>
<td>Amisulpiride</td>
</tr>
<tr>
<td>Risperidone</td>
<td>Haloperidol</td>
<td>Olanzapine</td>
<td>Risperidone</td>
</tr>
<tr>
<td>Quetiapine</td>
<td>Olanzapine</td>
<td>Risperidone</td>
<td>Olanzapine</td>
</tr>
<tr>
<td>Amisulpiride</td>
<td>Quetiapine</td>
<td>Amisulpiride</td>
<td>Quetiapine</td>
</tr>
<tr>
<td>Aripiprazole</td>
<td>Clozapine</td>
<td>Haloperidol</td>
<td>Clozapine</td>
</tr>
<tr>
<td>Ziprazidone</td>
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</tbody>
</table>
profound learning disability and antipsychotic medications are known to lower the convulsive threshold.

- Clozapine can be used in refractory instances but requires careful blood count monitoring for possible bone marrow suppression.
- Anticholinergic drugs to counter movement disorders should be considered when high doses of antipsychotics are prescribed, or when extrapyramidal reactions or other adverse effects persist even after the dosage of antipsychotic medication has been decreased.

## Aggression

- Underlying causes of aggression such as psychiatric disorder, physical pathology with associated pain and distress, epilepsy, post-traumatic stress disorder, bereavement, abuse, neglect or other unfavourable and adverse environmental factors should always be considered and addressed if present.
- The psychological impact of extreme puzzlement, anxiety and confusion associated with autistic social, communicatory and ritualistic features must always be borne in mind.
- Antipsychotics have been used to treat aggression but their cost–benefit ratio remains unclear because of frequent side-effects.
- Risperidone can improve behavioural problems, including aggression (McCracken et al, 2002; Shea et al, 2004).
- If weight gain on risperidone is a clinically significant problem try amisulpiride or aripiprazole.
- These powerful medications should usually be prescribed under the supervision of a consultant psychiatrist trained in paediatric psychopharmacology as it relates to children and young people with developmental disabilities. Careful bio-psychosocial assessment and formulation before prescribing is required to ensure appropriate screening and monitoring.
- Height, weight, pulse, blood pressure, possible sexual side-effects, behavioural changes, extrapyramidal symptoms, bowel habit alterations and bladder disturbance should be monitored regularly.
- If a child is more than 10 centile points above the expected weight, fasting blood glucose, lipids and prolactin concentrations should be measured, to help prevent illness associated with excessive weight, following discussion on risk–benefit analysis with carers.
- Propranolol, a beta-blocker, may be of benefit for aggression.
- Carbamazepine, sodium valproate, lamotrigine and topiramate have been identified as being potentially useful for aggression.
- SSRIs may be useful in preventing aggression, through the treatment of anxiety and impulsivity.
- Buspirone is reportedly useful in decreasing aggression (Ratey et al, 1991), particularly in relation to arousal and anxiety.
• Where ADHD underlies aggression, stimulant medication may be indicated.
• Quick-acting benzodiazepine drugs can be used to treat acute aggressive episodes, but caution is needed with regard to habituation, tolerance and addiction in the medium to long term.

Self-injurious behaviour

• The extreme distress of severe self-injury, for sufferer and observers alike, results in frequent requests for medication.
• Treatment targets should be sensible and candid, especially when dealing with persistent or entrenched behaviour.
• Neurochemical hypotheses centre largely on the roles of dopamine, serotonin and endogenous opioids (King, 2000).
• Risperidone can be effective and well tolerated for the treatment of self-injurious behaviour in children with autistic disorder (McCracken et al, 2002).
• SSRIs can be used, especially if self-injury appears to be associated with depressive, anxiety or obsessive–compulsive features.
• A trial of naltrexone, an opioid antagonist, may be of use in preventing potentially reinforcing endogenous opioid effects in response to self-injury.
• There have been reports of success with buspirone for children who deliberately injure themselves (Verhoeven & Tuinier, 1996).
• Carbamazepine has also been described as being of potential benefit (Deb et al, 2008).

Sleep disorder

• Sleep hygiene measures, bedtime routines, social and environmental factors, and psychological treatments (cognitive–behavioural) should be used first with those suffering with sleep disorders.
• The use of any stimulants (caffeine, food colourings and flavourings, but also excessive television or computer time) should be minimised.
• Melatonin can be beneficial, especially for difficulties with sleep induction.
  • It is administered 20–30 minutes before the desired bedtime, initially at a low dose (e.g. 1–3 mg), which may be increased in 0.5–3 mg increments.
  • Tolerance and habituation have been reported, but these respond to drug holidays.
• Clonidine may be beneficial for repeated night-time waking, including insomnia aggravated by stimulant medication.
• Early-morning waking should trigger exploration for possible depressive disorder. If the latter is present, cognitive–behavioural therapy or an SSRI is indicated.

Tics

• Child and carer education and reassurance are the most important treatments.
• Antipsychotics (risperidone, sulpiride, pimozide) are most commonly used for tic suppression (see above for side-effect profiles).
• The lowest possible dose, at bedtime, should be used (two divided doses may give better control through the day).
• Haloperidol has prominent side-effects, some potentially long term and irreversible, and is therefore contraindicated.
• Occasionally individuals benefit from clonidine, and experience minimal side-effects.
  • Treatment with clonidine begins with 0.025–0.05 mg/day, increased in increments of 0.025–0.05 mg/day every 5–7 days.
  • Adverse effects of clonidine include sedation, cognitive blunting, irritability, headaches, decreased salivation and, at higher doses, hypotension and dizziness.
• Higher doses of neuroleptics and clonidine are not necessarily more effective but are more frequently associated with sedation.
• Reducing dosage can produce benefit where higher doses have failed.

Further reading


Multi-agency working

Which agencies?

Depending on who is within the team, a CAMHS learning disability team will probably need close links with a number of agencies to supplement the skills mix (Table 8.1).

Liaison with tier 1

Several professionals in tier 1 (see Chapter 11) may be involved with the same families; for example specialist health visitors, special school nurses, Portage workers, child development service professionals.

All professionals should consider whether they require further training in aspects of learning disability. Are there opportunities for this be reciprocated or undertaken jointly?

At what point do different professionals involve a CAMHS learning disability service in consultation, or referral? For example, would a referral be made by a school nurse working with a family whose teenage son is showing inappropriate sexualised behaviour, or by a teacher of an autistic child who is very anxious about transitions?

Benefits

The benefits of liaison with tier 1 include:

- learning from different skills and perspectives
- complementing what the CAMHS team cannot provide
- joining up packages of care and support for families
Table 8.1 Agencies with which a CAMHS learning disability team will probably need close links

<table>
<thead>
<tr>
<th>Agency</th>
<th>Function</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generic CAMHS</td>
<td>May have other disciplines to which to refer (e.g. systemic family therapy, psychotherapy, child psychiatry)</td>
</tr>
<tr>
<td>Community paediatrics</td>
<td>Manage medical care, especially epilepsy. May be able to organise routine blood monitoring for those patients on neuroleptic medication. May share some of the autism, ADHD assessments and management</td>
</tr>
<tr>
<td>Speech and language therapy</td>
<td>Contribute to assessment (particularly autistic-spectrum disorder). Contribute to interventions where supporting communication is vital</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>Assessment, particularly of sensory issues. May contribute to interventions that need a sensory ‘diet’ or physical protection (e.g. for children who self-injure)</td>
</tr>
<tr>
<td>School nurses</td>
<td>May already be offering general advice on feeding, sleeping, toileting, emotional and behavioural issues, sexuality, etc. May know families well and help parents to implement suggested strategies</td>
</tr>
<tr>
<td>School staff (teaching and support)</td>
<td>Contribute to assessment, particularly in recording behaviour in classroom setting. May know families well and help parents to implement suggested strategies</td>
</tr>
<tr>
<td>Portage</td>
<td>May already offer general advice on feeding, sleeping, toileting, emotional and behavioural issues, sexuality, etc. May know families well and help parents to implement the suggested strategies</td>
</tr>
<tr>
<td>Social care</td>
<td>Care and support packages to families. Child protection</td>
</tr>
<tr>
<td>Educational psychology</td>
<td>Provide information for assessments</td>
</tr>
<tr>
<td>Voluntary sector</td>
<td>Play and home support schemes</td>
</tr>
<tr>
<td>Adult learning disability services</td>
<td>May have a transition worker who will be part of the ‘team around the child’ planning transition</td>
</tr>
</tbody>
</table>

- adding variety to jobs, in terms of both colleagues and settings
- feeling valued by other agencies.

Difficulties

- Different professional ‘languages’ and ‘cultures’. For example, social care, education and child health settings may have different understandings of terms such as ‘mental health problem’, ‘assessment’, ‘treatment’.
- Different structures for line management. Line management structures will determine who is able to represent the team at meetings and make decisions that have strategic or funding implications.
Inappropriate referrals or lack of appropriate cases referred. Clear referral criteria are required. The use of a screening tool such as the Developmental Behaviour Checklist (Einfeld & Tonge, 1995) or ChA-PAS (Moss et al, 2007) or Social Communication Questionnaire (Rutter et al, 2003) may help to identify those with clinically significant problems.

Inappropriate expectations of what CAMHS can do. The CAMHS learning disability service should draw up its own specification and communicate this to other agencies. Other agencies should be informed of its practice through training, presentations at team meetings, leaflets, and so on.

Different standards for sharing information and maintaining confidentiality.
- Is there a common understanding of Caldicott principles?
- Is there a cross-agency agreement for information sharing already in place? If not, with whom and how could this be worked on?
- Is there a secure system for exchanging information by email?
- Is there a locked place for keeping written records if patients are seen in different agencies?
- What is the policy for who can access these records, including patients and families?
- How are records disposed of?

Virtual teams

Where the skills mix of the team is limited, it may be possible to build up a ‘virtual team’. Examples might include:

- a speech and language or educational psychologist to attend a regular social communication assessment clinic
- staff from special schools co-running groups
- a social worker who agrees to be part of the ‘team around the child’, supporting a mother in buying toys and organising the home environment for some behavioural work in the home.

Supervision and line management structures must be clear, particularly in the work around the direct activity (e.g. writing reports, audit).

Pathways for joint working

There need to be clear, written pathways and protocols for joint working relationships. Because many of the families are struggling with the care of their children, social care services may need to provide more support. For example, support with extra respite or care in the home whilst you are working with parents to change behavioural management. Who can arrange for this Care package to be funded, resourced, recruited and reviewed? Similarly, what are the arrangements with paediatricians to undertake
medical assessment or routine blood monitoring of those on neuroleptic medication?

Other relevant pathways are for demarcating the referral routes between tiers 1 and 2/3 and between child and adult services. The protocols need to cover a range of operational standards, including sharing information and confidentiality, documentation of clinical reports and correspondence, monitoring of clinical activity and effectiveness.

Consultation

There are many issues surrounding consultation. Teams will have to decide:

- whether consultation is given on general themes or the specific problems of particular cases
- whether they consult on an ‘issue’ rather than a ‘named-patient’ basis and whether the appropriate consent from parents or carers is required
- whether consultation is used to discuss referrals or to provide clinical advice
- how the consultation is documented and where records are kept
- who is clinically responsible for the advice given.

Strategy

Professionals working with different agencies will be asked to attend a large number of meetings. They may need to prioritise and find ways to keep up to date with the meetings they cannot attend. They need to work out how their team is represented at a local strategic level.

Further reading


Most children and young people with learning disabilities live with their families at home. Although it is very obvious, it is important to remember that a child cannot be considered in isolation – he or she is a son, daughter, brother, sister, grandchild, cousin, niece or nephew.

**Diversity**

- Family situations vary enormously.
- None the less, the same ‘general life issues’ (bereavement, illness, etc.) happen to these families as they do to everyone else, in addition to the complexities of supporting a child with a disability.

**Expertise**

- Families provide the vast majority of care and support for their child.
- Families will vary in their knowledge and understanding of the nature of their child’s disability, *but*:
  - Families know their child very well and are a valuable source of information.
  - Families are important advocates for their child with a learning disability.
  - Families may provide a high level of very specialised care and support for their child with little support themselves and minimal respite.
- Families want to feel listened to yet often report feeling they do not receive this courtesy.

**Effective support**

- Families require information to be provided in an accessible manner (according to individual need and circumstances).
• Families do not care how the support they receive is funded or organised – they just want to access the support their child requires for a good quality of life.
• Families need support that is practical, timely and tailored to individual need.
• This covers all aspects of support, from appointments with professionals to intervention programmes.
• Any treatment for the child should take into account the effect on the family.
• The complex systems and processes that are in place to support families are often fragmented and difficult to negotiate. Every effort should be made by professionals to provide a range of seamless and coordinated supports to the family.
• Families and professionals should all be working towards the same shared goals. Most goals can be achieved when professionals work as equal partners with families. This means the professionals should listen to the families, value their knowledge and experience, and understand what things are important for them.
Service tiers and models

There are four tiers of service:

1. primary – front-line clinical services
2. secondary – unidisciplinary specialist services, often community based
3. tertiary – multidisciplinary specialist services
4. quarternary – highly specialised/super-regional services.

Mental health provision for children and young people with learning disability should, where possible, be embedded within generic, local CAMHS, that is, as part of existing CAMHS provision, with allocation dependent on age, needs, locality, degree of learning disability. Such a service requires:

- ring-fencing of professional time
- identification of ‘champions’
- commitment from all to become involved
- collaborations with colleagues in child health, education, social services and the private and voluntary sectors.

In certain instances, highly specialist CAMHS learning disability services may exist. Life-span services for individuals with learning disability who have mental health problems may have historically served this client group, and may continue to provide a high-quality, progressive service, or other agencies such as community and developmental paediatrics or clinical psychology may act as local champions. However, there are national and international legal as well as clinical imperatives dictating that children and young people with mental health problems must be helped by child and adolescent mental health services irrespective of the nature, number and severity of their disabilities.
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There is an ever-increasing obligation on child and adolescent mental health services to meet the needs of children and young people with learning disabilities. This practical and concise book will help clinicians, service managers and commissioners to rapidly develop the necessary skills and knowledge in this expanding area of clinical practice. It provides a comprehensive overview of epidemiology, mental health disorders and their clinical presentations, multidisciplinary assessment and intervention, and multi-agency working. It reviews the specific roles of different medical practitioners, such as clinical psychologists and occupational therapists. Plus there are sections on working in partnership with families, and on service tiers and models.

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With a foreword by Dawn Rees, National CAMHS Strategic Relationships and Programme Manager at the National CAMHS Support Service.
DEVELOPMENT OF A SERVICE MODEL AND CARE PATHWAY FOR CHILDREN AND YOUNG PEOPLE WITH LEARNING DISABILITIES AND MENTAL HEALTH NEEDS IN BRISTOL.

MARCH 2008
Sue Okell, Ann Raymond and Rosie White would like to thank everyone who contributed to this project.
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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:

<table>
<thead>
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<th>Category</th>
<th>Number</th>
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<tr>
<td>Profound and multiple learning disability</td>
<td>59</td>
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<tr>
<td>Severe learning disability</td>
<td>174</td>
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<tr>
<td>Moderate learning disability</td>
<td>793</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td><strong>1026</strong></td>
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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

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.

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.


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

**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’.

**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.
• 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/

**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 focused 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
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.
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.

Bristol Child Mental Health/ Learning Disability Care Pathway
Based on The DOAS project (Pote and Goodban 2007)

1. PRE-REFERRAL:
   Consultation with Specialist Services. Professional/parent requests service involvement.
   - Referrer seeks consent
   - Referrer collates info (CAF)
   - Send referral to Single Point of Entry

2. REFERRAL:
   CLDT meeting
   - Child attends Special School
   - Child attends Mainstream School
   - Can this service meet the child’s MH needs?
   - No: transfer
   - Yes: accept
   - Agree allocation between CAMHS & CLDT
   - Define appropriate specialist assessments Identify Lead Professional

3. ASSESSMENT
   Complete holistic assessment of MH needs If required

4. INTERVENTION:
   Planning
   - Intervention delivery/ co-ordination
   - Outcome monitoring

5. WHAT NEXT?
   Discharge
   - Re-referral/open door
   - Define agency roles in relation to new concern
   - Non-MH agency input re. ongoing/ new concern
   - New MH intervention

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 (e.g., 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 Tiers 1/2 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 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

<table>
<thead>
<tr>
<th>Name</th>
<th>Position/Title</th>
<th>Organization</th>
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<tbody>
<tr>
<td>Nicola Bishop</td>
<td>Senior Social Worker, The Transitions Team</td>
<td>BCC</td>
</tr>
<tr>
<td>Francesco Brooke</td>
<td>COSI Team</td>
<td>BCC</td>
</tr>
<tr>
<td>Freddy Jackson Brown</td>
<td>Clinical Psychologist, CLDT</td>
<td>NBT</td>
</tr>
<tr>
<td>Katherine Byron</td>
<td>Primary Mental Health Specialist, CLDT</td>
<td>UBHT</td>
</tr>
<tr>
<td>Tracy Cox</td>
<td>Lead Nurse Specialist/Manager, Bristol Intensive Response Team</td>
<td>Bristol PCT</td>
</tr>
<tr>
<td>Rebecca Cross</td>
<td>Strategy Leader</td>
<td>Bristol PCT/BCC</td>
</tr>
<tr>
<td>Amanda Cundy</td>
<td>Consultant Community Paediatrician</td>
<td>NBT</td>
</tr>
<tr>
<td>Justin Daddow</td>
<td>Consultant Psychiatrist</td>
<td>Bath</td>
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<tr>
<td>Susie Essex</td>
<td>Family Therapist, CAMHS</td>
<td>NBT</td>
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<tr>
<td>Judy Evans</td>
<td>Senior Educational Psychologist</td>
<td>BCC</td>
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<tr>
<td>Peter Evans</td>
<td>Headteacher</td>
<td>Bristol PCT/BCC</td>
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<tr>
<td>Helen Ford</td>
<td>Commissioner</td>
<td>Glos</td>
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<tr>
<td>Chris Frost</td>
<td>Team Manager The Disabled Children’s Service</td>
<td>BCC</td>
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<tr>
<td>Jane Guvenir</td>
<td>CLD Nurse</td>
<td>NBT</td>
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<tr>
<td>Diane Hall</td>
<td>CLD Nurse</td>
<td>UBHT</td>
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<tr>
<td>Ann Holmes</td>
<td>Senior School Health Nurse</td>
<td>NBT</td>
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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 background 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.
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.

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.


**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.
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
A mental health care pathway for children and young people with learning disabilities

A resource pack for service planners and practitioners

by Helen Pote and David Goodban
Series Editor Jonathan Bureau
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Jill Davies, CAMHS Lead, Foundation for People with Learning Disabilities

Ian Gale, Consultant Child Psychologist, Northumberland Child and Adolescent Learning Disability Team

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Linda Wollam, Regional Change Agent – Children, Young People and Families, Care Services Improvement Partnership (CSIP)

Miranda Wolpert, Director, CAMHS Evidence-Based Practice Unit, University College London & Anna Freud Centre

Please note: at points within this pack we make reference to other training resources, courses and guidance that have been brought to our attention. This is for information only; they have not been reviewed by the authors.

Cover pictures courtesy of Speaking Up, Cambridge and The Down’s Syndrome Association
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This resource pack aims to help CAMHS partnerships and local providers in the planning and delivery of mental health services for children and young people with a learning disability (LD).

The resource pack is divided into three main sections.

Section A, Planning and Providing Services, provides an outline of a care pathway for this client group, developed in 2006 by consensus with stakeholders from across the UK.

Section B, Putting the Care Pathway into Practice, contains a guide to running a joint planning workshop, to enable service planners to implement such a care pathway locally.

Section C, Developing Practitioner Skills, aims to help develop skills in working with children and young people with mental health problems and learning disabilities, highlighting particular areas including:

- communicating effectively with children with a range of communication skills
- adapting mental health assessments and interventions to meet the needs of children with learning disabilities and their families
- prescribing issues particular to children with learning disabilities.

In addition, the appendices contain several tools and resources that may be of use, including tables to help with the mapping of existing resources, and a selection of common presentations and suggested interventions.

### NOTE ON DEFINITIONS

CAMHS comprises all four tiers of health provision, not just specialist services (see Appendix 2 for further information on the four tiers).

Learning disability is defined by Valuing People as:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence).
- A reduced ability to cope independently (impaired social functioning).
- That which started before adulthood, with a lasting effect on development.

LEARNING DISABILITIES AND MENTAL HEALTH

The pack is a result of the recognition that current access for children with learning disabilities is inadequate.

- Children and young people with a learning disability currently receive mental health services in a variety of settings, including not only traditional CAMHS but also community paediatric services, child development centres, specialist LD services and special needs educational services. The co-ordination of care between these services is variable nationally.
- Only 49% of CAMHS services reported being accessible to children and young people with learning disabilities in 2005. ¹
- Improving access to CAMHS for children with learning disabilities has been a key national target in recent years.
- Children and young people with mental health problems and learning disabilities are children and young people first and foremost, and therefore should have access to children’s services. It could be argued that it is a breach of human rights to discriminate on the grounds of IQ, and therefore children and young people with learning disabilities must have the same access to mental health services as those without learning disabilities.

- Mental health problems are two to four times more common in children and young people with learning disabilities, with 30%-50% (approximately 4 out of 10) having a mental health problem, compared to 1 out of 10 without a learning disability. Furthermore, those with an IQ of below 50 have a 1 in 2 chance of experiencing mental health/behavioural difficulties. While all mental health problems are over-represented in children and young people with learning disabilities, autism and hyperkinetic disorder are particularly increased.

**BACKGROUND TO THIS PACK**

In 2006 the authors were involved in a Do Once and Share (DOAS) project, led by Professor Panos Vostanis. This set out to develop a national consensus on a care pathway for children and young people with learning disabilities and mental health needs, in order to guide IT developments in the NHS and link constructively with similar developments in education and social care. This pathway was developed following widespread consultation with practitioners, service users and other stakeholders from across the UK, and produced the report *Mental Health Services for Children with Learning Disabilities: A National Care Pathway* (2006).

This resource pack draws on the work of the DOAS project to provide practical advice about how to develop co-ordinated and accessible services for children and young people with learning disabilities and mental health needs.

A note on web addresses: all website references were correct at the time of going to press. However website content is subject to change. If you have any difficulty accessing any of the documents referred to, we suggest you go to the host home page and navigate from there.
Planning and providing services
A mental health care pathway for children and young people with learning disabilities

1. PRE-REFERRAL: Stakeholder requests service involvement

2. REFERRAL: Meeting
   - Referrer seeks consent
   - Referrer collates info (CAF)
   - Which service is the best first contact?
   - Can this service meet the child's MH needs?
     - Yes: accept
     - No: transfer

3. ASSESSMENT: Complete holistic assessment of MH needs

4. INTERVENTION: Planning
   - Intervention delivery/coordination
   - Outcome monitoring

5. WHAT NEXT?
   - Re-referral
   - Define appropriate assessments
   - Re-referral
   - Define agency roles in relation to new concern

6. New MH intervention
   - Non-MH agency input re. ongoing/new concern
   - Continuing networked action by stakeholders - CAF reviews etc.

Discharge
TEN GUIDING PRINCIPLES FOR DEVELOPING SERVICES

The Care Pathway is underpinned by the following guiding principles.

1. **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.

2. **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 first 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.

3. **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.
4. **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.

5. **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.

6. **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:

(i) 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.

(ii) 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.8

(iii) Clinicians should draw upon other resources and support the co-ordination of care in circumstances where they cannot directly meet the child’s needs.

7. **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.
8. **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.


9. **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.

10. **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.
QUALITY STANDARDS FOR EACH STEP OF THE CARE PATHWAY

The Care Pathway has a number of quality standards which can guide the development and evaluation of services.

<table>
<thead>
<tr>
<th>Step</th>
<th>Standards</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pre-referral</strong></td>
<td>- Clear referral criteria and processes are agreed across provider services to ensure new cases get to the most appropriate service to meet their needs.</td>
</tr>
<tr>
<td></td>
<td>- Agreements are made within the overlapping agency network about how to deal with children and young people who do not fit current criteria or are at risk of being bounced between services (e.g. CAMHS/LD services/local authority children’s services/special schools/challenging behaviour teams).</td>
</tr>
<tr>
<td><strong>Referral</strong></td>
<td>- First contact is made, ideally with both caregivers and referrer, to clarify referral expectations and what is possible (i.e. within team competencies).</td>
</tr>
<tr>
<td></td>
<td>- Ideally contact takes place at home or in a setting relevant to the child (e.g. school/short break care setting).</td>
</tr>
<tr>
<td><strong>Assessment</strong></td>
<td>- Assessments should be holistic and consider the child’s mental health needs within the context of their learning disability and their families’ needs.</td>
</tr>
<tr>
<td></td>
<td>- Assessment for mental health difficulties should follow established protocols and good practice (e.g. the NICE Depression and Self Harm Guideline, Children’s NSF).</td>
</tr>
<tr>
<td><strong>Intervention</strong></td>
<td>- 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.</td>
</tr>
<tr>
<td></td>
<td>- 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, psycho-dynamic and humanistic) in a variety of formats (direct individual, group or family therapy, and consultation), always being mindful of the needs for evidence-based practice and cost efficiency.</td>
</tr>
<tr>
<td></td>
<td>- Interventions targeted at mental health issues should be considered within the context of other interventions (social, educational, physical) which the child is receiving. Services should develop effective inter-agency co-ordination to achieve this.</td>
</tr>
<tr>
<td><strong>What next? Discharge &amp; re-referral</strong></td>
<td>- Discharge from mental health input should be clearly co-ordinated between agencies using existing review procedures.</td>
</tr>
<tr>
<td></td>
<td>- When considering re-referrals, there should be clear definition of agency roles in relation to new concerns, and an agreed inter-agency action plan.</td>
</tr>
<tr>
<td><strong>Implementing the care pathway</strong></td>
<td>- Local CAMHS partnerships (or multi-agency steering/commissioning groups) should take a significant lead role in implementing the guidance provided in this pathway, to develop local protocols for children and young people with learning disabilities and mental health needs.</td>
</tr>
</tbody>
</table>
A NETWORKED APPROACH

The Care Pathway promotes a networked approach to care. This is particularly relevant as it is likely that a child with both learning disabilities and mental health needs will have many practitioners and services involved in their care. The Disabled Child Standard in the NSF states (page 39 Sect. 8.1) ‘Families of disabled children have contact with an average of 10 different professionals and over 20 visits per year to hospitals and clinics.’ These will be drawn from health, social care and voluntary service providers. Often difficulties in getting a service response can lead to ‘scatter gun’ referrals to several agencies for the same presenting difficulties, which irritates service providers and is an unnecessary burden on already sparse resources. Clear referral criteria and processes, agreed across services, should ensure that children and young people reach the appropriate service.

Mapping the network of services and liaising with key individuals can be a confusing process for families and practitioners alike, but such networking is vital. Such an approach will be appropriate for all children and young people with mental health problems, but it is particularly helpful for those with learning disabilities who use a greater range of support services and professionals. Though the knowledge about different networks may be new to some practitioners, networking skills should be familiar, and no different from those developed in working with children and young people without learning disabilities. It is important that time is ringfenced to facilitate liaison, and opportunities made for joint working through individual assessments, interventions, consultation or training.

To facilitate the development of a comprehensive network map, families and practitioners should acquire information about a range of people in their local area, and develop effective links with these service providers. These might include:

### Health sector

- Health visitors
- General practitioners
- Community paediatricians
- Community psychiatric nurses
- CAMHS social workers
- Psychiatrists
- Clinical psychologists
- Primary mental health workers
- Learning disability community nurses
- Paediatric speech and language therapists
- Paediatric occupational therapists
- Paediatric physiotherapists

### Education sector

- Special needs schools/units
- Emotional and behavioural disorder schools
- Special educational needs coordinators
- Special needs teachers
- Behavioural support workers
- Educational psychologists
- Behaviour support teams (peripatetic behavioural services)
The NSF and Every Child Matters promote the development of locally managed care networks. Further guidance is available at:


**Keyworkers and lead professionals**

The keyworker or lead professional contributes to the delivery of integrated frontline services across agencies. 11-13 They have three main functions which can be carried out by a range of practitioners (and in some cases family members):

- ensuring that services are co-ordinated, coherent and achieving intended outcomes
- acting as a single point of contact for children and young people being supported by more than one practitioner
- aiming to reduce overlap and inconsistency in the services received.

A lead professional is responsible to their home agency, and cannot be held responsible or accountable for the actions of others.

The intensity of the keyworking role needs to be recognised and supported by managers and commissioners. The co-ordination of care is likely to have an impact on the size of the individual professional’s caseload, with practitioners unlikely to be able to keywork for more than a very few families. In their review of keyworking in disabled services, Greco et al commented that ‘Designated keyworkers commonly worked with between 20 and 40 families... non-designated keyworkers usually worked with between one and five families in addition to their usual role and other caseload’. 14 Some services employ professionals solely in the role of keyworker/lead professional and others ensure that practitioners have a small number of clients to enable them to provide a more intensive and comprehensive service and play a role in co-ordination. Currently there is insufficient evidence to advocate one model of keyworking but relevant guidance on keyworkers and lead professionals is available at:

www.everychildmatters.gov.uk/leadprofessional

www.dh.gov.uk/assetRoot/04/11/90/10/04119010.pdf

www.york.ac.uk/inst/spru/research/summs/diffmodels.htm

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**Social care sector**
- Social workers in disability teams
- Short break (respite) providers
- Child protection social workers
- Early years workers

**Voluntary sector**
- Short break (respite) providers
- Family support services
- Advocacy services
- Social and recreational groups
- Play scheme providers

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14 A mental health care pathway for children and young people with learning disabilities
2 The care pathway – a step by step guide

1. PRE-REFERRAL

QUALITY STANDARDS

1. Clear referral criteria and processes are agreed across provider services to ensure new cases get to the most appropriate service to meet their needs.

2. 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.

1.1 Referrer requests service involvement/seeks consent

Stakeholders should have access to information about available services for children with mental health problems, and an awareness of what problems might prompt a request for service to any of the CAMHS tiers.

1.1 Stakeholder requests service involvement/seeks consent

1.2 Referrer collates information (CAF)

1.3 Which service is the best first contact?

REFERRAL MADE

Continuing networked action by stakeholders
Before a request for service is made, consent should be sought from parents in order to help decide which is the most appropriate service. That should include consent for:

1. Referral to an appropriate service.
2. Sharing of information about the nature of the child’s disability and its impact.
3. Making available past assessments or other relevant reports (e.g. review reports).

Local agreements and national guidelines will also apply to information sharing when requests for service are made. Special educational needs (SEN) legislation already has a statutory requirement to share information relevant to meeting the child’s needs in school. Guidance on safeguarding children also requires information sharing. With regard to information sharing between professionals, the welfare of the child is paramount (Children Act, 2004).

1.2 Referrer collates information

Having sought consent, it would be easier to identify the most appropriate services and service provider(s) if the referrer collates relevant information and reports about the child.

Children with learning disabilities are ‘children in need’ in terms of the Children Act 1989. If a request for mental health services is made for children or 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.

1.3 Which service is the best first contact?

To help primary care and community services to identify which CAMHS provider is likely to be the most appropriate first contact, there will need to be easily available information on what the different services provide, and clearly stated referral criteria. This information may be web-based to provide ease and openness of access, e.g. on local government websites.

For local networks of services to be co-ordinated effectively there will need to be local agreements on referral protocols and how decisions are to be made on which services are most appropriate for individual children.

Where local primary mental health workers exist, one of their roles may be to advise on the ‘best fit’ for initial contact.

2. REFERRAL

QUALITY STANDARDS

1. 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.

2. 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).
As children’s trusts and integrated service delivery develop, services may consider a move to a single entry point for CAMH provision that includes children both with and without learning disabilities. In the longer term, models should develop that make a single request for service, the gateway to a range of services – a ‘virtual front door’.

2.1 Referral meeting

The referral meeting:
- considers the referral information provided
- seeks further appropriate information if this is not available or is insufficient to determine which service is most appropriate.

If a given provider appears to be the most appropriate then the meeting determines an appropriate allocation within the team based on available skills and resources.
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). Services should be flexible in the timing; for example, appointments at school or outside school hours ensure a minimum absence from school.¹⁵

When a request for service is made the referrer should include information from any assessment using the Common Assessment Framework (CAF). If this is not included the practitioner should actively seek this information. Local versions of the CAF may differ, but will include the collation of information on and assessment of need in relation to:

- **The child’s development** (including health, impairment and impact of disability; emotional and social development; behavioural development; identity and self-esteem; family and social relationships; self-care skills and independence; learning).
- **The family’s parenting capacity** (including basic care ensuring safety; emotional warmth and stability; guidance, boundaries and stimulation).
- **Family and environmental factors** (including history; extended family; housing and other economic factors; social and community resources; respite; play provision; sibling support).

In completing CAF or other holistic assessment, practitioners should include information collated from other agencies involved. For children and young people with learning disabilities, it is important that this includes relevant educational assessments and reports; for example, advice provided by other professionals as part of the assessment of Special Educational Needs (SEN), recent Annual Educational Reviews of Statements, and/or Individual Educational Plans. Other relevant reports would include risk assessments or youth justice reports.

For children and young people with moderate, severe and profound learning disabilities, it will be especially important to supplement information from the assessment interview with

- observations in context (especially for challenging behaviour)
- existing knowledge and previously completed assessments (e.g. what has worked/is working and what has not/does not work).

### 2.2 Can this service best meet the child’s mental health needs?

The outcome of the referral meeting will determine whether the request is accepted as appropriate or whether it is considered inappropriate and requires transfer procedures to a more appropriate service provider.

Where another service is considered more appropriate, then responsibility for initiating the transfer to that service would lie with the service receiving the initial request.

Letters acknowledging acceptance of a request for service should go to the referrer, the family and their GP, and also to other agencies as appropriate (e.g. if the request has come from a multi-agency planning or review meeting).
3. ASSESSMENT

QUALITY STANDARDS

1. Assessments should be holistic, considering the child’s mental health needs within the context of their learning disability and their family’s needs.

2. Assessment for mental health difficulties should follow established protocols and good practice (e.g. the NICE depression and self harm guideline).

Complete holistic assessment of mental health in the context of other needs

Assessment is a continuous process. It starts before referral (when the referrer assesses the situation and identifies relevant information to include with the request for service) and continues throughout service involvement. However, one should emphasise that the Common Assessment Framework (CAF) uses the principle of not repeatedly collecting information needlessly.

The initial phase of a mental health assessment for children and young people with learning disabilities will be similar to other CAMHS assessments. For example, it may include family demographics, support networks and a developmental and clinical history, but may also include observations and communications and sensory assessments.

Assessments should be holistic, consider the difficulties in context, consider 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 target of concern. Putting mental health presentations within such a developmental framework should be a basic approach with which all practitioners are familiar. Assessment for mental health difficulties should take into account established protocols and good practice e.g. the National Initiative for Autism: Screening and Assessment (NIASA) guidelines.16

A holistic view will:

1. Make full and efficient use of existing information including:
   - education information such as SEN assessments; past annual educational reviews (especially information on behaviour patterns, language progress and so on).
   - other assessments such as paediatric assessments, speech and language therapy, occupational therapy and child in need assessments
   - building up a chronology of developmental history.

2. Maintain effective links with other agencies as part of the ongoing mental health assessment and intervention.
**Standard assessment** models and guidance on identifying mental health needs might also be appropriate to children and young people with learning disabilities (e.g. National Institute for Clinical Excellence (NICE) guidelines on depression in children). There may, however, need to be some modification to these, for example adapting for chronological age or differentiating for developmental level.

Other diagnostic assessments may be important in putting the mental health concerns in context. Examples might be autistic spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), other pervasive developmental disorders (PDDs) and epilepsy. Protocols for such assessments should follow appropriate national protocols and guidelines (e.g. NIASA, NICE). These protocols may have been carried out before referral or require further clarification alongside the mental health assessment.

**Modification of standard assessments** may particularly apply to carrying out specialised assessments, e.g. depression, autism, cognitive assessments. Such assessments are likely to need adaptation in either wording or presentation to children and young people with learning disabilities. It may be necessary to ensure that assessments are either:

- developmentally appropriate, by using the age-appropriate instrument but modifying wording or using more visual representation;

or

- age-appropriate, by using instruments for younger children, but adapting language and examples to make them age-appropriate.

Advice should be taken from caregivers who know the child well (e.g. family, school staff, short break carers or other professionals who have worked with the child) about how best to undertake assessments to meet the child’s needs.

Such modifications will have an impact upon the standardisation of an assessment tool. Practitioners should acknowledge and take this into account when drawing conclusions from the data collected.
4. INTERVENTIONS

QUALITY STANDARDS

1. 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.

2. 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).

3. 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-ordination to achieve this.

4. INTERVENTION

4.1 Intervention planning

4.2 Intervention delivery

4.3 Evaluation of intervention outcomes

Continuing networked action by stakeholders
4.1 Intervention planning

Intervention planning should draw upon a broad and thorough assessment (itself drawing on the full range of assessment sources available). Following assessment, interventions should be determined by holistically formulating the mental health needs of the child within the context of their:

- age and developmental level
- significant relationships and culture
- educational, social and physical healthcare needs.

Intervention planning should address the needs of the whole family, and should draw on the current evidence base for all children and young people.17

Intervention goals should be specific but flexible, and should be clearly defined at the beginning of the intervention, given the likely complexity of the child's presenting problems. Goals should be developed in a collaborative manner with the child and family.

The impact of, or need for, pharmacological interventions must be comprehensively integrated into assessment and intervention planning. A medication's interaction with other interventions offered will need to be monitored carefully and assessed alongside other aspects of outcome. For example, clients with epilepsy may be taking antiepileptic medication which has an indirect impact on their behavioural control, and may affect any assessment of, or intervention for, other concurrent behavioural and emotional difficulties. (See also Prescribing Issues in Section C)

4.2 Intervention delivery

Emotional and behavioural interventions should be available at all levels of service delivery, always being mindful of the needs for evidence-based practice and cost efficiency. Interventions will need to be individually tailored to be developmentally appropriate and age-appropriate for the child.

Staff will need to develop basic competencies in tailoring interventions and communicating with children and young people across a range of developmental levels and with a range of functional abilities. They should also possess, or have access to, an appropriate level of knowledge about specific difficulties which may be associated with learning disabilities (e.g. chromosomal disorders, sensory disabilities and motor difficulties – see resources at the end of this section). Those who know the child should be involved in intervention planning and delivery.

Services should strive to be flexible in the timing and location of appointments to enhance access to services, with appointments made at school or outside school hours, to ensure a minimum absence from school.18 Staff should recognise the difficulties many families may experience in attending appointments and engaging with services, given the multiple needs and service contacts their child is likely to require. Failure to attend clinic-based appointments should not be seen as a reason to close the case.

A range of verbal and non-verbal communication methods will need to be drawn upon to make interventions accessible to the child (see Section C Developing Practitioner Skills), while consultation with others may be necessary in supporting the success of the emotional and behavioural intervention.
4.3 Evaluation of intervention outcomes

The development of effective outcome monitoring for individuals, and of the evidence base for this client group as a whole, is a responsibility of all practitioners, managers and commissioners, and should be taken seriously. Effective research in this area is greatly needed to enhance the quality of services.

Practitioners’ judgement and a range of standardised and individualised outcome measures should be used to determine the effectiveness of the mental health interventions offered. Outcome measures should consider the presenting symptoms in context. It will be particularly useful to monitor the outcomes for the children and young people and their parents/carers. Simple, individualised measures, focusing on specific goals for interventions, will be useful in measuring change and engaging the children and young people themselves in the outcome monitoring process. Useful standardised outcome measures for children and young people with mild learning disabilities may include the Strengths and Difficulties Questionnaire.

A national consensus on appropriate standardised measures of mental health outcomes has not yet been determined for people with moderate and severe learning disabilities. There is widespread recognition that existing standardised tools struggle to capture the progress gains that are made by this client group in relation to mental health interventions. This is because gains are often made in a more graded manner than for children with milder disabilities. In addition, measures of change are sometimes confounded by the significant difficulties (often associated with the learning disability) which remain, despite successful mental health interventions. Progress is therefore lost within standardised measures that capture behavioural and emotional change as a whole. Currently the CAMHS Outcomes Research Consortium (CORC) is developing a national consensus on suitable outcome measures for this client group. For more information go to www.corc.uk.net

Resources

- The Contact a Family Directory – Index of Specific Conditions and Rare Disorders www.cafamily.org.uk/home.html
- Society for the Study of Behavioural Phenotypes www.ssbp.co.uk
5. WHAT HAPPENS NEXT?

QUALITY STANDARDS

1. Discharge from mental health input should be clearly co-ordinated between agencies using existing review procedures.

2. When considering re-referrals, there should be clear definition of agency roles in relation to new concerns, and an agreed inter-agency action plan.

5.1 Discharge

Specialist CAMHS involvement should normally be targeted, rather than open-ended. There will be some exceptions, however, where the child and family needs indicate a level of infrequent but regular contact, which should be justified. At all times it is important to distinguish between the child’s mental health needs (often episodic), and other needs related to the disability or social circumstances (often ongoing).
Discharge from mental health input should be clearly co-ordinated between agencies using existing review procedures. Following the completion of an intervention, the role of CAMHS should be clearly reviewed in conjunction with other agency involvement and the needs of the child and family. If the intervention has addressed the reasons for CAMHS involvement at this stage, the discharge should be negotiated and agreed upon by the family and agencies involved. There should be an indication of future CAMHS involvement and completion of Care Programme Approach (CPA) and CAF follow-up procedures where appropriate.

5.2 Re-referral

If children and families need to re-access the mental health service, it is important to avoid replication of the first referral pathway and extensive re-assessments, unless they add to the existing assessment information. It is also important to avoid duplication of review meetings between agencies. Re-entry into the system should thus be as rapid as possible, without a repeat of the referral cycle.

The following process discussions will need to take place:

- define new concern/problem
- define agency roles in relation to new concern
- define action plan and discuss appropriate joint interventions, for example:
  - consultation
  - inter-agency review
  - joint re-assessment
  - re-assessment
  - new CAMHS intervention
  - new non-mental health intervention
  - emergency contact required.

5.3 Define agency roles in relation to new concerns

If new concerns are raised by a family or agency it is important first to define these concerns, both in relation to the previous and potential role of specialist CAMHS and other agencies. For example, this could be a recurrence of a previous mental health problem dealt by CAMHS, a new mental health problem, or an ongoing or new need which is important, albeit not in the CAMHS remit. If this is unclear, or there are overlapping issues between agencies, it would be useful to discuss this promptly and clarify with CAMHS staff without the formality of a new referral cycle.

New concerns should be clearly defined in relation to:

- the child and family
- previous assessment
- previous intervention (What has changed? Why did it not work? Is there an indication that the same type of treatment will work or not again?)
- agency roles and input (Is there a genuine need for CAMHS involvement? Are related needs met by relevant agencies?).
The nature and severity of the concern will determine whether and what kind of CAMHS input is required, as well as the role of other agencies. In addition to telephone consultation, a face-to-face meeting with CAMHS may be required, with plans for further consultative arrangements. Alternatively, existing forums such as inter-agency reviews may be used effectively to avoid duplication. If a re-assessment of the child is required, this might be done jointly with the referrer, if it is likely that both CAMHS and the referrer will overlap significantly.

Therefore, the clarification of agency roles is essential. These roles should have preferably been clarified at the end of the previous intervention, rather than at re-referral.

A local inter-agency protocol will facilitate clarity of roles in relation to re-referrals. This should include an agreement on the role and remit of a lead professional or keyworker in co-ordinating re-referrals.

5.4 Non-mental health agency input

Family resources should be taken into consideration where longer term service involvement may be required. Other agencies and support mechanisms should be considered in order to maximise the impact of community resources. Specialist CAMHS have an important role in supporting these agencies, both at organisational level (e.g. through regular consultation, joint work and training) and on individual casework.

5.5 New mental health intervention

If a new mental health intervention is indicated, it is important to justify the reasons, specify the objective, and consider why the same or a different type of treatment modality is necessary. A new intervention should not be initiated by default, i.e. because ‘nothing else’ worked. An acute psychiatric presentation would require immediate access to CAMHS through existing arrangements.

Transition to adult services

A transition pathway needs to be established with the education, adult health, social care and learning disability services to provide:

- seamless continuity of clinical care
- informed person-centred planning
- continuing education/vocational training.

This transition pathway needs to be linked with education structures, such as annual reviews.
Putting the care pathway into practice
Pathway development, service delivery and quality improvement do not happen spontaneously. The commissioning process cannot be separated from the delivery process, as there needs to be a partnership between all involved. 21

Joint planning is vitally important to the achievement of effective care pathways, which can only happen with extensive consultation between practitioners, managers and commissioners and a range of other providers.

It needs to be acknowledged from the outset that real challenges stand in the way of developing accessible services. A national survey of providers, carried out as part of the DOAS project in 2006, identified a number of barriers to the implementation of comprehensive CAMHS for children and young people with LD. 22 These included:

- **Resources**
  - insufficient staffing levels
  - insufficient expertise (CAMHS and LD)
  - fear of ‘opening the floodgates’
- **Inter-agency working**
  - lack of awareness of others’ work
- **Rigidity**
  - language/diagnosis
  - referral criteria

In the light of this, the approach taken by planners and practitioners needs to be realistic and build on a thorough understanding of existing services, of models of good practice and potential barriers to change, as well as on a mapping of need within a local community.

Developing accessible services requires multi-disciplinary and multi-professional ownership across agencies and organisations.

Factors that have been found to help this include:

- **Ongoing dedicated leadership** at a strategic level.
- **A dedicated post for service development** to co-ordinate the step by step process. The person fulfilling this role would ideally have management and project management skills, along with experience of working in a clinical and/or multi-disciplinary environment.
- **Ringfenced time for project management** and for holding a relevant workshop.
Experience suggests that establishing a project team/planning group can be vital in order to develop and implement local care pathways. (This could develop into a managed care network at a later stage).

At a minimum membership of an effective planning group should include:
- CAMHS partnership chair
- PCT commissioner
- provider clinical leads from health (e.g. CAMHS and paediatrics)
- education representatives (preferably lead for educational psychologists and ‘inclusion’); heads of special schools
- social care representatives (including disability community leaders)
- user representation/participation lead/advocacy
- transition lead from adult learning disability services
- voluntary organisations
- administrative support
- anyone who would be crucial to developing the plan.

The following factors will help promote successful working in a planning group.
- Have a clear strategic direction, together with a shared vision and value base, across the agencies who are participating in the development of the care pathway.
- Members of the group should have sufficient authority to represent their professional group or organisation.\(^{23}\)
- There should be clarity of roles and responsibilities within the planning group.
- The planning group needs to link into the local commissioning and children and young people’s planning structure.
- Smaller-sized planning groups will enable better participation and effective decision-making.
- Performance should be principally measured through the eyes of service users, citizens and other stakeholders.

1. Running a joint planning workshop

Local services are beginning to use the national pathway to develop their services. They report that a time-effective way of achieving this is through the running of ‘joint planning workshops’. A model for a joint planning workshop is described below. It draws on the experience of workshops already run but can obviously be adapted in the light of local circumstance.

The aims of the joint planning workshop is to bring commissioners, key mental health providers and other stakeholders together in order to:
- develop a local care pathway for learning disability CAMHS provision
- reach agreement between providers and commissioners regarding the provision of CAMHS to children and young people with a learning disability
- determine actions and training needs required to develop services and identify a working group, action plan and resources available to support this development
- achieve the required commissioning of learning disability services to children and young people from CAMHS.
2. PRE-WORKSHOP PLANNING

Preliminary work needs to be done by planning group members in order to gather information about clinical needs, existing provision and training needs. This will enable the workshop to focus on decision-making rather than fact-finding and debate.

This information and additional background reading should be shared between participants (ideally at least a fortnight before the date of the workshop) to enable participants to consider the issues in preparation for the workshop.

All participants should be encouraged to re-read standards 8 and 9 of the Children’s NSF, so that everyone present is reminded about what is expected by way of support and joint working for this group of children and young people. These can be found at:

www.dh.gov.uk/assetRoot/04/09/05/56/04090556.pdf

3. SERVICE PROVIDERS’ PREPARATION FOR THE WORKSHOP

It is suggested that service providers undertake the following steps before the workshop.

Complete a local needs assessment

Everyone in the purchasing, planning and prioritisation of healthcare needs accurate, comprehensive and well-packaged information to answer at least four crucial questions:

- with which population are we concerned?
- what services are provided?
- what is the evidence of the effectiveness of those services?
- what is the optimum set of services?

In other words, what is the need and how can it best be met?

Unfortunately such needs-led planning of services is rarely achieved. For a full normative or population-based needs assessment the following should be considered.

Prepare data on epidemiology

This is possible via three sources:

1. If there is a high quality local CAMHS needs assessment then this can be used to assess the numbers of pre-, primary and secondary school-age learning disabled children in the area.
2. The learning disability team may have data on epidemiology.
3. Alternatively, use the census data for your area, via the Public Health Observatory and Office of National Statistics, and make estimates of need.

www.apho.org.uk
www.statistics.gov.uk
Patterns of the spread of referrals should be estimated. Not all children and young people with learning disabilities and emotional and behavioural difficulties will be seen in specialist CAMHS or learning disability services – their needs may be managed successfully within paediatric out-patient services, educational services or voluntary services. Referral numbers for all services should be gathered and possible unmet needs determined.

In addition to this population-based needs assessment, practitioners may have a clear understanding of ‘felt’ need (their impression of the areas of most need or urgency) or ‘expressed’ need (what clients suggest is crucial to meet their needs). This information should be used to complement the population-based needs assessment to give a full indication of comprehensive services that would meet the needs of the local communities being served.

**Estimate clinical time required to meet existing and unmet needs and skill mix required**

Existing estimates of practitioner contact time are likely to be conservative and not recognise the longer engagement phase often required when working with this client group. For example, the York/Kingsbury model which has been designed for generic CAMHS would apply six patient appointments as the average length of assessment/intervention required in a generic specialist CAMH service. However, for specialist CAMHS LD, you will need to allow for a significant number of additional sessions to cover:

- extended assessments (often requiring multi-agency input and observation visits often extending up to six sessions)
- ongoing multi-agency liaison
- additional travel time for home and school visits
- co-ordinating interventions across all contexts
- prolonged therapeutic work taking several months or years
- the fact that in general, this group of children and young people have persistent difficulties which require long-term care.

**Map existing provision and resources**

Service maps can be developed according to three criteria:
- geographically (physical location)
- within the CAMHS tiers framework (strategic)
- by domain (provider organisations)

Baseline information to be included in service maps should include:
- where services are
- when they are available
- what they offer and who offers it
- how they are funded
- who they are intended to serve and who actually uses them
- what their outcomes are
- what they cost

Consider time implications of learning disability provision and if necessary identify what it is the service is doing which is at a lesser level of priority.
Develop recommendations to commissioners as to essential services which can only be purchased from out of area.

**Draft a local care pathway**
- develop outlines of existing skills base
- develop draft protocols for interagency working
- identify the critical elements of the National Care Pathway which are missing locally.

**Determine training needs required to develop services**
- map the range of skills required to work with the range of need presenting (See Section C – Developing Practitioner Skills)
- look at the numbers of people in your service who possess these skills and map the skills mix within the team.
- check out how and where it may be possible for your team to acquire further training to make up deficits, for example around the complex nature of communication skills. Do any of your team have these skills? If not, who locally can provide some training?

Service maps and the table provided in Appendix 3 may be used to summarise information for the provider-led session. It may be helpful to complete one summary table for each of tiers 1 and 2 and one for specialist provision (Tiers 3 and 4).

**4. COMMISSIONERS’ PREPARATION FOR THE WORKSHOP**

Commissioners are asked to do the following before the workshop:
- give providers the necessary child population data and relevant needs assessment documentation to enable them to do their preliminary work
- outline the long-term action plans for addressing any structural weakness in service provision
- provide a copy of the current commissioning document for children and young people with learning disabilities, and describe how a binding Service Level Agreement would be agreed at chief executive level
- provide the financial information about what is invested in the CAMHS service by each commissioner (from CAMHS mapping and any additional information)
- consider the fallback position in terms of re-commissioning the necessary resource from within existing provision or elsewhere in order to achieve the proxy target. In the event that agreement cannot be reached at the workshop about the necessary capacity you will need to be able to explain how you will follow through on this
- identify who will present this information at the workshop and who will chair the commissioner-led sections. The chair should have responsibility for seeing that the necessary work is done prior to the workshop
- identify from your perspective essential and non-essential aspects of CAMHS service delivery
- identify any amounts of financial resources for training or service modernisation that will lead, for example, to the issue of additional capacity being found by monitoring and cutting DNA rates.
5. ADDITIONAL STAKEHOLDERS’ PREPARATION FOR THE WORKSHOP

Stakeholders attending the workshop are likely to have been making a substantial contribution to the mental wellbeing of children and young people with learning disabilities for many years, though they may be considered outside the existing traditional/specialist CAMHS provision. Examples include representatives from the areas of paediatrics; primary care including general practice; health visiting and school nursing; speech, language and occupational therapy; adult mental health providers; voluntary sector providers; local authority learning disability teams; and respite care services, behaviour and education support services.

Stakeholders are asked to do the following before the workshop:

- identify the service they provide and under what auspices – statutory, voluntary, service level agreement (SLA), strategy, contract etc
- who they provide it to
  - numbers of children and young people
  - nature of difficulties
- identify the resource they have currently invested in this issue in
  - money
  - whole-time equivalent (WTE) staff and their skills
- comment on what is currently provided and where the gaps are, so that they are able to contribute clearly in respect of:
  - what they think is actually available
  - what is not available and should be in their view
  - where the opportunities are to improve services to children and young people and their families using locally available resources
  - what they think they need to do to facilitate this
  - what they think other parties – providers and commissioners need to do.
- appoint a chair or spokesperson to collect these views beforehand, and represent their views in the workshop discussions.

6. SUGGESTED STRUCTURE OF THE JOINT PLANNING WORKSHOP

The workshop could be facilitated by an independent person with a working awareness of the topic. Regional development workers (National CAMHS Support Service) have been facilitating many of these workshops. The workshop can take a whole day or certain elements of it can be customised to meet local needs, and integrated with local strategic planning. One possible approach is outlined overleaf:
Suggested exercises for developing a local care pathway.

Exercise 1

Consider the range of services discussed in Section 5.3 of the LD/CAMHS National Care Pathway that might be providing mental health services for children and young people with a learning disability locally.

Map out the services, including key roles and contacts.

Consider the following:
1. What improvements could be made to facilitate awareness of these services locally?
2. Identify areas where inter-agency protocols do and do not exist for management of referrals. Make action plans to develop protocols where needed.
3. Identify three key actions to promote inter-agency working and skills sharing.

SAMPLE WORKSHOP OUTLINE

Session 1: Introductions and facilitator presentation (45 mins)
- Very brief policy overview: NSF, ECM etc incorporating performance context and drivers for change.
- Overview of objectives and outcomes for the day.
- Consideration of the DOAS Care Pathway – what it is, and how it can be implemented locally.

Session 2: Provider-led discussion (2 hours)
- Provider presentations of needs assessment, map of services, likely referral numbers, capacity, workforce and training issues and the necessary changes to service provision and prioritisation to deliver the required service.
- By the end of the session, there should be agreement on a care pathway and a clear statement from providers and stakeholders about the extent to which they are able to deliver on the proxy from within existing resources.

Session 3: Commissioner-led discussion (2 hours)
- Commissioner-led session which drafts the commissioning agreements and service level agreements in relation to work done in the provider-led session.
- Providers and stakeholders reflecting and advising.
- The physical process of writing a draft document may require someone with a laptop to log the first draft.
- Present draft commissioning and training plan.
Exercise 2

Consider the Ten Guiding Principles of the National Care Pathway (see page 9) and discuss the following:
1. What immediate improvements could be made to bring local services in line with these principles?
2. What longer term developments would be necessary to fulfil these principles?
3. Develop a preliminary action plan for the most critical of these longer term objectives.

Exercise 3

Consider the model National Care Pathway (see page 8) and the nine associated quality standards (see page 12).
1. Identify any quality standards local services are not currently meeting.
2. Prioritise these according to local relevance, and the likelihood of improving services.
3. Develop an action plan for service development to meet the three key unmet standards.

Suggested exercises for the development of a draft commissioning agreement.

Exercise 1
Work as a mixed tier group on commissioning agreement for the whole LD/CAMHS from tiers 1-4. Commissioners to lead discussions and start drafting document – providers to reflect at a minimum half way through and at the end.

Exercise 2
As above but two groups:
- tiers 1-2
- tiers 3-4

Exercise 3
Work as separate groups, commissioners and providers, with commissioners drafting the commissioning document on the basis of work done in the morning and providers working on draft protocols to support arrangements with multi-agency colleagues.

7. FOLLOW-UP

An action plan should be presented by the facilitator and agreed by participants. It should include:
- follow-up dates
- what needs completing
- when
- by whom.

The action plan format outlined in Appendix 4 may be used as a guide.

Develop guidelines/resource pack for skills development aimed at managers and front-line professionals, (this should link to the workforce plan), making better use of existing staff and developing their skills and enhancing competencies.
RESOURCES – PUTTING THE CARE PATHWAY INTO PRACTICE

CAMHS Do Once and Share (DOAS) projects
www.camhs.org.uk/default.aspx?q=DOAS&c=8970
For details and key documents from:
– Mental Health Services for Children with Learning Disabilities: A National Care Pathway
– Developing a General Care Record DOAS project, which sought to produce a national multi-agency consensus on the necessary data elements of a care record for child and adolescent mental health services (CAMHS).


– Information sharing
www.everychildmatters.gov.uk/resources-and-practice/IG00065/
– Key workers and lead professionals
www.everychildmatters.gov.uk/leadprofessional
– Multi-agency working: Toolkit for Practitioners available through Every Child Matters:
www.everychildmatters.gov.uk/deliveringservices/multiagencyworking/practitionerstoolkit/

An exploration of different models of multi-agency partnerships in key worker services for disabled children: effectiveness and costs.

www.ncb-books.org.uk/NCB_Books_Children_with_disabilities_27.html

www.dfes.gov.uk/commoncore/docs/CAFGuide.doc

Mapping of CAMHS
Child and Maternity Services Information: interactive map of national services and projects.
www.icservices.nhs.uk/childhealth/index.html

MATCH Project – University of Leeds
Multi-Agency Teams Work for Children (MATCH) project has produced an audit tool that services can use to check how they are doing with regards to multi-agency working
www.education.leeds.ac.uk/research/lifelong/projects.php?project=18&page=1
Developing Effective Multi-Agency Working: Lessons from Research – the full report can be downloaded from:

Principles and practice that define the team-around-the-child (TAC) approach and their relationship to accepted good practice.
Developing practitioner skills
1. INTRODUCTION

Many practitioners already working with mental health and allied specialist services are concerned that a ‘specialist’ set of knowledge or skills is needed to work with children and young people with a learning disability. They underestimate the excellent core skills they have in relation to:

- knowledge of child development, normal and abnormal
- communicating with children and young people across a range of ages and developmental levels
- adapting interventions to meet the individual needs of the child and family.

All of these are essential in working with children and young people with learning disabilities.

The following is intended as a guide for both individual practitioners and service developers. It is perhaps most applicable to clinicians currently working in specialist child mental health or learning disability services, although it may have wider application. Appendix 5 outlines some common presenting difficulties.

It is hoped and anticipated that working with children and young people with learning disabilities and mental health problems will become commonplace for many practitioners in specialist services and those working within the community. To facilitate this development each area should be drawing up a skills development plan to map existing skills and plan towards the development of skills within the locality. This plan should promote joint working between agencies as an excellent way of sharing knowledge and skills to meet the needs of individual children and young people with learning disabilities.

2. MAKING COMMUNICATION ACCESSIBLE

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 their developmental level. Children with learning disabilities may show a more variable pattern of development 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.

Communicating with children with a learning disability therefore requires practitioners to thoroughly consider their developmental understanding of the child from a range of perspectives. These include the chronological age of the child, their level of verbal understanding, their level of verbal expression and the non-verbal communication skills they are using to augment communication.

There are particular communication issues that children with learning disabilities and those practitioners working with them may face. Children may be more likely than those without learning disabilities to be acquiescent, inarticulate, unresponsive, have a concrete frame of reference with poor abstract thinking, and have difficulties generalising from experience. The concept of time may pose particular difficulties. Children and young people on the autistic spectrum pose particular challenges. Practitioners therefore need to think carefully and creatively about their own communication style when working with children with a learning disability in order that they maximise the contributions the child can make to the interaction.
Children and young people with learning disabilities often find it difficult to express their feelings, and tend to communicate with people they know and trust. Some can only communicate in non-verbal ways. Consideration should be given to involve key people (e.g. parent, carer, teacher or teaching assistant) that the child already knows. The type of person is paramount, with the emphasis on someone who has gained an understanding of their language and their needs through constant interaction and advocacy.

For children with severe learning or communication difficulties it will always be necessary to supplement direct interactions with interviews with parents, carers and teachers.

In setting up meetings it is helpful for practitioners to use known links – people who know the child or family well, to explain the referral and meeting process before it begins. This will help in establishing trust and understanding. The process of meetings needs to be made explicit at the beginning and during meetings so that the child has a clear structure for understanding the interactions.

Verbal communication often requires simplification and techniques to ensure that conversations are understood over time. Practitioners should aim to:

- ensure questions have a ‘here and now’ focus
- rely less on open questions – instead try successive approximations of answers, or present two alternative choices
- avoid time-reliant questions and ‘why’ questions where possible
- use reminders in the form of key people, places and concrete events when asking questions based on past events.

The pace of meetings is likely to be slower than when working with children without learning disabilities. More time should be allowed for clients to consider their ideas and answer questions. Practitioners should repeat answers and check at frequent intervals that they have understood the client, and that the client has understood them. Questions may need to be repeated to clarify the reliability and certainty of answers.

Practitioners should expect to summarise discussions and agreements frequently throughout a meeting, and must always do this at the start and end of meetings. It may be helpful to write down key points too, so that a carer or advocate can repeat them to the client later.

Verbal communication will often need to be augmented by non-verbal measures. Communication boards, drawings and visual representations, use of video, puppets and enactments are often useful methods for helping to cement verbal communications.
RESOURCES – COMMUNICATION

British Institute of Learning Disabilities (BILD)
Courses, books and training materials
www.bild.org.uk/

CANDLE – CAMHS and new directions in learning disability and ethnicity

Centre for Excellence in Teaching and Learning (CETL)
Conference held in December 2006: Learning Clinical & Communication Skills for Practice – Maximising Learning in Practice Conference
www.cetl.org.uk/conference.php

Child In Mind
A course designed for trainees new to paediatrics and for GP trainees.
www.rcpch.ac.uk/Education/Education-Courses-and-Programmes/Child-In-Mind

Do 2 Learn
Comprehensive website with education resources e.g. picture cards, games (both free), books. (American site)
www.dotolearn.com

The Foundation for People with Learning Disabilities (FPLD)
- What's Happening? DVD featuring young people with learning disabilities experiencing anxiety or depression.
- Mind the Gap A project where young people and family carers developed and ran workshops focusing on keeping mentally healthy. Materials include We are the Strongest Link training manual and Linking Up guide for Connexions and transition workers.
- You are Not Alone web-based guidelines for parents and carers to get help in identifying problems and getting support.
- All About Feeling Down: a Booklet for Young People with Learning Disabilities.
To download the guides log on to www.learningdisabilities.org.uk

National Children's Bureau
Training events
www.ncb.org.uk

Paediatric Intensive Care
Have produced own accredited training to expand recruitment.

SEN Teacher
Free special needs teaching resources
www.senteacher.org

Training pack: Beyond the Label, Young Minds.
Info at www.youngminds.org.uk/beyondthelabel

Valuing People
This site has all the relevant guidance, legislation and advice relating to people who have a learning disability and links to a range of other resources.
www.valuingpeople.gov.uk
3. TAKING INTO ACCOUNT POSSIBLE COMPLEX PHYSICAL HEALTH NEEDS

Children and young people with learning disabilities are at a greater risk of having physical health needs. These include:

- chronic illness such as epilepsy
- sensory disabilities
- mobility difficulties such as cerebral palsy
- feeding problems.

The mental health team should understand these areas of need, liaise with paediatricians, neurologists, dieticians and others involved with these needs, but also ensure that they understand how these needs impact on the young person's mental health and behaviour.

RESOURCES – COMPLEX PHYSICAL HEALTH NEEDS

British Institute of Learning Disabilities (BILD)
Courses, books and training materials
www.bild.org.uk

CANDLE – CAMHS and new directions in learning disability and ethnicity.

Centre for Excellence in Teaching and Learning (CETL)
Conference in December 2006: Learning Clinical & Communication Skills for Practice – Maximising Learning in Practice Conference
www.cetl.org.uk/conference.php

Child In Mind
A course designed for trainees new to paediatrics and for GP trainees.
www.rcpch.ac.uk/Education/Education-Courses-and-Programmes/Child-In-Mind

Do 2 Learn
Comprehensive website with education resources e.g. picture cards, games (both free), books etc. (American site)
www.dotolearn.com

The Foundation for People with Learning Disabilities (FPLD)
The Well-being Workshop: a multimedia CD and training resource to enable services to run workshops for family carers and support staff – includes guidelines and practical tools.
www.learningdisabilities.org.uk

National Children’s Bureau
Training events
www.ncb.org.uk

Paediatric Intensive Care
Have produced own accredited training to expand recruitment.
SEN Teacher
Free special needs teaching resources
www.senteacher.org

Beyond the Label, Young Minds.
Training pack. Info at www.youngminds.org.uk/beyondthelabel

Valuing People
This site has all the relevant guidance, legislation and advice relating to people who have a learning disability and links to a range of other resources.
www.valuingpeople.gov.uk
4. TRANSITION PLANNING

A transition pathway needs to be established with the education, adult health, social care and learning disability services to:
- provide seamless continuity of clinical care
- inform the person-centred planning
- provide continuing education/vocational training.

This transition pathway needs to be linked with education structures, such as annual reviews.

5. PRESCRIBING ISSUES

The use of medication for difficult behaviours in people with learning disabilities has a chequered history. It remains a contentious issue.\textsuperscript{25,26} However there is a place for the cautious use of certain medications alongside social, educational and psychological interventions.

The following outlines some guidelines for effective prescribing with this client group:\textsuperscript{27}

1. Medication should never be the initial intervention. Consider psychological, educational, family and social approaches first.
2. Thorough multi-disciplinary assessment must be undertaken.
3. If problems still persist, consider medication in addition to other approaches as a means to an end – not an end in itself.
4. Treat symptoms (e.g. self-injury, aggression) not syndrome.
5. Undertake a clinical trial of medication. Does it work or not? Are there side effects?
6. Consider the ‘cost-benefit’ ratio. What is the likelihood of improvement? How important is this? What are the likelihoods of side effects? How serious might they be?
7. Beware of the increased risk of adverse effects in people with learning disability and other developmental disabilities.
8. If medication does not work, stop it.
9. If medication does work: give it for the minimum time possible with frequent monitoring and reviews regarding continuing need and possible adverse effects.
10. Don’t ask whether medication works for children and young people with emotional and behavioural problems. Ask whether a specific medication works for a specific child who has a specific behavioural difficulty.

In addition, emphasis has also been placed on the importance of accurate diagnostic skills in practitioners working with children and young people with a learning disability.\textsuperscript{28} Allington-Smith also outlines the need for a proper diagnosis, without which no appropriate medical treatments can be provided.
A further review of the research literature is needed before the evidence base for particular medications can be presented. It should be noted that most of the medications currently employed are not licensed for children and young people or for the management of behavioural problems. Drug trials have not included children and young people with learning disabilities in their studies and there is little, if any, information on the risk of adverse effects particularly in long term treatment. Practitioners are therefore often reliant on experience or small scale studies to guide their prescribing practice.

However initial investigations of the literature suggest that medication may have a role in relation to the following difficulties commonly experienced by children and young people with learning disabilities:

- epilepsy and associated emotional and behavioural problems
- hyperactivity and attentional deficits.
- aggression, violence, and self-injurious behaviour
- mood disorders
- sleep disorders.

RESOURCES – PRESCRIBING ISSUES

BNF for Children
http://bnfc.org/bnfc/


References

NB All websites accessed on 30 May 2007

   It should be acknowledged that there has been significant progress in this
   area in recent years. Also, care should be taken in interpreting this data, as
   small service providers may have no specific learning disability provision
   because a service is provided by a neighbouring trust through a partnership
   arrangement.

2 Dekker MC, Koot HM. DSM-IV disorders in children with borderline to
   moderate intellectual disability I: prevalence and impact. J Am Acad Child

3 Emerson E. Prevalence of psychiatric disorders in children and adolescents
   with and without intellectual disabilities. J Intellectual Disability Res 2003;47:
   51-8.

4 Emerson E. (2003) ibid

5 Child Mental Health – Learning Disabilities – Do Once and Share (DOAS)
   www.camhs.org.uk/default.aspx?q=DOAS&c=8970

6 For an electronic (MS PowerPoint) version with clickable links go to
   www.camhs.org.uk/documentdownload.aspx?doc=DOAS%20LD-
   MH%20Services%20Care%20Pathway%20PPT%20v1.1%20July%2006.ppt

7 CAMHS Do Once and Share (DOAS) projects
   www.camhs.org.uk/default.aspx?c=8971&m=10&p=1&q=DOAS

8 Department of Health (2004) National Service Framework for Children,
   Young People and Maternity Services: The mental health and psychological
   well-being of children and young people
   www.dh.gov.uk/assetRoot/04/09/05/60/04090560.pdf

9 Department of Health (2004) ibid

    Young People and Maternity Services: Disabled children and young people
    and those with complex health needs.
    Web

    and Practitioners’ Guides www.dfes.gov.uk/commoncore/docs/CAFGuide.doc

12 National Service Framework for Children, External Working Group on
    Disabled Children (2002) Background paper on key workers
    www.dh.gov.uk/assetRoot/04/11/90/10/04119010.pdf

    Young People and Maternity Services: The mental health and psychological
    well-being of children and young people
    www.dh.gov.uk/assetRoot/04/09/05/60/04090560.pdf


19 In Bradford District Care Trust a local multi-agency referral panel is developing outcome based discussions using Goal Attainment Scales. For further details contact David.Sims@bdct.nhs.uk


29 Allington-Smith P. (2006) ibid
Key documents

All website references were correct at the time of going to press. However website content is subject to change. If you have any difficulty accessing any of the documents referred to, we suggest you go to the host home page and navigate from there.


CAMHS Do Once and Share (DOAS) projects  
www.camhs.org.uk/default.aspx?c=8971&m=10&p=1&q=DOAS

For details and key documents from:

- Mental Health Services for Children with Learning Disabilities: A National Care Pathway
- Developing a General Care Record DOAS project, which sought to produce a national multi-agency consensus on the necessary data elements of a care record for child and adolescent mental health services (CAMHS)

*Establishing the responsible commissioner: Guidance for PCT commissioners on the application of the legal framework on PCTs’ secondary care commissioning responsibilities (2006).* Department of Health.  

www.everychildmatters.gov.uk

- Children’s Trusts  
  www.everychildmatters.gov.uk/aims/childrenstrusts
- Common Assessment Framework  
  www.ecm.gov.uk/caf
- Information sharing  
  www.everychildmatters.gov.uk/resources-and-practice/IG00065/
- Key workers and lead professionals  
  www.everychildmatters.gov.uk/leadprofessional
- Multi-agency working  
  www.ecm.gov.uk/multiagencyworking


www.act.org.uk/component/option,com_docman/task,cat_view/gid,15/Itemid,26/

Limbrick P. (2005) *Principles and practice that define the team-around-the-child (TAC) approach and their relationship to accepted good practice.*  
www.icwhatsnew.com/bulletin/articles/TAC.pdf


O’Brien J & Lovett H. (1992). Finding a way toward everyday lives: the contribution of person centred planning. Toronto, Inclusion Press. This article and others on PCP can be found at: www.valuingpeople.gov.uk


Youth In Mind. Information for researchers and professionals about the Strengths & Difficulties Questionnaires. www.sdqinfo.com
KEY NATIONAL POLICY DRIVERS FOR CAMHS-LD 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

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.

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.


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.


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

Appendix 2

THE 4 TIERS OF CAMHS

This section identifies the four tiers within those services meeting children’s needs for psychological wellbeing and mental health. It takes these definitions from Standard 9 within the National Service Framework for Children, Young People and Maternity Services (2004) – *The Mental Health and Psychological Well-being of Children and Young People*. Other needs relating to disability can be considered in the same way, and might follow a similar progression of requests for more specialised provision (e.g. needs relating to physical disability might range from making activities accessible [tier 1] to interventions such as the use of Botulinum to reduce muscle tightness in cerebral palsy [tier 3] or in exceptional cases surgical interventions [tier 4]). A second table gives some indication of what might trigger a move from one level of service to another.

NB It is important to understand that the four tier strategic framework for CAMHS is not linear in nature (for more detail see the original source document by the NHS Health Advisory Service *Together we stand: thematic review of the commissioning, role and management of child and adolescent mental health services*, 1995). Children and their families may be receiving support at more than one level at the same time, e.g. to support family resilience. See also sections on the Common Assessment Framework.

Reference is made below to existing clinical guidelines.

It should be noted that the guidelines for timeframes, e.g. the NICE depression guidelines for children, may need to be extended for children and adolescents with learning disabilities as they typically respond more slowly to intervention programmes.

Symptoms of possible difficulties related to psychological wellbeing or mental health can also be overshadowed by other conditions such as autism or severe learning disabilities.
The four tiers of mental health provision for children and young people

Tier 1 – Universal services
Mental health providers working in universal services that are in a position to:
- identify mental health problems early in their development
- offer general advice
- pursue opportunities for mental health promotion and prevention.

(Professionals providing such input include GPs, health visitors, school nurses, social workers, teachers, juvenile justice workers, voluntary agencies, other social services – most of these professionals will not see themselves as ‘mental health providers’ but they provide the first line of response to potential difficulties)
Child, family and other caregivers involvement throughout process.

Tier 2 – Targeted services
Mental health providers able to offer:
- training and consultation to other professionals (who might be within tier 1)
- consultation to professionals and families
- outreach
- assessment.

(A level of service usually provided by uniprofessional groups that relate to each other through a network rather than a mental health team, e.g. community paediatricians, social workers, educational psychologists, primary mental health workers, clinical child psychologists, child & adolescent psychiatrists, community nurses/nurse specialists)
Child, family and other caregivers involvement throughout process.

Tier 3 – Specialised services
Mental health providers able to offer a specialised service for more severe, complex or persistent disorders, including:
- assessment and treatment
- assessment for referrals to tier 4
- contributions to the services, consultation and training at tier 1 and tier 2.

(A level of service provided by a multi-disciplinary mental health team that may include child & adolescent psychiatrists, clinical child psychologists, nurses, social workers, child psychotherapists, occupational therapists, speech and language therapists, art, music and drama therapists)
Child, family and other caregivers involvement throughout process.

Tier 4 – Highly specialised services
Mental health providers able to offer essential tertiary level services such as day units, highly specialised out-patient teams and in-patient units, including:
- highly specialised assessment and treatment
- contributions to the services, consultation and training at tiers 1, 2 and 3

(Multi-disciplinary mental health team members as for tier 3)
Child, family and other caregivers involvement throughout process.

Key
- ‘Conventional’ routes between tiers
- Other possible routes
How children and adolescents with learning disabilities with mental health problems might move between service tiers

**Tier 1 – Universal services**

**Interventions:** ‘Frontline’ staff provide counselling, advice and consultation to carers and also delivery of systemic interventions e.g. changes to curriculum delivery in school, anti-bullying packages, parenting skills training, emotional intelligence etc. RECORDING and MONITORING. CAF assessments.

**Problems:** temporary mood disturbances, everyday anxieties, normal grief and bereavement, friendship problems, inappropriate behaviour etc.

**Interactions across tiers:** regular contact with direct carers dependent on the role of professional, consultation with tier 2 through multi-agency groups. Occasional consultation with tier 3.

**Requests for service:** when problems persist or worsen following watchful waiting and/or normally available responses fail to lead to improvement. Incidents of serious concern e.g. sexually inappropriate behaviour, unusually intense reactions to events.

**Tier 2 – Targeted services**

**Interventions:** individual practitioner-led, but more complex problems may lead to intervention within a multi-agency care plan following CAF and multi-agency reviews (including statutory reviews). Consultation to tier 1 and families, support to planning and short term systemic interventions (e.g. 2+1), time limited direct interventions (psycho-educational, SFBT, CBT etc). Assessment of psychological wellbeing. Building and maintaining resilience.

**Problems:** persistent mood disturbance, anxiety or depression that persists and/or interferes with daily life, behaviour that interferes with access to normally available activities, low level self harm. Behaviours giving rise to serious concern.

**Interaction across tiers:** consultation with direct carers and tier 1, either through regularly available (e.g. drop in) or planned contacts. Consultation with tier 3 e.g. as part of watchful waiting, against clinical guidelines.

**Requests for service:** when problems persist or worsen following watchful waiting and/or normally available responses fail to lead to improvement in line with clinical guidelines. Incidents of serious concern not satisfactorily resolved.

**Tier 3 – Specialised services**

**Interventions:** specialist mental health assessment, extended episodic interventions e.g. CBT, psycho-educational interventions, psychotherapy, art therapy. Intensive support to tier 1 & 2 e.g. to review and develop existing strategies for autism.

**Problems:** requests for specialist assessment (e.g. complex ASD or learning disabilities), significant and continuing concerns about behaviours not responding to normally available interventions at tier 1 & 2. Responses to severe or extended trauma or abuse. Possible placement breakdown etc, self harm and eating disorders.

**Interactions across tiers:** consultation with tier 2 e.g. primary mental health workers, educational psychologists e.g. to build resilience to tier 3 & 2, e.g. community paediatricians, primary mental health workers, educational psychologists etc, either through regularly available multi-agency meetings or planned contacts. Consultation with tier 1, usually mediated by tier 2, e.g. as part of watchful waiting, against clinical guidelines, or supporting current interventions. In cases of concern, or low incidence cases, consultation with tier 4 possibly in relation to requesting more specialised services.

**Requests for service:** When problems persist or worsen following watchful waiting and/or normally available responses fail to lead to improvement in line with clinical guidelines. Incidents of serious concern.

**Tier 4 – Highly specialised services**

**Interventions:** highly specialist and/or intensive assessments and interventions, that may also be longer term or require in-patient admission.

**Problems:** highly specialised e.g. forensic, neuro-psychiatric, degenerative or highly complex cases not responding to normal interventions particularly where there may be significant risks to the young person or to others.

**Interaction across tiers:** consultation with tier 3, particularly re requests for service, and with tiers 1 & 2 e.g. community paediatricians, primary mental health workers, educational psychologists etc, particularly in relation to building resilience following discharge. Consultation with tier 3, e.g. as part of watchful waiting, against clinical guidelines, or supporting current interventions. In cases of concern, or low incidence cases, consultation with all tiers possibly in relation to planning more specialised co-ordinated responses e.g. where multi-systemic interventions are required.

**Requests for service:** when problems are likely to persist following intervention and/or available responses on discharge need to be considered in relation to building resilience, or to manage long term problems. Cases of serious concern due to risk factors.
TABLE FOR MAPPING EXISTING CAMHS-LD RESOURCES

It may be helpful to complete 3 tables, one each for Tier 1, 2 and Specialist Provision

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<td>Who are the professionals involved? (e.g. psychiatrists, mental health trust special units)</td>
<td>What actions or interventions are required?</td>
<td>Are there any guidelines/protocols, referrals or care pathways?</td>
<td>Are there relevant time frames? Response times</td>
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A mental health care pathway for children and young people with learning disabilities
## CAMHS-LD ACTION PLAN OUTLINE

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<th>Task</th>
<th>Resources needed to achieve</th>
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COMMON PRESENTING DIFFICULTIES: SOME TIPS FOR PRACTITIONERS

This section outlines some common presenting difficulties:

- Challenging behaviour
- Emotional difficulties – depression and anxiety
- Attention difficulties
- Autism and other social-communication difficulties

For each of these, a definition is given, followed by a vignette of common presentation, with suggested interventions and resources. Naturally the circumstances and presenting issues of each child or young person is different. However, it is hoped that this section will give some indication of possible courses of action. In addition, this section may also act as useful background information for both commissioners and providers.

CHALLENGING BEHAVIOUR

Definition

In many ways challenging behaviour overlaps with many of the conduct disorders seen commonly in child and adolescent mental health services.

The term ‘challenging behaviour’ has different definitions but in learning disability contexts it has been used to refer to the ‘difficult’ or ‘problem’ behaviours which may be shown by children or adults with a learning disability. Such behaviours include aggression (e.g. hitting, kicking, biting), destruction (e.g. ripping clothes, breaking windows, throwing objects), self-injury (e.g. head banging, self-biting, skin picking), tantrums and many other behaviours (e.g. running away, eating inedible objects, rocking or other stereotyped movements). Characteristically, challenging behaviour puts the safety of the person or others in some jeopardy or has a significant impact on the person’s or other people’s quality of life.¹ In some contexts, such as in schools, much lower criteria may be used to define ‘challenging behaviour’. It may be that local areas need to be clear that there is a single definition; alternately, it may be decided that a more flexible approach to definition is needed.

In general, challenging behaviour is rather more common in people with learning disabilities than in people without disabilities, though the pattern varies considerably depending on the type of behaviour being considered and the age of the people. For example, significant self-injury occurs in between 3% and 12% of children attending schools for those with severe learning disabilities and is, therefore, much more common than in children without disabilities, where the rate is negligible.²

¹ The Challenging Behaviour Foundation www.thecbf.org.uk
² ibid
Vignette of common presentation

Jacob is a 12-year-old boy with severe learning disabilities and epilepsy which is poorly controlled. He is also seriously overweight. Jacob lives in supported housing provided by a Jewish independent charity but has regular weekend visits to see his family. He attends a local special school and has one-to-one support from a classroom assistant due to his behaviour and the frequency of his seizures.

Recently Jacob’s behaviour has become more difficult to manage; he has become aggressive to his classroom assistant, with whom he always had a positive relationship. On a recent occasion he seriously injured her arm as she tried to restrain him from stealing other children’s lunchtime snacks.

Jacob’s family consist of his parents who are in 50s and his four older sisters. His parents have always found it difficult to accept his disabilities and often over-indulge him on weekends home. There has been some recent marital tension and Jacob is reported to be tearful and aggressive following weekend visits.

The school nurse refers to your service for help with Jacob’s low mood and aggressive behaviour. She also refers to a dietician for help with his over-eating.

Suggested interventions: 3

As with any child, Jacob’s behavioural difficulties need to be considered within context. For Jacob significant contextual issues may be:

- His severe learning disability and likely poor expressive and communication abilities. The current behaviours may have a strong communicative element and may be a way of Jacob expressing distress he cannot express in other, more functional ways.
- Adolescence – recent changes in his behaviour may be associated with his stage of the life span.
- Physical health concerns – Jacob’s epilepsy, eating behaviour and weight may be associated with behavioural difficulties. The effects of medication for these may also be playing a role in the presentation of the challenging behaviour.
- Mood – his low mood is likely to be interacting with his behavioural difficulties. However, Jacob may not have access to emotional language to express his mood changes, and his environment may or may not be responsive to these emotional changes.
- School environment – the support that is required to facilitate his interactions at school may or may not be appropriate.
- Home environment – there are significant life events happening or his family and supported living with contact with his family may or may not be currently meeting his emotional and behavioural needs.

Assessing and addressing these difficulties will require a full assessment of the behaviour in context. This would be very similar to any assessment of a child with conduct difficulties but due to the level of learning disabilities will require observations to supplement any self or carer report of difficulties when considering a functional analysis of the behaviour. Particular attention may need to be paid to the medical/medication interaction with the behavioural and emotional concerns.

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3 It should be noted that research regarding effective interventions for children with a learning disability and behavioural and emotional difficulties is still in its infancy. Children with learning disabilities have been excluded from many of the randomised treatment trials undertaken. Caution should be applied in generalising the conclusions from such evidence to those with a learning disability. Suggestions here are therefore based on the evidence of practitioner consensus.
such as those associated with his epilepsy. Liaison with paediatric, psychiatric or general practitioner services may be necessary to achieve this.

For conduct difficulties, parent training is the treatment of choice in children under 10-years-old, particularly those with moderately severe disability, less co-morbidity and less social disadvantage, and they may be useful in working with children with a learning disability. Many parent training interventions have been specifically adapted for this client group to enable work through a range of carers.

It is important that any intervention to address the behavioural and emotional difficulties have specific, small and realistic goals. The work is likely to be slower, and engagement may take longer due to communication difficulties, so achievement of realistic goals is important for the client, carers and practitioners in encouraging ongoing motivation for the intervention.

Given the multiple contexts within which Jacob is functioning it may be necessary to develop an inter-agency, co-ordinated approach to any intervention suggested. It is likely that Jacob is receiving services from a range of agencies to address his learning, emotional and behavioural needs, and it will be important for any new practitioner to be aware of and engaged with this support network. It may be necessary to have a keyworker to co-ordinate such a multi-agency approach, and explain the different roles of professionals to Jacob and his family.

Resources – challenging behaviour

- The Challenging Behaviour Foundation
  Provides information and support to parents and professionals, promote research, influence policy and improve local service provision.
  www.theCBF.org.uk

- E-Epilepsy – The National Society for Epilepsy
  News, conferences/seminars/study days, leaflets etc for people with a professional interest in epilepsy.
  www.e-epilepsy.org.uk

  www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Section=1&SubSection=4&Product=399


- Managing challenging behaviour: trainer pack. Bradley A.
  www.bild.org.uk/03books_behaviour.htm#06ManagingChallengingBehaviourTrainerPack
EMOTIONAL DIFFICULTIES – DEPRESSION AND ANXIETY

Definition

Depression is characterised by sadness, loss of interest in activities, and decreased energy. Other symptoms may include loss of confidence and self-esteem, diminished concentration, and disturbance of sleep and appetite. In children with a learning disability the learning or communication difficulties may mask the usual presentation of depressive or anxious symptomology. Children may be more likely to show their emotional distress through aggressive behaviours or increased stereotypical behaviour such as rocking or self-injury and they may have difficulty discussing emotional states or expressing these more functionally. This problem of communicating emotional distress effectively obviously increases with the severity of learning disability. Emotional difficulties can therefore be hard to detect and it is therefore important to assess baseline levels of functioning.

In 2004 it was estimated that 4% of children aged 5-16 without a learning disability had a clinically diagnosed emotional disorder (anxiety or depression), with a generally higher prevalence among boys than girls. Exact figures for children with learning disabilities are not available. However children with a learning disability are likely to have a number of factors in their environment which may contribute to increased levels of emotional distress. For example, they have increased likelihood of hospitalisations and parental separation. Teenagers with a mild learning disability are particularly vulnerable to feelings of depression when they begin to appreciate that they are different from other children and more dependent on their parents.

Vignette of common presentation

Carly is a 12-year-old girl with a mild learning disability who is in the care of the local authority. She moved to a foster family three years ago, following neglect. Her father has longstanding mental health and alcohol problems, and had been unable to care for Carly after the death of her mother. Carly has a younger sister aged six, also living with the foster family. The foster carers found it difficult to deal with Carly's behaviour during the first year of her placement. She had aggressive outbursts, usually directed at the foster mother, but also at other children; ran away; and approached or tried to attach herself to strangers.

The foster carers attended a group on the impact of trauma on children with attachment and behavioural difficulties, and gradually developed strategies to deal with Carly's behaviours. Although these have not completely subsided, the carers now feel better equipped to handle them, and are committed to Carly for the future. Carly is attending a special school, and is functioning well within her ability range. She has made some friends. She moved to this school last year, following some debate between agencies about whether a mainstream-based unit would be preferable. Carly has monthly supervised contact with her biological father.

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5 Mental health of children and young people in Great Britain, Office for National Statistics, 2004 www.ic.nhs.uk/pubs/mentalhealth04
Despite the improvement in several areas of Carly's life, her foster carers are now predominantly concerned about her emotional state. She is often withdrawn, looks sad and tearful, and has expressed a wish to die. Sometimes Carly 'talks' to her mother when she goes to bed. She does not open up, and neither her carers nor the professionals involved (teacher, social worker, link worker) are sure whether she needs specialist help, a different approach/help from them, or whether this is a phase that will resolve itself.

**Suggested interventions**

As with any child Carly's emotional difficulties need to be considered within context. For Carly significant contextual issues may be:

- Her mild learning disability and likely difficulty with understanding and verbally expressing and addressing distressing emotional states.
- Mood – her low mood is likely to be interacting with her behavioural difficulties but Carly may not have access to emotional language to express her mood changes, and her environment may or may not be responsive to these emotional changes.
- Adolescence – recent changes in her behaviour may be associated with her stage in life. Carly may have begun to appreciate that she is different from other children and more dependent on carers.
- Early trauma and loss – multiple losses are common for children with a learning disability and they often struggle to understand their changing environmental context and express grief reactions functionally. The multiple losses may have left Carly vulnerable to low self-esteem and depression and she may be struggling to make sense of the many losses and changes that have happened in her life.
- School environment – the support that is required to facilitate her interactions at school may or may not be appropriate.
- Home environment – foster care with contact with her family may or may not be currently meeting her emotional and behavioural needs.

It is important that a full assessment includes an evaluation of her functioning prior to the onset of the current episode of low mood. Reports from carers, her father and Carly herself will be important in achieving this. There should be some contributions from mental health services regarding assessment of risk and suicidal ideation.

An individual assessment with Carly will be important, with the help of a known carer to facilitate engagement and understand the severity of, and triggers for, the current difficulties. The assessment should consider not only assessment of the emotional difficulties but also consideration of Carly's emotional, cognitive and communication abilities – each child with learning disabilities will have a very individual pattern of abilities, with skills not necessarily consistent across the domains. The purpose of the latter would be to determine Carly's ability to make use of recommended ‘talking therapies’ for emotional difficulties, such as cognitive behavioural therapy (CBT).

NICE (National Institute for Clinical Excellence) guidance on the treatment of childhood depression recommends that psychotherapies such as CBT, family therapy or interpersonal therapy (IPT) be offered for up to three months as the first line of treatment. These should be used in preference to medication. If medication is required, for severe depression or when psychotherapeutic interventions have not been beneficial (after six weeks) or have been refused, it advocates fluoxetine as first-line treatment with sertraline and citalopram as the only second-line agents in
combination with psychotherapeutic interventions. However the document makes it clear that children with learning disabilities were not considered specifically or separately in drawing up the guidelines.

It may be possible to adapt psychotherapeutic interventions such as CBT for more able children such as Carly by including more concrete behavioural aspects to the work, or including carers in the treatment. Such adaptations will be essential for younger children or those functioning below secondary school level in terms of their cognitive and emotional abilities. Some children such as those with autism may find it impossible to apply CBT techniques learnt in a clinical setting to everyday life. Antidepressant medication may therefore still have a place for less able children who are unlikely to benefit from a psychotherapeutic approach.

Given that relapse in emotional difficulties is common, carers and parents should be enabled to develop strategies in the recognition and prevention of emotional distress shown by the child. This will contribute to the overall support for the child with learning disabilities to be able to express their emotional concerns effectively.

**Resources – emotional difficulties**

- **Mental Health Foundation**
  Mental health charity
  Information, booklets, research, for everyone affected by mental health problems

- **Mental health of children with learning disabilities**. Allington-Smith P. *Advances in Psychiatric Treatment* 2006; 12:130-140

- **Mind**
  Mental health charity
  Factsheets, links to conferences/training etc.
  [www.mind.org.uk/Information/Factsheets/Learning+disabilities](http://www.mind.org.uk/Information/Factsheets/Learning+disabilities)


**ATTENTION DIFFICULTIES**

**Definition**

Attention Deficit Hyperactivity Disorder (ADHD) is a developmental disorder that presents during childhood, in most cases before the age of seven, and is characterised by developmentally inappropriate levels of inattention and/or hyperactive-impulsive behaviour. A prerequisite of the condition is that it must result in significant impairment of one or more major life activities, including interpersonal relations, educational or occupational goals, as well as cognitive or adaptive functioning.

In 2004 2% of children aged 5-16 had a clinically diagnosed hyperkinetic disorder. The diagnosis is probably more common in children with a learning disability than in the normal population but is often overlooked as the attention problems are seen to be an integral part of the learning disability.

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6 *Mental health of children and young people in Great Britain, Office for National Statistics, 2004*  
[www.ic.nhs.uk/pubs/mentalhealth04](http://www.ic.nhs.uk/pubs/mentalhealth04)
Vignette of common presentation

Tobias is an eight-year-old boy with moderate learning disabilities. He lives with his mother and father and grandparents. He has attended a special school for children with moderate and severe learning disabilities since the age of five. He struggles to make use of the structured classroom setting, and is often agitated, distracted, impulsive and has poor concentration. Last year he became more easily distracted and his low levels of attention made it impossible for him to participate in activities set by the classroom teacher.

The school has been using a temporary teaching assistant to give Tobias additional individual support in the classroom. They are concerned that this individual support is included in his statement of special educational needs, which is due for annual review shortly. The school refers to the mental health service for an ADHD assessment and advice on behavioural management within the classroom.

Suggested interventions

As with any child, Tobias’ attention and behavioural difficulties need to be considered within context. For Tobias, significant contextual issues may be:

- His moderate learning disability and likely poor expressive and communication abilities – the current behaviours may have a strong communicative element and may be a way of Tobias expressing distress he cannot express in other, more functional ways. There is often difficulty in recognising and diagnosing attention problems as these are often assumed to be an integral part of the learning disability. The interactions between the difficulties are often difficult to determine or distill.

- Middle childhood – recent changes in his behaviour may be associated with his stage of the life span. The demands of the classroom may be increasing as he grows older and he may be struggling to meet these demands.

- School environment – the support that is required to facilitate his interactions at school may or may not be appropriate. There is considerable pressure from the system to increase support but this may not be associated with Tobias’ difficulties, but rather with other wider system factors such as the experience of the teacher, understanding of attention difficulties, class size and composition etc.

- Home environment – family concerns are not mentioned. They may have effective ways of addressing the behavioural and attention concerns or these may show themselves differently at home.

Assessing and addressing these difficulties will require a full assessment of the behaviour in several contexts, including both home and school, to assess the consistency of the attention difficulties across settings. This would be very similar to any assessment of a child with attention difficulties, though in assessment the child’s developmental level needs to be borne in mind. Rating scales that are available, e.g. Conner’s questionnaires, are standardised on normal populations but nevertheless can be useful. They must be used alongside a detailed developmental and clinical history, particularly in deciding whether the child’s problem occurs in more than the home setting. They can also be used to assess a response if medication is used. Observations will be needed to supplement any self or carer report of difficulties when considering a functional analysis of the behaviour. Unfortunately some of the
assessment tools used in the UK to diagnose ADHD use the presence of a learning disability as an exclusion criteria. This has meant that young people have been denied treatment that can significantly contribute to them achieving their full potential.

Stimulant medication is often recommended as a primary treatment, but learning disabled children seem to be more prone to side effects, particularly appetite suppression and weight, so effects of medication need to be closely monitored.

Individual behavioural interventions might be useful for Tobias within the school and home setting. There is a risk that behavioural interventions will not be targeted enough to address the attention difficulties, given the range of other behavioural and learning problems. It is therefore important that any intervention to address the attention difficulties have specific, small and realistic goals. The work is likely to be slower, and engagement may take longer due to communication difficulties, so achievement of realistic goals is important for the client, carers and practitioners in encouraging ongoing motivation for the intervention.

Given the multiple contexts within which Tobias may be experiencing difficulties, it may be necessary to develop an inter-agency, co-ordinated approach to any intervention suggested. It is likely that Tobias is receiving services from a range of agencies to address his learning, emotional and behavioural needs, and it will be important for any new practitioner to be aware of and engaged with this support network. It may be necessary to have a keyworker to co-ordinate such a multi-agency approach, and explain the different roles of professionals to Tobias and his family.

Resources – attention difficulties

- ADDISS, The National Attention Deficit Disorder Information and Support Service Information; bookshop; training courses for SENCOs, teachers and LSAs
  www.addiss.co.uk
- ADHD training and support for practitioners
  www.adhdtraining.co.uk
  Free A5 booklet with pull-out care pathway model, including examples of good practice and a service user perspective.
  www.hascas.org.uk/camhs_projects_adhd.shtml
AUTISM AND OTHER SOCIAL-COMMUNICATION DIFFICULTIES

Definition

ICD10 (an international means of coding diseases and conditions) defines autism as a pervasive developmental disorder defined by the presence of abnormal and/or impaired development that is manifest before the age of three years, and by the characteristic type of abnormal functioning in all three areas of social interaction, communication, and restricted, repetitive behaviour. The disorder occurs three to four times more often in boys than in girls.

The diagnosis of autistic spectrum disorders in children with a learning disability is one of the main reasons for referral to psychiatric services. The more severe the degree of learning disability, the greater the prevalence of an autistic disorder. Children with an autistic spectrum disorder and a learning disability are much more likely to develop serious behavioural problems than children who just have a learning disability.

Vignette of common presentation

Donald is 15, with mild learning disabilities and a diagnosis of autism. He lives with his mother, father and younger sister (13); his father is a long-distance lorry driver and is often away from home. Donald’s mother has refused an offer of short break care, but he does have an enabler who takes him swimming and to the gym. He was considered for a specialist school for children with autism. However, due to the distance his parents opted to have his needs met locally in a school for children with learning difficulties, with a full time additional classroom support assistant and some additional teaching time. He has achieved some basic literacy and numeracy, and his scores are 5-6 years behind his chronological age.

Donald has sensory sensitivities to sounds and can become emotionally distressed by songs. He is obsessed with making moon-landers from technical Lego (his favourite ‘non-work’ activity in school) and insists on school staff recording these each day with a digital camera; if they do not he can have physical outbursts and has injured staff. He prefers to communicate in writing rather than verbally and has developed no friendships outside his family, though he has a good relationship with his sister.

Donald is being referred by the disabled children team social worker who is seeking support and advice for his family, because recently Donald has become much more withdrawn at home. In addition his parents believe that Donald is now accessing inappropriate websites on his computer, and he has made inappropriate comments about female neighbours within their hearing.

Suggested interventions

As with any child, Donald’s behaviour needs to be considered within context. For Donald significant contextual issues may be:

- His mild learning disability, autism and poor expressive and communication abilities – the current withdrawal behaviour may have a strong communicative element and may be a way of Donald expressing distress he cannot express in other, more functional ways. There is often difficulty in recognising and diagnosing emotional problems as these can be assumed to be an integral part of the autism. The interactions between the difficulties are often problematic to determine or distill.

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Adolescence – recent changes in his behaviour may be associated with his stage of the life span. There may be a developing awareness of his difficulties and comparison of his abilities with peers without autism. Expectations of social relationships and maturity are increasing. At this stage of increased independence and developing sexuality, parents often become concerned about the development of appropriate social and intimate relationships.

School environment – the support that is required to facilitate his interactions at school may or may not be appropriate. He is in a non-specialist setting and there may be limited understanding of his particular social communication difficulties.

Home environment – concerns are mentioned from the family, and these focus on social relationships. The family may be concerned about appropriate strategies for managing these now Donald is an adolescent and previous strategies may be inappropriate given his life stage. They may also be confused about which difficulties might be associated with his autism and which relate to Donald as an adolescent.

Assessing and addressing these difficulties will require a full assessment of the behaviour in several contexts, including both home and school, to assess the consistency of the withdrawal and relational difficulties across settings. This would be very similar to any assessment of a child with emotional difficulties, but in assessment the child’s developmental level and social-communication abilities need to be borne in mind. One can thus determine which aspects of the presentation are consistent with usual functioning and may be associated with an autistic disorder, and which may be part of some specific additional difficulties. A detailed developmental and clinical history will be useful in determining this but this may be gained from previous assessments rather than repeating assessments with the child and family.

Observations will be needed to supplement any self or carer report of difficulties when considering a functional analysis of the behaviour.

The aim of interventions focusing on the core symptoms of autism is to maximise the child’s communication and understanding and improve the physical environment. Giving the child a certain amount of predictability and escape from over-stimulation is often very helpful to their day, and a calm place to unwind when upset can also be of benefit.

In relation to children with complex additional physical health needs there are particular issues that CAMHS teams may need to take into account, including postural care/body shape protection, pain and distress recognition in people who don’t communicate in traditional ways, dysphagia, impact of living with medical technology, epilepsy.

Individual behavioural interventions are often helpful for autism-related behaviours and might be useful for Donald within the school and home setting. Intensive behavioural interventions, either individual or group, should be considered to help improve the adaptive behaviour of children with autism.

If behavioural measures have been employed and the behaviours still exist and are clearly linked to anxiety, there may be a case for adapted psychotherapeutic interventions or medication. However, many of the medications commonly used are not licensed for use in autism and should only be prescribed by a specialist after a careful evaluation. Medication is not indicated for the treatment of core symptoms of autism but may be used to reduce specific behaviours associated with autism in children.
It is crucial that there is recognition that autism has important implications for the educational provision for the child, and that it may influence which school the child attends or the method of teaching employed in the classroom. The educational provision for Donald may need to be re-assessed to determine whether it is meeting his needs or if further support for teachers in understanding and addressing his difficulties is required.

**Psycho-education for parents and teachers** about autism, and available support services, may give them a better insight into the way that Donald perceives the world and what expectations and behaviours one might anticipate in adolescence. This in turn may lead to more effective behavioural management at home as well as increased empathy with him.

Given the multiple contexts within which Donald may be experiencing difficulties it may be necessary to develop an inter-agency, co-ordinated approach to any intervention suggested. It is likely that Donald is receiving services from a range of agencies to address his learning, emotional and behavioural needs, and it will be important for any new practitioner to be aware of and engaged with this support network. It may be necessary to have a [keyworker](#) to co-ordinate such a multi-agency approach, and explain the different roles of professionals to Donald and his family.

**Resources – autism and other social-communication difficulties**

- **Autism Cymru**
  Training courses

- **Autism Northern Ireland**
  Training courses
  [www.autismni.org/trainings.php](http://www.autismni.org/trainings.php)

- **Foundation for People with Learning Disabilities**
  News links, fact sheets, links to organisations, selected publications
  [www.learningdisabilities.org.uk/page.cfm?pagecode=ISCSAUAR](http://www.learningdisabilities.org.uk/page.cfm?pagecode=ISCSAUAR)

- **National Autistic Society**
  Pointers to good practice for schools and local education authorities
  - diagnosis of autistic spectrum disorders – a brief guide for health professionals
  - publications catalogue

- **Teachernet**
  Good practice guidance from the Autism Working Group
  [www.teachernet.gov.uk/wholeschool/sen/asds/asdgoodpractice](http://www.teachernet.gov.uk/wholeschool/sen/asds/asdgoodpractice)
Child Mental Health / Learning Disabilities Care Pathway

1. PRE-REFERRAL: Stakeholder requests service involvement
   - Referrer seeks consent
   - Referrer collates info (CAF)
   - Which service is the best first contact?

2. REFERRAL: Meeting
   - Can this service meet the child’s MH needs?
     - No: transfer
     - Yes: accept
   - Define appropriate assessments

3. ASSESSMENT
   Complete holistic assessment of MH needs

4. INTERVENTION: Planning
   - Intervention delivery/co-ordination
   - Outcome monitoring

5. WHAT NEXT?
   - Re-referral
   - Define agency roles in relation to new concern
   - Non-MH agency input re. ongoing/new concern
   - New MH intervention
   - Discharge

Continuing networked action by stakeholders – CAF reviews etc.