

PART A **the guide**



green light for mental health

**how good are your mental health services
for people with learning disabilities?
a service improvement toolkit**



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Introducing **green light**

What it is

green light is a toolkit for improving mental health support services for people with learning disabilities. It paints a picture of what good mental health support services for people with learning disabilities look like, and gives a way of assessing how well your local services measure up to it.

The term ‘**mental health support services**’ is used because support for people with learning disabilities around their mental health is not the exclusive responsibility of just one service. People may get support from primary care services, mental health services, learning disability services, public and voluntary sector services, and others. This pack is about what all of those services can do to improve mental health support for people with learning disabilities.

There are **two policy papers** and **three publications** that are helpful companions to this pack.

THE MENTAL HEALTH NATIONAL SERVICE FRAMEWORK (Department of Health, 1999)

The main policy document governing mental health services, giving an overview of how mental health services should be developed and improved.

VALUING PEOPLE A new strategy for learning disability in the 21st Century

(Department of Health, 2001) The main policy document governing services for people with learning disabilities, giving direction on how services should be developed and improved.

INCLUDE US TOO (IAHSP, King’s College London, 2002).

An overview of issues and examples of good practice in meeting the specific needs of people with mental health problems who have learning disabilities.

COUNT ME IN (Mental Health Foundation, 2002)

A report of the findings from a national enquiry into services and support for young people with learning disabilities who have mental health problems.

WORKING TOGETHER (IAHSP, King’s College London, 2003)

A service and staff development resource pack to underpin achievement of NSF standards for people with mental health problems and learning disabilities.

What and who it's for

The toolkit addresses a fundamental question:

What do we need to do to improve mental health support for people with learning disabilities?

It has been developed to help services implement the Mental Health National Service Framework in ways that include and address the particular needs of people with mental health problems who have a learning disability.

It is for –

- Mental Health Local Implementation Teams and Learning Disability Partnership Boards to help them lead and oversee service developments and service improvements.
- People with mental health problems who have a learning disability, their carers, clinicians, commissioners, managers and staff in mental health, learning disability and primary care services, to give everyone:
 - a clear picture of what you should be aiming to achieve locally
 - a way of working out what needs to be developed locally
 - some ideas about how to take things forward.
- You! It will help you work out what you can personally do to help improve mental health support services for people with a learning disability.

How the pack is organised

The pack has two parts – **a guide** (this part) and some **tools** which you will find in part B.

Part A – the guide – has five sections:

Section One (this section)

tells you about the pack, what's in it and what it's for. It also gives some ideas about getting the most benefit from the **green light** toolkit.

Section Two

is an easy to read summary of the pack designed primarily for use with and by people who have learning disabilities.

Section Three

has two parts that, when added together, give an overall picture of what services should be aiming to achieve. The first part gives the national policy context and highlights what the government expects of services in relation to people with mental health problems who have learning disabilities. The second part is about quality outcomes for people with mental health problems who have learning disabilities and for their carers, from their own perspectives.

Section Four

creates a concrete picture of what needs to happen 'out there' in the reality of services. It:

- highlights key challenges for services in moving towards integrated mental health services for people with learning disabilities.
- explores what the national policy objectives actually look like in practice i.e. accessible, integrated mental health support services, using examples from around the UK wherever possible.

Section Five

is about how to work out what needs to be sustained or changed locally. It introduces the self-assessment checklist and some ready-to-use survey tools which are found in Part B. The self-assessment checklist is at the core of the service improvement toolkit. There is guidance about getting information and evidence to underpin your local self-assessment, and about presenting your findings to the Local Implementation Teams and Partnership Board.

What is self-assessment?

Self-assessment is an approach that enables an organisation to look closely at itself and the systems it has in place in order to identify strengths and areas for further development. It is usually a structured tool asking teams to look at themselves against clearly defined measures, reflect on progress and think about future action. (Centre for Health Improvement)

Part B – the toolkit – has four sections:

Section One

contains the self-assessment checklist and an action planning proforma

Section Two

is a survey of in-patient experience

Section Three

is a survey of community support experiences

Section Four

is a survey of carers' experiences

Throughout the guide there are:

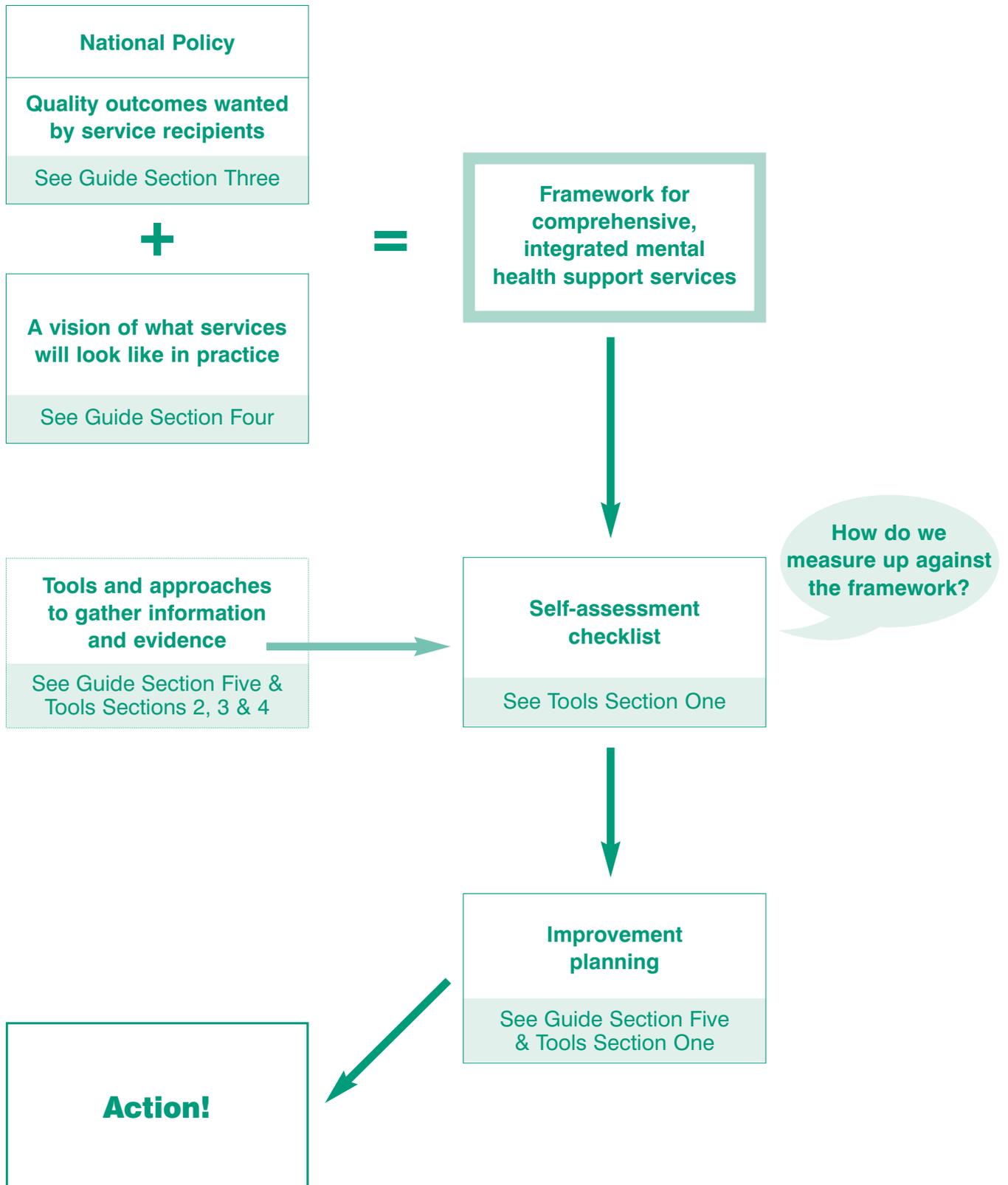


Quotations from the test sites and from people with mental health problems who have learning disabilities. These reinforce points in the text.



References to publications, resources and sources of information. These are flagged up with the symbol on the left, and details are listed at the end of the guide.

A bird's eye view of the **green light** toolkit



Using the toolkit

To get the best from this toolkit you will need to consider two important things from the start:

PARTNERSHIPS and PROCESS

A range of providers and professions are currently involved in supporting people with mental health problems who have learning disabilities. This means that people need to work in partnership to deliver *and* plan good quality, joined-up services and support. Using the toolkit can help you strengthen local partnerships and involvement - but that is *unlikely* to happen if a service uses the toolkit on its own to assess the state of local services, and then tells other services or professions what they need to change!

“Using the checklist was very, very helpful. It formed a really good basis for information sharing across services”



Involving service users and carers in planning in order to make sure that services are responsive to people who receive them means doing things in more accessible and transparent ways. When people have both mental health problems and learning disabilities there needs to be careful consideration about how best to involve them and how to make it a good experience. There are some ideas about this in **Box 1.1**.

When using this toolkit it will be important to take into account the day-to-day constraints and pressures that services are facing so that developments feel ‘doable’ and not overwhelming. The process you adopt needs to maintain people’s enthusiasm and commitment right through to taking action and making things happen.

It may help to think about this toolkit as helping you to develop a local ‘snapshot’. In photography, a snapshot is usually the result of a fairly quick and simple process, not too technical; most people find it a fairly easy thing to do; it doesn’t give the complete picture (as no photo can) but it reflects what was happening at one point in time. Snapshots give us a record to go back to later, and help us see how things have changed. It probably won’t be a top class photo, but it will be ‘good enough’ for your everyday purposes.

BOX 1.1

INVOLVING PEOPLE WITH MENTAL HEALTH PROBLEMS WHO HAVE LEARNING DISABILITIES

National policy supports an inclusive approach, and people with learning disabilities have advised policy makers that there should be “nothing about us without us” (Department of Health 2001).

Working Together (2003) has highlighted some of the key things to consider when planning how best to involve people with mental health problems who have learning disabilities:

- People with learning disabilities involved in the regular self-advocacy groups may have little personal experience of ‘mental health problems’.
- It may take time to identify, locate and bring together a group of people with significant experience of mental health support, including those with experience of mainstream mental health service provision, to get their perspective.
- The concepts ‘mental health’, ‘mental health problems’ and ‘mental illness’ are complex. They may not have been explored very much previously with people who have learning disabilities in your area: people may need time and help to think about what they mean. Finding the right words to use, that mean something to people, is a critical starting point.
- Including people in mixed discussion forums with clinicians, professionals and carers before they have had much chance to consider the issues and what they want to say may effectively ‘exclude’ them from making an effective contribution.
- People need time to feel comfortable in groups, and to think about the issues being discussed. The picture will evolve and become more comprehensive and informative over time.
- People from ethnic minority groups who have mental health problems and learning disabilities may have had different experiences that are important to capture and learn from.
- People may have periods when they do not feel well enough to participate, but it does not mean they have lost interest.
- Groups will need facilitators who can use approaches and techniques that get the most out of people. The facilitators will need knowledge and skills around mental health as well as how best to support people with learning disabilities to communicate and contribute their views.

The question is how to get ‘meaningful’ involvement? It may require that people with mental health problems who have learning disabilities be supported to meet together for a period of time to develop their agenda for change before they are asked to contribute to development planning.

Organisations also need to do things that support people to participate, such as:

- Using plain language
- Listening carefully and valuing people’s contribution
- Talking one to one, in private, if someone prefers
- Using visual and audio formats to aid communication
- Having easy to read summaries of written documents
- Funding support workers
- Giving people adequate information and time to prepare their response
- Going at a pace that allows people to take part
- Creating a relaxed and comfortable atmosphere in meetings, with regular breaks
- Paying people for their time and meeting their expenses.

For a more detailed exploration of things to do to support people’s participation see:

Deciding Together: Working with people with learning disabilities to plan services and support (2001)



Getting together and getting started

“People will only fully and effectively participate in partnerships and teamwork when they believe that they need each other to achieve mutually desired outcomes”. Working Together



Working Together (2003) and Include Us Too (2002) contain helpful ideas about what commissioners/planners/managers can do to get the development process underway in a spirit of partnership and inclusion. **Box 1.2** summarises some of the things you could do.

BOX 1.2

IDEAS FOR GETTING STARTED...

- read this pack, then plan the first steps **with** your counterpart in learning disability or mental health services
- bring people from across services together to reflect on the issues and think about what needs to change - at an agenda-setting conference or local, facilitated focus groups. Ask people to identify what's going well in addition to what needs to improve. Use the self-assessment checklist in this pack to focus thinking
- present information to both the LIT and the Partnership Board and get their support to pursue a joint development agenda
- seek out and talk to services, organisations, professions, groups who may have involvement with, or a stake in, services for people with mental health problems who have learning disabilities - ask them to contribute
- gather some individual stories that give people a picture of what it's been like for those in receipt of services
- stress interdependence i.e. the benefits to each service of working in partnership, and acknowledge existing effort
- identify and stress the links between this development agenda and the mental health/learning disability/primary care developments that people are already working on – join it up with existing work
- choose words carefully to overcome any reaction to 'yet more self-assessment', 'yet more development work'. People hear 'audit', review, evaluation... and groan.

Perhaps more than anything else it is important to bear in mind the three Rs:

Recognise what's happening to people with mental health problems who have learning disabilities

Respect people's views about the issues and the difficulties

Respond Keep the process action-oriented and make sure that changes happen.

It may help to take a look at the essential **Building Blocks for successful partnerships** in Greig and Poxton's 'Briefing Paper on Joint Commissioning and Partnership Working'. (1999 IAHSF, London).



Potential Partners

THE OBVIOUS

People with mental health problems who have learning disabilities and advocacy organisations.

Mental health and learning disability services – in-patient, residential and community, health and social services, including ASW representation.

Independent and voluntary sector services – mental health and learning disability.

The local Primary Care Trust

The LIT and Partnership Board leads

Mental health and learning disability psychiatry

Carers' organisations



AND WHAT ABOUT...

Pharmacy services

Older people's mental health services and CAMHS

Specialised autistic spectrum disorder organisations/advocacy groups

The local person-centred planning coordinator

Police and criminal justice services

Accident and Emergency services

Alcohol and substance misuse services

NHS Direct

Housing and homelessness services

Employment services

Learning & Skills Council

Workforce Confederation

Representation from the Local Strategic Partnership

Easy to read summary

In this **summary** we have used words and pictures so that as many people as possible can understand.

First, here's some information about 'mental health problems'

- Sometimes people feel sad or worried or that they are not thinking right.
- These feelings may last a long time.
- People may stop eating and sleeping properly, they may hurt themselves or frighten other people.
- Some people need help to feel better.
- We say that they have mental health problems or a 'mental illness'.

Who has mental health problems?

- Anybody can have mental health problems.
- You can have mental health problems and get better.
- People with and without learning disabilities can have mental health problems.

What the **green light** pack is about

The pack is about planning good services for people with mental health problems who also have learning disabilities.



There are two important planning groups in every area:

- **The Mental Health Local Implementation Team (LIT)**
- **The Learning Disability Partnership Board**



The pack will help these groups to improve services for people with mental health problems who have learning disabilities in your local area.

The **green light** pack is a **toolkit** for services. It has things in it that help people to work out how good local services are for people with mental health problems who have learning disabilities.



The pack has information about:

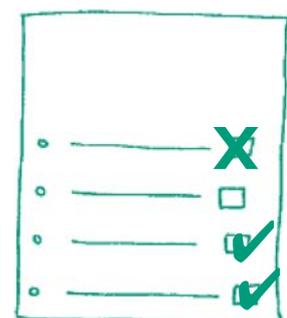
- what the government wants services to be like
- what people with mental health problems who have learning disabilities want
- what their carers want
- and what good services look like

Sections 2 and 3 are about these things.

It also has a checklist for people to use.

Section 4 says more about the checklist.

The checklist will help people in your area decide *what needs to be done* to improve local services for people with mental health problems who have learning disabilities.



What the government says

The government tells people about good mental health services in a report called the Mental Health 'National Service Framework'.



It is about mental health services for **all** adults, so...

people with learning disabilities who have mental health problems are included.

...and they should be included in the things that mental health services and Doctors' surgeries are doing to help people who have mental health problems.

The government tells people about good learning disability services in a report called 'Valuing People'.



It says that...

Staff in mental health and learning disability services need to work together to make it easy for people with learning disabilities to use ordinary mental health services.

Some people will need extra support to use ordinary mental health services.

For a small number of people it may not be good to go and stay in an ordinary mental health unit. They may need to go to a specialist unit for people with learning disabilities.

Mental health services often use 'traffic lights' – red, yellow and green – to show people how good the local services are.

Green means that services are good! Yellow and red mean that services have work to do to get better.



The checklist in this pack also uses red, yellow and green to show how good your local services are for people with mental health problems who have learning disabilities.



What people with learning disabilities have said

When they have mental health problems people have said they want ...

- to be given information and to be told what's happening.
- help to understand why they are unwell.
- help so they feel better.
- to be able to get help easily.
- to be able to get help so they still get on with people.
- to be included in meetings that are about them.
- to go to a small place nearby if they can't have treatment at home.
- and to be able to go back home when they are well again.

I don't think I have been told enough.



I felt drugged up. It's not always the answer.



I like to phone people to get reassurance.



The patient has to be there.

...somewhere we know... near people we know.



Big places are frightening.

People have said some other things about what services can do to give them good mental health support. Families have also talked about what they want from services. **Section 3 of green light** tells you about these things.

The government says it is important to find out how good services are by asking the people who use them.



There are some forms to help services do that in **Part B** of the pack.



What good mental health support services look like

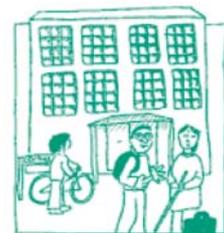
Good services are about:

- people with learning disabilities who have mental health problems using the same services as anyone else.
- mental health and learning disability services working really closely together to support people who have mental health problems and a learning disability.



There are a lot of different things that local services can do to be good. Here are a few examples:

- making information 'easy to read'.
- helping young people who have mental health problems and learning disabilities to get the support they need.
- having some beds in the local mental health unit that are just for people with mental health problems who have learning disabilities.
- supporting people with mental health problems who have learning disabilities to use the local mental health drop-in service.
- having a local house where people can go to stay if they need a break away from home because of their mental health problems, with support from staff who know the best ways to help them.



There are many more examples in **Section 4** of the **green light** pack.

How **YOU** can help

Here are some ideas:



Give people with learning disabilities information about mental health. Help them to think about it and talk about it.



Find out what people with mental health problems who have learning disabilities think about the services and support they get. Then tell the managers of your local mental health and learning disability services.



Get involved in local meetings and conferences about mental health support services for people with learning disabilities. Speak up (but listen too).



Tell managers and staff in mental health and learning disability services about the **green light** pack



Find out about the services in **Section 4**. Tell local managers and staff what you find out.



What's expected and what's wanted from services?

The Policy Context

The Mental Health National Service Framework (1999) and the White Paper *Valuing People: A new strategy for learning disability in the 21st Century* (2001) signal how services should be developing for people with mental health problems who have learning disabilities.

The National Service Framework applies to all adults of working age. It's provisions are intended to encompass everyone who has mental health problems, including people who have learning disabilities. It is inclusive.

Valuing People emphasises that people with learning disabilities should use the same services, resources and facilities as the rest of the population. It emphasises social inclusion: *"Most Psychiatric Disorders are more common amongst people with learning disabilities than in the general population. As with their other health needs, people with learning disabilities should be enabled to access general psychiatric services whenever possible."*

It is acknowledged, though, that there needs to be *"...access to an acute assessment and treatment resource for the small number of individuals with significant learning disabilities and mental health problems who cannot be appropriately admitted to general psychiatric services, even with specialist support."*

This toolkit is about putting the principles of inclusiveness and inclusion into practice. Neither mental health nor learning disability services can achieve this on their own – both need to play an active role. Inclusiveness requires *"mainstream mental health services to become more responsive, and specialist learning disability services to provide facilitation and support"* (Valuing People, 2001).

Success requires both mental health and learning disability services, and the professionals and staff working within them, to be prepared to do things differently.

Modernised Mental Health Services

An inclusive approach means that people with mental health problems who have learning disabilities are entitled to expect:

- skilled assessment of their mental state, and effective treatment options
- assertive outreach support or crisis resolution support 24 hours a day if they have severe and enduring problems
- mental health promotion materials
- full involvement in their care planning
- a single care plan drawn up by health and social services as one
- a copy of their care plan
- their services to be coordinated through the Care Programme Approach
- good mental health support through primary care services
- support to access employment, education and leisure opportunities
- single sex in-patient provision, including secure provision, as close to home as possible
- an after-care plan when leaving in-patient provision that says how they can get emergency support.

Local Implementation Teams (LITs) were set up in local areas to lead and oversee implementation of the Mental Health National Service Framework.

Learning Disability Partnership Boards were set up to undertake the same role in relation to the implementation of Valuing People.

A shared agenda

Include Us Too (2002) provides a helpful overview of the common ground in mental health and learning disability policy, reproduced below.

<p>Both share guiding principles about:</p> <ul style="list-style-type: none">● user involvement● family/carer involvement● supporting people to achieve ordinary lives● combating social exclusion● user satisfaction and rights● evidence based services● person-centred and non-discriminatory approaches● commissioning services on an individualised basis● promoting health● people getting help where and when they need it● least-restrictive interventions● environments that are safe for users, and the public● promoting people's independence and offering choices● continuity of support, for as long as needed	<p>Both want services to be</p> <ul style="list-style-type: none">● well coordinated across staff groups and agencies● monitoring performance against agreed outcome goals● accountable to the public, users and carers● developing cultural competence● empowering staff to achieve best practice● increasingly cost-effective, demonstrating 'best value'● effectively led● competently delivered● prioritising people with complex, challenging and enduring needs.
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Both expect:

- working partnerships and protocols to be in place to deliver on improvements. Effective management of interfaces and boundaries between services is stressed.
- a focus on development of local provision based on a 'whole systems' approach i.e. ensuring that services and support are coherent, linked and comprehensive, including access to local medium secure facilities.
- an emphasis on community based support to prevent admission or re-admission to hospital, particularly assertive outreach teams and crisis resolution services.
- people with mental health problems to have a single plan that governs the services and support they receive, co-ordinated through the Care Programme Approach.
- family carers to be able to get their needs assessed and receive support in their own right.

Working together to achieve success

The National Service Framework specifies seven standards for mental health services in the areas of:

- Mental Health Promotion
- Primary care and access to services
- Common mental health problems
- Effective services for people with severe mental illness
- Care away from home
- Caring for Carers
- Preventing suicide

The government has made a number of commitments in the NHS Plan (2000) and set a number of targets in *Improvement, Expansion and Reform* (2002) the Priorities and Planning Framework that sets out what the NHS is expected to do over the following three years.

The Autumn Assessment which LITs have been using currently covers 41 areas. Mental health Local Implementation Teams assess local performance using a 'traffic lights' system. The aim is to achieve a **green light** meaning that services are effectively implementing the National Service Framework.

In 2003 a specific area was added to the Assessment framework (no 40) about partnership working between mental health and learning disability services and application of the NSF to people with mental health problems who have learning disabilities.

The 40th Autumn Assessment area

For a **green** rating services need to show that: there is clarity of agreement between mental health and learning disability services about commissioning and provision roles and responsibilities and people receive the standards of mental health services described in the NSF and 'Valuing People'.

Helping you decide whether people in your local area are receiving the standards of mental health services described in the NSF and Valuing People is the core purpose of this toolkit. The self-assessment checklist in **Part B** is specifically designed to help local services achieve a green rating on area 40.

Section 3 explores what the seven standards look like in practice for people with mental health problems who have learning disabilities.

Commitments in the National Health Service Plan (2000)

- Services re-designed to ensure availability of women-only mental health day services.
- Patient Advocacy and Liaison Service (PALS) established in every NHS Trust to support specialist advocacy services from 2002.
- Improved access to general community mental health services.

'Improvement, Expansion and Reform' targets (2002)

- Assertive outreach must be available for all that need it by 2003.
- Crisis resolution services must be available by 2005 for all people in contact with specialist mental health services. There should be 24-hour access.
- All child and adolescent mental health services to provide comprehensive services by 2006, with year on year improvements in CAMHS access.
- Development of 50 early intervention teams for young people with a first episode of psychosis by 2004.
- A maximum of 3 months waiting time for a first outpatient appointment by the end of 2005.

Working together or merger?

At present, most people with mental health problems who have learning disabilities receive the majority of their mental health support from specialist learning disability services.

Research across the South West region, reported in 2003, showed that only 11% of people with learning disabilities hospitalised for mental health treatment were admitted to mainstream mental health units. See Simons & Russell 2003.



It is clear from policy that mental health services have a very central role in relation to the mental health of people with learning disabilities as part and parcel of meeting the needs of *any and all* people with mental health problems in the local population. It can be argued that the natural consequence of the Mental Health National Service Framework is that the organisational home of *all* mental health support services for people with learning disabilities should actually be mental health services. This would mean services providing mental health support from within learning disability services being transferred into mental health services.

This may be easier to achieve in some areas than others. The reality is that discussions and decisions about the 'right' organisational home and location of services tend to take energy away from more crucial things that need to happen to achieve comprehensive and competent provision. At this stage in the delivery of the NSF to people with learning disabilities protracted 'ownership' arguments may not be very helpful. Changing the organisational home of services and staff should only be part of the local plan if there will be concrete benefits in terms of making the NSF work for people with learning disabilities.

To deliver the NSF there is now an even greater need for learning disability services to work **with** mental health services, in whatever ways will achieve the best results locally. Co-location of staff and services will not necessarily mean good partnership working. It has to be worked at.

Valuing People gives permission for staff to “*continue to work within specialist clinical directorates*” but “*their tasks will need to be refocused*”. There is more about this on page 27. Irrespective of who staff are employed by, it is important that they are accountable for the outcomes and style of their work back into both the mental health and learning disability 'systems', ultimately to the mental health LIT and the Learning Disability Partnership Board.

Mental Health Trust star ratings

In 2003 Mental Health Trusts became subject to ‘**star ratings**’. Several of the ratings are based on the NSF standards and can be viewed on the Commission for Healthcare Audit and Inspection (CHAI) website at: www.chai.nhs.uk At the time of writing 30 areas of performance are assessed. These will change over time to promote continuous service improvement.



It is important that specialist learning disability services are aware of and aiming to achieve the performance criteria. It will require a close working partnership with local mental health services. For example, the 2003 criteria required services to work together to include people with mental health problems who have learning disabilities in the Mental Health Minimum Dataset and the central CPA database.

The 2003 performance thresholds for **out of catchment area treatments** are of particular interest given that people with mental health problems who have learning disabilities have often been placed outside of their local area. The thresholds are reproduced below in Box 3.1.

BOX 3.1

PERFORMANCE AREA

Percentage of the total adult general psychiatric admissions from the catchment population that take place outside of the catchment area.

RATIONALE

Evidence suggests that people with severe mental illness are socially excluded, finding it difficult to sustain social and family networks, access education systems and obtain and sustain employment. Local inpatient care should therefore be provided as close as possible to the home so that family and community links can be maintained. This relates to standards 4/5 of the Mental Health NSF.

PERFORMANCE	THRESHOLD
Significantly below average	greater than 17.0% of adults placed outside of area
Below average	less than or equal to 17.0% and greater than 10.9%
Average	less than or equal to 10.9% and greater than 4.0%
Above average	less than or equal to 4.0% and greater than 2.4%
Significantly above average	less than or equal to 2.4%

People with learning disabilities: some specific considerations

Valuing People says that services should recognise that people with learning disabilities:

1. have the same rights as everyone else.
2. have the right to choices about their life, like everyone else.
3. want to be supported to be as independent as possible.
4. want to be included in their community.

The government wants to ensure that:

- mental health promotion materials and information about services are provided in accessible formats for people with learning disabilities, including those from minority ethnic communities.
- strategies that aim to enhance and promote mental health by improving access to education, housing and employment include people with learning disabilities who have mental health problems.
- clear local protocols are in place for collaboration between specialist learning disability services and specialist mental health services.
- all people with learning disabilities have a Health Action Plan. For someone with additional mental health problems it will be integrated into their overall care plan through the Care Programme Approach i.e. there will be a single plan.
- all people with learning disabilities (eventually) have their own person-centred plan. For someone with additional mental health problems their care plan through the Care Programme Approach will integrate and aim to deliver their person-centred plan.
- care co-ordinators have expertise in both mental health and learning disabilities, and there is close collaboration between psychiatrists in the relevant specialities.
- specialist staff from the learning disability services will if necessary provide support to crisis resolution/home treatment services or other alternatives to in-patient admission.
- if admission to an in-patient resource is unavoidable, specialist staff will help a person with learning disabilities understand their treatment.
- each local service has access to an acute assessment and treatment resource for a small number of people who cannot be appropriately admitted to general psychiatric services, even with specialist support (see page 28).
- referral to a specialist health service outside of the local area is a rare event.
- services are 'person-centred' in all aspects of service delivery and service development. It means putting people's preferences and needs at the heart of *all* systems, procedures and processes.

“Person-centred approaches are ways of commissioning, providing and organising services rooted in listening to what people want, to help them live in their communities as they choose. These approaches work to use resources flexibly, designed around what is important to a person from their own perspective and work to remove any cultural and organisational barriers to this. People are not simply placed in pre-existing services and expected to adjust, rather the service strives to adjust to the person. Person-centred approaches look to mainstream services and community resources for assistance...” Routledge and Sanderson (2001)

Effective individual planning

Both mental health and learning disability policy emphasise the importance of good individual planning and coordination so that people receive services and support to match their requirements. The Care Programme Approach, commonly referred to as CPA, is the framework for co-ordinating support and treatment for people receiving secondary mental health services. CPA encompasses care management i.e. there is a single assessment process that is the gateway to both health and social services support. People with learning disabilities who are receiving support from specialist mental health services are required to be on the Care Programme Approach, and it applies to people regardless of setting.

Valuing People introduced two new requirements into the policy framework.

- people with learning disabilities are to be helped to develop Health Action Plans, which will be part and parcel of a single individual care plan.
- people with learning disabilities are to be helped to develop person-centred plans. People with mental health problems who have learning disabilities whose support is co-ordinated through the CPA must be considered by Partnership Boards as a possible priority for person-centred planning.

“The primary purpose of the CPA is to ensure that the needs of all mental health service users are assessed and that appropriate care is delivered to meet those needs.”

*“The principle is getting people to the **right place** for the **right intervention** at the **right time**...”*

Effective Care
Co-ordination in Mental
Health Services (DH, 1999)

A 'person-centred approach' to planning with people means that the person's wishes and needs are at the heart of the planning process. The *whole process* is carried out in ways that create a positive and inclusive experience for the person and so they have as much control as possible. It requires a shift in the balance of power. It is not the same as assessment and care planning, but can add to its quality and effectiveness. It can help get the plans right for people and is seen as a central characteristic of quality services.

The challenge for mental health and learning disability services is to develop a person-centred care plan with an individual that meets the requirements of the CPA and also integrates a health action plan.

“When we use the term ‘person-centred’ we mean activities which are based upon what is important to a person from their own perspective and which contribute to their full inclusion in society. Person-centred planning discovers and acts on what is important to a person.”
Routledge & Sanderson (2001)

Policies indicate that:

- people acting as person-centred planning facilitators need to be trained for it.
- person-centred planning facilitators can be brought in from beyond services if the availability of local people with appropriate training is limited.
- risk considerations should not exclude people from person-centred planning.
- the CPA is expected to put the person at the centre and address their need for employment, housing and leisure. This is fundamental in good person-centred planning.
- CPA care coordinators for people with learning disabilities will need an understanding of person-centred planning and person-centred approaches.

For more detailed information about CPA and person-centred planning see:

Working Together (2003): pages 55-59 of the Reader.

Advice from the Valuing People Support Team – available on www.valuingpeople.gov.uk



An inclusive approach in ‘the real world’

An inclusive approach does not mean that mental health services are simply expected to serve people with learning disabilities without help. Specialist learning disability services continue to have an important role.

A changing role for specialist learning disability services

Valuing People makes it clear that the Government values the support that specialist learning disability health services provide but that “*their role must change*”. The future vision is about:

- Supporting people to access mainstream services
- Facilitating Health Action Planning for individuals
- Providing high quality specialist expertise that facilitates the work of others in mainstream services and develops the capacity of mainstream services to support those with complex needs
- Partnership between different agencies and professions
- Service development and design more than direct intervention
- Health promotion

Advice on learning disability specialist health services is available on the Valuing People Support Team website www.valuingpeople.gov.uk



Existing specialist **facilities** - in-patient units for people with mental health problems who have learning disabilities that are run by learning disability services - may continue to play an important role too, but to do so most will probably need to change in some way. ‘How’ is explored in more detail through examples in **Section 4**.

One of the challenges of the development agenda is working out how best to use all the staff and facilities in the system – across primary care, specialist learning disability and generic mental health services, in the voluntary as well as the public sector – to provide services that ‘fit’ with the tenets of the mental health NSF and Valuing People. It’s about putting everything into the pot and creating something different with it. It may be about freeing money up by stopping some things and reinvesting in something different; it may be about changing how a facility is used or changing staff roles. To deliver the mental health NSF for people with mental health problems who have learning disabilities nothing can be sacrosanct.

Other Considerations

- Valuing People stresses that for people who need intensive healthcare support over a prolonged period of time the aim is to provide them with *ordinary* housing and support services, in the least restrictive environment possible. The Supporting People policy (DETR 2001) presents an opportunity for new developments that *combine* mental health and learning disability objectives.
- It also states that a “*need for **nursing** supervision is not a sufficient reason for NHS in-patient care*”. In-patients should require “*continuous **medical** supervision*”.
- Learning Disability Partnership Boards are required to develop a local policy on ‘exclusions’ from services. It is expected that alternative support services will be provided in such situations. The policy clearly needs to include and be agreed with mental health services.
- The Health Act (1999) places increased emphasis on using funds flexibly and creating pooled budgets.
- The Learning Disability Development Fund, launched to support the implementation of Valuing People, has money available for the capital element of new, local specialist services for people with severe challenging behaviours and/or autism. People with severe mental health problems who have learning disabilities are included in this definition.
- Direct payments are now more widely available to people with mental health problems as well as to adults with learning disabilities. Independent Living Fund monies and direct payments through social services may assist some people to secure more personal support and greater control.
- The government has increased the funding available through the Carers’ grant, creating opportunities for new local developments.



For more information about exclusions policies and ‘sticking with people’ see: advice from the Valuing People Support Team available on www.valuingpeople.gov.uk

Pages 90 – 92 of the Working Together Reader.

All carers who provide ‘regular and substantial’ care for a person on Care Programme Approach (CPA) should:

- have an assessment of their caring, physical and mental health needs
- have their own written care plan

And finally...

A summary of essential requirements

Services should be:

- Safe.
- Sound.
- Supportive.
- Person-centred.
- Easy to access.
- Co-ordinated through local agreements (protocols).
- As local as possible.
- Competent at all levels (including primary care) to recognise a mental health problem in someone with a learning disability.
- Competent to offer appropriate, effective, evidence-based interventions.
- Willing and able to provide people with ongoing monitoring and care.
- Able to offer the full range of interventions to people with mental health problems who have learning disabilities, including assertive outreach, early intervention and crisis resolution.

What's wanted?

Themes from people with mental health problems who have learning disabilities

Recent consultations have highlighted that people with mental health problems who have learning disabilities want some specific things from mental health support services, whoever provides them. They are organised here to show what people want in relation to:

- their contact with any and all mental health support services
- community-based support
- in-patient support.

These quality criteria for mental health support services have been used as the basis for two surveys, which you will find in Part B. The surveys will help you find out about the in-patient and community support experiences of people with mental health problems who have learning disabilities, and their views about them.

In their contact with mental health support services generally people want:

- to be given information and be told what's happening.
- to be asked what they want, and for people to listen.
- help to understand why they are unwell.
- help so they feel better.
- someone to talk to about themselves.
- good advice and help to make decisions.
- people to do what they say they are going to do.
- people to respect their religious beliefs.
- to be treated well.



"I don't think I have been told enough."

"People don't really listen to me properly and support me the way that I want them to."

"I felt drugged up. It's not always the answer."

"Sometimes they say bad things at my CPA meeting."

In terms of community life people with mental health problems and learning disabilities want:

- information about where and how to get help when they need it.
- to feel safe where they live, and to have a room where they can get away from other people.
- to live with people they like in a quiet and peaceful home.
- to have things to do that they like doing, like working, learning and exercise, to take their mind off things.
- to be able to do things to relax, like having a holiday.
- to be able to get in touch with, and talk to friends easily.

They want services to make sure that they –

- get help to manage their money.
- get support to do things they like doing and which take their mind off things.
- get help so they still get on with people when they are mentally unwell.
- can get help easily when they are feeling unhappy or 'stressed out'...
- get ongoing support, that doesn't stop.
- get support to know about and take their medicine.
- are included in meetings that are about them.
- are visited at home by a psychiatrist or people who know about mental health, or that they can see them near to home.

"Make sure people don't fall out with their friends."

"I like to phone people to get reassurance."

"The patient has to be there."

If they need in-patient treatment people want:

The place to be:

- near to home, family & friends so they can visit easily.
- in the centre of things, not in the middle of nowhere.
- near enough to be able to collect post and things they need, and to be able to do the things they are used to doing each day and to go to the places they usually go.
- familiar to them.
- small, for no more than five people.
- quiet and peaceful, and safe.
- just for women or just for men.
- equipped with private bedrooms, nice bathrooms and toilets, and rooms where they can get away from other people.

"...be somewhere we know... near people we know."

"Big places are frightening."

They want services to make sure that they:

- will get on with the other people there. They want them to be nice.
- can have visitors at any time.
- are able to make their own meals if they want, and eat when they choose.
- will see the doctor that they know best whilst they are there.
- will go back home when they are well again.
- can manage their own money, with support, whilst they are there.
- have good things to do each day.
- are not made to do things that they don't want to do, and are not bossed around.

“Worst thing is being stuck with nothing to do.”

Themes from family carers

The caring experience is different for each person. People caring for a person with learning disabilities who then develops mental health problems may experience both a maze of mental health issues that are very confusing, and a maze of services. Like other carers of people with mental health problems, they may not initially understand what is happening to the person they care for, or to themselves.

The views of carers of people with mental health problems who also have learning disabilities have been organised to show:

- What they want generally from their contact with services.
- What they want specifically in relation to the mental health system.

These quality criteria for supporting carers of people with mental health problems and learning disabilities have also been used as the basis for a survey to be found at the end of **Part B**. The survey will help you find out about the experience and views of carers.

In their contact generally with mental health support services carers want:

- to be treated with courtesy and respect, as individuals.
- to have what they do recognised and valued.
- to be recognised and involved as partners in care.
- to have continuity of contact and support from someone who will listen to their concerns.
- support if there is a disagreement with professionals.
- help to consider their own needs, when the person they care for is not in crisis.
- professionals to keep trying to help even if the carer is not very receptive.
- a single place for information and to access advice.
- signposting to carers' organisations and benefits to claim.
- the chance to have a carer's assessment that is separate from the person cared for.

In relation to the mental health system carers specifically want:

- information about the diagnosis and its potential impact on the person they care for.
- a break at short notice if they really need it.
- to be given a proper explanation of the sectioning process under the Mental Health Act, if that is what is needed.
- to be given time to do the things they need to do during the sectioning process.
- a proper explanation of the Care Programme Approach, what a CPA meeting is, and who is involved.
- to be properly introduced to people at CPA meetings.
- to have access to an advocate to accompany and support them at CPA meetings, if wanted.
- support if the person they care for is admitted to a secure unit or mental health ward.
- to feel that information is being shared between mental health and learning disability services and they are not having to repeat things.
- an emergency contact telephone number.

Putting policy into practice

Key challenges for services

There are 13 key challenges that most areas will need to address in delivering the Mental Health NSF for people with mental health problems who have learning disabilities. These challenges become clear when comparing what's expected and what's wanted (as outlined in Section 3) with the reality of services around the UK at the present time.

THE 13 KEY CHALLENGES:

DEVELOPING PARTNERSHIPS AND WORKING AGREEMENTS, BOTH STRATEGIC AND OPERATIONAL

- wide partnerships that include not only mental health and learning disability organisations, but advocacy agencies, carers' organisations, the police and criminal justice agencies, housing, employment, leisure.

PLANNING, AND SECURING BACKING AND SUPPORT

- working out what needs to happen by gathering information, involving and listening to people, reflecting. Designing a comprehensive, coherent and 'joined up' network of provision. Getting approval and commitment from the LIT, Partnership Board, Health Trusts and others.

SUPPORTING PEOPLE WITH MENTAL HEALTH PROBLEMS WHO HAVE LEARNING DISABILITIES TO BE INVOLVED IN SERVICE DEVELOPMENT

- bringing people together, making practical help available, addressing information and communication requirements, and training staff. Ensuring advocacy services are available and involved.

MANAGING CHANGES

- ensuring improvements and developments are manageable, that people know about them, and that there is capacity to achieve them. Monitoring implementation and giving people feedback.

STRENGTHENING THE ROLE OF PRIMARY CARE

- agreeing roles, responsibilities and a single referral pathway for specialist assessment. Ensuring specialist learning disability staff, 'gateway' mental health workers and graduate primary care workers have appropriate knowledge and links.

DELIVERING A JOINED-UP, PERSON-CENTRED ASSESSMENT AND CARE PLANNING PROCESS

- delivering integrated assessments; agreeing psychiatrist and Approved Social Worker responsibilities, and assessment approaches that are appropriate for people with mental health problems who have learning disabilities. Creating person-centred planning capacity and a clear link into CPA, and generally making the CPA process a better experience for people and their carers.

By 2004, 500 community mental health staff will be employed to "improve the gateway to specialist services" by working with GPs and primary care teams, NHS Direct, and A & E units to respond to people who need immediate help. 1000 new graduate primary care mental health workers will also be employed to help GPs manage and treat common mental health problems in all age groups (the NHS Plan commitment included in the Priorities and Planning Framework 2002).

RESPONDING TO PEOPLE WHO MIGHT FALL BETWEEN SERVICES

- addressing service eligibility issues, creating overlap and an effective way of resolving disputes.

WORKING OUT WHAT NEEDS TO HAPPEN SO THAT ALL MENTAL HEALTH COMMUNITY SERVICES CAN RESPOND TO PEOPLE WITH MENTAL HEALTH PROBLEMS WHO HAVE LEARNING DISABILITIES

- identifying training and support needs, clarifying and agreeing the role of specialist learning disability staff, and how it all fits together.

AGREEING HOW IN-PATIENT PROVISION WILL CHANGE

- clarifying the role of specialist learning disability in-patient provision in the short term and longer term; developing mental health in-patient expertise in relation to people with learning disabilities; creating single-sex provision and addressing cultural fitness.

DEVELOPING WAYS TO STOP ‘OUT OF AREA PLACEMENTS’ QUICKLY

- addressing the need for accommodation and skilled support; developing access to secure provision locally; strengthening crisis support and short breaks, and fast access to funding.

ENSURING PEOPLE ARE SUPPORTED BY STAFF WITH RELEVANT, UP TO DATE KNOWLEDGE AND SKILLS

- addressing workforce shortages and patterns, and training needs; developing cultural competence; organising staff to share expertise and bring a combination of knowledge and skills together around people.

DEVELOPING INDIVIDUALISED PURCHASING AND FLEXIBLE FUNDING ARRANGEMENTS

- supporting an increase in ILF applications and direct payments; ensuring a framework for individualised service agreements; training staff; devolving budgets; developing the provider networks.

INTEGRATING PLANNING AND BUDGETS, AND ACTIVELY MANAGING RESOURCES

- mapping mental health and learning disability planning pathways and agreeing crossover points; pooling funds and resources; costing plans and tracking expenditure; seeking funding and moving money around.

What services might look like

The Mental Health National Service Framework highlights seven standards that local mental health services are working to achieve. Each of the standards is examined individually here, with illustrations of what it might actually look like in practice when applied to people with mental health problems who have learning disabilities.

The focus is on achieving the standard in ways that:

- include and address the needs of people with learning disabilities within **mainstream** mental health provision.
- deliver **integrated** mental health support services to people with learning disabilities.

The illustrations are about ways of configuring and organising services and support – the framework – rather than about day to day service delivery or practice.

There is no one way of doing things. The objectives of the NSF can be realised in several different ways. This is reflected in the range of illustrations to show how the seven standards might be achieved.

Services around the UK that are implementing the type of development highlighted in the boxes are shown in dark relief. Contact details for further information are listed in the Resources section at the end of this guide.

Standard one

MENTAL HEALTH PROMOTION

Health and social services should:

- Promote mental health for all, working with individuals and communities.
- Combat discrimination against individuals and groups with mental health problems and promote their social inclusion.

What it might look like in practice

A mental health promotion strategy published by mental health services that includes and addresses the specific requirements of people with learning disabilities e.g. around accessible information, targeted employment support, support for people to access leisure activities, support around friendships, etc, cross referenced to learning disability strategies.

An *integrated* project to identify mental health support needs and develop mutual support activities amongst local ethnic minority communities ie that includes specific actions and/or workers to focus on people with learning disabilities and their carers.

Deliberate commissioning of housing and supported living schemes that provide specific input which helps people develop friendships and connections, mutual support and 'community'.

KEYRING LIVING SUPPORT NETWORKS

A clear pathway for staff in learning disability services to access mental health support for carers - through primary care mental health workers and GP surgeries.

A voluntary sector drop-in for vulnerable people in the community that is able to recognise and appropriately support people with learning disabilities who have mental health problems.

Staff in the local 'homelessness' service equipped to 'pick up on' people with learning disabilities who may need additional support, with a pathway for accessing specialist support for individuals.

Supported employment schemes and other employment initiatives for people with mental health problems having specific workers that focus on people with mental health problems who also have learning disabilities.

Development of a 'social firm' run by people with mental health problems, including people with additional learning disabilities, that provides disability related training.

@ LIBERTY IN HOUNSLOW

The local adult education provider running a series of sessions for the general public on relaxation techniques, with some allocated spaces and support for people with learning disabilities.

Questions about mental health support needs built into the Community Care Assessment and Health Action Planning formats within general learning disability services.

Positive media coverage of the ordinary life achievements of people with mental health problems who have learning disabilities.

Guidelines for the Connexions service so they assess and refer young people with mental health problems who have learning disabilities to appropriate support.

MIND THE GAP PROJECT SOMERSET

Standard two

PRIMARY CARE AND ACCESS TO SERVICES

Any service user who contacts their primary healthcare team with a common mental health problem should:

- Have their mental health needs identified and assessed
- Be offered effective treatments, including referral to specialist services for further assessment, treatment and care if they require it.

What it might look like in practice

A specialist learning disability community nurse working in partnership with the graduate primary care worker &/or gateway community mental health worker to develop an information pack for GPs and primary care staff about recognising and responding to mental health problems in people with learning disabilities.

Expectations specified in Personal Medical Service agreements between PCTs and GPs.

Joined-up planning achieved through Learning Disability representation on the local Professional Executive Committee (PEC) & the mental health LIT, and PCT representation on the Partnership Board & LIT.

A single referral pathway, agreed by mental health and learning disability services, for GPs to access specialised mental health assessment for a person with learning disabilities.

e.g. to a 'virtual' team of staff and clinicians with mental health *and* learning disability expertise, coming together from across service boundaries to undertake specialised assessment and care planning.

e.g. initially to the mental health service (to register as a mental health referral), with a pathway forward to specialised assessment which involves learning disability staff.

Targeted use of ASWs to work with people who might 'fall through the net' of services.

SOMERSET

A community pharmacist with a specific information and quality monitoring brief around effective use of medication for people with mental health problems who have learning disabilities.

A written agreement (protocol) between the PCT, mental health and learning disability services.

MANCHESTER

Contracts with therapists who have specific experience and expertise in working therapeutically with people who have learning disabilities, to work with individuals but also to provide training & mentoring so that skills are developed *within* local mental health services.

Health Action Planning for people with mental health problems who have learning disabilities undertaken by health facilitators drawn from a 'virtual' team of staff from across mental health and learning disability services.

'Flagging up' of people with mental health problems who have learning disabilities, and their carers, within GP surgeries - with supporting information to assist the GP with communication and assessment.

GPs accessing summary information from a centralised mental health service database that includes people with mental health problems who have learning disabilities.

A project within ethnic minority communities to identify people with learning disabilities who may need support with their mental health.

BRADFORD

Structured input from a member of the learning disability team into the substance misuse team to assist with developing appropriate screening tools and ways of communicating with people who have learning disabilities.

PRESTON

Commissioned places for people with mental health problems who have learning disabilities within mental health voluntary sector day/drop-in services.

SANDWELL

What is a virtual team?

Staff may not be based together and do not have to come from the same organisation, service or profession, but they work together on a shared agenda (or around an individual). Team members come together at specified times and share accountability for the outcomes of their work. Similar to 'managed clinical networks' in cancer care, and 'practitioner partnerships' in Valuing People Support Team guidance on community team reviews (2002)

Standard three

COMMON MENTAL HEALTH PROBLEMS

Any individual with a common mental health problem should:

- Be able to make contact round the clock with the local services necessary to meet their needs and receive adequate care
- Be able to use NHS Direct, as it develops, for first level advice and referral on to specialist helplines or to local services.

What it might look like in practice

A referral pathway from NHS Direct to a local crisis team that can provide knowledgeable and skilled support to someone with mental health problems who has learning disabilities.

SOUTH BIRMINGHAM

e.g. a 'virtual' mental health & learning disability specialist team with a 24-hour call service and members with both mental health and learning disability training and experience from across services.

A project to support carers of people with mental health problems who have learning disabilities, and people living independently, to develop 'short break' and crisis plans that are built around their natural supports, but have a service back-up too.

A clear agreement between mental health & learning disability services about what is to be provided for people who are 'vulnerable adults' but whose eligibility for services is unclear, and pooling of funds to achieve it.

Individualised supported living arrangements, based on person-centred planning, where there are clear, easy and agreed ways for people to access 24-hour assistance from their support provider.

LING TRUST

e.g. the mental health crisis team with members who have been trained and receive specialised support to respond to people with learning disabilities, with an agreed pathway for onward referral.

An information pack, produced by mental health and learning disability services together, about mental health and people with learning disabilities, and ways to access support - for distribution to learning disability residential and community support providers, advocacy schemes and to carers.

The Learning Disability Partnership Board prioritise people with mental health problems and learning disabilities for person centred planning, including help to develop a crisis plan and a 'my life book' in the process.

With the crisis plans lodged on the central mental health database or with the crisis team.

A community project to identify and train a very local network of support that people can call on in a crisis.

HEART ATTACK PROJECTS AROUND THE UK

Standard four

EFFECTIVE SERVICES FOR PEOPLE WITH SEVERE MENTAL ILLNESS

All mental health service users on CPA (Care Programme Approach) should:

- Receive care which optimises engagement, anticipates or prevents a crisis and reduces risk
- Have a copy of a written care plan which:
 - includes the action to be taken in a crisis by the service user and their care co-ordinator
 - advises their GP how they should respond if the service user needs additional help
 - is regularly reviewed by their care co-ordinator
 - be able to access services 24 hours a day, 365 days a year.

What it might look like in practice

Designated staff from the mental health service included in introductory person-centred planning training.

A group of person-centred planning facilitators identified from across mental health & learning disability services and specifically trained & supported to plan with people with mental health problems and learning disabilities.

A common system for use of 'advance directives' within CPA agreed across mental health & learning disability services.

MIDDLESBOROUGH

A local advocacy organisation given support to develop expertise in both mental health and learning disability, with individualised commissioning of their services for people with learning disabilities on CPA.

Some learning disability staff transfer part-time into mental health assertive outreach teams and community mental health teams to provide a single integrated service, but maintaining a specific focus on people with learning disabilities. A foot in both services.

Formal agreements with housing providers that generate secure independent tenancies for people with mental health problems who have learning disabilities.

A pooled budget (from mental health & learning disability services) to commission individualised services for people at risk of inappropriate placement or prolonged in-patient stay.

A person-centred CPA system agreed across services.

"Expert" person-centred planning facilitators bought in from beyond services.

Information about CPA designed for people with learning disabilities.

EAST YORKSHIRE

People with learning disabilities on CPA routinely recorded onto the mental health data system.

LAMBETH, SOUTHWARK & LEWISHAM

People with learning disabilities and carers involved in setting quality standards for the CPA process and in the associated monitoring system.

Mental health & learning disability psychiatrists physically based together for part of the week.

Backed up by joint commissioning (mental health & learning disability) of support organisations that can deliver individualised, person-centred services and that have both the commitment and systems to 'stick' with people during mental health crises.

Standard five

CARE AWAY FROM HOME

Each service user who is assessed as requiring a period of care away from home should have:

- Timely access to an appropriate hospital bed or alternative bed or place, which is:
 - in the least restrictive environment, consistent with the need to protect them and the public
 - as close to home as possible
- a copy of a written after care plan agreed on discharge which sets out the care coordinator, and specifies the action to be taken in a crisis.

What it might look like in practice

Development of a 'safe haven' or crisis accommodation for a short term break from home – e.g. a designated house, with a pool of staff from across services to call on; or a very sheltered and supported lodgings scheme.

TAMESIDE & GLOSSOP

Specialist learning disability in-patient provision for people with mental health problems is transferred to the mental health service along with designated staff.

24-hour support, assessment and treatment is provided to a person in their own home for a defined period, as a first option.

Or a small 'residential/nursing home' run by a provider specifically commissioned for their mental health and learning disability expertise, with a supporting protocol for intensive clinical and inreach support from mental health and learning disability staff.

Approved Social Workers receive training around communication and approaches to people with learning disabilities, and have a named person to call on for advice and support.

Names and emergency contact details of care coordinators of people with learning disabilities are logged on the mental health data system &/or with the ASW team.

Ordinary houses used as single-sex in-patient provision for 2 or 3 people with learning disabilities, run by the mental health service with staff seconded part-time from the learning disability service (a foot in both services).

A secure service with a specialised arm within it for people who have learning disabilities, commissioned for a local consortium of mental health services.

Designated beds for people with learning disabilities provided within mental health units locally, with extra staff and a training plan to develop their learning disabilities knowledge and skills.

CAMDEN & ISLINGTON

With 'in-reach' support from learning disability staff.

Standard six

CARING FOR CARERS

All individuals who provide regular and substantial care for a person on CPA should:

- Have an assessment of their caring, physical, and mental health needs, repeated on at least an annual basis.
- Have their own written care plan, which is given to them and implemented in discussion with them.

What it might look like in practice

A supported holiday for the cared for person - achieving both a break for the carer and a preventative intervention for the person.

Commissioning of advocacy support from a local mental health voluntary agency for carers of people with learning disabilities involved in the CPA process.

Carers' assessments completed through a self-assessment process for those that want it.

The local carers' centre contracted to maintain 3 monthly contact with carers of people with mental health problems who have learning disabilities.

Carers of people with mental health problems who have learning disabilities supported to meet and network.

...and to meet with other carers of people with mental health problems.

The needs of carers of people with mental health problems who have learning disabilities incorporated into the local carers' strategy.

A fund held by mental health services to commission individualised support for carers of people with mental health problems to ease stress and maintain their mental health, with clear access criteria.

A project to develop support circles around families where a member has mental health problems, with a designated number of circles to be developed for families of people with learning disabilities.

An 'at home' breaks service for carers of people with mental health problems that has defined provision for carers of people with learning disabilities within it.

For more ideas see - the Valuing People 'Family Carers Toolkit' available on www.valuingpeople.gov.uk



Standard seven

PREVENTING SUICIDE

Local health and social care committees should prevent suicides by:

- Promoting mental health for all, working with individuals and communities (Standard One).
- Delivering high quality primary mental health care (Standard Two).
- Ensuring that anyone with a mental health problem can contact local services via the primary care team, a help-line or an A & E department (Standard Three).
- Ensuring that individuals with severe and enduring mental illness have a care plan which meets their specific needs, including access to services round the clock (Standard Four).
- Providing safe hospital accommodation for individuals who need it (Standard Five).
- Enabling individuals caring for someone with severe and enduring mental illness to receive the support which they need to continue to care. (Standard Six).
- Support local prison staff in preventing suicides among prisoners.
- Ensure that staff are competent to assess risk of suicide among individuals at greatest risk.

Suicide amongst people with mental health problems and learning disabilities is thought to be less common than for other people, but it can and does happen. Self-harm or 'self-injurious' behaviour, however, is not uncommon. This standard is therefore taken in a wide sense to encompass self-harm.

What it might look like in practice

A common risk management process and procedure across mental health and learning disability services.

A protocol developed and agreed between mental health, learning disability, police and forensic services.

'Flagging up' of people with mental health problems who have learning disabilities who are assessed to be at risk of self-harm on the mental health service central database &/or with the ASW & crisis teams.

The learning disability service involved in court diversion and appropriate adult schemes.

TAMESIDE & GLOSSOP

A clear pathway for staff working in mental health teams to access 'expert advice' from the learning disability service, and vice-versa.

Learning disability services integrated into prison in-reach schemes run by mental health services.

DEVON

SECTION FIVE

Moving forward in your local area

Using the self-assessment checklist

“A helpful tool to frame and direct work.”



Successfully putting policy into practice starts with recognising what the service landscape is like now. It is about using the things that ‘fit’ with policy and are working well as foundation stones, and building from there.

The self-assessment checklist that can be found in **Part B** is designed to help you survey the service landscape in your area and work out what improvements are needed.

The checklist is based on the Autumn Assessment format that mental health Local Implementation Teams have been using to assess local progress towards achieving mental health National Service Framework standards. The self-assessment checklist in this toolkit aims to help local partnerships identify how well the NSF is being implemented in *relation to people with learning disabilities*.

The checklist stands on its own, with an introduction on the first page and guidance towards the end. It can simply be photocopied and distributed to people, and should be fairly self-explanatory thereafter.

Section One of this guide introduces the self-assessment process, and gives some hints about how to get the best from it.

“The more representative the group of people carrying out the checklist the more useful and accurate the ratings are.”



Mapping

The checklist requires people to select a rating that fairly accurately reflects the performance of local services.

There is a range of things that people might want or need to know in order to make informed decisions. Here are some examples:

If services cover a large area it may help to take a 'more local' approach when using the checklist.

INFORMATION ABOUT PEOPLE WHO NEED SERVICES AND SUPPORT

- How many people with mental health problems have a learning disability, and what are their ages, genders, and ethnicity?
- How many people fall between services (including people with Asperger's Syndrome) and what are their ages, genders and ethnicity?
- What's the rate of new referrals, and patterns?
- What are the projections for future demand?
- Where are people living, and who with? How many are in temporary accommodation or with no security of tenure, or outside of the local area, or with family carers? What are the ages, genders, ethnicity and health of those carers?



See the Valuing People 'ethnicity toolkit' available on www.valuing_people.gov.uk

Finding out about the population will probably mean you will need to respond to some people whose needs had not previously been recognised or met.

INFORMATION ABOUT SERVICES BEING USED

- What community support services are people using? How many are being supported solely by generic mental health services, or solely by specialist learning disability services? What role are primary health care services taking?
- What in-patient services are people using, and where are they? What do the different services cost? What is the level of in-patient admissions, both voluntarily and under Mental Health Act section, and the re-admission rate and frequency?

How to find these things out

You will probably want to do some of the information gathering activities on pages 48 and 49. As a starting point, though, identify and find out about the population of people with mental health problems and learning disabilities and the services they are using through:

- community care assessments
- care package information
- carers' assessments
- funding panel applications
- referral paperwork
- mental health and learning disability psychiatrists
- exclusions data from the Learning Disability Partnership Board
- GPs, via the PCT
- prescribing of medication for mental health problems to people with learning disabilities
- voluntary sector drop-in services and the homelessness service
- projects operating within ethnic communities
- work targeting older carers of people with learning disabilities
- carers' networks.

“Talk to people! Important details are not always written down!”



INFORMATION ABOUT PEOPLE'S EXPERIENCES

- How do people with mental health problems who have learning disabilities access services? What happens to people receiving community support, as in-patients, on CPA, in crisis...
- What happens to carers?
- What has given people cause to complain?

There are three survey formats in Part B that will help you to gather information about the experiences and views of people with mental health problems who have learning disabilities, and their carers.

PEOPLE'S SATISFACTION AND VIEWS ABOUT THE SERVICES THEY RECEIVE

- What do people think about their experiences? What's okay, what's not okay from their perspective?
- What do carers think of the services their person has received? What do they think of the services and support they themselves have received?

Gathering information is not a perfect science! People could spend a lot of time, energy and resources getting evidence to underpin decision-making, but at the end of the day what's needed is information that is 'good enough'. You are looking for a reasonably sound indication of what is happening – it doesn't have to be perfect.

Don't reinvent the wheel! Seek out information that's already been gathered; find out what other local audits/reviews have said about mental health support for people with learning disabilities.

Consider 'consultation overload'. Make use of relevant information that's already been gathered from user and carer consultations.

There are a number of tools and approaches that could be used or adapted to help you. Some are suggested below. Be selective! Choose those that will help you to fill information gaps, rather than those that will just confirm what most people already know through practice experience. Don't make things too complicated!

Ways of getting information



“The checklist was useful in highlighting gaps and identifying work to be progressed, and it generated discussion.”

- **USE THE SELF-ASSESSMENT CHECKLIST** in this toolkit to generate initial discussion and identify what you need to find out more about. Come back together to complete the ratings and do some action planning once you’ve gathered all the information and people have had chance to digest it. Using the checklist in this way can be useful because it brings people together twice with a clear focus.
- **QUALITY CHECKS** undertaken by mixed teams of people with mental health problems and people with learning disabilities, using a structured format based on *their* criteria of what good services should be like.
- **COSTING SERVICE PACKAGES**, taking a representative sample of people with mental health problems who have learning disabilities.
- **STORIES, AND ISSUE ANALYSIS.** A person’s personal experiences, presented in their own words, can be very illuminating. Collect some stories at the beginning of the service development process to help focus people. They can then be analysed and common themes or issues identified.
- **TRACKING/PROFILING** the service journeys of a sample of people with mental health problems who have learning disabilities, using video, direct observation, written records and interviews, etc. Can be very useful for monitoring how things change over time.
- **USE A STRUCTURED, VISUAL CONSULTATION TOOL.** Very useful for large-scale consultation exercises as well as in work with strategic planning groups to focus on what they want to achieve, the existing context and issues, and what might help achieve change. Highly participative and creative, requiring skilled facilitation.
- **DOING A SWOT ANALYSIS** It’s been around a long time, but it can still be helpful for mixed groups of people to identify strengths, weaknesses, opportunities and threats in local mental health support for people with learning disabilities. Needs to be used as a step towards action planning.
- **GETTING AN OUTSIDE PERSPECTIVE** Bringing in external organisations can be helpful, but only if they are able to tailor their approach to specifically address both the mental health and learning disability dimensions.

Getting an ‘independent view’ can sometimes help persuade people that change is really needed.

Other tools and approaches that could be adapted



WHAT IT IS	WHAT IT MIGHT BE HELPFUL FOR
The CPA audit tool (DH)	Gathering detailed information about about how the CPA is being implemented for people with mental health problems who have learning disabilities. Includes a helpful framework for getting the views of people subject to CPA – but would need to be adapted for use with people with learning disabilities.
How Good is your Service to Carers? A Guide to checking quality standards for local carer support services (Blunden 2002).	Mental health and learning disability services could use the framework to share information about how they are supporting carers and identify gaps that neither service fills.
The Partnership Readiness Framework & audit tool (Greig & Poxton).	The audit tool can help local areas assess the strengths and weaknesses of their inter-agency relationships. Could be used by a cross-service strategic planning group, and may be particularly useful for feedback to the Mental Health Local Implementation Team and Learning Disability Partnership Board to influence their thinking.
The CUES questionnaire (Carers' and Users' Expectations of Services).	A survey or monitoring format for people with mental health problems to comment on their life and their care. Could be fairly easily adapted for people with learning disabilities.
The Commission for Healthcare Audit and Inspection self-assessment tools.	The tools for senior management teams and clinical/care teams may be a useful aid for reflection, but they are general and would need to be applied very specifically to services for people with mental health problems who have learning disabilities.

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Planning for action

Using the self-assessment checklist in **Part B** that follows will help you identify what you need to work on in your area, but it won't help you decide **how** to actually move things forward or what to work on first. Here are some pointers that may help:

- People with mental health problems who have learning disabilities, and their carers, know better than most what needs to change and their perspectives can be very helpful when setting the priorities.
- Consider the needs of people from ethnic minority groups even if numbers appear to be small. Other neighbouring services may be facing the same issue so a consortium approach may help.
- Decide what action to take in ways that create ownership and commitment - a partnership approach! Consider using a structured action-planning tool to involve a range of people, ideally a visual one that makes it easier for people with learning disabilities.

PATH – A STRUCTURED ACTION PLANNING TOOL

“Path is a way for diverse people, who share a common problem or situation, to align...their purposes...their understanding of their situation...their action...” (Pearpoint et al). A very visual reflection and action planning tool that can help people get working quite quickly towards an agreed vision and some specific goals. It is participative and action-oriented, and can be built on over time. PATH workshops need to be facilitated.

- Identify any local directives, policies or factors from across services and professions that people need to take account of when planning action to be taken to achieve service improvements.
- Consider which bodies have to agree any service improvement plan before it can proceed – like the LIT and the Partnership Board - and when you can get it onto their agenda. Make early links with unions and involve staff representatives in the planning if changes are likely to be proposed about how staff are used.
- Make sure people hear about cutting edge developments happening elsewhere to generate ideas and creative thinking.
- Mental health and primary care teams are actively developing their services. Merge development agendas so that appropriate mental health support for people with learning disabilities is encompassed within new initiatives.

- Staff and clinicians with the right knowledge and skills may be based in a range of services. Think about creating 'virtual teams' where staff come together for a specific purpose.
- Stay focused on the overall range of services and support you're trying to achieve – check each action against the vision. Ask, will this really move us in the right direction? Does it 'fit' with our beliefs and principles, and with policy?
- Consider the knowledge and skills needed by the mental health, learning disability and primary care workforce: have a training and staff development plan.
- Ensure any plans are fully integrated with Local Delivery Plans, showing how developments will be resourced, how money freed up will be re-invested, any shortfalls, and plans to secure funding.

Presenting to the LIT and the Partnership Board

You will hopefully have involved some members of the LIT and the Partnership Board in the process of assessing local implementation of the NSF in relation to people with mental health problems who have learning disabilities. They are obvious people to help present the findings and any service development plan for approval. A presentation by people with mental health problems who have learning disabilities can also be a powerful and persuasive tool, but they will need support and time to prepare.

At the end of the self-assessment checklist there is a **proforma** for summarising the action you plan to take locally in relation to the areas on the checklist. The areas are based on the NSF Autumn Assessment, which LITs have been using, so by using the proforma your action planning will automatically be focused on the mental health NSF.

References and resources

References

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- Department of Health (2000) *Modernising the Care Programme Approach* London: HMSO.
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- Department of Health (2001) *Making it Happen: A guide to delivering mental health promotion* London: HMSO.

* All available from The Foundation for People with Learning Disabilities (FPLD) Tel: 020 7802 0300 or email: fpld@fpld.org.uk

Other resources for information gathering

Care Programme Approach Audit Tool

See: *An Audit Pack for Monitoring the Care Programme Approach* (2001)
(2001) Department of Health. London: HMSO

How good is your service to carers?

A guide to checking quality standards for local carer support services

(2002) Blunden, R. London: King's Fund

CUES Questionnaire (Service user version)

Contact the Research Department, NSF, 30 Tabernacle Street, London EC2A 4DD

Partnership Readiness Framework and Audit Tool

See: Briefing Paper on Joint Commissioning and Partnership Working.

(1999) Greig, R. & Poxton, RJ. IAHSF, King's College London.

Commission for Healthcare Audit and Inspection Self-assessment Tools

See: www.chai.nhs.uk

Useful sources of information and advice

Choice Forum

An online discussion forum on issues in the lives of people with learning disabilities in the UK.

See: www.learningdisabilities.org.uk

The (American) National Association for the Dually Diagnosed (NADD)

See: www.thenadd.org.com

The Mental Health Foundation and Foundation for People with Learning Disabilities

Tel: 020 7802 0300 See: www.mentalhealth.org.uk and www.learningdisabilities.org.uk

The Centre for Mental Health Services Development at the Health & Social Care Advisory Service (HASCAS)

Emerson Business Centre, 5th Floor, St.James's House, Pendleton Way, Pendleton,
Manchester M6 5FW Tel: 0161 873 7444

National Institute for Mental Health in England (NIMHE)

Regional development centres. See: www.nimhe.org.uk

MIND

Granta House, 15-19 Broadway, Stratford, London E15 4BQ Tel: 0207 802 0300

Department of Health websites

For Mental Health see: www.dh.gov.uk/policyandguidance/healthandsocialcaretopics/mentalhealth

For the Valuing People Support Team see: www.valuingpeople.gov.uk

British Institute of Learning Disabilities

Wolverhampton Road, Kidderminster, Worcs DY10 3PP See: www.bild.org.uk

The Tizard Centre

Beverley Farm, University of Kent at Canterbury, Canterbury, Kent CT2 7LZ. See: www.ukc.ac.uk/tizard

The Estia Centre

Munro-Guy's Hospital, 66 Snowfields, London SE1 3SS Email: estia@kcl.ac.uk

Royal College of Psychiatrists

17 Belgrave Square, London SW1X 8PG See: www.rcpsych.ac.uk

Contact details (for services mentioned in Section Three)

@LIBERTY, HOUNSLOW

Development of a social firm providing disability related training run by people with mental health problems, including people who have additional learning disabilities.

Contact: Wendy Williams, Social Enterprise Development Manager on 0208 230 0058 or email wendy.williams@tesco.net

KEYRING LIVING SUPPORT NETWORKS

Housing and support schemes that provide specific input to help people develop friendships and connections, and that pay attention to the development of mutual support and 'community'.

Contact Keyring National Office on 0207 749 9414 or email enquiries@keyring.org

MANCHESTER

Written agreement in the shape of a formal protocol between the Primary Care Trust, mental health and learning disability services. Contact Mike Kellaway on 0161 958 4050 or email mike.kellaway@centralpct.manchester.nwest.nhs.uk or Mark Burton on 0161 881 0911 or email mark.burton@notes.manchester.gov.uk

SANDWELL

Commissioned places for people with mental health problems who have learning disabilities within the MIND day/drop-in service. Contact Enid Berwick on 0121 500 1512 or email enid_berwick@sandwell.gov.uk

SOMERSET

Designing guidelines for the Connexions service to help them assess and guide people with mental health problems and learning disabilities towards appropriate support (**Mind the Gap project**). Contact Val Williams, Norah Fry Research Centre, 3 Priory Road, Bristol BS8 1TX. Telephone 0117 923 8137 or email val.williams@bristol.ac.uk

Targeted use of Approved Social Workers to identify and support people who might 'fall through the net' of services. Contact Pat O'Connell, ASW (learning disabilities), Belmont House, Technical Street, Burnham on Sea TA8 1PN. Telephone 01278 792673 or email Pat.O'Connell@sompar.nhs.uk

BRADFORD

Use of a liaison worker to help young people with learning disabilities access culturally sensitive mental health services. Contact Dr Raghu Raghavan, University of Bradford. Tel: 01274 236446 or email R.Raghavan@Bradford.ac.uk

PRESTON

Learning disability input into the mental health substance misuse service. Contact Andy Shaw on 01772 401200 or email Andrew.Shaw@PrestonPCT.nhs.uk

SOUTH BIRMINGHAM

Referral pathway from NHS Direct to a local crisis team that can provide knowledgeable and skilled support to someone with mental health problems who has learning disabilities. Contact Abda Graham, Clinical Team Manager on 0121 627 8242 or email Abda.Graham@SouthBirminghamPCT.nhs.uk

LING TRUST

Individualised supported living arrangements, based on person-centred planning, where there are clear, easy and agreed ways for people to access 24-hour assistance from their support provider. Contact Jayne Knight, Chief Executive on 01206 769246 or access the website on www.lingtrust.org.uk or email lingtrust@hotmail.com

EAST YORKSHIRE

Information about CPA designed for people with learning disabilities. Contact Nicki Hollingsworth or George Stewart on 01482 886511 or email nicki.hollingsworth@herch-tr.nhs.uk or george.stewart@herch-tr.nhs.uk

TAMESIDE & GLOSSOP

Involvement of the learning disability service in court diversion and appropriate adult schemes coordinated by mental health services.

Availability of local temporary accommodation and support for use by a person with learning disabilities in mental health crisis. Contact Stephen Parsons, Tameside MBC on 0161 330 5892.

LAMBETH, SOUTHWARK AND LEWISHAM

People with learning disabilities on CPA recorded as a matter of course onto the mental health data system. Contact Steve Hardy on 0207 378 3217/8 or email estia@kcl.ac.uk

LONDON BOROUGH OF CAMDEN & ISLINGTON

Designated beds for people with learning disabilities provided within the mental health unit, with extra staff and a training plan to develop their learning disability knowledge and skills. Contact Alan Higgins, Clinical Nurse Manager/MHSPLD Coordinator on 0207 527 6675 or email alan.higgins@islington.gov.uk

DEVON

Support for people with learning disabilities integrated into the prison in-reach scheme run by mental health services. Contact Roger Bell on 01626 888372 ext 285 or email roger.bell@devonptnrs.nhs.uk

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Use of the CUES questionnaire with people who have learning disabilities and mental health problems. Contact Hannah Morrow on 01638 731300 or email spuppeople@hotmail.com

Notes