

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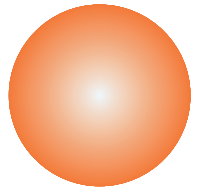
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Please note: at points within this pack we make
reference to other training resources, courses and
guidance that have been brought to our attention.
This is for information only; they have not been
reviewed by the authors.

*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.



www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf

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.² Furthermore, those with an IQ of below 50 have a 1 in 2 chance of experiencing mental health/behavioural difficulties.³ While all mental health problems are over-represented in children and young people with learning disabilities, autism and hyperkinetic disorder are particularly increased.⁴

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).⁵

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.

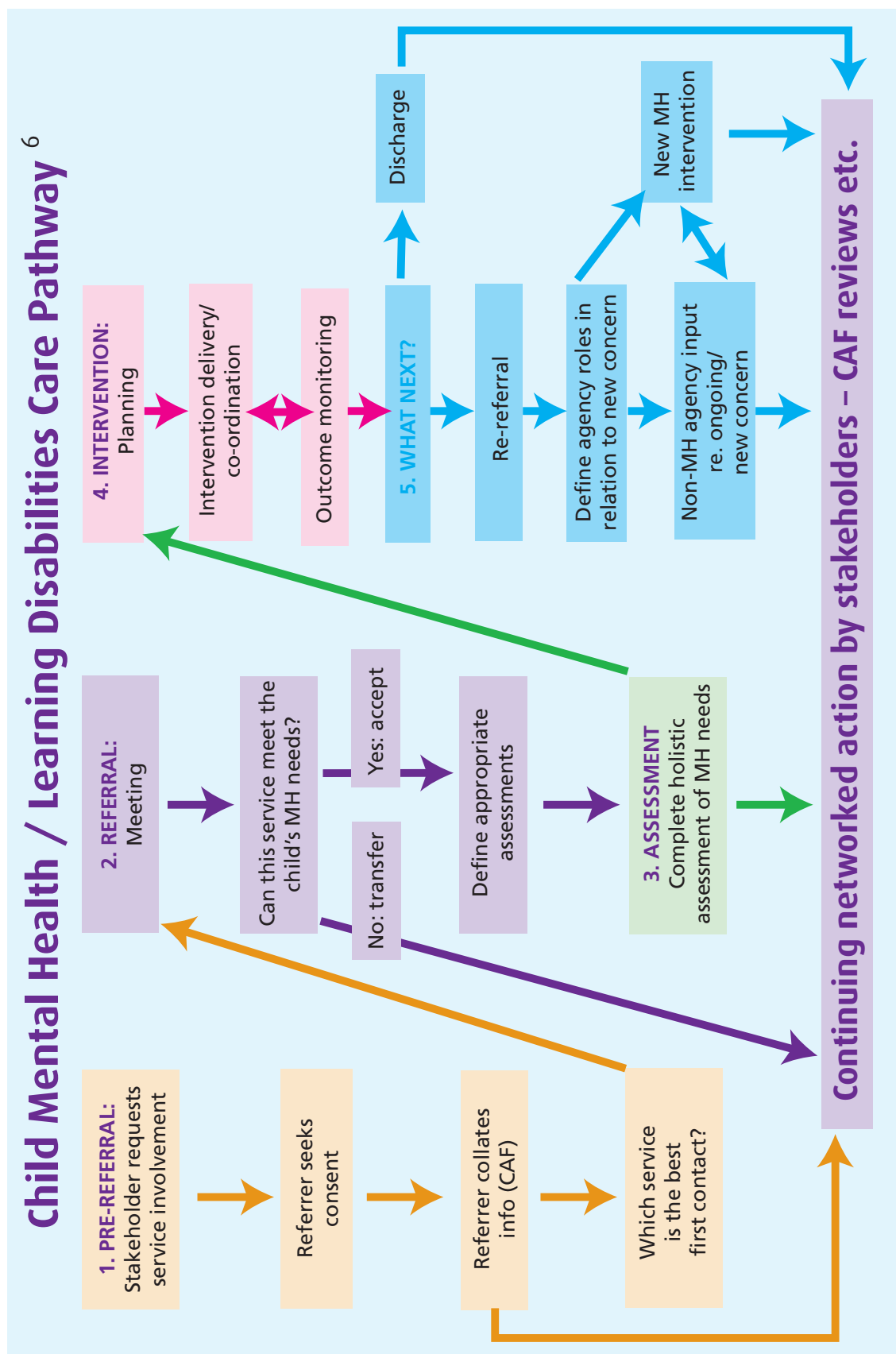
A note on web addresses: all website references were correct at the time of going to press. However website content is subject to change. If you have any difficulty accessing any of the documents referred to, we suggest you go to the host home page and navigate from there.

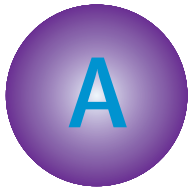
Section

A

Planning and providing services

A





ABOUT THE CARE PATHWAY

This care pathway was developed after extensive consultation with a wide range of stakeholders as part of the *Do Once and Share* (DOAS) project.⁷ It aims to describe the processes involved in service delivery for the full range of mental health services provided – at all levels of service delivery. It is applicable to those providing support for behavioural and emotional difficulties in a variety of non-specialist and specialist services.

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 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

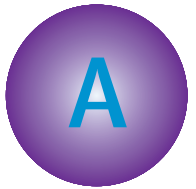
Services and individual professionals should take a pro-active and problem-solving approach in addressing the needs of children and their families. They should seek to equip themselves with any necessary knowledge base or skills to meet the needs of the child. Working pro-actively will require services 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.



See www.everychildmatters.gov.uk/resources-and-practice/IG00065/

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.

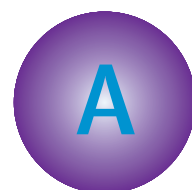
10. Therapeutic and quality services

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

Pre-referral	<ul style="list-style-type: none"> ● 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 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)
Referral	<ul style="list-style-type: none"> ● First contact is made, ideally with both caregivers and referrer, to clarify referral expectations 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 setting).
Assessment	<ul style="list-style-type: none"> ● Assessments should be holistic and consider the child's mental health needs within the context of their learning disability and their families' needs. ● Assessment for mental health difficulties should follow established protocols and good practice (e.g. the NICE Depression and Self Harm Guideline, Children's NSF).⁹
Intervention	<ul style="list-style-type: none"> ● 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), always being mindful of the needs for evidence-based practice and cost efficiency. ● 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.
What next? Discharge & re-referral	<ul style="list-style-type: none"> ● 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.
Implementing the care pathway	<ul style="list-style-type: none"> ● 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.



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.'¹⁰ 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 co-ordinators
- Special needs teachers
- Behavioural support workers
- Educational psychologists
- Behaviour support teams (peripatetic behavioural services)

continued

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

The NSF and Every Child Matters promote the development of locally managed care networks. Further guidance is available at:

www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4114364&chk=ebDqj9



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



2 The care pathway – a step by step guide

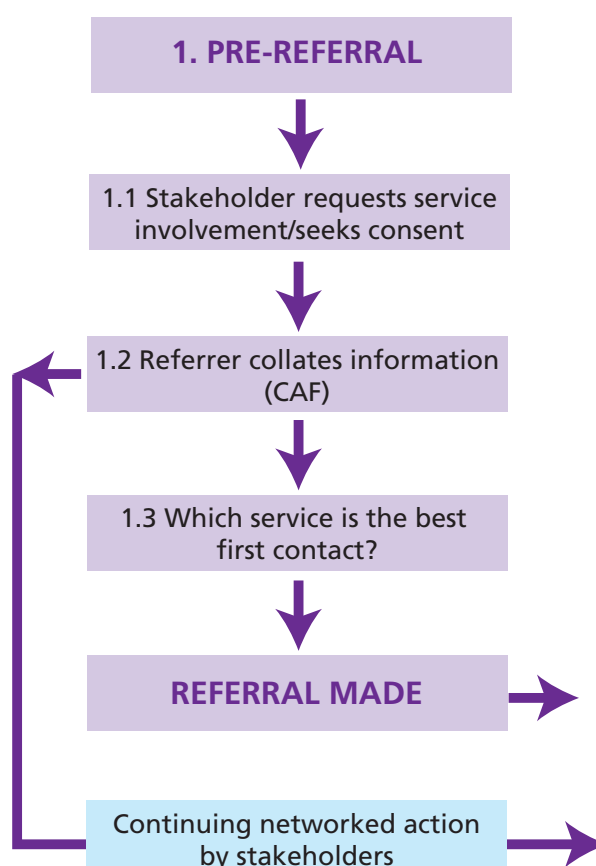
1. PRE-REFERRAL

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/seeking 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.



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

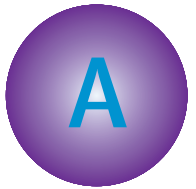
- observations in context (especially for challenging behaviour)
- existing knowledge and previously completed assessments (e.g. what has worked/is working and what has not/does not work).

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
2. Maintain effective links with other agencies as part of the ongoing mental health assessment and intervention.



www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008144

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:

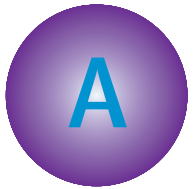
- developmentally appropriate, by using the age-appropriate instrument but modifying wording or using more visual representation;

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.

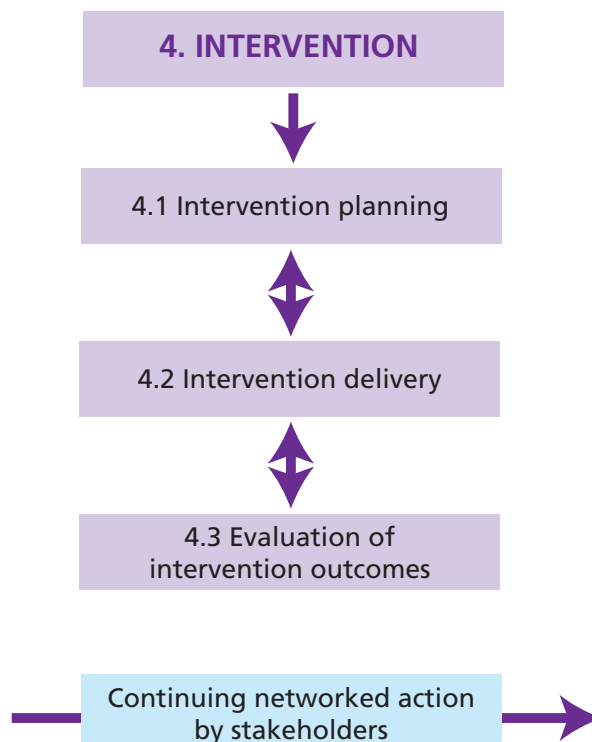
Such modifications will have an impact upon the standardisation of an assessment tool. Practitioners should acknowledge and take this into account when drawing conclusions from the data collected.



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.



4.1 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*)

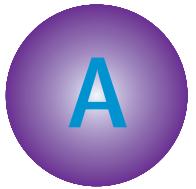
4.2 Intervention delivery

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.¹⁹ Useful standardised outcome measures for children and young people with mild learning disabilities may include the Strengths and Difficulties Questionnaire.²⁰

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

- **Behaviour Phenotypes in Clinical Practice.** O'Brien G. (ed) London, MacKeith Press, 2002.
- **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

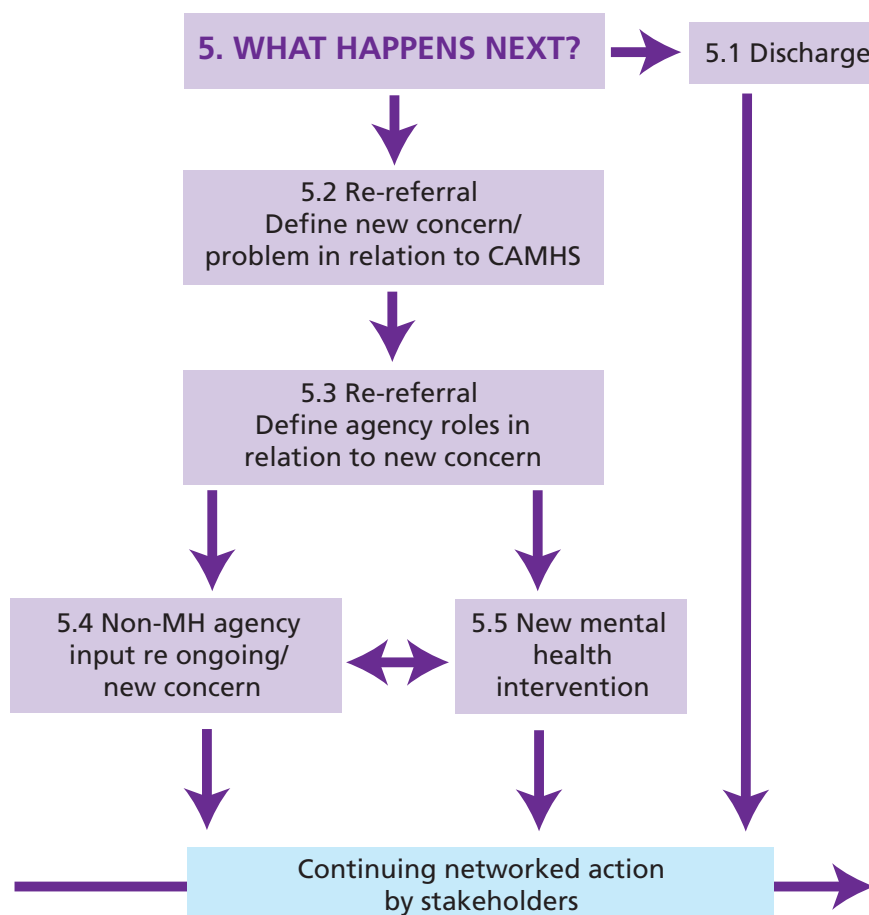
5. WHAT HAPPENS NEXT?

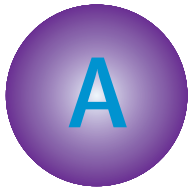
QUALITY STANDARDS

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.

Section

B

Putting the care pathway into practice

B

*'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 ²⁴ 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:

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.

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.

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).

CAMHS Partnership Development Programme – unpublished document for the National CAMHS Support Service. Anderson Y. (2004)

Every Child Matters – Change For Children. Department for Education and Skills (2004).

- 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.

Greco V, Sloper P, Webb R, and Beecham J. SPRU report, York University, 2005.

How to create inclusive services for disabled children and their families. Dickins M. with Denziloe J. (2nd edition) NCB Books.

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

The Lead Professional: Managers' and Practitioners' Guide. Department for Education and Skills (2002).

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

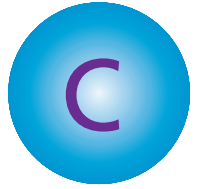
Developing Effective Multi-Agency Working: Lessons from Research – the full report can be downloaded from:

www.camhs.org.uk/documentdownload.aspx?doc=MatchFinalfullreport.pdf

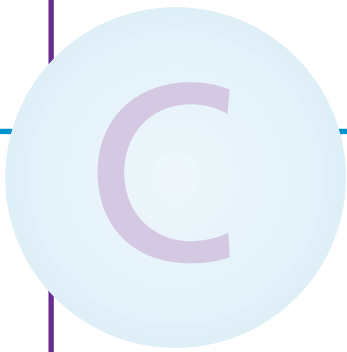
Principles and practice that define the team-around-the-child (TAC) approach and their relationship to accepted good practice.

Limbrick P. (2005). www.icwhatsnew.com/bulletin/articles/TAC.pdf

Section



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

Association for Real Change CAMHS Team, Chesterfield. Resource Pack for Tier 1 Practitioners. To be published 2007.

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.

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005760

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 .

Association for Real Change CAMHS Team, Chesterfield. Resource Pack for Tier 1 Practitioners. To be published 2007.

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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.

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005760

SEN Teacher

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Beyond the Label, Young Minds.

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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.^{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: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.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.²⁹ 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

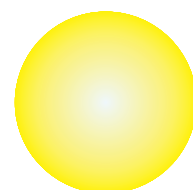
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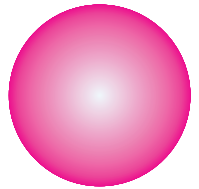


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- ¹ CAMHS Mapping 2005 www.camhsmapping.org.uk/2005/reports/15509FINAL.pdf
It should be acknowledged that there has been significant progress in this area in recent years. Also, care should be taken in interpreting this data, as small service providers 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 Adolesc Psychiatry* 2003;42: 915-22.
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- 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 wellbeing of children and young people* www.dh.gov.uk/assetRoot/04/09/05/60/04090560.pdf
- ⁹ Department of Health (2004) *ibid*
- ¹⁰ Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services: Disabled children and young people and those with complex health needs.* www.dh.gov.uk/prod_consum_dh/idcplg?IdcService=GET_FILE&dID=2221&Rendition=Web
- ¹¹ Department for Education and Skills (2002) *The Lead Professional: Managers' 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
- ¹³ Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services: The mental health and psychological wellbeing of children and young people* www.dh.gov.uk/assetRoot/04/09/05/60/04090560.pdf

- 14 Greco V, Sloper P, Webb R and Beecham J. (2005) *An exploration of different models of multi-agency partnerships in key worker services for disabled children: effectiveness and costs*. SPRU report, York, York University.
- 15 Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services: The mental health and psychological wellbeing of children and young people* www.dh.gov.uk/assetRoot/04/09/05/60/04090560.pdf
- 16 National Initiative for Autism: Screening and Assessment
www.nas.org.uk/nas/jsp/polopoly.jsp?d=368&a=2178
- 17 Wolpert M, Fuggle P, Cottrell D, Fonagy P, Phillips J, Pilling S, Stein S and Target M. (2006) *Drawing on the evidence: advice for mental health professionals working with children and adolescents* (2nd edition) London, CORE-DCP.
- 18 Department of Health (2004) *National Service Framework for Children, Young People and Maternity Services: The mental health and psychological wellbeing 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
- 20 Goodman R. Psychometric properties of the strengths and difficulties questionnaire. *Journal of the American Academy of Child & Adolescent Psychiatry* 2001; vol. 40; pp.1337-1345. See also www.sdqinfo.com
- 21 Lenton S. *Pathway/network thinking: potential application to multi-agency commissioning, delivery, quality assurance and inspection of children's services* www.icwhatsnew.com/bulletin/articles/BACCH1.pdf
- 22 DOAS CAMHS-LD Survey 2006
www.camhs.org.uk/default.aspx?q=DOAS&c=8970
- 23 Audit Commission (1998) *A fruitful partnership: effective partnership working*. www.audit-commission.gov.uk/Products/NATIONAL-REPORT/A190CA25-7A7E-47D1-BCAB-373A86B709C0/A%20Fruitful%20Partnership.pdf
- 24 Seven HELPFUL Habits of Effective CAMHS
<http://camhsnetwork.co.uk/Childlayer1pages/7helpfulhabits.htm>
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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.

Autism Exemplar: Autistic Spectrum Disorders (2004)

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089206

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.

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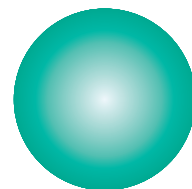
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Appendix 1

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



www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4055830.pdf

Disability Discrimination Act 2005

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

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



Specified secretaries of state must report on progress.

www.opsi.gov.uk/ACTS/acts2005/20050013.htm

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

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

Aims include that children and young people with learning disabilities should receive equal access to CAMHS including:

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

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

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

Aims include that:

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

www.childhealthmapping.org.uk/help/guidance/2006_LA_Rating.pdf



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

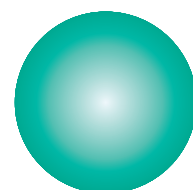


Every Child Matters/NSF

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'.



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.

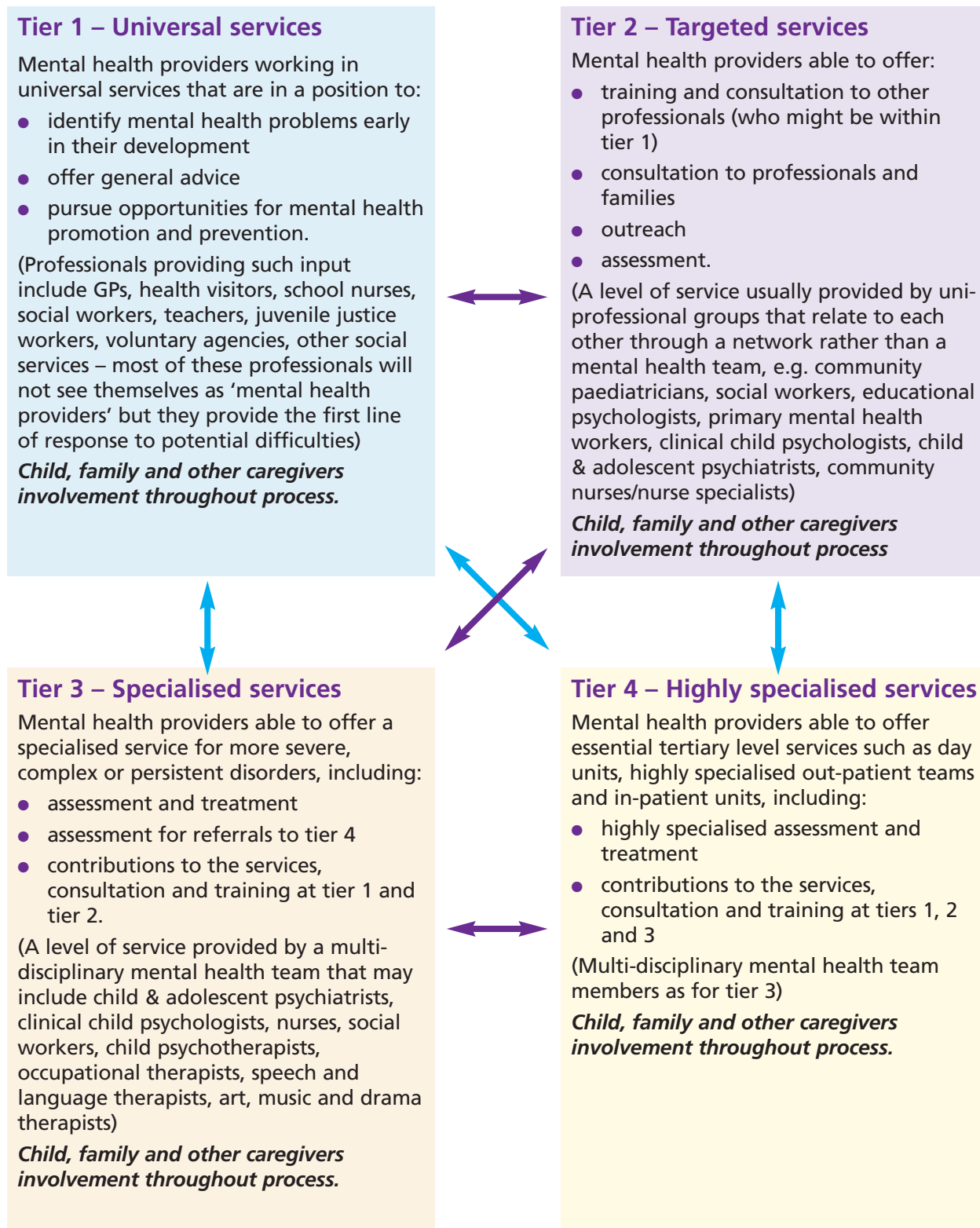
NB It is important to understand that the four tier strategic framework for CAMHS is not linear in nature (for more detail see the original source document by the NHS Health Advisory Service *Together we stand: thematic review of the commissioning, role and management of child and adolescent mental health 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.

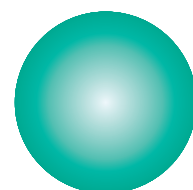
Reference is made below to existing clinical guidelines.

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





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 and interventions 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 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, neuropsychiatric, degenerative or highly complex cases not responding to normal interventions and particularly where there may be significant risks to the young person or to others.

Interactions 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.

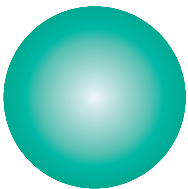
Requests for service: when problems are likely to persist following intervention and/or available responses on discharge need to be considered in relation to building resilience, or to manage long term problems. Cases of serious concern due to risk factors.

Appendix 3

TABLE FOR MAPPING EXISTING CAMHS-LD RESOURCES

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

Who? Who are the professionals/ services involved? (e.g. psychiatrists, mental health trust special units)	What? What actions or interventions are required?	How? Are there any guidelines/protocols referrals or care pathways?	How? What are the skills and competences required/ implications for training?	When Are there relevant time frames? Response times	Comments



Appendix 4

CAMHS-LD ACTION PLAN OUTLINE

LEARNING DISABILITY AND CAMHS		ACTION PLANNING			
Task	Resources needed to achieve	Who will be carrying it out	Deadline for completion	Reported to/signed off by (name/group)	

Appendix 5

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

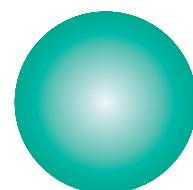
In many ways challenging behaviour overlaps with many of the conduct disorders seen commonly in child and adolescent mental health services.

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,

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.

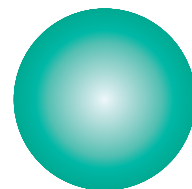
It is important that any intervention to address the behavioural and emotional difficulties have **specific, small and realistic goals**. The work is likely to be slower, and engagement may take longer due to communication difficulties, so achievement of realistic goals is important for the client, carers 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
- **Epilepsy and learning disabilities: a training pack to aid teaching on epilepsy and its management.** Codling M. MacDonald N., Simpson F. and Chandler B. Berkshire Healthcare NHS Trust, 2004.
www.pavpub.com/pavpub/trainingmaterials/showfull.asp?Section=1&SubSection=4&Product=399
- **Legal issues arising from the care and control of children with LD who also present severe challenging behaviour – a guide for parents and carers.** Lyon C. and Ashcroft E. London, Mental Health Foundation, 1994.
- **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.⁴ 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.⁵ 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.

⁴ *The World Health Report 2001 – Mental health: new understanding, new hope.* World Health Organisation www.who.int/whr/2001/en/

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

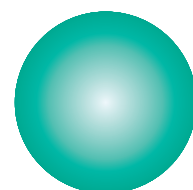
As with any child Carly's emotional difficulties need to be considered within **context**. For Carly significant contextual issues may be:

- 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
- **Psychiatric and behavioural disorders in children and adolescents with intellectual disabilities.** Allington-Smith, P. In: A.Roy, M.Roy, D. Clarke (eds), *The psychiatry of intellectual disability*. Oxford, Radcliffe, 2006.

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.⁶ 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.

⁶ *Mental health of children and young people in Great Britain*, Office for National Statistics, 2004
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.

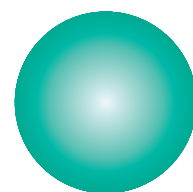
Suggested interventions

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.⁷ **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

⁷ Allington-Smith P. Mental health of children with learning disabilities. *Advances in Psychiatric Treatment* 2006: 12:130-140



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
- **HASCAS – Health and Social Care Advisory Service, (2004) Best Practice in ADHD – a comprehensive literature review to identify a care pathway**
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.⁸

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.

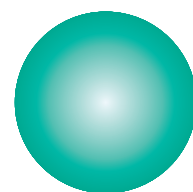
Donald is being referred by the disabled children team social worker who is seeking support and advice for his family, because recently Donald has become much more withdrawn at home. In addition his parents believe that Donald is now accessing inappropriate websites on his computer, and he has made inappropriate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

⁸ Allington-Smith P. Mental health of children with learning disabilities. *Advances in Psychiatric Treatment* 2006; 12:130-140



- 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
www.autismcymru.org/english/section2.asp
- **Autism Northern Ireland**
Training courses
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
- **National Autistic Society**
Pointers to good practice for schools and local education authorities
www.nas.org.uk/nas/jsp/polopoly.jsp?d=303&a=10156
 - diagnosis of autistic spectrum disorders – a brief guide for health professionals www.nas.org.uk/nas/jsp/polopoly.jsp?d=128&a=2224
 - publications catalogue
www.nas.org.uk/nas/jsp/polopoly.jsp?d=109
- **Teachernet**
Good practice guidance from the Autism Working Group
www.teachernet.gov.uk/wholeschool/sen/asds/asdgoodpractice

Child Mental Health / Learning Disabilities Care Pathway ⁶

