

## PART B **the tools**



**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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# The self-assessment checklist

## Introduction

### Delivering on the Mental Health National Service Framework for people with learning disabilities

This self-assessment checklist is the core of the **green light** toolkit. It is based on the self-assessment framework (the Autumn Assessment) that mental health Local Implementation Teams have been completing to assess their progress in implementing the National Service Framework (NSF). Because the NSF applies to all adults of working age it should be expected that the provisions within it are available to people with mental health problems who also have learning disabilities. This self-assessment framework aims to help local partnerships identify how well the NSF is being implemented in relation to people with learning disabilities.

The checklist uses a scoring system based on traffic lights. All you have to do for your local area is decide whether it's a red, amber or green light that best matches the local situation.

## Using the checklist

The checklist should help you to establish what's in place and working well for people with learning disabilities as a first step towards service improvement and development. You may decide that you need to gather more information before you can 'rate' some of the sections in the checklist – so that ratings are 'evidence based'. *Section 5* of the **green light** guide and the remaining sections of *this* pack include some tools and approaches you could use to gather information to underpin your ratings.

Or, you may feel that you need to do more to establish your local partnership before embarking on the full self-assessment checklist. The first heading in the checklist focuses on local partnership arrangements between mental health, learning disability, and primary care services, and including service users (people with learning disabilities who have mental health problems), carers, and their representatives. If your local area rates a red light on partnership arrangements then it may be necessary to stop and build them up before progressing too far with the checklist. If one service fills out the checklist on its own it is unlikely to promote a sense of *shared* ownership and commitment to improving things for people with learning disabilities who have mental health problems.

**You may have many protocols and systems in place, but it is important to consider how things are actually working *in practice*. The checklist gives you space to comment on the actual implementation and impact of protocols, systems and services in your area.**

## Guidance for completion of the checklist

- (1) The framework should be completed by (at least) mental health and learning disability services **as a partnership**, and ideally be based on a process that involves key stakeholder services, users and carers.
- (2) Remember, each statement should be considered as it relates to **services and support for people with mental health problems who have a learning disability**
- (3) The checklist uses descriptive statements. Circle '**green**', '**amber**' or '**red**' as appropriate for the statement that most nearly matches the situation in your locality. Some questions in the checklist also ask for the elements to be specified which contribute to your response. There is provision for this on the rating sheets.
- (4) Only circle 'green' if the situation is constantly positive across the whole of your local area. If it isn't, circle amber or red – reflect the **poorest** level of progress across the locality.
- (5) Complete the checklist as openly and honestly as possible. Most localities will probably see the whole range of red, amber and green ratings. At this stage there are likely to be more red and amber ratings than green. The aim is to see a different distribution, more green and amber, in 2 or 3 years' time.
- (6) There are **guidance notes** to help you with specific points **after the checklist** itself.

## Reporting on progress

At the end of this Section there is a proforma summary and action-planning sheet based on the checklist headings. It is designed to make it easy to present findings and conclusions to the mental health Local Implementation Team and the learning disability Partnership Board, and to feed back to other key stakeholders.

## Seeing change

Using the self-assessment checklist at regular intervals will help you to track developments, celebrate achievements and keep moving forward towards even better services and support for people with learning disabilities who experience mental health problems.

LOCALITY:

DATE:

## Local Partnerships

**1**

### **Between mental health and learning disability services**

**RED**

There is **no** agreement between mental health and learning disability services about commissioning and provision roles, frequent disputes between the two services and no plans for integrated service development.

**AMBER**

There is a **degree** of agreement between mental health and learning disability services about commissioning and provision roles and responsibilities, but also some disputes.

**GREEN**

There is **clear** agreement between mental health and learning disability services about commissioning and provision roles and responsibilities.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

**2**

### **With primary care services**

**RED**

There is no agreement between mental health, learning disability and primary care services about the role and responsibilities of primary care staff, and referral routes for specialist support.

**AMBER**

There is a **degree** of agreement.

**GREEN**

There is **clear** agreement between mental health, learning disability and primary care services about the role and responsibilities of primary care staff, and referral routes for specialist support.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

**3**

### **With people with learning disabilities**

**RED**

People with learning disabilities have had **no involvement** in deciding on or agreeing the local service/support configuration and plans related to mental health support.

**AMBER**

People with learning disabilities have had **some involvement in agreeing** the local service/support configuration and plans related to mental health support.

**GREEN**

People with learning disabilities have **contributed to and agreed** the local service/support configuration and plans related to mental health support.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

#### 4 With carers of people with learning disabilities

RED

Carers of people with learning disabilities have had **no involvement** in deciding on or agreeing the local service/support configuration and plans.

AMBER

Carers of people with learning disabilities have had **some involvement in agreeing** the local service/support configuration and plans.

GREEN

Carers of people with learning disabilities have **contributed to and agreed** the local service/support configuration and plans.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

## Local Planning

#### 5 The Planning Process

Looking at the box below, how many of the listed standards are met locally? Please specify.

RED

The local planning process meets only **two or fewer** of the standards.

AMBER

The local planning process meets **three or four** of the standards.

GREEN

The local planning process meets **all** of the standards

- there is local action planning to improve service provision for people with mental health problems who have learning disabilities and there is a coordinated, joined-up approach agreed by both the Mental Health LIT and the Learning Disability Partnership Board
- local planning takes into account national priorities and targets as well as other locally determined priorities based on assessment of local needs
- local planning includes measurable outcomes and timescales
- clear responsibility for implementation has been agreed for most or all of the goals, with all main partners taking some responsibility

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

## Local Planning

### 6 Commissioning - Planning

RED

Commissioning of services/support for people with learning disabilities experiencing mental health problems is **completely separate** from the commissioning of mental health services, and is **not linked into the mental health Local Development Plan** (the comprehensive commissioning plan for mental health services).

AMBER

There is a joint commissioning structure in place for mental health services generally, but **some commissioning** of services/support for people with learning disabilities experiencing mental health problems **is separate** from it and not linked into the mental health LDP (the comprehensive commissioning plan for mental health services).

GREEN

There is a joint commissioning structure in place for mental health services generally, and services/support for people with learning disabilities experiencing mental health problems are commissioned **through** that structure as **an integrated part of the mental health LDP** (the comprehensive commissioning plan for mental health services).

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

### 7 Commissioning – Health Act Flexibilities

RED

There is **no pooling** of funds from health (PCT), LA, mental health and learning disability services for the commissioning of services/support to meet the needs of people with learning disabilities experiencing mental health problems

AMBER

There is **some pooling** of funds from health (PCT), LA, mental health and learning disability services for the commissioning of services/support to meet the needs of people with learning disabilities experiencing mental health problems

GREEN

There is a **pooled budget** with funds from health (PCT), LA, mental health and learning disability services to cover the commissioning of services/support to meet the needs of people with learning disabilities experiencing mental health problems

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

**8 Agreed criteria and boundaries between services**

**RED**  
**AMBER**  
**GREEN**

Looking at the box below:

**One or none** of the features apply.

**Two** of the features apply.

**All** of the features apply.

There are clear criteria for access to services by people with learning disabilities, agreed by commissioners, learning disability services & generic mental health services

Entry criteria for generic mental health services and specialist learning disability services overlap so that nobody is excluded by both services

Entry criteria for generic mental health services for people with learning disabilities are based on mental health needs, functional level and vulnerability

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

**9 Transition Protocols**

**RED**  
**AMBER**  
**GREEN**

Looking at the box below:

The arrangements for **both** of the following are **inadequate or ineffective** for people with learning disabilities who have mental health problems:

The arrangements for **only one** of the following are **adequate and effective** for people with learning disabilities who have mental health problems (please specify)

The arrangements for **both** of the following are **adequate and effective** for people with learning disabilities who have mental health problems.

- transition of care between child and adolescent services and adult learning disability and mental health services
- transition between adult learning disability and mental health services and services for older people.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

10

**Roles, Responsibilities and cross-service support**

Looking at the box below:

**RED**  
**AMBER**  
**GREEN**

**One or none** of the features apply.

**Two or three** of the features apply.

**All** of the features apply.

Protocols for transfer or shared care between LD and generic Mental Health services exist and clearly specify consultant responsibility

Protocols for transfer or shared care between LD and Mental Health services exist and clearly specify the roles and responsibilities of in-patient and community teams in both mental health and learning disability services

Where a person with a learning disability is having services from both mental health and learning disability services there is joint care planning at an individual level

Where a person with a learning disability is having services from both mental health and learning disability services the written care plan specifies what support each service can expect from the other.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

## Key Services

11

### Assertive Outreach

RED

There is nothing available which **both** meets the mental health Policy implementation Guide definition of 'assertive outreach' **and** provides an appropriate, skilled response to people with learning disabilities experiencing mental health problems but not engaging with services.

AMBER

There is a service that **both** meets the mental health Policy Implementation Guide definition of 'assertive outreach' **and** provides an appropriate, skilled response to some people with learning disabilities experiencing mental health problems, **but** it is not available or appropriate to all people with learning disabilities who might benefit from it.

GREEN

There is a service that **both** meets the mental health Policy Implementation Guide definition of 'assertive outreach' **and** provides an appropriate, skilled response to any person with learning disabilities experiencing mental health problems who might benefit from it.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

12

### Crisis Resolution

RED

Community- based services which provide appropriate, skilled assessment and intervention to people with learning disabilities at times of mental health crisis are **not available** 24 hours a day, 7 days a week as defined by the mental health Policy Implementation Guide.

AMBER

Community-based services which provide appropriate, skilled assessment and intervention to people with learning disabilities at times of mental health crisis **are available** 24 hours a day, 7 days a week, as defined by the Policy Implementation Guide **but at a level which is insufficient** to meet local needs.

GREEN

Community-based services which provide appropriate, skilled assessment and intervention to people with learning disabilities at times of mental health crisis **are available** 24 hours a day, 7 days a week - as defined by the mental health Policy Implementation Guide, and **at a level sufficient** to meet local needs.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

## Key Services

13

### Early Intervention in Psychosis

RED

There is no service available which **both** meets the mental health Policy Implementation Guide definition of 'early intervention in psychosis' and can provide an appropriate, skilled response to people with learning disabilities experiencing psychosis.

AMBER

There is a service that **both** meets the mental health Policy Implementation Guide definition of 'early intervention in psychosis' **and** can provide an appropriate, skilled response to people with learning disabilities experiencing psychosis but it is not available or appropriate to all people with learning disabilities who might need it.

GREEN

There is a service that **both** meets the mental health Policy Implementation Guide definition of 'early intervention in psychosis' **and** can provide an appropriate, skilled response to any person with learning disabilities experiencing psychosis that might need it.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

14

### Secure Places

RED

There is a **significant shortfall** in local availability of medium and/or low secure beds for people with learning disabilities experiencing mental health problems.

AMBER

There is **some shortfall** in local availability of medium and/or low secure beds for people with learning disabilities experiencing mental health problems.

GREEN

There is **no shortfall** in local availability of **both** medium and low secure beds for people with learning disabilities experiencing mental health problems.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

15

### Women's Services

RED

There are **no** local women-only services that can provide an appropriate, skilled response to women with learning disabilities experiencing mental health problems.

AMBER

There are **some** local women-only services that can provide an appropriate, skilled response to women with learning disabilities experiencing mental health problems.

GREEN

There are **sufficient** local women-only services that can provide an appropriate, skilled response to women with learning disabilities experiencing mental health problems.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

## Key Services

16

### Carers' Services

RED

There are no development plans, or plans are insufficient to meet the respite and support needs of carers of people with mental health problems who have a learning disability.

AMBER

There are plans being implemented to provide a sufficient range and level of services to ensure that carers of people with mental health problems who have a learning disability can get breaks and support to meet their needs.

GREEN

There is already a sufficient range and level of services to ensure that carers of people with mental health problems who have a learning disability can get breaks and support to meet their needs.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

17

### Black and Minority Ethnic People's Services

RED

No data is being collected about people with learning disabilities from ethnic minorities who have mental health problems (as in guidelines EL(94) 77), and nothing is being reported to the LIT and Partnership Board. It is not part of service governance.

AMBER

Data is collected about people with learning disabilities from ethnic minorities who have mental health problems (as in guidelines EL(94) 77), and reported to the LIT and Partnership Board **but** there is no link to service planning or service governance.

GREEN

Data is *collected* about people with learning disabilities from ethnic minorities who have mental health problems (as in guidelines EL(94) 77), *and reported* to the LIT and Partnership Board. This is linked to service planning and monitored through service governance.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

18

### 'Gateway' workers and graduate primary care workers

RED

There are **no** plans for a 'gateway' community mental health worker knowledgeable and skilled in work with people with learning disabilities **or** for graduate primary care workers to receive appropriate training and supervision in relation to people with a learning disability.

AMBER

Plans are in place for **either** – a 'gateway' community mental health worker knowledgeable and skilled in work with people with a learning disability **or** for new graduate primary care workers to receive appropriate training and supervision in relation to people with a learning disability.

GREEN

Plans are in place for **both** – a 'gateway' community mental health worker knowledgeable and skilled in work with people with a learning disability **and** for new graduate primary care workers to receive appropriate training and supervision in relation to people with a learning disability.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

## Key Services

19

### Primary-secondary interface

Looking at the box below, how many of the listed features do you have in place locally:

RED  
AMBER  
GREEN

**Up to two** are in place (please specify).

**Three** are in place (please specify).

**All four** are in place.

- Severe Mental Illness (SMI) registers identify people with a learning disability
- There are mental health/learning disability/primary care referral agreements (protocols), reviewed systematically to ensure they are effective
- There are protocols on exchange of information across mental health, learning disability and primary care services
- There are systems and protocols for delivery of specialised support services to people with mental health problems who have a learning disability on the primary care site (out-posted clinics, liaison workers, etc).

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

20

### Acute Inpatient Services

Looking at the box below, how many of the listed features do you have in place locally:

RED  
AMBER  
GREEN

**Less than 3** of these are in place (please specify).

**3 to 5** of these are in place (please specify).

**6 or 7** of these are in place (please specify).

- An agreement between mental health and learning disability services about provision of specialised support for people with learning disabilities admitted to inpatient units
- Local inpatient provision with staff who have significant mental health training **and** knowledge/skills in supporting people with learning disabilities
- Sufficient local provision of the above to meet needs
- Advocacy support for people with learning disabilities so they can participate fully in staff/user forums on wards
- Named clinical and professional leads from **both** mental health and learning disability services linked to each inpatient unit, responsible for ensuring regular multi-disciplinary input
- Named consultant psychiatrist leads from **both** mental health and learning disability services for each in-patient unit
- People with learning disabilities are represented on the local Acute Care Forum

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

## Key Services

### 21 Police and Criminal Justice Services

RED

There are **no** strategies or systems to identify people with mental health problems who have a learning disability in the police and criminal justice system, and ensure they receive appropriate, skilled support.

AMBER

There are **some** strategies or systems to identify people with mental health problems who have a learning disability in the police and criminal justice system, and ensure they receive appropriate, skilled support - but they are **not operated consistently and effectively**.

GREEN

There are strategies or systems that operate **consistently and effectively** to identify people with mental health problems who have a learning disability in the police and criminal justice system, and ensure they receive appropriate, skilled support.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

### 22 NHS Direct

RED

Protocols are **not in place** between NHS Direct and local specialist mental health providers **or** they **do not specifically** address the needs of people with mental health problems who have a learning disability, which would enable fast access to support for people with learning disabilities in a mental health crisis.

AMBER

Protocols are in place between NHS Direct and local specialist mental health providers and **specifically address** the needs of people with mental health problems who have a learning disability, enabling fast access to support in a mental health crisis. Direct referrals for assessment from NHS Direct are **either** not accepted **or** an appropriately skilled response is **not** provided by local crisis services.

GREEN

Protocols are **in place** between NHS Direct and local specialist mental health providers and **specifically address** the needs of people with mental health problems who have a learning disability, enabling fast access to support in a mental health crisis. Direct referrals for assessment from NHS Direct are accepted and an **appropriately skilled response** is provided by local crisis services.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

## Care Planning

23

### Care Programme Approach (CPA) - Shared systems and Protocols

RED

One or both services **do not use** CPA  
**and/or** -

There is **no** agreement between learning disability and mental health services about roles, responsibilities and where people 'fit' in relation to CPA.

AMBER

Both mental health & learning disability services in the local area operate CPA but use **different systems**  
**and/or** -

Progress has been made towards an agreement between learning disability and mental health services about roles, responsibilities and where people 'fit' in relation to CPA, but it is **not yet finalised**.

GREEN

There is a **uniform system** for CPA across mental health & learning disability services  
**and** -

There is a **clear agreement** between learning disability and mental health services about roles and responsibilities in relation to CPA, including where people with mental health problems who have a learning disability 'fit' with standard and enhanced CPA and how it will apply to them.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

24

### CPA - Sharing information and accessing Care Plans

RED

Looking at the box below:

**None** of the features apply.

AMBER

**One or two** of the features apply (please specify).

GREEN

**All** of the features apply.

CPA recording systems allow the identification of people with a learning disability and such information is routinely recorded.

There is an agreed information sharing protocol between learning disability, mental health, primary care services and other relevant local agencies.

Care plans for people with learning disabilities known to have mental health problems can be accessed 24 hours a day by staff providing direct care to him/her from across services.

INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS

**25**

### CPA – person-centred and whole life

Looking at the box below, how does your local CPA system match up to the statements?

**RED**

Locally we **cannot say yes** to any of the statements

**AMBER**

Locally we can say **yes to one or two** of the statements (please specify).

**GREEN**

Locally we can say **yes to all** statements

The local CPA system **is** person-centred in the way it operates and people with mental health problems who have a learning disability are empowered by the process

The local enhanced CPA system **does** include assessment and action planning for all of the following: Employment or other occupation; housing; welfare benefits; crisis plans, including 24-hour access arrangements. This information is always recorded and there are sufficient support services available to meet people's assessed needs in these areas.

There is a clear process for integrating someone's person-centred plan into their CPA.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

**26**

### CPA – Carers' Plans

**RED**

Very few if any carers of people with mental health problems who have a learning disability have written care plans which address their own needs as carers

**AMBER**

Carers of people with learning disabilities **on enhanced CPA** have written care plans, which address their own needs as carers, but many other carers of people with mental health problems who have a learning disability do not.

**GREEN**

**All** regular carers of people with mental health problems who have a learning disability have a written care plan, which addresses their own needs as carers.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

## Diversity of Provision

**27**

### **User led initiatives and services**

**RED**

There are no initiatives or services in the area being led by people with learning disabilities who have mental health problems (with appropriate support).

**AMBER**

Work is actively taking place to establish or increase the number of initiatives and services led by people with mental health problems who have a learning disability in the local area (with appropriate support).

**GREEN**

There are some initiatives and services being led by people with mental health problems who have a learning disability (with appropriate support) and there are enough to give an adequate mix within the overall service provider map.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

**28**

### **Voluntary sector services**

**RED**

There are no local mental health voluntary sector services that offer support to people with mental health problems who have learning disabilities.

**AMBER**

There are local mental health voluntary sector services that offer support to people with mental health problems who have a learning disability, but they struggle to appropriately respond to people's needs, and/or their funding is not secure.

**GREEN**

There are local mental health voluntary sector services that offer support to people with mental health problems who have a learning disability. They are able to appropriately respond to people's needs, and arrangements are in place to ensure continuity of funding.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

**29**

### **Culturally specific services**

**RED**

Culturally specific services available in the area do not meet assessed needs, or they cannot appropriately support people with mental health problems who have learning disabilities.

**AMBER**

There are culturally specific services available in the area that meet local assessed needs, but they cannot yet appropriately support people with mental health problems who have learning disabilities.

**GREEN**

There are culturally specific services available in the area that meet local assessed needs, and they can appropriately support people with mental health problems who have learning disabilities.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

## Underpinning Programmes

**30**

### Recruitment and Retention

**RED**

There are **significant** problems with the recruitment and retention of staff and clinicians with knowledge/skills in both mental health and learning disability.

**AMBER**

There are **some** problems with the recruitment and retention of staff and clinicians with knowledge/skills in both mental health and learning disability.

**GREEN**

There are **no** significant problems with the recruitment and retention of staff and clinicians with knowledge/skills in both mental health and learning disability.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

**31**

### Workforce Planning

**RED**

An agreed, cross-agency workforce strategy and related action planning are not in place, and are not yet in development.

**AMBER**

**Either** – There is an agreed workforce strategy and related action planning across agencies, but not covering all settings.  
**Or** – A cross agency workforce strategy and action planning are being developed but are not yet finalised and agreed.

**GREEN**

There is agreed, cross-agency workforce planning to ensure that staff knowledgeable and competent in mental health and learning disabilities are available to support people in **any** setting.  
**And** – It is integrated into the main mental health & learning disability workforce planning.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

**32**

### Representative Workforce

**RED**

The mental health and learning disability services are not yet considering how to build a workforce that reflects the diversity of the local population of people with mental health problems who have a learning disability and promote cultural competence in the workforce.

**AMBER**

The mental health and learning disability services are discussing how to build a workforce that reflects the diversity of the local population of people with mental health problems who have a learning disability and promote cultural competence in the workforce.

**GREEN**

The mental health and learning disability services are implementing a comprehensive strategy to build a workforce reflecting the diversity of the local population of people with mental health problems who have a learning disability and to promote cultural competence in the workforce.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

## Underpinning Programmes

**33**

### **Integrated MHER**

**RED**

A mental health electronic record spanning health and social care is not in place and/or there are no plans to identify/include people with mental health problems who have a learning disability on it.

**AMBER**

Work is underway to ensure that people with mental health problems who have a learning disability are identified and included on the mental health electronic record spanning health and social care.

**GREEN**

People with mental health problems who have a learning disability are identified and included on the mental health electronic record spanning health and social care.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

**34**

### **Local Directory**

**RED**

There is no comprehensive directory of local mental health services or the one that exists does not include or identify services that work with people with mental health problems who have a learning disability

**AMBER**

There is work underway to include and specifically identify services that work with people with mental health problems who have a learning disability in the local comprehensive directory of mental health services

**GREEN**

The comprehensive directory of local mental health services includes and specifically identifies services that work with people with mental health problems who have a learning disability

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

**35**

### **Funding**

**RED**

Funds have not been identified / allocated to meet the costs of implementing the NSF and NHS plan in ways that specifically meet the needs of people with a learning disability

**AMBER**

Funds have been identified / allocated only partially or provisionally to meet the costs of implementing the NSF and NHS plan in ways that specifically meet the needs of people with a learning disability

**GREEN**

There is full local agreement to the identification / allocation of funds to meet the costs of implementing the NSF and NHS plan in ways that specifically meet the needs of people with a learning disability

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

## Other Priorities

**36**

### **Safety, privacy & dignity in mental health units: single sex accommodation**

**RED**

There is still mainly mixed sex in-patient accommodation being used by people with mental health problems who have a learning disability, and no plans to develop or access more single sex accommodation.

**AMBER**

There is still some mixed sex in-patient accommodation being used by people with mental health problems who have a learning disability, but there are plans to develop &/or access more single sex accommodation.

**GREEN**

There is no mixed sex in-patient accommodation (including secure services) being used by people with mental health problems who have a learning disability. Women-only day and visiting areas are available, if required.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

**37**

### **Mental Health Promotion**

**RED**

There is **not** a mental health promotion strategy that adequately addresses the requirements of people with a learning disability or there is a strategy but it is **completely separate** and not linked to the mainstream mental health one

**AMBER**

There **is** a mental health promotion strategy that adequately addresses the requirements of people with a learning disability, and work is underway to integrate it into the mainstream mental health strategy.

**GREEN**

A mainstream mental health promotion strategy is being implemented that **includes and adequately addresses** the requirements of people with a learning disability.

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

**38**

### **Specialist Services**

Looking at the box below, how many services do people with mental health problems who have a learning disability have access to?

**RED**

**Only one or none** at a level sufficient for local needs (please specify).

**AMBER**

**Two or three**, at a sufficient level for local needs (please specify).

**GREEN**

**Four or five**, at a level sufficient for local needs (please specify).

- services for people with sensory impairment and mental illness
- eating disorder services
- mother and baby services
- drug and alcohol services
- bereavement services
- forensic services

**INFO NEEDED? HOW ARE THINGS WORKING IN PRACTICE? COMMENTS**

## Other Priorities

39

### **Mental Health Act 1983 Section 135/136/ Places of Safety**

RED

There is no written policy or regular monitoring which covers people with learning disabilities subject to Section 135/136 powers and places of safety.

AMBER

There is a **separate** policy and separate monitoring by learning disability services of people with learning disabilities subject to Section 135/136 powers and places of safety.

GREEN

People with learning disabilities are **covered by** the mental health service policy and associated monitoring of the appropriateness and frequency of use of Section 135/136 powers and places of safety within the LIT area, and figures can also be identified separately.

INFO NEEDED? HOW ARE  
THINGS WORKING IN  
PRACTICE? COMMENTS

Please refer to guidance notes for further details throughout.

# Notes for Guidance

## Local Partnerships

- 1. between mental health and learning disability services**  
This is one of the mainstream mental health Autumn Assessment areas. It is the starting point for developing mental health services that are 'right' for people with learning disabilities. If there are disputes locally, what are they about - are there any themes? Try to identify any 'sticking points' that need to be resolved.
- 2. between mental health, learning disability and primary care services**  
Many people with learning disabilities access specialist mental health support through their GP, and may be monitored by primary care services. A tripartite agreement, clarifying pathways, roles and responsibilities reduces confusion and helps to ensure people get the support they need. If you have one, how is it working in practice? Are there any primary care practices that need support?
- 3. with people with a learning disability**  
People with a learning disability sit on the local Learning Disability Partnership Board, but to get a green rating people will have participated in *developing* the local vision and in planning mental health services and support for people with learning disabilities i.e. *before* the service map is approved by the Partnership Board or LIT.
- 4. with carers**  
Carers also sit on the local Learning Disability Partnership Board, but this statement is specifically about involving carers of people *with mental health problems* who have a learning disability in developing the local vision and plans for mental health services and support.

## Local Planning

- 5. Planning Process**  
Please tick those elements that **are** in place. Action agreed by the LIT and Partnership Board should have been reviewed within the past year. The Green Light pack provides guidance on information gathering to help assess local needs. The emphasis is on assessment rather than assumption of local needs: evidence-based planning.
- 6. Commissioning - Planning**  
The mental health Local Development Plan should incorporate service development plans and priorities that relate to people with mental health problems who have a learning disability. This indicator reflects the degree to which there is commitment to the joint planning process recommended within the Mental Health NSF.
- 7. Commissioning - Health Act Flexibilities**  
Integrated and seamless service provision is likely to be achieved better where pooled budgets exist. This measure identifies the degree to which local organisations have utilised the Health Act Flexibilities to smooth service delivery to people with mental health problems who have a learning disability.

## Access to Services

- 8. Agreed criteria and boundaries between services**  
It is important here to consider people who, in the past, may have fallen between mental health and learning disability services, for example those with Asperger's Syndrome. The criteria need to explicitly address people who have an 'unclear label', and will not be based upon IQ.

## 9. Transition protocols

'Adequate' and 'effective' means, as a minimum, the person and their carer(s) receiving continuity of treatment and support, and knowing and agreeing who will be doing what to support them, from when. Consider the systems in place between services locally and whether these help you to achieve those outcomes. Are adult mental health and learning disability services involved in transition planning? If not, what can you do to achieve a more joined-up approach around individuals?

## Joint Working

### 10. Roles, responsibilities and cross-service support

If there are psychiatrists specialising in learning disability in your area (whether posts are filled or not) protocols should specify working arrangements with mental health psychiatrists, even where they are employed by the same organisation. The protocols should allow some flexibility and encourage partnership approaches to achieve the best possible response to individuals. Key questions in relation to cross-service support are - how consistently is it specified in care plans, is it happening in practice, and how do you know?

## Key services

The Mental Health Policy Implementation Guide can be downloaded from the Department of Health website.

### 11. Assertive Outreach

The Mental Health Policy Implementation Guide (section 4) gives a detailed specification for an Assertive Outreach service. For a green rating, people with a learning disability should have access to a service that accords with this specification. An 'appropriate, skilled response' would come from staff who have knowledge and skills that cover both mental health and learning disability (though not necessarily from one and the same person).

### 12. Crisis Resolution

The Mental Health Policy Implementation Guide (section 3) provides a detailed specification for this service but states that a crisis resolution service would "not usually be appropriate for" people with a learning disability. However, people with a learning disability can experience mental health crises like anyone else with a mental health problem, and should be treated in the least restrictive environment with the minimum disruption to their lives. For a green rating people with a learning disability in your local area should have access to a service that accords with the specification. "Appropriate skilled assessment and intervention" would come from staff with knowledge and skills covering both mental health and learning disability (though not necessarily from one and the same person) using assessment frameworks and interventions carefully selected for their relevance to people with a learning disability.

### 13. Early Intervention in Psychosis

The Mental Health Policy Implementation Guide (section 5) provides a detailed specification for this service. For a green rating, people with a learning disability should have access to a service that accords with this specification. An 'appropriate, skilled response' would come from staff who have knowledge and skills that cover both mental health and learning disability (though not necessarily from one and the same person).

### 14. Secure Places

If provision is below 50% of the assessed level of need, the rating should be red; from 50% to 99% amber; if 100% green. Secure places should be 'local' e.g. ideally no more than two hours travelling from the normal home of the person placed.

15. **Women's Services**

This means women-only mental health support services in the community that are open to and inclusive of women who also have a learning disability. They may not be labelled "mental health services" by the agencies that run them, but they provide services and support that meet mental health needs. Staff are available to support women with learning disabilities who have knowledge and skills in mental health and learning disability.

16. **Carers' Services**

The NHS Plan made a commitment to increase the breaks available to carers, and to strengthen carer support networks. A 'sufficient range and level of services' for carers of people with mental health problems who have a learning disability should be specified and agreed in consultation with local carer organisations, including those in the mental health and learning disability arenas

17. **Black and Minority Ethnic People's Services**

Valuing People identified that provision of culturally sensitive and culturally competent services for people with a learning disability is a significant area for development. The development and monitoring of planning processes and outcomes should involve people from ethnic minority communities.

18. **'Gateway' workers and new Graduate Primary Care Workers**

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 (The NHS Plan and PPF). 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 and PPF). This indicator focuses on the extent to which the specific requirements of people who have a learning disability are being addressed through these new initiatives in your area. 'Appropriate education, training and supervision in relation to people with learning disabilities' will be based on a clear and carefully devised plan drawn up and agreed by mental health and learning disability services.

19. **Primary-secondary interface**

Please tick those elements which **are** in place. The four elements listed have been identified as the core structural elements of a good working relationship between primary and secondary care. 'Specialised support services' means availability of specialised support from workers with both mental health and learning disability knowledge and skills.

20. **Acute Inpatient Services**

'Inpatient units' mean those run by mental health **and/or** learning disability services. Specialised support should operate in both directions if in-patient provision is provided by both services i.e. specialised learning disability support being available to people in mental health units, and specialised mental health support being available to people in learning disability units. It's the *availability* of specialised workers, and *whether they are actually being used* for people with mental health problems who have a learning disability that is the focus here. The point about **Acute Care Forums** reflects a recommendation within the Acute Care Guidance, May 2002, as part of the Mental Health Policy Implementation Guide.

21. **Police and Criminal Justice Services**

Systems for early identification, and provision of appropriately skilled support to people with mental health problems who have a learning disability should be agreed by mental health, learning disability and police and criminal justice services, including the prison service. There should be clear pathways to access appropriately skilled support for the person.

## 22. **NHS Direct**

Local services must work with NHS Direct to facilitate access to local specialist mental health crisis provision, 24 hours a day, 7 days a week. Local mental health services will have agreed protocols with NHS Direct. This indicator seeks to ensure that people with mental health problems who have a learning disability (and their carers) are able to access a timely and “appropriately skilled response” through this system. An “appropriately skilled response” would come from staff with knowledge and skills covering both mental health and learning disability (though not necessarily from one and the same person).

## Care Planning

### 23. **Care Programme Approach: Shared systems and Protocols**

Shared systems and protocols should specifically address:

- how standard and enhanced CPA will apply to people who have a learning disability,
- how CPA fits with Health Action Planning
- how CPA fits with person-centred planning (see point 25 below)

Valuing People (DH 2001) sees the Health Action Plan as being part and parcel of the CPA care plan. The health plan must be coordinated with the individual’s person-centred plan so that they are “integrated and coherent”.

### 24. **Care Programme Approach: Information sharing and access to Care Plans**

Effective care and safe approaches are more likely when staff have ready access to people’s existing care plans. Care plan details should be accessible by staff from across services who may have infrequent contact (e.g. primary care staff) or who are engaging with a person out of hours.

### 25. **Care Programme Approach – person-centred and whole life**

The NSF expects comprehensive assessment for people subject to enhanced CPA. Valuing People encourages a whole life, person-centred approach for all people who have a learning disability. This may include person-centred planning. A person-centred *approach* to planning means that the person’s wishes as well as needs are at the heart of it, and the way the process operates is itself very person-centred. Person centred *planning* is not seen as being the same as assessment and care planning, but as being something that can add to its quality and effectiveness. It can help get the plans right for people! *“Assessment and care planning is greatly assisted by person-centred planning undertaken independently of it”* (2001 Routledge & Sanderson).

### 26. **Care Programme Approach - Carers' Plans**

Having written care plans for carers of people with mental health problems on enhanced CPA is an NSF aim. This indicator recognises that many people with mental health problems who have a learning disability may not be subject to enhanced CPA, but their carers face additional pressures because of the duality of the person’s impairment.

## Diversity of Provision

### 27. **User Led Services**

Consider the range and nature of initiatives and services in your area and whether there are sufficient being led/run by people with mental health problems who have a learning disability (including people with Asperger’s syndrome) or their representative organisations. Some may be hosted by other providers e.g. the NHS, but be led by users. This indicator recognises that people need choice in provision and may prefer to access services run by peers. “With appropriate support” means that such initiatives/services must include support for people with a learning disability to develop as leaders and they should have confidence in funding streams to be able to plan for more than a year at a time.

28. **Voluntary Sector**

Voluntary sector mental health services play an important part in meeting the needs of people who may be hard to engage with, or who have slipped between the net of services. It is important to consider the contribution that voluntary sector mental health services can make in meeting the needs of people who also have a learning disability. An “appropriate response” would address the person’s support needs related to their learning disability as well as their mental health.

29. **Culturally specific services**

The Mental Health LIT will assess the need for culturally specific mental health services locally. It is important that people with mental health problems who have a learning disability are identified and included in the assessment. It may be that some people are already in specialised placements beyond their home area. They should be included in the figures.

## Underpinning Programmes

30. **Recruitment and Retention**

If there are problems be specific about where the problems lie: which staff/professionals are difficult to attract, in which services? The significance of problems should be judged in terms of the impact on service provision. If services have dealt with staffing issues in creative ways, ensuring minimal service impact, they could be rated amber or even green.

31. **Workforce Planning**

Workforce requirements specific to delivering a competent, integrated service to people with mental health problems who have a learning disability should be built into mental health workforce planning, following agreement with the specialist learning disability service. As a guide, planning might include: trends in recruitment and retention and plans to address any shortfalls; the future numbers, types and skill mix of staff needed to deliver the NSF standards to people with mental health problems and learning disabilities; training to develop specific skills, knowledge and leadership. The workforce planning should be linked to a **clear** agreement between mental health & learning disability services about commissioning and provision roles and responsibilities (points 1 & 10).

32. **Representative Workforce**

The extent to which targeted approaches are necessary will depend on the local population and assessment of its needs. At minimum, there must be easy access to culturally specific support, when required, from people who are knowledgeable and skilled in work with people who have mental health problems plus a learning disability.

33. **Integrated MHER**

The Mental Health Information Strategy provides guidance on the Mental Health Electronic Record. The local MHER should specifically identify people who have mental health problems *and* a learning disability.

34. **Local Directory**

Again, the Mental Health Information Strategy provides mental health services with guidance on the requirements for this directory. Services that welcome and can appropriately support people with mental health problems who have a learning disability should be specifically highlighted in the directory. You may want to consider whether services that welcome and are able to support people with autistic spectrum disorders who have mental health problems should be separately identified.

35. **Funding**

Your rating will reflect local confidence that commissioners will allocate/secure any necessary funding to implement the NSF and NHS Plan in ways that include people with mental health problems who have a learning disability. A green rating is based on funding being contributed from more than one service, reflecting a partnership approach.

## Other Priorities

36. **“Safety, Privacy and Dignity” - Single Sex Accommodation**

This indicator applies to in-patient accommodation that is used by people with a learning disability experiencing mental health problems whether run by specialist mental health **or** learning disability services, including secure provision. If single sex accommodation is being accessed but is not local (e.g. within 2 hours travelling from the person’s home) a green rating will not apply.

37. **Mental Health Promotion**

“Making it Happen” (DH 2001) offers comprehensive guidance on the development and implementation of local strategies for mental health promotion. For a green rating, a strategy that “adequately addresses” the requirements of people with a learning disability would at minimum cover –

- *accessible* information
- *provision of support* to understand information
- *advocacy*
- information for *family carers*
- ordinary life opportunities
- *information and training for staff* working with people who have a learning disability

38. **Specialist Services**

This indicator measures adequacy of access to specialist services, irrespective of location. However, if services are very geographically remote, this may affect local views as to the “sufficiency” of access.

39. **Section 135/136 - Places of Safety**

The Code of Practice to the Mental Health Act offers guidance on this issue. This indicator seeks to ensure that people with mental health problems who have a learning disability are covered by policy and monitoring arrangements, and can be identified separately within the information produced.

# Delivering on the Mental Health National Service Framework for people with learning disabilities

## Summary

DATE OF PLAN:

DATE FOR PROGRESS REVIEW:

**What we are doing well on (our 'green light' areas)**

---

**What we are on track with, but there's still more to do (our 'amber light' areas)**

---

**What we are not doing well on (our 'red light' areas)**

---

**Our 5 development priorities -**

1.

2.

3.

4.

5.

**and the reasons why**

THE PRIORITY	WHAT WE PLAN TO DO	WHO IS THE LEAD	WHAT SUCCESS WILL LOOK LIKE	WHEN WE AIM TO HAVE ACHIEVED IT
Priority 1				
Priority 2				
Priority 3				
Priority 4				
Priority 5				

## SECTION TWO

# Survey of in-patient experience

## Introduction

This tool will help you learn about the in-patient experiences of people with mental health problems who have a learning disability, and what they think of those experiences.

It is based on what people who have mental health problems and a learning disability have said is important to them.

## How to use the tool

Carry out the survey over a two or three month period.

During the survey period interview -

- all people with a learning disability who have been in-patients for more than a month because of mental health problems. Interview people in both mainstream mental health and in specialist learning disability units.
- all people with a learning disability who leave i.e. stop being in-patients. Try to interview people within 2 weeks of them leaving.

Try to write down what people actually say. Quotes are very helpful.

Ideally the interviews would be carried out by people with a learning disability, with appropriate training and support.

## Preparation

Explain to each person what the survey is all about, and make sure the person understands and agrees to take part. Ask if they would like someone with them for support.

Explain what the survey is about to the people who are supporting the person day to day as well. They can then clarify things afterwards if the person has questions.

Ask the person if s/he would like a copy of the form once it's filled out, and tell the person how they will hear about the findings from the survey. Reassure the person that their name will not be used in reports.

## Asking questions

The form does not give specific questions to ask. It lists things that people with mental health problems who have a learning disability have said are important to them. The interviewer should ask any questions that are appropriate to get a picture of -

**What things were like for the person.**

**What they think about it.**

This allows you to tailor the interview to the person. It may mean asking several different questions to build a picture of what things were like, or what the person thought of them. It may mean finding out some of the factual details from other people if the person has difficulties recalling – but first ask the person if they are happy for you to do that, and who they think would know.

There are some important things to do when interviewing people with a learning disability. Here are some thoughts from Norfolk People First -

- Ask the person what they think 'mental health' means. If they don't know, explain what mental health and mental health problems are.
- Ask nice **clear** questions
  - no jargon
  - no double dutch
  - no complicated words
- Use booklets that tell a story to help people think about the service they received
- The people who are interviewing need to be good at listening
- Ask people where they want the interview to be. It is important that it is private
- People interviewing need to know the names of local services and places people might go to
- Watch people's faces to see if they understand
- Read back what's written down so people can change it if they want

## Analysing the information

Collate and analyse the completed survey forms at the end of the two months, and prepare a summary. Draw out **themes**.

If you want to compare results year on year use the 'yes/no' responses – but it is not an exact science! Completing the 'yes/no' column means making a judgement about whether the goal in column one has been achieved. It will be more reliable if the same person has carried out all the interviews and applied the same standards when deciding on a 'yes' or a 'no' rating.

# Survey Factsheet

Ask **the person** about these things. If they can't recall or seem hazy about the details ask their permission to find out from someone else. Ask them who you should approach.

THE NAME OF THE PERSON INTERVIEWED:

THEIR SEX:

AGE:

ETHNICITY:

WHERE DID THE PERSON LIVE BEFORE BECOMING AN IN-PATIENT?

WHO DID THE PERSON LIVE WITH  
(HOW MANY PEOPLE? WAS IT FRIENDS, FAMILY, LODGINGS, ETC?):

NAME OF THE IN-PATIENT UNIT THE PERSON WENT TO:

WHERE WAS THE UNIT?

WAS IT A COMPULSORY ADMISSION (A 'SECTION')?

YES

NO

WHAT MHA ORDER WAS THE PERSON UNDER?

HOW LONG WAS THE PERSON THERE?  
(OR HOW LONG HAVE THEY BEEN THERE SO FAR?)

IS THE PERSON STILL THERE (AT DATE OF INTERVIEW)?

YES

NO

HAD THE PERSON STAYED THERE BEFORE?

YES

NO

NAME OF INTERVIEWER: (print)

DATE OF THE INTERVIEW:

## A) About the place the person went to

WHAT PEOPLE WITH LEARNING DISABILITY SAY IS IMPORTANT	WHAT THE PERSON EXPERIENCED	WHAT THE PERSON THINKS ABOUT THAT EXPERIENCE	WAS THE GOAL ACHIEVED FOR THE PERSON?
<p>To go to a place near to home &amp; family/friends so they can visit easily</p>			<p>YES / NO</p>
<p>To go to a place that's in the centre of things, not in the middle of nowhere</p>			<p>YES / NO</p>
<p>To go to a place we know</p>			<p>YES / NO</p>
<p>The place to be small, for no more than 5 people</p>			<p>YES / NO</p>
<p>To be able to collect our post and things we need from home</p>			<p>YES / NO</p>

WHAT PEOPLE WITH LEARNING DISABILITY SAY IS IMPORTANT	WHAT THE PERSON EXPERIENCED	WHAT THE PERSON THINKS ABOUT THAT EXPERIENCE	WAS THE GOAL ACHIEVED FOR THE PERSON?
A private bedroom			YES / NO
Nice bathrooms and toilets			YES / NO
Rooms where you can get away from other people			YES / NO
For the other people there to be nice			YES / NO
For it to be quiet and peaceful			YES / NO

WHAT PEOPLE WITH LEARNING DISABILITY SAY IS IMPORTANT	WHAT THE PERSON EXPERIENCED	WHAT THE PERSON THINKS ABOUT THAT EXPERIENCE	WAS THE GOAL ACHIEVED FOR THE PERSON?
To be able to have visitors at any time			YES / NO
As a woman, to be in a place that's just for women			YES / NO
To be helped to do the things we are used to doing each day & to go to the places we usually go			YES / NO
To be able to make our own meals if we want, and eat when we choose			YES / NO
To be able to go back home when we are well again			YES / NO

## B) About the help and support the person received there

WHAT PEOPLE WITH LEARNING DISABILITY SAY IS IMPORTANT	WHAT THE PERSON EXPERIENCED	WHAT THE PERSON THINKS ABOUT THAT EXPERIENCE	WAS THE GOAL ACHIEVED FOR THE PERSON?
<p>To be given information and be told what's happening</p>			<p>YES / NO</p>
<p>To be asked what we want, and for people to listen</p>			<p>YES / NO</p>
<p>To have help to manage our own money there</p>			<p>YES / NO</p>
<p>To have good things to do each day</p>			<p>YES / NO</p>
<p>Not to be made to do things that we don't want to do. Not to be bossed around.</p>			<p>YES / NO</p>

WHAT PEOPLE WITH LEARNING DISABILITY SAY IS IMPORTANT	WHAT THE PERSON EXPERIENCED	WHAT THE PERSON THINKS ABOUT THAT EXPERIENCE	WAS THE GOAL ACHIEVED FOR THE PERSON?
To have help to make decisions			YES / NO
Staff who treat us well			YES / NO
Someone there you can talk to about yourself			YES / NO
For staff to respect our religious beliefs			YES / NO
Help to understand why we are unwell			YES / NO

WHAT PEOPLE WITH LEARNING DISABILITY SAY IS IMPORTANT	WHAT THE PERSON EXPERIENCED	WHAT THE PERSON THINKS ABOUT THAT EXPERIENCE	WAS THE GOAL ACHIEVED FOR THE PERSON?
<p>Help so that we feel better</p>			<p>YES / NO</p>
<p>A doctor that we know to come and see us</p>			<p>YES / NO</p>

## SECTION THREE

# Survey of community support experience

## Introduction

This tool will help you find out about the community support experiences of people with mental health problems who have a learning disability, and what they think of the support and opportunities they get.

It is based on what people who have mental health problems and a learning disability have said is important to them.

## How to use the tool

Set a timeframe for when interviews need to have been completed by – but make sure people have enough time to prepare and do it well.

Interview a sample of people. A useful sample would reflect the overall profile of people with mental health problems who have a learning disability in your area, and include –

- people who live with family carers, independently, and in residential homes
- people from different ethnic and cultural communities
- both men and women
- some people known to each of mental health, learning disability and primary care services

Try to write down what people actually say. Quotes are very helpful.

Ideally the interviews would be carried out by people with a learning disability, with appropriate training and support.

## Preparation

Explain to each person what the survey is all about, and make sure the person understands and agrees to take part. Ask if they would like someone with them for support.

Explain what the survey is about to people supporting the person day to day as well. They can then clarify things if the person has questions. Ask the person if s/he would like a copy of the form once it's filled out, and tell the person how they will hear about the findings from the survey.

Reassure the person that their name will not be used in reports.

## Asking questions

The form does **not** give specific questions to ask. It lists things that people with mental health problems who have a learning disability have said are important to them. The interviewer should ask any questions that are appropriate to get a picture of:

**What things are like for the person.**

**What they think about it.**

This allows you to tailor the interview to the person. It may mean asking several different questions to build a picture of what things are like, or what the person thinks of them. It may mean finding out some of the factual details from other people if the person has difficulties recalling – but first ask the person if they are happy for you to do that, and who they think would know.

There are some important things to do when interviewing people with a learning disability. Here are some thoughts from Norfolk People First:

- Ask the person what they think ‘mental health’ means. If they don’t know, explain what mental health and mental health problems are.
- Ask nice **clear** questions
  - no jargon
  - no double dutch
  - no complicated words
- Use booklets that tell a story to help people think about the service they received
- The people who are interviewing need to be good at listening
- Ask people where they want the interview to be. It is important that it is private
- Interviewers need to know the names of local services and places people might go to
- Watch people’s faces to see if they understand
- Read back what’s written down so people can change it if they want

## Analysing the information

Collate and analyse the completed survey forms at the end of the two months, and prepare a summary. Draw out **themes**.

If you want to compare results year on year use the ‘yes/no’ responses – but it is not an exact science! Completing the ‘yes/no’ column means making a judgement about whether the goal in column one has been achieved. It will be more reliable if the same person has carried out all the interviews and applied the same standards when deciding on a ‘yes’ or a ‘no’ rating.

# Survey Factsheet

Ask **the person** about these things. If they can't recall or seem hazy about the details ask their permission to find out from someone else. Ask them who you should approach.

**THE PERSON'S NAME:**

**THEIR SEX:**

**AGE:**

**ETHNICITY:**

**WHERE DOES THE PERSON LIVE?**

**WHO DOES THE PERSON LIVE WITH**

**(HOW MANY PEOPLE? IS IT FRIENDS, FAMILY, LODGINGS, ETC?):**

**WHO REGULARLY SUPPORTS THE PERSON TO MANAGE THEIR MENTAL HEALTH?**

**(TICK THOSE THAT APPLY)**

- SOCIAL WORKER/CARE MANAGER
- COMMUNITY MENTAL HEALTH NURSE
- COMMUNITY LEARNING DISABILITY NURSE
- GP
- PSYCHIATRIST
- PSYCHOLOGIST
- VOLUNTARY SECTOR MENTAL HEALTH SERVICE
- OTHER

**DETAILS:**

**NAME OF INTERVIEWER: (print)**

**DATE OF THE INTERVIEW:**

## A) About day to day life

WHAT PEOPLE WITH LEARNING DISABILITY SAY IS IMPORTANT	WHAT THE PERSON EXPERIENCES	WHAT THE PERSON THINKS ABOUT THAT EXPERIENCE	IS THE GOAL ACHIEVED FOR THE PERSON?
For the people we live with to be nice			YES / NO
Having a room where you can get away from other people			YES / NO
To feel safe where we live			YES / NO
For our home to be quiet and peaceful			YES / NO
To have help to manage our money			YES / NO

WHAT PEOPLE WITH LEARNING DISABILITY SAY IS IMPORTANT	WHAT THE PERSON EXPERIENCES	WHAT THE PERSON THINKS ABOUT THAT EXPERIENCE	IS THE GOAL ACHIEVED FOR THE PERSON?
<p>Having things to do (that we like doing) to take our mind off things - like working, learning, exercise</p>			<p>YES / NO</p>
<p>Getting support so that we can do those things</p>			<p>YES / NO</p>
<p>Having a holiday to relax</p>			<p>YES / NO</p>
<p>Being able to talk to friends</p>			<p>YES / NO</p>

## B) About the help/support the person gets with their mental health problems

WHAT PEOPLE WITH LEARNING DISABILITY SAY IS IMPORTANT	WHAT THE PERSON EXPERIENCES	WHAT THE PERSON THINKS ABOUT THAT EXPERIENCE	IS THE GOAL ACHIEVED FOR THE PERSON?
<p>To be given information about where and how to get help</p>			<p>YES / NO</p>
<p>To be asked what we want, and for people to listen</p>			<p>YES / NO</p>
<p>To have support to know about and to take our medicine</p>			<p>YES / NO</p>
<p>To have help to make sure we still get on with people when we are unwell mentally</p>			<p>YES / NO</p>
<p>Not to be made to do things that we don't want to do. Not to be bossed around.</p>			<p>YES / NO</p>

WHAT PEOPLE WITH LEARNING DISABILITY SAY IS IMPORTANT	WHAT THE PERSON EXPERIENCES	WHAT THE PERSON THINKS ABOUT THAT EXPERIENCE	IS THE GOAL ACHIEVED FOR THE PERSON?
To get good advice and help to make decisions			YES / NO
Staff who treat us well			YES / NO
Someone you can talk to about yourself			YES / NO
To be able to get help easily when we are feeling unhappy, stressed out...			YES / NO
Ongoing support, that doesn't stop			YES / NO

WHAT PEOPLE WITH LEARNING DISABILITY SAY IS IMPORTANT	WHAT THE PERSON EXPERIENCES	WHAT THE PERSON THINKS ABOUT THAT EXPERIENCE	IS THE GOAL ACHIEVED FOR THE PERSON?
<p><b>For staff supporting us to respect our religious beliefs</b></p>			<p><b>YES / NO</b></p>
<p><b>To get help so that we get better</b></p>			<p><b>YES / NO</b></p>
<p><b>A psychiatrist (or people who know about mental health) to come and see us at home, or who we can see near to home</b></p>			<p><b>YES / NO</b></p>

## SECTION FOUR

# Survey of carers' experience

## Introduction

This tool will help you find out about the experiences of family carers of people with mental health problems who have a learning disability, and what they think of the information and support they get.

It is based on what carers of people with mental health problems and learning disability have said is important to them.

This tool focuses on experiences that relate specifically to caring for a person with mental health problems and a learning disability. For a comprehensive approach to assessing carer support services generally see the King's Fund publication "How good is your service to carers? A guide to checking quality standards for local carer support services" (R. Blunden 2002).

## How to use the tool

Set a timeframe for when interviews need to have been completed – but make sure people have enough time to prepare and do it well. Remember that carers will need plenty of notice to organise some free time for the interview.

Interview a sample of carers. A useful sample would reflect the overall profile of people with mental health problems who have a learning disability living with family carers in your area, and include –

- family carers both under and over retirement age
- carers from different ethnic and cultural communities
- both men and women
- some family carers who have experience of the CPA system

Try to write down what people actually say. Quotes are very helpful.

Collate and analyse the completed survey forms at the end of the survey, and prepare a summary.

Ideally the interviews would be carried out by people who are carers themselves, with appropriate training and support.

## Preparation

Explain to each carer what the survey is all about, and make sure the person is happy to take part. Ask if they would like someone with them for support.

Ask the carer if s/he would like a copy of the form once it's filled out, and tell them how they will hear about the findings from the survey. Reassure the carer that their name will not be used in reports.

## Asking questions

The form does not give specific questions to ask. It lists things that carers of people with mental health problems who have a learning disability have said are important to them. The interviewer should ask any questions that are appropriate to get a picture of -

### **The carer's experience of services and support**

#### **What they think about it**

This allows you to tailor the interview to the person. It may mean asking several different questions to build a picture of what things are like, or what the carer thinks of them. It may mean finding out some of the facts from other people if the carer can't recall details – but first ask the person if they are happy for you to do that, and who they think you should approach.

## Analysing the information

Collate and analyse the completed survey forms at the end of the survey period, and prepare a summary. Draw out **themes**.

If you want to compare results year on year use the 'yes/no' responses – but it is not an exact science! Completing the 'yes/no' column means making a judgement about whether the goal in column one has been achieved. It will be more reliable if the same person has carried out all the interviews and applied the same standards when deciding on a 'yes' or a 'no' rating.

# Survey Factsheet

Ask **the carer** about these things. If they can't recall the details ask their permission to find out from someone else. Ask them who to approach.

**THE NAME OF THE CARER INTERVIEWED:**

**THEIR SEX:**

**AGE:**

**ETHNICITY:**

**WHERE DOES THE CARER LIVE?:**

**DOES ANYONE ELSE LIVING THERE HELP WITH THE CARING?**

**YES**

**NO**

**DETAILS (WHO? HOW MUCH?):**

**HAS THE CARER BEEN INVOLVED IN CARE PROGRAMME APPROACH (CPA) MEETINGS?**

**YES**

**NO**

**HAS THE CARER EXPERIENCED A COMPULSORY ADMISSION (SECTIONING) OF THEIR RELATIVE IN THE PAST TWO YEARS?**

**YES**

**NO**

**HAS S/HE HAD A CARER'S ASSESSMENT?**

**YES**

**NO**

**WHO DOES THE CARER HAVE REGULAR CONTACT WITH IN RELATION TO THE MENTAL HEALTH OF THE PERSON WITH A LEARNING DISABILITY?  
(TICK THOSE THAT APPLY)**

- SOCIAL WORKER/CARE MANAGER
- COMMUNITY MENTAL HEALTH NURSE
- COMMUNITY LEARNING DISABILITY NURSE
- GP
- PSYCHIATRIST
- PSYCHOLOGIST
- VOLUNTARY SECTOR MENTAL HEALTH SERVICE
- OTHER

**DETAILS:**

**NAME OF INTERVIEWER: (print)**

**DATE OF THE INTERVIEW:**

## A) Information and advice

WHAT CARERS SAY IS IMPORTANT	WHAT THE CARER EXPERIENCED	WHAT THE CARER THOUGHT ABOUT THAT EXPERIENCE	WAS THE GOAL ACHIEVED FOR THE CARER?
Easy access to information - a single place or person to get information from			YES / NO
To be given information about the mental health diagnosis and what it means for my relative			YES / NO
To be given information about where to get welfare benefits advice			YES / NO
To be given information about local carers' organisations			YES / NO
A clear explanation of the Care Programme Approach & the CPA meeting (if it applies to who I care for)			YES / NO
A clear explanation of the 'sectioning' process under the Mental Health Act, if it needs to be used			YES / NO
To feel that information is being shared by professionals and I don't have to keep repeating things			YES / NO

## B) Support

WHAT CARERS SAY IS IMPORTANT	WHAT THE CARER EXPERIENCED	WHAT THE CARER THOUGHT ABOUT THAT EXPERIENCE	WAS THE GOAL ACHIEVED FOR THE CARER?
<p><b>Continuity of contact with someone who will listen to my concerns</b></p>			<p><b>YES / NO</b></p>
<p><b>The offer of a carers' assessment that is separate from the assessment of the person I care for</b></p>			<p><b>YES / NO</b></p>
<p><b>Help to think about my own needs when things are calm and the person I care for is <i>not</i> in crisis</b></p>			<p><b>YES / NO</b></p>
<p><b>A break at short notice if I really need it</b></p>			<p><b>YES / NO</b></p>
<p><b>An emergency contact number so I can get help if I need it</b></p>			<p><b>YES / NO</b></p>

WHAT CARERS SAY IS IMPORTANT	WHAT THE CARER EXPERIENCED	WHAT THE CARER THOUGHT ABOUT THAT EXPERIENCE	WAS THE GOAL ACHIEVED FOR THE CARER?
<p>Professionals to keep making contact even if I'm sometimes not very receptive</p>			<p>YES / NO</p>
<p>Access to an advocate if I do not agree with the professionals or if I want support at CPA meetings</p>			<p>YES / NO</p>
<p>To receive support if the person I care for is admitted to hospital or a secure unit</p>			<p>YES / NO</p>
<p>To have enough time to do things when the person I care for is being 'sectioned'</p>			<p>YES / NO</p>

## C) Involvement

WHAT CARERS SAY IS IMPORTANT	WHAT THE CARER EXPERIENCED	WHAT THE CARER THOUGHT ABOUT THAT EXPERIENCE	WAS THE GOAL ACHIEVED FOR THE CARER?
To feel that I have been treated with courtesy and respect			YES / NO
To feel that what I do as a carer is recognised and valued			YES / NO
To feel that I am involved as a <i>partner in care</i> by services			YES / NO