



## **Making health services better for people with learning disabilities**

### **The Health Self Assessment Framework**

#### **Questions to help group facilitators**

These questions have been developed by people who have led or facilitated getting ready meetings.

They might help you prepare for or facilitate a conversation at a Getting Ready meeting.

This paper includes some ideas about what is good under the target in preparation for when people are scoring against the targets at the Big Health Check Day

**These questions are not intended to be given out to people like a questionnaire**

**People might talk about other issues too – these questions should not restrict people**



## Target 1

**Campus homes will be closed by 2010 and people who lived in hospitals will have moved into their new homes**

1.1

**To score well here, you will not have any people left living in hospitals who don't need to be there. If there are some people in hospital still, the Partnership Board should know about them**

- Do you know if there are still some people left in hospital and who need to move out?
- If there are, does your Partnership Board hear about the plans being made to help them move?



## Target 2

**People with a learning disability can use the same health services and get the same treatment as everybody else**

2.1

**To score well here your local GPs know about (and have a note of) people with learning disabilities who need a bit more help to stay healthy – like people with lots of health problems; people from other countries or older people who have a son or daughter with a learning disability still living at home**

**Self advocates:** (1) Can you have a bit longer with your GP if you want to? (2) Have you been asked to go to the surgery for checkups and advice on general health – for example help with things like asthma or losing weight?

**Carers:** (1) Does your GP know you are a carer? (2) Has your GP offered you some support or advice about how you can stay healthy and well?

**Staff; commissioners:** Can you give us information about:

- (1) consistency of use of Read codes across practices;
- (2) Accuracy and consistency of registers cross-checked across GP Practice and Local Authority registers or data.
- (3) With reference to measures requested in the Feedback form – can you at present get hold of the requested level of GP registration information on all groups?

## **2.2**

**To score well here GP practices need to be giving people a really good all round local health service – including Annual Health Checks**

**Self advocates:**

- (1) Have you been offered a Health Check at your GP surgery?
- (2) Did you have one?
- (3) Do you have a Health Action Plan? If so, who helped you to make it?

**Staff; Carers:**

- (1) Have you been involved in helping to carry out a Health Check for the person you care for?
- (2) Have you been involved in helping to do a Health Action Plan for the person you care for?

**Commissioners:**

- (1) Can you provide numbers of GPs implementing the DES expressed as a percentage of your practices?
- (2) Do you know how many people have (a) had an annual health check? (b) a Health Action Plan?

## **2.3**

**To score well here, you need to be sure that people with learning disabilities are able to get involved in things that keep them healthy – just as easily as everyone else can.**

These are things like:

- Being asked in for checkups for particular illnesses like cancer. Breast screening and cervical smears
- Doing things to get healthier – like being asked to join stopping smoking groups – or joining in Healthy Heart Days

**Self advocates:**

- (1) What kinds of things are you getting involved in to stay healthy?
- (2) Does your Doctor have information about health issues that is easy to read?

**Staff; Carers:**

- (1) Have the people you care for been invited to get involved in health promoting clinics or activities in the past 12 months?
- (2) Has your organisation developed activities to promote the better health of the people in your care?
- (3) Have you heard about the Joint Strategic Needs Assessment?

**Commissioners:**

- (1) Does the PCT have systems in place to collect the data requested in the Framework?
- (2) Do you have a learning disability section in your local JSNA?
- (3) Have you agreed specific expectations in your general health and social care contracts linked to promoting people's health?

**2.4**

**To score well here people like district nurses, dentists, chemists and opticians in your local area need to be offering a really good service to people with learning disabilities who might need a bit more help when they go to the chemist or to the dentist etc**

**Self advocates:**

- (1) Do you feel OK about going to the dentist, chemist or other people about your health?
- (2) When did you last go?
- (3) Are you registered with a local dentist?
- (4) When you go to the chemist or dentist, etc can you get easier to read information about your treatment or the pills you are taking?

**Staff; Carers:**

- (1) Can you tell us about your recent experiences in supporting a person to use wider primary care services?

**Staff; commissioners:** (1) What have you done in past year to raise awareness and improve practice amongst wider primary care practitioners

## 2.5

**For this point we need to know about people's recent visits to hospital. We also need to know about the agreements that your PCT has with your local hospitals.**

### **Self advocates:**

- (1) If you were in hospital in the last year or so, can you tell us about it?
  - (a) What went well?
  - (b) What didn't go too well?
  - (c) What can be done to make hospital stays better?

### **Self advocates:**

- (2) Do you know your rights when you use the health service – for example that you should not wait longer than 18 weeks to go to hospital after your first GP visit?

### **Staff; Carers:**

- (1) If you were closely involved with supporting someone through a recent stay in hospital can you tell us:
  - (a) What was the preparation like (e.g. pre admission checks and information)?
  - (b) What particular things did the hospital staff do to know about and help with the patient's support needs?
  - (c) Were you involved and informed?
  - (d) Were you happy with discharge arrangements and aftercare?

**Self advocates; Staff; Carers:** Do you know if anyone has done a survey about how people with learning disabilities and their carers find the service they receive from local hospitals?

### **Commissioners:**

- (1) What work have you done with NHS organisations in light of 'Six Lives' and Healthcare for All, etc?
- (2) Have you included explicit clauses in all your healthcare contracts in respect of reasonable adjustments?

## 2.6

**To score well here, you need to know if people with learning disabilities are mentioned in the plans being made to improve general services for anyone with cancer, heart problems, breathing problems etc.**

**Carers; Self advocates:** Do you think things have improved in your area in the way people in health services treat you or the person you care for since Valuing People came out in 2001?

**Self advocates:** If you have a medical condition, do you go to see the doctor regularly for a check up about your condition?

**Commissioners:**

(1) Are you liaising with mainstream commissioners and influencing what they put in their contracts? Can you give an example of how things have changed or improved from this?

## 2.7

**To score well here, you need to know from your doctor and your PCT about the new things happening in health linked to information about your health which is held on computer – and about knowing what this means for you**

**Self advocates:**

(1) Has your doctor talked to you about the information from your Health Check or your Health Action Plan?

## 2.8

**The government says that people from other countries or of other religions who live in this country now, should be getting as good care from the NHS as everyone else**

**Self advocates; Staff; Carers:**

(1) Do you know if there is a big plan in your local area – or in your Partnership Board - about people who live here who are from other countries or religious groups?

(2) Have you seen this plan or being part of making it?

**Commissioners:** Do you have data about the numbers and needs of people with learning disabilities from minority ethnic groups in your area?

## 2.9

**Your score here will depend on how good you think health services are for people with very complex learning disabilities and their families**

**Self advocates:** Does your Partnership Board talk about people who have lots of health needs and who need a lot of care – and about their parents who look after them?

**Carers:**

- (1) Do you feel the range and quality of support for you and the person you care for has improved since Valuing People Now came out.
- (2) Can you give us some examples of how things have improved?
- (3) What do you think still needs to get better?

**Commissioners:**

- (1) Do you have up to date, comprehensive statistics about the numbers of young people and adults who have profound and multiple learning disabilities in your area?
- (2) Do you have a plan - and the money you need - to improve services for people and their families?



## Target 3

### People with a learning disability are safe in the National Health Service

#### 3.1

Lots of reports have come out about the poor treatment some people have had like 'Healthcare for All' – and Partnership Boards have asked people to have plans to make sure that local services are safe.

To score well here, you need to know that people are learning from what has happened in other places – and that they are doing what they said they would in their plans

#### **Self advocates; Staff; Carers:**

(1) Have you heard about the Healthcare Commission investigations (like Cornwall) and reports and about 'Healthcare for All'?

(2) Do the Partnership Board and other groups hear about what plans the local hospitals and the PCT have made to stop this happening again and how they are working?

**Commissioners:** (1) What steps have you taken with local partner organisations following 'Healthcare for All' and 'Six Lives' etc?

#### 3.2

Health organisations need to have policies which are notes which tell their employees what to do in certain situations.

Some of these policies are about protecting patient's rights – especially if they have a learning disability.

To score well here organisations need to show that they have these policies, and that they work well for people and that the people who use services need to feel that they are in control of what happens to them.

#### **Self advocates:**

(1) Have you been asked to give permission (consent) to medical treatment for example having a tooth out, or having an operation?

(2) Has anyone else signed (permission) consent forms for you - or been asked instead of you?

**Staff; Carers:**

(1) Have you been asked to agree to medical treatment for the adult you support? If so, what did you do?

**Self advocates; Staff; Carers; Commissioners:**

(1) Do you feel you know all about laws like the Disability Discrimination Act, Human Rights Act, and so on, that protect people's rights – and of how these should apply for people with learning disabilities when they are getting health care?

### 3.3

**Health Services and Social Services need to listen to complaints and investigate bad things that happen to people with a learning disability. They then need to change how things happen to make things better.**

**To score well here, you need to be sure that local health services make it easy for people to complain if they want to; and that they change things for the better after complaints.**

**Self advocates:** (1) Do you know how to make a complaint about the health services you receive, if you need to? (2) Have you ever made a complaint about the health care you have received? Did things change afterwards?

**Carers:** (1) Do you know how to make a complaint about the health services your family member has received, if you need to? (2) Have you ever made a complaint about the health care you have received? Did things change afterwards?

**Staff; Carers; Self advocates:** (1) Are you a member of a group in the hospital or PCT which talks about this? (2) Have you heard of LINKS and are you involved in this?

**Commissioners:**

(1) Do you systematically receive details of serious incidents and complaints in all healthcare organisations with which you have contracts?

(2) Do you systematically report trends and action taken to your executive teams?

(3) Do you systematically report trends and action taken to your Partnership Board?

### **3.4**

**All local services like health and social services need to work together very well to make sure people are safe from possible harm or abuse.**

**Each local area should have a policy or plan about this.**

**Inspectors come in to check this regularly.**

**To score well here people need to have information about the policy, and about what the Inspectors said when they came. As well as this, people on Partnership Boards should be getting information about how this affects people with learning disabilities locally.**

**Self advocates; Staff; Carers; Commissioners:**

(1) What kind of things are Health Services and Social Services doing in Your area to try and make sure that vulnerable people are protected from abuse?

**Self advocates:** Do you have a person on your Partnership Board who goes to the meetings of the local Safeguarding Board?



## Target 4

**We are making progress on the things that Valuing People says will help people's health**

### 4.1

**This is about the PCT and social services having up to date information about every person with a learning disability whose care is being funded by the health service – and about knowing how all those people are doing and if they are getting the care they want.**

**This could be young people about to leave school, or people in private hospitals far from home.**

**To score well here, you need to be getting regular reports from the PCT to the Partnership Board about the work they are doing**

**Self advocates; Carers:** Do you feel you know about the people with learning disabilities the PCT buys services for – and if they are the services that people want?

**Self advocates:** Do you feel that you have been able to have a choice about who you live with and where you live?

**Commissioners:** (1) Do you have all the data outlined in the full framework document about numbers of people, where they are, how much they cost etc?

### 4.2

**To score well here, you need to be sure that there are enough specialist learning disability services available to people locally. This means that people can stay near home with the right support, without having to go to hospital and without being sent far away from home**

**Self advocates; Carers:**

(1) Do you know if there are still people who have to leave your area to get the special services they need?

(2) Do you know if people who left long stay hospitals had to go back into hospital, because there were not the services to look after them?

**Commissioners:**

- (1) Are you collecting and analysing the information in the 'measures' column of the Framework?
- (2) Are there delays in discharging people from I/P Assessment and Treatment places in Your area?

**4.3**

**This is about planning better for young people when they leave school – especially for young people who might need a bit more support with their health.**

**To score well here you will need to be happy that there is a good range of skilled support locally in both mainstream and specialist health services, to look after people when they leave school.**

**Self advocates; Carers:**

- (1) Do you feel there is a difference between the support you have from mainstream and specialist services before you are 18 - and after?
- (2) What would have been helpful - for you and your family – when you, or your family member, were coming up to the time to leave school?

**Self advocates; Staff; Carers:**

- (1) Do you know if your PCT and local authority are making plans early on to make sure that there are enough services to support local young people who are coming up to age 18 ?
- (2) Does your Partnership Board get reports about this?

**Commissioners:**

- (1) Do you have data about the numbers of young people in your area who are likely to require support from health services when they leave school? Are you making plans on this basis and are you telling the Partnership Board about this?
- (2) Do you commission youth advocacy services?

#### 4.4

**People with learning disabilities and the people close to them should be able to give their views on health services. They should get help to do this - and it should lead to changes in the way that services are planned and arranged.**

**To score well here, you need to build up a picture about how people with learning disabilities and their carers and supporters are involved in making decisions and plans**

**Self advocates; Staff; Carers:**

(1) Are you asked to go to meetings or to give your views about things?

(2) Do you feel as if you can have a say about big health plans?

(3) Does your GP and local hospital give you information that is easy to understand – and do people explain things to you or the person you care for clearly when you are poorly?

**Self advocates:** (1) Are you invited to meetings where people talk about certain health conditions and how to look after yourself better?

**Staff; commissioners:** (1) Can you tell us about the steps you are taking to make sure that people have access to easier to understand information about their health in all healthcare settings?

#### 4.5

**Local organizations should work well together in a way which makes services better for people – and uses their money well. They should have agreements about how they share information, about how they plan things together, and who pays for what. To score well here, people need to know that all of this is happening**

**Self advocates; Staff; Carers:** (1) Do you know about Valuing People Now and about how people are making sure all the things in it are happening?

**Staff; commissioners:** (1) Can you tell us about the work that is happening in your area to make sure the Joint Strategic Needs Assessment has really good information about people's health needs?

#### 4.6

**This point is about planning better for people as they get older – especially for people who might need a bit more support with their health.**

**To score well here you will need to be happy that there is a good range of skilled support locally in both mainstream and specialist health services, to look after people when they get older**

**Self advocates; Staff; Carers:** (1) Have you seen or helped to write any plans about people with learning disabilities who are getting older? The plans should link into – or be part of - other local plans for people who are getting older

**Commissioners:** (1) Do you have comprehensive information about the numbers and needs of people who are ageing in Your area with a learning disability, and how are you using this information to enable person-centred care for these people?

#### 4.7

**The PCT and other partners should have a big plan about how to make sure people with learning disabilities and autism can get good, skilled services locally – and not have to go away from home if they need health care.**

**To score well here, you would need to be confident that your local PCT and social services know all the people locally who have autism, and have good plans about having services locally for them now and in the future. This includes the needs of young people in transition to adult services.**

**Self advocates; Staff; Carers:**

(1) Has your Partnership Board talked about people with autism?

(2) Have you helped to write a Big Plan about this?

**Commissioners:**

(1) Do you have comprehensive information about the numbers and needs of young people and adults who have autism in Your area, and how are you using this information to enable person-centred care for these people?

#### **4.8**

**The PCT and other partners should have a big plan about how to make sure people with learning disabilities and behaviour that challenges can get good, skilled services locally – and not have to go away from home if they need health care.**

**To score well here, you would need to be confident that your local PCT and social services know all the people locally who have behaviour that challenges, and have good plans about having services locally for them now and in the future. This includes the needs of young people in transition to adult services**

**Self advocates; Staff; Carers:**

- (1) Has your Partnership Board talked about people with behaviour that challenges?
- (2) Have you helped to write a Big Plan about this?

**Commissioners:**

- (1) Do you have a specialist services strategy in place?

#### **4.9**

**This is about people with a learning disability being able to use mental health services if they choose, and making sure that those services are skilled in providing the care needed.**

**The Green Light Toolkit written by Valuing People should help Partnership Boards and PCTs to see what more work is needed.**

**To score well here, people should be using the Green Light Toolkit and working with mental health services to make a Big Plan about future services for people.**

**Self advocates; Carers: Staff:**

- (1) If you or the person you care for have or has had a mental health problem in the past, was it easy to get the right help?

**Self advocates:**

- (1) Is your care manager from a Learning Disability team or another team?
- (2) Do you think your care manager is from the team that can help most?

**Commissioners:**

- (1) Do you have an explicit strategy in place for people whose main need is for mental health services and support?
- (2) Do your contracts with local mental health services specify your service requirements in the context of the strategy?

#### **4.10**

**This point is about how plans are made in your local area about the training that people working in services, need.**

**As the way that people live their lives changes, the help and support that they need changes too – so training courses and education need to change too. To score well here, you need to know that there are good up to date plans about how college courses and professional training are being designed and improved in line with the changing lifestyles of people with learning disabilities**

**Self advocates: Carers: Staff: Commissioners:**

(1) Has your local Partnership Board helped to write your local Workforce Big Plan?