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Any errors or omissions are, of course, our own.
Good health is important to everyone and we all have the same rights to use NHS services. But many people with learning disabilities find it difficult to keep healthy and to get the services they need.

The White Paper *Valuing People: A New Strategy for Learning Disability for the 21 Century* set out the Government’s proposals for improving the life chances of people with learning disabilities. It showed how the commitment in the NHS Plan to a person-centred health service will improve health care for people with learning disabilities too. Personal health action plans, supported with extra help or facilitation if necessary, will play a key part in this.

This good practice guidance explains how people can be supported to access the health care they need from both primary care and other NHS services. It shows how personal health action plans can help to improve the health of all people with learning disabilities.

In his foreword to Valuing People the Prime Minister said:

“I know the publication of a White Paper, however good its proposals, does not itself solve problems. The challenge for us all is to deliver the vision set out in the document so the lives of many thousands of people with learning disabilities will be brighter and more fulfilling”.

I know that many people working in primary care teams and other parts of the NHS are eager to take up this challenge. It is essential that both children and adults with learning disabilities, are helped to be full citizens using NHS services like everyone else. This may not always be easy but the good practice guidance contained in this booklet will help this to happen.

David Colin-Thome  
National Director for Primary Care
Introduction

A Health Action Plan details the actions needed to maintain and improve the health of an individual and any help needed to accomplish these. It is a mechanism to link the individual and the range of services and supports they need, if they are to have better health. Health Action Plans need to be supported by wider changes that assist and sustain this individual approach. The Plan is primarily for the person with learning disabilities and is usually co-produced with them.

Useful (secondary) functions of Health Action Plans might also be:

- to educate or inform the individual and people working with them about health
- to improve the co-ordination of services for the individual
- to influence services and other structures that affect the person’s life (including the collection of data to inform change).

However, if there is conflict between the primary purpose of the Heath Action Plan in maintaining and improving the health of the individual and these secondary purposes, the former must take precedence.

It has often been difficult for people with learning disabilities to maintain and improve their health in the past, for a number of reasons:

- they may be living lives that are not conducive to good health, including the effects of discrimination and disadvantage
- inadequate attention has been paid to health issues
- people have not had enough knowledgeable support to identify and address health concerns
- people have had poor access to health care and an inadequate response from health care providers.

“We don’t get to talk about our health much.”
Health Action Plans can help people to maintain and improve their health by:

- focusing attention on health issues
- identifying health concerns, and how to address them
- ensuring there is an adequate response, from a range of services including positive responses from the NHS
- supporting changes in the wider context of people’s lives and addressing health issues that prevent people from achieving greater social inclusion

**Putting the White Paper into practice**


‘*All people with a learning disability to have a Health Action Plan by June 2005.*’ (p.61)

‘*The Government expects all Learning Disability Partnership Boards to have agreed a framework for the introduction of Health Action Plans and to have ensured that there are clearly identified health facilitators for all people with a learning disability by June 2003.*’ (p.65)

It outlines some important related actions:

‘*Primary Care Trusts in their commissioning role should ensure that general health care for people with learning disabilities is built into existing priorities. Partnership Boards need to work with the Primary Care Trusts to ensure there is an integrated plan for supporting the primary care and general health services to work with people with learning disabilities, with clarity about expectations upon both general practice and general hospitals.*’ (p.65)

The White Paper also says:

- All people with learning disabilities should be registered with a GP by June 2004.
- GPs should identify all people with learning disabilities registered with their practice by June 2004. Progress will be monitored by the Department of Health.

(These issues are relevant to Health Action Plans and are covered in section 2)

*Valuing People* emphasises that health care should be delivered with an emphasis on the whole person – good health is important if people are to achieve what they want from life.
This guidance builds on *Valuing People* and provides more detailed information to assist Partnership Boards in their responsibility to ensure Health Action Plans are implemented. The guidance has been developed hand-in-hand with a series of consultation meetings with those groups who will be involved in implementing Health Action Plans. Some of their comments are quoted throughout the text. They include: people with learning disabilities, family carers, support staff, primary care, other generic health professionals, learning disability health professionals and members of learning disability partnership boards. The consultations included members of black and minority ethnic groups. The guidance attempts to address and answer the issues raised in the course of those consultations.
Section 2
What is Health Facilitation?

Health Facilitation has evolved from roles developed by family carers, practitioners and others wishing to improve the health of people with learning disabilities. It has also emerged from the wishes of people with learning disabilities and their relatives and support workers who wanted someone to help support and navigate them through the NHS to access the best and most appropriate healthcare.

Valuing People stated that there should be clearly identified Health Facilitators for people with learning disabilities by 2003.

This section outlines the role of Health Facilitators in terms of their skills, knowledge, and expertise and outlines the competencies required. It is helpful to see Health Facilitation as a role rather than necessarily a specific post.

Health Facilitation involves both case work to help people access mainstream services and also development work within mainstream services to help all parts of the NHS to develop the necessary skills. The impetus for both is to help ensure good health care is delivered in primary and secondary care as well as by specialist learning disabilities services.

The Health Facilitation role needs to be developed at 2 levels:

Level 1 – Service development work and informing planning and commissioning

Level 2 – Person to person work with people with learning disabilities

Level 1 – Service Development work

At this level, responsibility for the outcomes described in Valuing People include

1. Supporting the achievement of specific Valuing People targets including:
   • that all people with learning disabilities are registered with a GP by June 2004
   • that all GPs know the people with learning disabilities on their list.
Developing, monitoring and auditing initiatives designed to reduce health inequalities such as:

- liaising with the Patient Advice and Liaison services (PALs) in each NHS trust
- monitoring the health status of people with Learning disabilities relative to the general population with public health colleagues to reduce health inequalities
- helping services become culturally competent and meet the needs of people with learning disabilities from and within black and ethnic minority communities
- auditing discriminatory practice in access to healthcare, including access to mainstream screening programmes (e.g. cervical screening) and acute healthcare and linking to clinical governance responsibilities
- auditing health information provided for its ease of use by people with limited reading skill

Practice Example: South Birmingham PCT has appointed a Community Learning Disability Nurse as a PRIMIS facilitator in learning disabilities. She is supporting 205 GPs to identify their patients with learning disabilities with the help of a GP advisor. Her role includes sharing information about people with learning disabilities known to the community learning disability team. Each practice must review its own list of patients to identify people with learning disabilities and then to update their computerised record with the appropriate Read Code*. This elementary tag is sufficient to meet the Valuing People target. It is important to note that other health conditions such as CHD or cancer or the cause of the learning disability can also be recorded.

In Birmingham this process is also being used to identify people who are a higher priority for HAPs.

*PRIMIS, the primary care information system uses Read codes to collect information about patients with particular needs. For example, the Coronary Heart Disease (CHD) National Service Framework has developed a minimum data set for GPs to collect about their patients who meet the criteria for CHD. The Read Codes are based on the International Classification of Diseases (ICD10 published by the World Health Organization). The term used internationally for learning disability is mental retardation (not learning difficulties or specific learning disability, these 2 codes refer to difficulties such as dyslexia).
• liasing with Workforce Development Confederations to develop training plans, e.g. for mainstream healthcare staff and for direct support staff within the Learning Disability Awards Framework (LDAF).

A range of health professionals, managers and commissioners could fulfil these responsibilities.

**Practice example**

**Plymouth Primary Care Trust and Plymouth Hospitals Trust** have operated under an acute services liaison protocol since 1999. Two Learning Disability Community Nurses work with 28 General or Community Hospital nurses to ensure that acute care is adjusted or facilitated to meet the communication and individual needs of people with learning disabilities. The two NHS Trusts collaborated to produce a training video aimed at improving hospital services for people with learning disabilities.

**Practice example**

**The Home Farm Trust (HFT)**, a national, voluntary sector service provider, has a ‘Health Action Plan’, addressing organisational, local service and individual needs. At an organisational level, the plan addresses three key, inter-related areas: competence and training; innovations and resources and information and communication. The plan is reviewed and monitored and priorities are identified in accordance with changing service needs.

Local service plans support the development of partnership working, not only with each person through the Person Centred Planning approach, but also with health services, multi-disciplinary teams, commissioners and local providers. Individual plans are developed with the person, identifying specialist support and promoting a healthy lifestyle.

Health Action Planning has lead to a number of developments within HFT, including health profile checklists (produced in an accessible and understandable format) and the dissemination of good practice guidelines to all services (for example on health screening). Future work includes the drafting of good practice guidelines on invasive treatments; working with older people; working with people who have mental health support needs and supporting people who have epilepsy.

Health facilitators can build up knowledge of services and supports that are available locally (for example, health education and health promotion initiatives) and help people to draw on such resources.

People with learning disabilities should be able to access the skills and experience of all the people and agencies in their area, who can contribute to their good health.
As mainstream service providers get more support, and become more confident in providing a service to people with learning disabilities, they should be able to play a greater part in meeting their health related needs. As people with learning disabilities learn more about their own health and have greater access to advocacy initiatives, they should be able to play an increasing role in advocating for their own health, and that of their peers. As social care staff access more training about health issues they should be able to provide more effective support around health and accessing health care. Supporting these developments will be a key role for Partnership Boards (see Section 11).

Level 2 Person to person work with people with learning disabilities

At this level health facilitation will focus on individual health outcomes. A health professional or support worker can facilitate this. An advocate, friend; or family carer could also fulfil the role.

It will be important to be sure that the person with learning disabilities has confidence in the person.

Health professionals would be expected to fulfil a wide range of the responsibilities, others might wish to take some responsibilities while getting support for others.

The key role played by many support workers, family carers, friends and advocates is recognised. Many people with learning disabilities and their carers have said they need additional advice and support so that they can be more effective themselves in accessing the best and most appropriate health care.

The essential responsibilities are:

- helping to identify and record health targets for the Health Action Plan
- supporting access to all health services including NHS screening programmes
- ensuring the Health Action Plan is an integral part of Person Centred Planning, a transition plan or other personal care plan
- helping to identify and meet health education needs
- monitoring individual health outcomes through regular review and where necessary agreeing changes to the Health Action Plan.
Additional responsibilities may include:

- ensuring a person living in residential care has an annual health check in primary care as specified in line with the National Minimum Standards for Care Homes
- ensuring an older person with a learning disability benefits from the Single Assessment Process as specified in the National Service Framework for Older People
- training family carers to ensure optimum health outcomes
- supporting people with learning disabilities and carers to raise concerns, complain or complement service providers on the quality of services provided; liaising with PALs in a NHS trust about a complaint or concern where necessary
- reporting discriminatory practice to Partnership Boards to ensure they are aware of concerns in practice
- reporting any service deficits which limit individual health improvement.

People with profound and multiple disabilities, severe mental illness or other complex health needs are likely to need a specialist health professional to assist them with their Health Action Plans. e.g. Someone with cerebral palsy, severe learning and communication difficulties and swallowing problems would benefit from a speech and language therapist with dysphasia expertise to play a key facilitation role.

Whatever their current role, all specialist learning disability health professionals should incorporate a health facilitation function within their responsibilities. Some specialist learning disability health professionals may need to obtain additional training to prepare them for this new support and training role.

Health facilitation who ever does it and in whatever way in whatever setting is about ensuring healthier lives and better health for people with learning disabilities.

Partnership Boards will want to assure themselves that there are plans in place for health facilitation as well as health action plans and that they are working well to improve health and health services for people with learning disabilities.
Section 3
How Health Action Plans might work in different circumstances

The implementation of Health Action Plans will vary in different areas, and for individuals. The following are intended as examples, to show how Health Action Planning might work in practice. The stories are fictitious, but include elements based on genuine practice.

It is important to be sure that the Health Action Plan works within other systems and approaches so that people have a co-ordinated response from services

Lucy Peyton

Lucy is a 49-year-old woman with learning disabilities, living in her own flat, with support from a care worker. She attends a work placement once a week and sees her mum and dad regularly. They are quite elderly.

In Lucy’s area, GPs have begun to identify patients with learning disabilities on their list. Their policy is to invite each person identified for a health assessment, if they have not had a full assessment in recent years. The Practice Nurses carry out the assessments.

At the assessment it is noted that Lucy has not had a dental check up or an eye test since she left home (over five years ago). Lucy’s conversation suggests she is in the menopause though is not sure what this means and requests help to lose weight. The result of her health assessment shows that she has previously undiagnosed high blood pressure.

The Practice Nurse helps Lucy to devise a Health Action Plan in which the GP and Practice Nurse advise Lucy on managing her high blood pressure and information about the menopause. Lucy is given information about user-friendly dentists and opticians (from the Health Promotion Team) and requests that her carer assist her with appointments. A referral is made to the health promotion team (which includes a Learning Disability Nurse) for support with weight management, education about high blood pressure, and a women’s group (for education and support with menopause).

Lucy is also worried about the health of her elderly parents. The Practice Nurse helps Lucy by agreeing who they can approach about her concerns.

Lucy has recently been given a personal health information file by the health promotion team. She really likes this file, as it is small and can fit into her handbag. Lucy likes writing and writes down all her health appointments in the diary section and other health details in other parts of the file. At the back there is a section for her to write her Health Action Plan. She
gives a copy of this plan to her GP. Part of her Health Action Plan is illustrated here. Lucy monitors and updates her Health Action Plan with the help of the Practice Nurse, each time she attends her surgery for an appointment. She finds it useful to have the plan written down and feels reassured that her health has been assessed, in spite of having had problems detected.

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<th>Health Action</th>
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<td>1st Feb 2002</td>
<td>high blood pressure</td>
<td>Visit practice nurse Sue every month to have my blood pressure checked. Sam the health promotion nurse will visit me at home to help me learn more about high blood pressure. Start doing exercises on sheets from each month of any exercise, and if I am worried I can talk to Sue or drill Sam or Sue will help in losing weight. I might go to slimming club to eat more fruit and veg eat smaller portions and so must take away units in head of smoking.</td>
</tr>
<tr>
<td>1st Feb 2002</td>
<td>hot flushes due to Menopause</td>
<td>I will try 12st 4/18 I want to loose weight</td>
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Martha James

Martha is a 24-year-old woman, who lives in her own supported accommodation. Martha works in a hotel and goes to college some days. She has lots of friends and a boyfriend. Martha belongs to her local self-advocacy group. She makes the decisions about her life, and tells people what she wants. Martha has a circle of support, which includes her mum. Martha’s circle worked with her to make a Person Centred Plan. This helped her to move from her family home and get a job. Martha is usually very healthy.

Martha hears about Health Action Plans from her local self-advocacy group. She wants to put one together because she has put on weight recently and wants to think about using contraception. She obtains a booklet from the local health promotion service, to help her work on her own Health Action Plan.

Martha asks a member of her circle of support to help her put together her Health Action Plan which says that she will join a slimming club, and find out about contraception. Martha takes her plan to her GP to check it out and get further advice. Martha’s GP decides that she, like most other patients, does not need a full health assessment. Martha had a new patient check about 18 months ago, when she moved into her new flat; it showed no worrying family
Martha’s GP is happy with the approach taken by the slimming club, and tells Martha about the local family planning clinic and how to make an appointment. The GP explains that it would also be a good idea for Martha to find out about breast health and cervical screening, and that she can find out more from the family planning clinic, or make an appointment with the Practice Nurse.

The GP writes the advice into Martha’s plan, and with her agreement, takes a photocopy of it for Martha’s file. The GP suggests she come back if there are any problems in putting her plan into practice, or with any other health concerns. Martha has used her Health Action Plan to manage her health in a way that suits her. She has got the information and help she needs to take control of and improve her own health.

Martha’s Health Action Plan is part of her person centred plan and her circle of support which includes her family, all helping her achieve the things she wants in her life.

Othman Ali

Othman is 23 years old and lives with his parents, three younger sisters and grandmother. He attends a ‘special care unit’ at a day centre and has profound and multiple disabilities. Othman has a range of health needs and also needs a lot of help in his everyday life. He uses a wheelchair for getting around.

Othman and his family are supported by a range of professionals. The Physiotherapist from the local Community Learning Disability Team visits Othman weekly. She also sees him at his weekly hydrotherapy session. Othman enjoys food but has problems with swallowing, maintaining his weight and getting a well balanced diet. The Speech and Language Therapist monitors his swallowing and the Dietician reviews his diet and food supplements. The District Nurses visit to record his weight and to administer enemas to relieve chronic constipation. They arrange to provide incontinence supplies. The Community Learning Disability Nurse and Learning Disability Consultant Psychiatrist monitor his poorly controlled epilepsy and review his epilepsy in a joint clinic with the Consultant Neurologist. The GP visits when Othman is ill. Othman has not seen a dentist since leaving school.

Othman’s family tell the District Nurses that he is due to go into hospital for orthopaedic surgery. The nurses talk with his parents about all of Othman’s care and discuss which of the professionals involved knows him best. As a result they contact the Physiotherapist and they all agree that a Health Action Plan would be useful to co-ordinate, plan and record short term and longer-term actions to maintain and improve Othman’s health care. The Physiotherapist, as the professional who knows him best, agrees to facilitate this process.

Othman has a temporary Health Action Plan to cover his hospital stay and discharge. He also has a longer term Health Action Plan, which helps to inform all professionals and carers of
Othman’s individual, current and future needs and who is responsible for meeting them. It reassures Othman’s family that his needs are met in a co-ordinated way, and that they are recorded and known by them. They are happy that their knowledge of Othman’s needs is shared with professionals and other carers. The Physiotherapist regularly reviews the Health Action Plan.

In planning the development of Othman’s HAP the physiotherapist wants to ensure that all health care provision is culturally appropriate. After discussion with Othman’s mother, the physiotherapist liaises with the local hospital Asian link worker, who agrees to support Othman and his family, both at home and in hospital. The link worker also agrees to assist in the translation of the written plan into the family’s first language.

Due to the complexity of Othman’s needs and the difficulty in including him in the development of his Health Action Plan, at the family’s request a simple Health Action Plan is written, using a local pre-prepared form. A front sheet lists the names and contact details of all 22 professionals working with Othman. Copies of his HAP are sent to all professionals. To facilitate Othman’s Health Action Plan the physiotherapist reviews his HAP six-monthly or more often as required. A small section of his plan is illustrated here. A programme to increase Othman’s self-awareness is developed and his increasing inclusion is considered by all professionals in their future role with Othman.
Joseph Spencer

Joseph is a 43-year-old man who has Down’s syndrome. He has limited verbal communication and needs help with most aspects of daily living. He lives in a large residential home. Apart from having dry skin he has no known health problems and he has not visited his GP practice for many years.

Over the past few months, staff and his family have noticed a change in Joseph’s behaviour. He has become very irritable, hitting himself and others. In addition he has started spending lots of time in the toilet and has wet the bed on several occasions. Staff feel he may be sexually frustrated and have referred him to the local Community Learning Disability Team.

The Community Learning Disability Nurse visits Joseph and helps his key worker consider a Health Action Plan. They agree that Joseph needs a full health assessment from his general practitioner. An appointment is made and a plan of how to prepare Joseph for this is developed. The need for an eye test and an approach to managing his recent changed behaviour is also acknowledged.

As a result of the health assessment Joseph is found to have type 2 diabetes. He is put on to a diabetic diet and given regular hospital and GP and diabetes specialist nurse appointments. An annual appointment is booked to check his thyroxine and cholesterol blood levels. He will have a referral to more specialist expertise if required.

Joseph’s Health Action Plan contains a plan of all of his health actions and the name of who will prepare and support him in each, so everyone involved in his care is clear what is needed. Joseph’s key worker, Simon, talks with the community nurse to think about how to involve Joseph in his Health Action Plan. They consider how they could use Joseph’s main interest of looking at picture books and magazines in the plan’s development. They agree to work with Joseph in helping him develop his Health Action Plan in the format of a book.

Simon and Joseph go shopping together and buy a ring-binder file, some thick paper and card inserts. A front section is written which details Joseph’s specific health needs, mainly to help inform the staff. Over a period of months Simon works with Joseph to develop different sections of his Health Action Plan. These include a series of photographs of Joseph visiting the health centre and of having a blood test. Simon subsequently uses these photographs when preparing Joseph for each appointment. Joseph’s family are very involved and also need to learn about how they can help support Joseph.

To help Joseph understand his diabetes and specifically his diabetic diet, Joseph is assisted to collect pictures of food that he should and should not eat. These are cut out by Joseph and stuck onto pages in his book. They are then used as a focus for education. A sample of Joseph’s plan is illustrated here.
His Plan has enabled a speedy diagnosis of his medical condition and a co-ordinated approach to his future health care. It has also provided a starting point for Joseph’s increased understanding of his own health.

David Harding

David is 37 years old and lives in a small staffed group home with three other people. He has very little contact with his family and has very few friends.

David has a key worker at the group home. He also sees a Psychiatrist and Community Nurse. They have worked with him using the Care Programme Approach (CPA) because of his need for support with severe depression. The Community Nurse is David’s care co-ordinator.

David’s Community Nurse has attended a seminar on Health Action Planning, organised through the local Primary Care Trust. When reviewing David’s Care Programme, the nurse identifies that his care plan needs more emphasis on his general health. She also identifies that his health would benefit from wider social networks. The nurse talks to David and his support staff and they agree that because he has a care plan there is no need for a separate Health Action Plan. David learns more about Health Action Planning and health, with the help of his support staff and accessible information provided by the local Health Promotion Department.
At David’s CPA meeting, it is agreed that his keyworker will support David to attend his general surgery, to assess and plan any further health actions that might be needed within his care plan. In David’s surgery, it has been agreed that the Practice Nurse co-ordinates Health Action Plans. Longer appointments can be offered to discuss them.

Because his health needs have not been assessed recently, the Practice Nurse carries out a health assessment, based on a locally developed protocol. The nurse finds that, apart from his depression, there are few concerns about David’s physical health, but that he needs a tetanus booster and has not had an eye test in recent years. The Practice Nurse, with David’s agreement, gives him the tetanus booster and records the need for an eye test. David’s key worker agrees to make sure this happens.

With the help of his key worker, David goes for an eye test. They explore options for developing social networks, and David joins a befriending scheme. He goes to the pub once a week with a volunteer from the scheme, and is starting to learn snooker.

With the improved health input David now has a fully comprehensive care plan using the Care Programme Approach.

David now knows more about his own health. He is more at ease using his general practice and knows who to contact if he has concerns. David and the people working with him are now confident that he has no known additional health problems to worry about: He knows that he does not yet need glasses, his immunisation status is up to date and he is widening his social networks, which may in turn help his depression.

The Community Nurse may be a Community Psychiatric Nurse or a Community Learning Disability Nurse, depending on local arrangements.
Section 4
Principles of Health Action Planning

The implementation of Health Action Plans will vary, depending on local needs and resources. Nonetheless, Health Action Planning everywhere should be informed by five key principles:

- **Principle 1. Health Action Planning should support the White Paper’s values of rights, independence, choice and inclusion**

  The White Paper is clear in its commitment to the inclusion of people with learning disabilities in all areas of life, and confirms that people with learning disabilities have the same right of access to mainstream health services as the rest of the population (p.6).

  During consultation for this guidance, people with learning disabilities talked of the importance of being involved in their Health Action Plan:

  “Write it with me and not without me.”

  Health Action Planning needs to be person centered in both *process* and *outcomes*. It should keep the person at the centre, reflecting what is important to them, now and in the future and minimise health barriers to achieving life goals (see DoH, 2002).

- **Principle 2. Health Action Planning will be about more than individual plans. It should include strategic actions to support and sustain their implementation**

  Health Action Planning needs to take place on several levels:

  - an individual level, with personal Health Action Plans
  - at local level, with actions to support and facilitate the implementation of plans within the area
  - at national level, with the implementation of the broader goals of *Valuing People*, and any additional national changes that are found to be necessary (such as input into national training programmes).
Principle 3. Health Action Planning should address both individual and societal influences on the health of people with learning disabilities

Health Action Planning needs to ensure that individual medical matters are properly addressed for people with learning disabilities, including those relating to specific syndromes with health consequences. People should have access to appropriate screening programmes and proper diagnosis, treatment and monitoring of medical conditions.

Health Action Planning equally needs to address the wider determinants of health. People’s socio-economic status, the environment in which they live and their lifestyle, are major influences on health. Low social status and poor social networks are probably the most powerful risk factors for poor health (Marmot and Wilkinson, 1999).

Health Action Planning also needs to address service barriers to good health for people with learning disabilities. Services can make changes so they become more accessible to everyone, including people with learning disabilities.

Principle 4. Health Action Planning is a shared responsibility, with each person and agency playing a role appropriate to their skills and experience

The individual with learning disabilities, with support and advocacy as appropriate, will play a key part in the development and implementation of their own Health Action Plan.

Health Action Planning will also involve a wide range of service providers, as well as families and support staff playing a part; the role of Primary Care will be particularly important. It is expected that –

‘…GPs, practice nurses and other members of primary care teams will provide the main contact with the NHS’ (Department of Health, 2001).

This breadth of involvement will be both a key strength and a challenge for effective joint working.

Principle 5. Health Action Planning will support the mainstream health agenda and the drive to reduce health inequalities

People with learning disabilities need access to health care that meets their particular needs; they also need better access to the health care available to the population as a whole.

Valuing People states that all health initiatives aimed at the general population and all policies on health inequalities should make explicit reference to people with learning disabilities. If the health needs of a person with learning disabilities fall into any of the categories covered by a National Service Framework, they should have equal access to the care outlined in that framework.
Section 5
Who will have Health Action Plans?

The Government wants to ensure that all people with learning disabilities have their own Health Action Plan by Summer 2005. *Valuing People Implementation Guidance* (HSC2001/016, LAC(2001)23) adds the proviso that people should have one if they want one. This is to recognise the importance of offering them as a choice.

Definitions of ‘learning disabilities’

The White Paper offers a definition of learning disabilities (p.14), though there may not always have been a formal assessment that confirms this. A pragmatic starting point to the assessment of who should be offered a Health Action Plan is to include people who use, or who have used learning disability services (for example: special schools, day centres, Community Learning Disability Teams). Other approaches will need to be developed, as people with learning disabilities make less use of segregated services.

GP practices will become better at identifying people with LD, as they work towards achieving the VP target of identifying all PLD on their list by June 2004. Teams will share their records in order to help identify people with learning disabilities in the area.

Many people with learning disabilities are not in touch with statutory services. People with mild learning disabilities who are not known to specialist services may be particularly vulnerable to some health risks, for example, drug, substance or alcohol abuse.

Where there is uncertainty about whether an individual has learning disabilities, the most productive approach may be to consider whether a Health Action Plan could be a helpful way of maintaining and improving their health. The use of a Health Action Plan should not constitute a definition of learning disabilities, however.

Priorities

*Valuing People* (p.64) identifies a number of priority stages when Health Action Plans should be offered and reviewed:

- *transition from secondary education, with a process for ongoing referral (see Section 9)*
- *leaving home to move into a residential service*
- *moving home from one provider to another*
• moving to an out of area placement

• changes to health status, for example as a result of a period of out-patient care or in-patient treatment

• on retirement

• when planning transition for those living with older family carers.

Local Partnership Boards (in association with Primary Care Trusts) may define other priorities based on local needs, for example people from minority ethnic groups (see Section 8) or others experiencing inequalities, people whose health needs are covered by a National Service Framework or parents with learning disabilities.

**Eligibility criteria**

There are no eligibility criteria for access to a Health Action Plan, or to any action in the plan involving the use of mainstream health services.

**Children’s services**

Partnership Boards will need to keep close links with those responsible for planning and improving children’s services locally. They will need to consider pathways from children’s to adult services. Children and adults with learning disabilities need to be in contact with their own GP not just specialist services. This is particularly important at the time of transition.

Health Action Plans will normally begin with transition planning, around the age of 14, so that the system is in place over the period of transition to adulthood, involving relevant health and other professionals (including school nurses and paediatric health professionals) and including access to Personal, Health and Social Education (QCA, 2000). (see Section 9).

Health Action Plans could be implemented in childhood if an equivalent approach to assessing, facilitating and meeting health-related needs is not in place.
Section 6
Health Action Planning in practice

Health Action Planning is not a ‘one off’ event but involves recurring processes, at both the individual and strategic levels. At an individual level, there will be five basic stages:

Stage 1. Initiation of a Health Action Plan

Health Action Planning will begin through a number of different routes:

- The Primary Health Care Team can initiate a Health Action Plan with the person. This might be linked to the identification of people with learning disabilities on each GP’s list.

- Other health care professionals involved with the person can assist in the initiation of a Health Action Plan.

If other planning is taking place in a person’s life (for example Person Centred Planning, Transition Planning, the Care Programme Approach or care management), health should be addressed within that plan. Efforts should be made to avoid people having to engage in multiple forms of planning where co-ordination by professionals can make this unnecessary. It is crucial that no “competition” arises between those responsible for different planning inputs

- People with learning disabilities and their families may begin a Health Action Plan on their own initiative, for example in the context of broader Person Centred Planning.

- Support staff (in housing and day services) can help people to initiate a Health Action Plan.

It is expected that a Health facilitator(s) will be identified in each PCT, and that there will be a named point of contact for Health Facilitation for each general practice. They will provide assistance and support to those initiating and implementing plans, as required. The PCT lead for Health Facilitation will be well informed about local arrangements for Person Centred Planning and act to ensure that activity around Health Action Planning fits with these arrangements. They should understand the five key features of Person Centred Planning (DH 2002) and encourage the use of person centred approaches in Health Action Planning.
Having a number of different ‘entry points’ to Health Action Plans helps ensure that everyone can have one. However, with this approach, it is important that one service takes responsibility for ensuring that everyone is offered a Health Action Plan and that they are reviewed at appropriate times. This can be done most appropriately by general practices, with help from health facilitators if necessary. This approach will also ensure that people who have out of area placements have a Health Action Plan.

If Health Action Plans are not initiated by a generic health professional, they should be checked by them to ensure they do not include actions that are inappropriate for that person’s general health status (for example a sudden vigorous exercise programme for someone who has a heart condition), and that no health improvement opportunities have been missed.

Temporary Health Action Plans can be formulated to cover periods of acute hospital care, or other episodes of acute ill health. They can be formulated by the health professionals working with that person, with support from health facilitators, as required. Such temporary plans can aid consistency if people move from ward to ward and can link to discharge planning.

**Stage 2. An assessment of the actions needed to maintain and improve that person’s health**

Assessments should:

- be agreed or developed locally, with full involvement from Primary Care staff and others who will be involved in implementing them
- be evidence based
- give the opportunity to identify issues particular to that individual
- be administered in a way that is person centred in approach (for example, using easy language and allowing sufficient time)
- reflect current health policy (for example, on screening and immunisations).

Assessments should consider:

- *Health issues of particular relevance to that person*
  The opportunity for the person with learning disabilities and those close to them to address health issues that are important to them from their own perspective is vital, if the Health Action Plan is to be person centered in its approach. These might include:
  - mental health, behaviour and psychological issues
actions that reflect more vulnerable health because the person:
• has a current illness.
• has epilepsy
• has a particular syndrome with health consequences
• has issues relating to self abuse – drugs, alcohol, tobacco, solvents
• has issues relating to their sexuality (i.e. being lesbian, gay, bisexual and/or heterosexual) and/or their sexual health
• has profound and multiple impairments
• is from a minority ethnic group
• is an older person
• has a sensory impairment
• has issues relating to physical and sexual abuse
- health issues, applicable to this person, that are the focus of national or local health initiatives (for example, National Service Frameworks).

Assessments should pay particular attention to:

• Health issues identified as particularly relevant to people with learning disabilities including:
  - oral health and dental care
  - fitness and mobility
  - continence
  - vision
  - hearing
  - nutrition
  - emotional needs
  - medication taken and side effects
  - records of any screening tests.
  
  (Valuing People p.64)

It can be helpful to look at examples when developing or adopting a protocol for local use. Some structured health assessments are available that focus on health issues particularly relevant to people with learning disabilities. For example, Beange et al (1999) have identified 15 areas of ill-health that are highly prevalent amongst people with learning disabilities, which are easily detected and amenable to readily available treatments. These are reflected in the Comprehensive Health Assessment (Lennox et al 2001). This is a validated and evidence based tool; it includes ‘problem behaviours’, mental health and medications as well as physical health matters, health promotion, screening and immunisations (see Appendix 1).

Other examples include:

• The Cardiff Health Check (see Appendix 1). This includes a systems enquiry and physical examination by the GP, and is being evaluated by the Welsh Centre for Learning Disabilities.
• St George's Hospital Medical School health check. This was developed in conjunction with faculty staff who have learning disabilities, as a training aid for medical students (see Appendix 1) and is used in Student Primary Care Placements as part of their learning disability course.

• Mental health problems are also prevalent amongst people with learning disabilities and may be missed. The PAS-ADD (Psychiatric Assessment Schedule for Adults with a Developmental Disability) can be administered as part of a general health assessment to identify people with significant mental health problems who are not receiving services (Roy et al, 1997, Moss et al 1993).

Assessments should address:

• Issues relating to the wider determinants of health

Where a Health Action Plan is the main, or only, planning in process, those involved need to consider how to tackle the broader issues (such as: poverty, poor housing, unemployment, isolation and abuse - see Mir et al, 2001) that may affect that person's health. For some people the Health Action Plan may be an entry point into more general Person Centred Planning and health professionals may have a useful part to play in this.

There can be some flexibility in the nature of the health assessment needed to formulate a Health Action Plan, depending on individual circumstances. Some people may have a Health Action Plan based on specific, already identified health issues. A full, structured assessment will be particularly important when:

• There has been no previous focus on that person's health.

• The person does not communicate symptoms conventionally and/or does not have someone close to them who is able to recognise and report changes in their health.

• A health problem is suspected and it is not possible or appropriate for those involved in initiating the Health Action Plan to decide if action is needed (for example, weight loss or unexplained behaviour change).

Actions:

• Equal emphasis must be given to implementing the actions, as to formulating the plan.
• For every health issue identified, a clear action must be formulated. Actions may include health care (including screening interventions), health education, and lifestyle changes.

• If a large number of lifestyle-related actions or health interventions are identified, it may be sensible to prioritise actions for that year, in order to avoid an overwhelming amount of activity in relation to health. These priorities can be set with the individual concerned and the carer. Clearly, urgent health matters should be addressed.

Stage 3. An assessment of the help needed to implement identified actions

For each health action identified, an assessment will be necessary to identify what help (if any) will be needed to implement it:

• If a person has good support available to focus on health issues and health routines, this could form the basis of much of the help needed.

• If the person has a good relationship with relevant health professionals, and receives a good service from them, additional help is less likely to be needed.

• If local leisure services are organised in ways that are accessible to all members of the community, and good accessible (public) transport is available, less help will be required to make use of them.

• The better local services are at meeting the needs of people with learning disabilities generally, the less help will be necessary on an individual basis.

Practice example

_Bath and North East Somerset Primary Care Trust_ are in the process of setting up a Food Co-operative, to be run by and for people with learning disabilities, in partnership with members of the local community. They are liaising with local wholesalers of fresh fruit and vegetables and working with a group of service users, to develop ideas around menu planning, budgeting, cooking and food preparation etc. They want to make eating fresh fruit and vegetables more affordable, more interesting and more fun(!) for people with learning disabilities.
**Stage 4. Response delivery**

The Health Action Plan will identify:

- the appropriate individual to address each area of health action listed
- who will provide any help needed to implement those actions.

If there is difficulty in finding specific resources and supports for any individual, health facilitators can help to identify or create them.

> “Finding appropriate community facilities can be difficult”

The help needed to implement the actions might include specific assistance, for example, if the action is to increase exercise, the person might need someone to accompany them. Or it might involve more general support such as learning to speak up more effectively. It might also include help to access a service by working with the service provider to make their service more accessible and responsive.

A number of different individuals and agencies might be involved, in both the actions and helping to implement them:

- the person with learning disabilities
- support staff in housing and day service provision
- family members
- advocates and self advocacy groups
- specialist learning disability health professionals
- physiotherapists
- speech and language therapists
- occupational therapists
- chiropodists
- dieticians
- pharmacists
- practice nurses
• GPs
• dentists, optometrists, audiologists and other health professionals
• health promotion workers
• social care agencies and professionals, including care managers
• other agencies and professionals (education, housing, leisure services etc.)
• Patient Advice and Liaison Services
• NHS Direct
• voluntary organisations.

The precise role of each person and agency will vary, according to a number of factors, in particular the situation, needs and wishes of the person with learning disabilities and those who most closely support them, as well as local factors.

[Boxed text]

Practice example

In West Hampshire NHS Trust a project has been set up to increase breast awareness amongst women who have learning disabilities. The project is a joint venture between the learning disability sexual health liaison nurse and the senior radiographer at the local breast clinic. A video and leaflets for local use are being developed. The project will also involve staff training at the local Hospital Breast Clinic, staff from the breast screening mobile services, and GPs.

National Good Practice Guidance is available from NHS Cancer Screening Programmes.

Partnership Boards (in association with Primary Care Trusts) will need to ensure investment in relevant resources and personnel at a local level. This is always going to be a challenge and will involve re-orientating the work of current staff. In addition, resources will have to come from a wider range of sources relating to health, for example PMS (Personal Medical Services) pilots or by partnerships with voluntary organisations.
Stage 5. Reviewing the Health Action Plan

Reviewing the Health Action Plan involves:

• checking the actions have happened and that any necessary help was given to achieve them
• evaluating their effectiveness
• assessing the need for any new actions.

A set date should be made to review each Heath Action Plan, with the person and with those involved with them.

Each person identified with a responsibility within the Heath Action Plan is responsible for successful implementation of that action. Given that people with learning disabilities have until now received a patchy response to their health-related needs, both the actions and the help given to achieve them, will need to be reviewed.

Health facilitators will increasingly build up knowledge of where there are problems in the systems and services that people need; this knowledge can then be fed to the Partnership Board to inform their strategic work.

Links between Health Action Plans and other planning

Co-ordination between different forms of planning will be important, to avoid confusion and duplication. There may be a widely varying set of connections between the different areas of people’s lives; there are also a number of forms of planning implemented differently across the country. A fixed model of how such plans can be co-ordinated is therefore not possible.

Practice example

‘Positive Futures’ is Nottingham’s joint strategy for people with learning disabilities. It has a ‘Staying Healthy’ group whose members offer training to Primary Care and Accident and Emergency staff, with the aim of improving access for people with learning disabilities. The group has also developed a basic health record, co-ordinated by a health promotion specialist. Forty-four specially recruited and trained Practice Nurses see people with learning disabilities at their practice, using their health record. Resources are provided for each nurse. The links and information sharing from both these initiatives should provide a good basis for the development of Health Action Plans.
It is easier to co-ordinate planning when the person and their supporters are centrally involved. They will have a much better idea of what is in the plans, and how they will be implemented, than if planning is done on their behalf. A person-centred approach should be adopted. The Department of Health Guidance on Person Centred Planning offers advice on this (DH 2002). See for example the “Five Key Features of Person Centred Planning” (pp 13-14).

Each plan should note any other planning going on for that individual and who is co-ordinating it. Existing planning should be taken into account when new plans are formulated, and each should inform and support the other.

It is particularly important for those involved in Health Action Plans to understand and support any Person Centred Plan, for example by addressing health issues that are having an adverse impact on the person’s plans for work, or other life changes.

When other forms of planning take place, those involved should check that a Health Action Plan has been initiated. Health Action Plans should cover health issues that are not covered by other forms of planning. While some health needs can most appropriately be met in the Primary Care environment, health needs should not be artificially separated from the rest of a person’s life.

Other forms of planning can address broader health issues arising from the Health Action Plan. Where a Health Action Plan is the main or only plan, consideration needs to be given about how to take forward broader issues that may affect that person’s health. (see section 4)
Section 7
Health Action Plans for people with sensory impairments and/or profound and multiple impairments

Background

‘About 30% of people with learning disabilities have a significant impairment of sight and 40% have significant hearing problems... There is a high rate of under-detection of sensory impairments, most of which can be treated.’ (NHS Executive, 1998: Appendix B – Sensory Disabilities)

‘Up to 30% of people with learning disabilities have associated physical disabilities most often due to cerebral palsy.’ (NHS Executive, 1998: Appendix B – Physical Disabilities)

‘Many people with learning disabilities have little or no functional speech although may have other means of communication. Communication problems are often associated with challenging behaviour.’ (NHS Executive, 1998: Appendix B – Communication)

There are some particular issues that are important when implementing Health Action Planning for people with sensory impairments and/or profound and multiple impairments. Many have conditions that have not been fully assessed; these unidentified health problems and impairments can so reduce people’s quality of life and their ability to participate, that others may underestimate their potential.

Some environments also work against making the best use of vision and hearing; equally, the abilities of people with ‘unconventional’ communication may not be appreciated. Concise and accessible explanations of an individual’s complex (and sometimes apparently conflicting) needs are therefore required to value and promote autonomy and wellbeing, and ensure multi-disciplinary and multi-agency working.
**Individual Health Action Plans**

In general it can help to ask:

- Have the person’s impairments been fully diagnosed?
- Have they had the full range of assessments available?
- Is individual preparation available for them to have all appropriate assessments?
- Is there continuity of support for the individual for appointments?
- Have the results of assessments been discussed with the individual and their supporters, families, key staff, health professionals?
- What follow up (if any) is required?
- Could they benefit from modern and/or appropriate equipment to enhance their abilities and independence? Do they use any aids or adaptations?
- Have they and their supporters received training to make the best use of them?
- What do this person’s impairment(s) mean to them – what are the implications that are specific and unique to them?
- How can people be supported to gain equal access to the health, social and environmental factors in settings they would wish to use?
- Can a Health Action Plan help to:
  - Release a person’s unidentified and untapped potential?
  - Help them understand and control their health and health care?
  - Increase other people’s understanding of the reasons for a person’s current and potential health needs and ‘limitations’ (which may be wrongly believed to be associated with their ‘condition’), and ensure they are appropriately identified, addressed and not mis-attributed?
  - Value the person as an individual, not ‘a collection of problems to be managed’?
  - Be informed by individual choice and Person Centred Planning?
Communication

Service co-ordination and continuity of care

When people have complex health needs or impairments, service co-ordination is particularly important as their individual impairments or medical conditions may have a ‘knock on effect’ on one or more impairments or disabilities. For example:

*As a hard of hearing person, I may only hear part of the information in certain settings. Because I have a learning disability and my hearing problems were picked up late, I missed out on lots of things – but I’m learning fast now! When I don’t hear everything, I can get confused and people don’t understand and talk down to me. For a long time people thought my physical impairment made me a bit unsteady on my feet. Now people know that my hearing loss also affects my balance and co-ordination. Sometimes people think that everyone with learning disabilities and hearing loss have the same needs – but we don’t. I’m me!*

Individual Health Action Plans may need to be supplemented by joint professional records, when one professional needs to highlight how their involvement should influence that of others in the person’s life.

Information should be shared so that:

- The person receives help and advice to use their existing vision and hearing, including adapting the environment (or environments) to promote choice, communication, independent movement and skills.

- The various professionals, staff and family know how to communicate with them and what particular support they can offer.

- Everyone knows how to approach the person in ways that avoid frightening them.

- Everyone knows exactly how a person’s visual and/or hearing impairment affects him/her, and what variations in their vision he/she experiences – such as changes in lighting, varying health, medication, tiredness.

- This information is regularly reviewed and updated, especially following health checks, changes of circumstance and so on. These reviews may also need to consider health promotion in the light of potential problems for individuals – such as family history, the incidence of certain conditions within minority ethnic groups and ageing.

In addition, consideration should be given to how the person’s emotional and physical wellbeing may be promoted. This might focus on enhancing communication, as people with sensory impairments and/or communication difficulties are prone to developing
behaviour that challenges. This, in turn, may result in their being placed in specialist services distant from the people who are important to them.

Respecting individuals in health care provision

Health workers may lack experience in talking with service users with sensory impairments and/or profound and multiple learning disabilities, who may have limited communication skills and be anxious and unforthcoming. Valuing people is only possible if their efforts to communicate (by whatever means) are recognised and responded to. Health care workers may therefore need specific information from key supporters about the person’s method of communication, prior to their appointment. More general suggestions include:

• If people can explain their symptoms and history, this must be encouraged. It may be time-consuming, but busy health workers should be discouraged from just talking to supporters, not service users.

• Many people need interpreters (for example language interpreters, British Sign Language interpreters) and extra time will be needed to work with them. There may also be informal ‘interpreters’ (such as family or staff) who understand the ways the person communicates. The patient must be included in all discussions.

• Information concerning the person’s method(s) of communication should be conveyed to key people to avoid creating unnecessary stress when accessing health care. The consistency of support available to the individual may influence their ability to co-operate with treatment and improve the likelihood of a successful outcome.

• Behaviour that challenges may express anxiety in frightening environments (such as clinical settings). People may need intensive support before their behaviour presents difficulties and reduces their ability to benefit from opportunities available.

• If a person has particular communication needs, then a ‘communication passport’ can give details of important things to know when communicating with them. This can be in written and symbol format, or on videotape. Ownership and confidentiality of passports must be considered. It would be helpful for the communication passport to include a summary of what their impairment(s), and family background may mean for them.

• Whilst some people may prefer to receive information verbally and to depend on supporters they trust, others will require information in different formats – such as leaflets in ‘Easy English’ or relevant language, illustrated material, taped booklets. People may want more than one format so they can ‘read’ the information with a supporter and by themselves.
Environmental adaptations

Environmental adaptations can help communication, not only at home and in healthcare environments, but also in settings which promote wellbeing, such as leisure centres. Helpful adaptations include:

- good lighting
- colour contrast
- induction loops for hearing aid users
- carefully planned auditory environments to enable people to use their hearing (to prevent sound ‘bouncing’ around)
- environments without auditory ‘clutter’ – such as background noise like a constant television or radio
- wheelchair access
- handrails at appropriate height, which include tactile marking (to help people know where they are)
- additional environmental clues, such as a sign giving the name ‘toilet’ in large print as well as a picture of a toilet
- textural changes to flooring (to help people locate where they are in a building).

Supporting communication and ‘sensory’ related aids

People with sensory impairments and/or profound and multiple learning disabilities and their supporters are often unaware of the ever-growing range of ‘ordinary’ and specialist communication equipment, formal sign language and systems, and individually devised informal communication methods.

Individuals and supporters may not know that some visually impaired people can successfully see signs, or that people with limited hand control can use picture dictionaries or adapted signs. They may never meet anyone using mechanical or electronic communication aids.

It is important that everyone understands what communication equipment is for, how it can be used most effectively and that the service user has access to it at all times. Many methods of communication (such as objects of reference) are only effective when used consistently and new concepts, words or objects added when appropriate.
Communication support must reflect what the person wants to communicate, how and with whom.

People may be helped by more commonplace sensory aids, such as glasses, low vision aids (magnifiers) and hearing aids. People need to understand how these work, what sort of difference they may make, and disadvantages and problems.

**Physical support, movement and independent mobility**

Access to physiotherapy, occupational therapy and a wide range of aids (such as specialist seating, walking aids, continence aids, bath aids) is important for people with physical disabilities.

A rehabilitation worker for visually impaired people (normally employed by social services departments or the local voluntary society for blind and partially sighted people) should be involved in the assessment of people with severe sight problems.

Some children and adults are sustained by ‘high tech’ equipment. Parents may become highly competent caring for their son or daughter. Where people are dependent on technology, there should be clear plans for emergencies – such as parental illness, and equipment or power failure.

**Primary Health Care**

Providers of primary health care need information, training and support if people with sensory impairments and/or profound and multiple learning disabilities are to have equality of access and outcome.

There must be flexibility to allow for individual need, such as extended appointments or time of appointment, if transport is problematic.

It may be cost-effective to send reminders for appointments to people, especially when they are supported by shift workers or teams with a high staff turnover. Mechanisms need to be established to enable people to receive appropriate preparation prior to appointments, such as visiting waiting rooms and familiarisation with equipment and procedures.

Some areas have a central budget to purchase special equipment, which may be available at a discount or on loan. For example, one area has bought Cardiff Acuity Cards, and sells them to optometrists half price (Cardiff acuity cards are a method of testing the sight of people who are not able to co operate—See appendix 1 for contact details). The Isle of Wight Society for the Blind loans them on request.
Primary care staff (including specialist advisors on cancer, osteoporosis, continence, stoma care, TB, HIV/Aids) needs access to:

- training on work with people with sensory impairments and/or profound and multiple disabilities
- resource packs with details including local specialist learning disability services, information providers, national organisations, charities providing funding for individuals; this should include where to obtain professional advice and second opinions.

All training and resource material should be produced and delivered in conjunction with service users and key stakeholders.

**Practice example**

**North Staffordshire Combined Healthcare NHS Trust Learning Disability Directorate (Sensory Impairment Service)** has developed close working partnerships with Audiology and Orthoptic departments at North Staffordshire Hospital NHS to provide a screening programme for people with learning disabilities. The partnership allows continual development of screening procedures and therefore effective identification of sensory impairments. This makes available to people with learning disabilities, services that have traditionally been difficult to access. Also provided is supportive education and training to people and their families or carers.

**What can Partnership Boards do?**

Partnership Boards should:

- Create mechanisms to consult and represent people with sensory impairments and/or profound and multiple learning disabilities, including people from minority ethnic groups.
- Provide training and support (including individual supporters, advocates, language interpreters, accessible information, and paying for travel and transport) for people with learning disabilities attending meetings.
- Promote equality of access and outcome in all health planning and establish ways of auditing and monitoring this with service users.
- Devise and promote ways of monitoring diversity, to ensure people with sensory impairments and/or profound and multiple disabilities are not discriminated against.
• Ensure that local policies and protocols do not discriminate on grounds of disability or employment status in their criteria or priorities.

• Ensure that there is a seamless service for people of all ages, including support for people needing palliative care.

• Put in place mechanisms to ensure that health actions are not prevented by an individual’s lack of money. For example, can free membership to a leisure centre be negotiated? Are people getting access to free eye tests? Could help with transport be available?

• Ensure accessible information is available on sensory impairments, which focuses on the implications for individuals and services, such as reduced learning opportunities, risk of developing behaviour that challenges because of lack of communication and support.

• Ensure training is available for mainstream and specialist health care staff, including those in private practice (such as optometrists) or funded by voluntary organisations, to help them meet the needs of people with learning disabilities.

• Ensure induction and on-going training is available for support staff on sensory impairments and profound and multiple impairments – delivered in partnership with people with learning disabilities.

• Ensure forums are available for staff involved in provision for people with sensory impairments and/or profound and multiple impairments.

• Gather and promote information on local services which blind and partially sighted people and deaf and hard of hearing people or deaf blind people with learning disabilities might use (with support where appropriate).

• Establish which local optometrists and audiologists are skilled in testing the sight and hearing of people with learning disabilities who have little or no obvious means of communication (perhaps identified as part of a survey). Provide training and support to increase their numbers. Because visual impairment is so common in people with learning disabilities (up to 30% have a significant impairment of sight) regular eye tests are crucial. No one is too disabled to have an eye test. Some tests for visual acuity (sharpness) requires the person to co-operate but other record on individual’s reflexes and involuntary eye movements.

• Promote registration as blind or partially sighted and ensure advice is available on entitlements, concessions and voluntary organisations.

• Ensure support is available for individuals in a range of settings, such as GP practices, screening, family planning and sexual health clinics, low vision and eye clinics, hearing clinics, hospital admissions and outpatient departments.
• Ensure that the Patient Advice Liaison Service (PALS) receive disability equality training (or disability awareness training) that enables them to support people with sensory impairments and/or profound and multiple learning disabilities.

• Ensure budgets are in place for:
  – the provision and replacement of equipment for individuals
  – improving environments and making them more accessible for people with physical impairments, sensory impairments and profound and multiple learning disabilities
  – one to one support, including training staff for individual needs.
Section 8
Health Action Plans and black and minority ethnic groups

Background

Partnership Boards will need to pay specific attention to implementing Health Action Plans for people from black and minority ethnic groups. *Valuing People*, emphasises the government’s commitment to promoting equality in the NHS for people with learning disabilities from minority ethnic communities. This is in accordance with its new general duty in the Race Relations (Amendment) Act 2000. The Race Relations (Amendment) Act requires that we outlaw race discrimination in all our functions and places us under a general statutory duty to promote race equality. The general duty requires listed public bodies to be proactive in promoting race equality. In carrying out their functions, public bodies must have due regard to:

- Eliminate unlawful racial discrimination;
- Promote equality of opportunity between persons of different racial groups; and
- Promote good race relations between persons of different racial groups.

Most health-related bodies are covered by the legislation including the Department of Health, Health Authorities, NHS Trusts, PCTs and Special Health Authorities. Strategic Health Authorities will be added to the list now they have been formally established.

The law makes it illegal to discriminate, whether the discrimination is direct or indirect (unintentional). In fact, the Act requires evidence of action. It places on public authorities a general duty to *promote* racial equality and the CRE has provided guidance to support this (www.doh.gov.uk/raceequality/gdprecre.pdf and www.cre.gov.uk)

Partnership Boards will therefore need to ensure they are familiar with the provisions of the Act and its impact on all their functions, as well as specifically working to ensure that people experience equality in the Health Action Planning process.
Meeting the needs of a diverse population

The population of England contains White minority ethnic groups as well as Black groups and there is great diversity within these broad political categories. There are also similarities. For example, Irish women and Pakistani women both have higher contact rates with a GP than women in the general population (Erens et al, 2001). Poverty and discrimination affect Irish people in the UK in similar ways to Black minority ethnic groups (Irish Times, 2000). Although acknowledging that White people have ethnicity as well as Black people, ‘minority ethnic’ is usually associated with groups who experience direct racism through their skin colour, and, more recently acknowledged, institutional racism (MacPherson, 1999). This section will concentrate on the minority ethnic groups in Britain of South Asian, African, Caribbean and Chinese origins, who made up approximately 7% of the population in 2001; in other words, Black minorities (Office for National Statistics, 2001). These groups share experiences of racism, but also experience the effects of racism differently. For example, Bangladeshi and Pakistani people are more likely to live in poverty than Indian and East African Asian people (Modood et al, 1997).

Health outcomes

Health Action Plans may be particularly important to maintain and improve the health of people with learning disabilities from black and minority ethnic groups, since they are especially likely to experience poor health. There is substantial evidence of poorer health outcomes affecting Black and minority ethnic groups in the UK (see DoH 2001). Findings include increased incidence of, amongst other things, long-standing illness, psychosocial health difficulties, cardiovascular disease, stroke and diabetes amongst some groups. There are gender differences as well as differences between ethnic groups. In addition, Valuing People (p.6) notes that people with learning disabilities, including Black minority ethnic people, are more likely to experience mental illness, chronic health problems, epilepsy and physical and sensory disabilities. Given that poverty and racism add further layers of need, Black minority ethnic people with learning disabilities may well be at greater risk than White people. Partnership Boards should therefore consider setting specific additional targets to avoid inequality in service delivery and outcomes.

Policies and guidance

It is a good general principle that all policies and guidance should include Black and minority ethnic people in their development and implementation, and be relevant to them. Much more work needs to be done to achieve this – policies and guidance often do not refer specifically to Black minority ethnic people, or offer messages for them.

1 Although some minority ethnic groups may not define themselves as ‘Black’, in this section, the term is used as a unifying one, to describe the shared experiences of people of African, Caribbean, South Asian and Chinese people. We have tried to be consistent and refer in this section to black minority ethnic groups. However, material from other documents often just uses ‘minority ethnic groups’ and we have kept to their original where necessary.
Work relating to people with learning disabilities needs to take account of the overall context in which minority ethnic people live, and the evidence of poorer health outcomes. Currently, there is lack of research that includes Black and minority ethnic people with learning disabilities. Research findings that have been available have not resulted in significant or widespread changes in service delivery. Disability and ethnicity have only relatively recently been bought together as related issues, rather than running as separate strands through policy and practice (see Banton and Hirsch, 2000; Jeewa, 2001). Partnership Boards can address this deficiency and include the needs of people from Black groups as an integral part of all their work from the start. It is important that attention to these needs does not simply take the form of a research project. Finding out about local priorities should be done in conjunction with acting on existing research about the needs of minority ethnic communities.

**Learning disability and ethnicity**

Partnership Boards will need to consider the particular disadvantages experienced by people with learning disabilities from black and minority ethnic groups, for Health Action Plans to be implemented successfully. People with learning disabilities from both Black and White groups are not homogeneous by culture, language or faith and reflect the diversity of the total population in Britain. However, those from Black minority ethnic groups share the experience of more than one form of discrimination: sexism, racism and disablism, and if they are lesbian, gay or bisexual, this brings additional discrimination. Evidence also points to other inequalities: the prevalence of learning disabilities in South Asian people aged between five and 32 appears to be up to three times higher than in other communities, and there is likely to be more than one person with learning disabilities in some South Asian families. Although under-researched, there is also likely to be relatively high prevalence within the African Caribbean community (Azmi et al 1996). Evidence also points to a well-established link between social and environmental deprivation and the prevalence of ‘mild’ or ‘moderate’ learning disabilities (Emerson, 1997). Disproportionate representation of some Black minority ethnic groups in the learning difficulty population can be most effectively and fairly addressed by the allocation of proportionate resources, cultural competence (see www.culturalcompetence.org.uk), and a service that is free of racism.

The minority ethnic population is a relatively young population. Between 1992-94 and 1997-99 the minority ethnic population grew by 15%, compared to an increase of 1% in the White population (Office for National Statistics, 2001) (reference is ONS Spotlights, October 2001). This will have an impact on the planning of services, particularly if health, social and economic inequalities persist. The evidence on learning disabilities and ethnicity, poverty and inequality and the myths and stereotypes surrounding them is summarised by Mir et al (2001).
Key findings, reproduced in *Valuing People* (p.20) include:

- prevalence of learning disability in some South Asian communities up to three times greater than in the general population
- diagnosis often made at a later age than for the population as a whole, and parents receiving less information about their child’s condition and the support available
- social exclusion made more severe by language barriers and racism, and negative stereotypes and attitudes contributing to disadvantage
- carers who do not speak English receiving less information about their support role and experiencing high levels of stress
- agencies often underestimating people’s attachments to cultural traditions and religious beliefs.

Implementation of Health Action Planning needs to be carried out in the context of all these issues, for equality to be achieved.

**What needs to be done?**

*Valuing People* identifies as a key action, the challenging of discrimination against people with learning disabilities from minority ethnic communities. Delivery of Health Action Plans therefore needs to be inclusive from the start.

Mir et al (2001, p.13 onwards) identify a number of principles that underpin current policy and practice development. These are: partnership working, advocacy, independence and empowerment. They also provide examples of authorities that have worked hard to try and achieve the inclusion of minority ethnic people.

Working with under-represented and marginalised groups entails making the invisible visible and addressing the specific needs of individuals and the general needs of the group without marginalising and pathologising them. It also means addressing needs inclusively within all other policies and practices, so services cover all people, as of right.

This involves:

- *Creating a climate for diversity and race equality in health care*

Kingsley (2001) writes about the Department of Health’s *Improving Health among Ethnic Minority Populations* initiative. She emphasises: embedding minority ethnic health into the mainstream; the importance of obtaining and disseminating relevant knowledge; and of changing practice on the basis of evidence based knowledge.
• **Knowledge of the population served**
Ethnic monitoring and record keeping are crucial here. But drawing on this information and using it when planning does not appear to be commonplace (see Banton and Hirsch, 2000). Details of the number of people from minority ethnic groups with learning disabilities, and the breakdown of information into the different ethnic groups will help to identify need. This can be supported by the best indicator of need, to ask people themselves. Involving Black and minority ethnic people in planning and developing services will help ensure the necessary expertise is included.

• **Clarity of responsibility**
All those involved need to draw on a shared a commitment to inclusion, racial equality and service improvement for Black minority ethnic people. But there must also be clarity about who has responsibility for the different aspects of the service. For example, recruitment of a diverse range of health facilitators; translating Health Action Plan material into community languages; a Partnership Board that actively tries to reflect the population it serves by seeking members of minority ethnic groups.

“We need information about breast screening and other issues in Urdu or Punjabi”

Where specific responsibility is located at a high level in service organisations, this ensures that meeting the needs of minority ethnic communities is given adequate priority within service development. It can also provide necessary structures of accountability and monitoring when agreed policies are being implemented.

• **Being informed**
Planning and service delivery can be hampered by myths, misinformation and racist stereotypes about minority ethnic groups. For example, that consanguinity is responsible for disability in South Asian families (Ahmad et al, 2000) or that increased incidence of Rubella and low rates of immunisation is blamed on cultural practices rather than barriers to information and communication (Shah and Priestley, 2001, p.11). It is important that everyone involved in Health Action Planning has access to accurate information to inform their work.

• **Advocacy and outreach**
Under-represented groups often lack information about services and the resources to proactively seek them out. A specific duty under the Race Relations (Amendment) Act 2000, is for public authorities to set out their arrangements for ensuring ethnic minorities have access to information and to the services it provides. Advocacy roles are being clarified and standards developed and can play a central part in services to Black minority ethnic people with learning disabilities (Silvera and Kapasi, 2001).

• **Monitoring and feedback**
Matching service provision with what is known about the population is crucial to developing effective services, as is regular consultation to find out what is working.
• **Respect for users and their diversity of languages, religions and cultures**

This should be taken for granted, backed up by specific skills for acting on these values (see Silvera and Kapasi, 2001; Silvera et al, 2001).

• **Consultation**

Greater consultation with people with learning disabilities from black and minority ethnic groups can be a most effective way of ensuring their needs are identified and met. Action should make sure their voices are heard, and that they play a full part in future developments. Facilitation should be provided to enable this participation to take place, for example the provision of suitable support, translation and information in community languages, easily (physically and geographically) accessible community venues for meetings and transport provision where needed.

Shah and Priestley’s research (2001) highlights what disabled people identify as the barriers to accessing good standards of health care, and summarises themes and recommendations (pp.32-34). Two examples are outlined here; readers are encouraged to follow up the references for further examples of good practice.

**Practice example**

*The situation in hospital may be helped by the introduction of a new scheme in Leeds, involving 15 PATH trainees from a variety of ethnic communities, based in reception areas, clinics and wards (particular unmet needs have been identified in coronary care, diabetic and renal clinics). The new trainees will be able to approach patients directly, to offer support and assistance in meeting their cultural needs.*

This kind of support could also be provided at GP practices.

The social contact and shared experience that self-help and support groups can provide should be encouraged. Groups run by Black minority ethnic people with learning disabilities, for example, Black People First need to be resourced to be able to meet this need (Shah and Priestley, 2001).

**Practice example**

*South Buckinghamshire NHS Trust has two Asian linkworkers/advocates, attached to Community Teams for people with learning disabilities. They link health and social services with the local Mirpuri and Punjabi Pakistani communities in High Wycombe and Chesham*

*The Trust also employs a project worker to look into and set up systems for the day care/education needs of Pakistani women with a learning disability post-16. This centres around moving the targeted service from a social services’ day centre setting to within a local college of Higher Education.*
Section 9
Health Action Plans at transition

Background

There is considerable evidence that young people with learning disabilities, in common with other young disabled people and their families, experience particular difficulties with regard to ensuring access to adequate health care at transition (Heslop et al, in press; Morris, 1999). Hence, the requirement for effective links to be in place between children's and adult services in both health and social care; the expectation that Partnership Boards will identify a member with lead responsibility for transition issues (the ‘transition champion’); the requirement that ensuring continuity in health care should be a key element of Health Action Plans (DoH, 2001); and the recommendation that young people with learning disabilities who are at the point of transition from childhood to adulthood (and from school to adult services) should be a priority for Health Action Planning.

Relevant policies and guidance

The main vehicle for considering the needs of young disabled people (including young people with learning disabilities) and their families at transition is the Transition Planning process, established by the Education Act 1993 and associated Code of Practice, which is school led. The Code of Practice has been recently revised (DfES, 2001a).

The young person’s first Transition Plan should be completed following the annual review of their Statement in Year 9 and updated on at least an annual basis. It...’should draw together information from a range of individuals within and beyond the school in order to plan coherently with the young person for their transition to adult life’ (DfES, 2001b, Section 10). The young person should be involved in preparing their plan and in decision making about their future. More details are given in the SEN (Special Educational Needs) Toolkit (DfES, 2001b).

The Connexions service is responsible for overseeing the delivery of the Transition Plan and the Connexions Personal Adviser should co-ordinate this. The Connexions Framework for Assessment Planning, Implementation and Review also contains details on Transition Planning; the assessment profile outlined there specifically covers health issues (DfES, Connexions, 2001).
Transition Plans are expected to address issues relating to the young person’s healthcare needs. The revised SEN Code of Practice (DfES, 2001a) states that:

‘Health professionals involved in the management and care of the young person should provide advice towards Transition Plans in writing and, wherever possible, should attend the annual review meeting in Year 9. They should advise on the services that are likely to be required and should discuss arrangements for transfer to adult health care services with the young person, their parents and their GP. They should facilitate any referrals on transfers of records, which may be necessary, subject to the informed consent of the young person and parents, and should liaise with the Connexions Service as appropriate’. (Section 9.60)

Both the physical and mental health needs of young people need to be considered. A wide range of agencies need to be involved in the planning and provision of appropriate support to young people at transition. Section 10 of the revised Code of Practice focuses on ‘Working in partnership with other agencies’ including: Learning and Skills Councils, social services, Child and Adolescent Mental Health Services as well as Connexions, health services and the voluntary sector.

**Current problems at transition**

Young people with learning disabilities and their families can experience a range of difficulties at transition:

- **Lack of a systematic individualised planning process** (despite official guidance that this should be routine for young people with Statements of Special Educational Needs).

- Problems with the **process** of transition (for example, difficulties in moving within or between Health Care Trusts).

- Problems with the **availability, quality and frequency** of health care provision available in adulthood.

- **Wider, health related issues**, which may impact adversely on other aspects of a successful transition to adulthood (for example, inadequate access to communication aids; lack of accessibility of college or employment environments).

The transition process spans the period 14 to 25 and involves a range of different services and agencies whose various responsibilities to the young person terminate at different ages. Partnership Boards will need to be aware of these different roles and responsibilities and also of the implications of transitions between different children’s and adult services happening at different times.
What needs to be done?

Partnership Boards, Connexions and other relevant agencies will need to check on a wide range of issues:

• Is there a system locally to ensure that all young people with learning disabilities have a comprehensive Transition Plan which addresses their health needs?

• Is there an adequate system for identifying the numbers of young people with significant health needs in advance of the move to adult services, including those young people currently placed out of area (for example, through social services’ responsibilities under the Disabled Persons Act or their registers of disabled children)? On the basis of this information, is it possible to identify or develop the resources that will be required, in sufficient time to meet the health needs of young people with learning disabilities promptly and effectively, and avoid inappropriate placements and uncertainty about the availability of services?

• Is there a shared assessment framework in use locally to avoid young people with learning disabilities and their families going through multiple assessments for different health or social care needs and services?

• Is there a satisfactory process for ensuring the effective involvement of primary, secondary and tertiary (where appropriate) health care professionals in Transition Planning meetings, either in person or via written information on the young person’s immediate and longer term health care needs? Is there a system for encouraging the paediatrician, school nurse and other relevant child health professionals to summarise key issues with regard to the health care needs of youngsters at transition to pass on to their GP, health facilitator or other relevant adult service provider?

• Is there any system locally for developing ‘hand held records’ for young people with learning disabilities and their families to take with them to adult services? Do they have access to relevant medical/health care information, which specifically names new, adult professionals and services and gives a strategy for their familiarisation with them at an early stage?

• Is accessible information available for young people with learning disabilities, and their families, on relevant health promotion issues, including sexuality and personal relationships and health screening?

• Is there an agreed policy on how the communication needs of young people with learning disabilities, particularly those who need communications aids, will be met after they leave school or college? Is information on the communication means employed by young people who do not use speech passed on to new, adult service providers in different care environments?
• Are there appropriate provisions, professionals and processes available locally to support young people with learning disabilities and their families around their health care needs at transition (for example, transition clinics for young people with particular health care needs or Link workers)? Is there an early identification protocol which would trigger involvement of a health facilitator?

• Is there appropriate support for any health care needs of young people in further education or training (for example, the provision of aids and equipment; assistance with administration of medication or personal care; therapy services; access to psychological or other advice) or a system for ensuring this?

• Is accessible information available locally for families, young people and service professionals/providers about the changes inherent in transition for young people with learning disabilities, including those relevant to meeting their health care needs?

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**Practice example**

*Transition assessment for young people with learning disabilities in Plymouth*

One of the four aims of the Plymouth Transitions Project has been the development of a multi-agency Year 9 Transition Assessment. With the advent of the Connexions Service and their new APIR assessment framework, the new Care Leavers Service, the Assessment Framework for Children in Need, ‘Valuing People’ and the new Code of Practice for Children with Special Educational Needs, this has been challenging. Pulling together essential professionals including head teachers, social services staff from Children and Families and Community Care, specialist health professionals in Children’s and Adult Services (both the local Primary Care Trust and Hospitals Trust), Connexions staff and Lifelong Learning staff has seen some innovative developments leading to shared assessment practice.

A ‘Pathway’ has now been devised with clear responsibilities for all professionals, including Connexions personal advisers. The Initial Assessment draws together requirements for information from all the services named above, thus enabling it to be used by a number of agencies. Within this, the needs for shared information about a young person’s health status has been highlighted. The underlying goal has been the cutting down of paperwork rather than the establishment of new ‘hefty’ pieces of assessment. Through a clear process and a shared understanding of people’s tasks within ‘transition’ it is intended that people will be able to do their jobs more effectively alongside each other.
Section 10
Choice, consent and confidentiality

Deciding to have a Health Action Plan

The Government is clear that everyone with learning disabilities should be offered a Health Action Plan. This guidance emphasises that Health Action Plans should be prepared with and for the person concerned, they should not be something that is ‘done to’ people. This means that the initiation of Health Action Plans will need to be supported by education and information, so people can understand as far as possible how such a plan might benefit them. The Department of Health is producing an easier to read booklet, which will help people to understand more about Health Action Plans. This will need to be supplemented by information about health issues particularly relevant to the person concerned, in forms that are accessible to them.

It is possible that some people will think they do not need a Health Action Plan. This is likely to be the exception, rather than the rule, for two reasons. Firstly, the evidence suggests that the health needs of people with learning disabilities have often been neglected, so most people will be likely to have at least one action that can help maintain or improve their health. Secondly, in the consultation for this guidance, the overwhelming response from people with learning disabilities was of interest in health and enthusiasm for having a Health Action Plan. If a person with learning disabilities suggests they do not need a Health Action Plan, it is important to explore the reasons for this:

- Is their perception of what a Health Action Plan will involve, oppressive?
- Is a particular aspect of health a worry to them, which they do not wish to address?
- Do poor previous experiences of health professionals or services mean that Health Action Plans have negative connotations for the individual?
- Might they be agreeable to a Health Action Plan that does not involve (for example) giving up chocolate, or seeing a particular doctor?

A partnership approach to deciding what will be in the Health Action Plan, and who will facilitate different aspects of it, may overcome initial reluctance. If an individual still decides not to have a Health Action Plan, careful thought will need to be given about how to ensure they stay healthy. They should be offered an opportunity to rethink their decision at a specified future date. Good practice by a GP or other health professional in the event that someone has specific health needs which are at risk of not being met, will be to record their own action plan to monitor the person’s health care.
If, despite every effort to support their involvement, a person is not able to understand about having a Health Action Plan, or not able to express their opinion, a plan can be implemented by people who know them well. The plan should still be person centred, and focus on the needs of the individual.

Consent

Health Action Plans may raise issues about consent for examination, treatment and other interventions (see Appendix 2 for helpful information on consent).

Partnership Boards can help people make an informed choice about actions identified within Health Action Plans. They can work with local library and Health Promotion services to provide accessible information about Health Action Plans, and make training available on the issue of informed consent. A nominated individual or group can provide advice where issues of consent prove difficult. Partnership Boards can also support self-advocacy groups and advocacy services to help promote the self-confidence and decision making skills of people with learning disabilities in their area.

Record keeping and confidentiality

Good records can support effective partnerships with service users and carers, and assist continuity when workers are unavailable, or change. The service user should give agreement before information is shared, and this agreement should be recorded (DoH, 2000).

In consultations with service users, issues of both ownership of Health Action Plans and their safe keeping arose:

“I should look after my things.”

“Staff would look after [my Health Action Plan] carefully in the office.”

Some service users identified various people they would not want to see their Health Action Plan, and many commented that they should be responsible for looking after it themselves.

To respond to these concerns, service users should get a summary of their Health Action Plan. This may form part of the client/patient held records that are being developed in parts of the country, It will be particularly helpful for the Health Action Plan to be accompanied by general information about the person concerned, for example their communication needs, family medical history and important relevant details known to family members or long standing support staff.

“Health Action Plans are a good idea. We want clear responsibility for meeting health needs when family carers are no longer caring.”
The Health Action Plan summary should be geared to the person’s communication preferences as far as possible, for example, embracing easy language, pictures or symbols and being available in tape format or their own language. Support staff, family and/or a health professional can help to produce these.

“Plans should help you. It doesn’t need to be beautiful, just mean something to that person.”

Since the plans will be personal to individuals, it will not be appropriate to give people a ‘ready made’ Heath Action Plan. If ‘ready made’ versions are developed, they should have sufficient flexibility to allow only issues relevant to that individual to be included.

A record of the plan should also be held at the GP surgery. This need not be an accessible version. It may be helpful for each plan to state how many copies there are and who holds them. Where there are aspects of a Heath Action Plan that the person does not want recorded in a patient held record, these can be recorded on the surgery held record. The Health Action Plan should be updated to include only current actions, to avoid cumbersome length.

Partnership Boards should have a strategy for good practice in relation to record keeping, record sharing and Data Protection, taking into account the requirements of the Data Protection Act. They should support staff to provide accessible information in relation to Health Action Plans, for example, by ensuring that appropriate training and administrative support is available.
Section 11
Taking forward Health Action Planning

The main way for Learning Disability Partnership Boards to discharge their responsibility for health issues will be through Primary Care Trusts. Primary Care Trusts, in their commissioning role, should take a lead to ensure that access to general health care for people with learning disabilities is built into existing priorities; they will need to work with Partnership Boards to ensure that there is an integrated plan for supporting primary and general health care services. Public Health leads in Primary Care Trusts can play an important part in promoting work at a community level to improve health.

The normal vehicle for expressing the intentions of the Partnership Board is through the local Joint Investment Plan (JIP). Health issues for people with learning disabilities should be fully included within the JIP.

Practice example

**Bristol South and West Primary Care Trust** have actively considered how they could improve their health care provision to people with learning disabilities. Using funding from health inequality budgets, they have employed a Learning Disability Nurse to work as a member of a large primary care team. The work has involved supporting practice staff to identify people with learning disabilities, to assess their health needs and to develop individual action plans.

Developing a local implementation framework

Health Action Plans will help identify some of the difficulties that people with learning disabilities in your area experience in accessing the services and supports that contribute to good health. However, Partnership Boards will need to be proactive and begin strategic actions to support and facilitate implementation from the outset.

Partnership Boards have to develop a framework for the implementation of Health Action Plans, by June 2003. To achieve this, it will be helpful to consider issues in three areas:

**Area 1. Building on current practice**

- Identify mainstream initiatives in your area that are relevant to improving health. Identify health promotion activity and assess how far the needs of people with learning disabilities are addressed within these initiatives. Identify changes that will make them more inclusive.
“People must be involved in their own health.”

**Practice example**

**The Merton, Sutton and Wandsworth** Health Alliance was formed in 2000, bringing together representatives of all local stakeholders concerned with promoting better health for people with learning disabilities including users and carers. The outcomes so far include:

- A seminar for 70 people chaired by the Chairman of St. George’s Hospital and the creation of working groups to develop local work on improving access to acute hospitals, primary care and health promotion. These working groups are now formal sub groups of three Partnership Boards, and plan to have an annual seminar to share progress.

- After meeting the occupational therapist who chairs the Hospital Access committee and attending the first seminar, they invited a self advocate, Michelle Chinery, to join the committee. Michelle has been helping to think about how to improve access for people with learning disabilities.

- The Public Health Department publishes an annual Health Equity Report. In 2002 this report will include a chapter on the health of local people with learning disabilities to increase awareness of their particular vulnerabilities and health inequalities in comparison with other local people.

- Identify local initiatives that aim to increase access to generic health services by people with learning disabilities. Identify gaps and how they can be filled. Consider ways of developing the capacity of specialist, primary care and other NHS providers, along with other service providers, to respond to the health needs of people with learning disabilities. Give particular emphasis to initiatives that involve joint working with people with learning disabilities and organisations that represent them.

- Identify how accessible local leisure and education services are to people with learning disabilities and establish the part they can play in improving their health.

- Identify how many people with learning disabilities are known in your area and analyse information such as ethnic grouping. Establish what further mapping exercises could help to identify people in relation to GP practices.

**Area 2. Taking forward new ideas**

- Establish a close working relationship with your local Primary Care Trust to take forward the health agenda of *Valuing People*. Grieg (2001), in a paper based on an analysis of the experiences of the Primary Care Trust/Learning Disabilities network,
outlines some of the key issues in enabling Primary Care Trusts to play an appropriate role in meeting the health needs of people with learning disabilities.

**Practice example**

**Bebington and West Wirral Primary Care Trust** have a Learning Disability Community Nurse on the executive committee of the board. She has the opportunity to raise issues relating to people with learning disabilities and other minority groups within the Primary Care Organisation agenda. This connection has also enabled closer joint working between the Primary Care Trust, Secondary Care and specialist learning disability services.

- Identify who has an interest in helping learning disability and generic health services work together to improve health. This may include people from a range of services, including specialist learning disability services, primary care, mental health, voluntary organisations and acute hospital care. Identify people in a position to lead developments and allocate resources or play other key roles.

- Identify how people with learning disabilities and family members are involved in decision making about health related services, and whether they reflect the whole diverse range of people, or just known funded groups. Plan ways to develop shared objectives on desired outcomes for people with learning disabilities. Ensure that people with learning disabilities and those supporting them have lead roles in determining individual and collective priorities, and can be strategic partners for change.

**Practice example**

‘Healthy Partners’ is a joint initiative by the Tower Hamlets Primary Care Trust, the Community Learning Disability Team and ‘One to One’, a local self-advocacy organisation. The project was funded in part by the City and East London Education Consortium (CELEC). Individuals with learning disabilities involved in the project have given a lot of thought to meeting their health needs. They are involved in training local General Practitioners, nurses and practice staff. The project has taken a lead in developing client-held health plans.

- Identify potential barriers to the implementation of Health Action Plans in your area. Think broadly about possible barriers, from differences in opinion to physical access to services. Establish how to address these and how to put in place joint organisational arrangements to deal with operational issues and difficulties.

- Consider setting local priorities (in addition to those set out in the White Paper) for who should get Health Action Plans first.
• Identify the roles and responsibilities of the different ‘stakeholders’ at individual and local levels of Health Action Planning. Establish how far these can be flexible in relation to each person with learning disabilities and how to ensure services move towards mainstream provision, with support where needed from learning disability services. Plan how different roles will be co-ordinated.

• Identify training needs and how and to whom training will be delivered.

Practice example

**Wendy Perez** is a self advocate who works as a trainer and co-researcher at St George’s Hospital Medical School. Wendy teaches medical students, and emphasises the importance of good communication. Wendy sits on some task groups at the medical school and with other organisations, including a local partnership board and the Department of Health. She helps make sure both learning disabilities and health issues get good attention. She also works on the production of accessible information about health. Wendy consults with other people with learning disabilities to get their views across, and is keen for everyone to know the importance of people with learning disabilities and managers working together. In her job she has shown that it works, and that everyone can do it.

• Plan a local strategy for record keeping in relation to Health Action Plans.

• Identify the support to be offered to help ensure accessible information is made available.

• Identify what material will be required for different groups (for example, social care staff, families, specialist and generic health staff) about their respective roles in supporting and responding to Health Action Plans.

Practice example

**West Hampshire NHS Trust** has developed a resource booklet for primary and secondary health care staff, in partnership with A&E and in-patient areas at the local acute hospital. The booklet identifies key issues around the needs of people with learning disabilities when accessing health care. The booklet has proved so successful that a further print run has just been commissioned. The booklet has been updated to include information on The White Paper ‘Valuing People’, consent and assent, communication and other useful information.
Area 3. Evaluating progress

- Establish the criteria to be used to judge progress in Health Action Planning. Consider measures at both the individual and local levels of Health Action Planning. Put in place systems for monitoring progress (see Section 12).

Practice example

The North West Training and Development Team have set up a project to consider how Learning Disability and Primary Care services can work more closely together. Across the region, each Community Learning Disability Team has nominated someone to lead on improving the local access to Primary Health care. Local networks have been set up, to share information and exchange examples of local and national practice. Network members are developing a framework to develop local strategies and approaches to service implementation. They are considering:

- strategic planning processes that need to be in place
- practical steps that need to be initiated, and the organisations that will take the lead on these
- issues and barriers to be aware of and suggestions to resolve them
- relevant resource issues.

(Website www.nwtdt.com)
Assessing the success of Health Action Plans

A number of approaches need to be taken to assess whether Health Action Planning is making a difference to the lives of people with learning disabilities.

Measuring health outcomes from Health Action Plans is difficult because there are no well established, validated outcome measures relating to the health of people with learning disabilities. Riemsma et al (2001) provide a review of health status measures that aim to assess general health status in people with cognitive impairment, including people with learning disabilities.

As well as measuring the extent of Health Action Planning locally (that is, the number of individuals covered), you may want to audit how well Health Action Planning is being undertaken. For example, in following up individual Health Action Plans, how many planned actions have been successfully carried out? Measures of process and qualitative measures will also have an important part to play in evaluation.

Measures can also reflect the local protocol for health assessment, and local circumstances and priorities and might include:

- the proportion of eligible women with learning disabilities who take up breast and cervical screening programmes
- the proportion of people with learning disabilities referred for an eye or hearing test within a defined amount of time
- the proportion of people with learning disabilities diagnosed as clinically obese
- the proportion of people with learning disabilities from specific ethnic groups who have a Health Action Plan.

When using such measures, it is important to remember that Health Action Plans are individual, and the existence of such measures does not necessarily mean that subsequent actions must be included in all plans.
You may wish to draw on the principles of evaluation suggested for Person Centred Planning:

- Are people doing it?
- Are people doing it right?
- Is it contributing to changing people’s lives for the better?
- Are services changing to reflect what is being learned? 

(DoH, 2002)

Some characteristics of a good Health Action Plan that may be helpful in evaluating progress are outlined below:

- The plan is individual for that person.
- The plan takes into account any relevant broader determinants of health and also pays due attention to individual lifestyle, culture and health care issues.
- The plan supports the White Paper values of rights, independence, choice and inclusion:
  - it involves primary care, and other generic health service staff
  - it is not ‘done to’ the person – they have a central involvement; it is prepared with them and where appropriate people close to them
  - the person concerned and/or those close to them know what is in the plan and are actively involved in implementing it.
- There is evidence that the plan fits in with other assessment and planning mechanisms in that person’s life; there is clarity and co-ordination, not confusion and duplication.
- The plan is ‘live’ with the focus on the action, not just the plan.
- The role and responsibilities of everyone involved in the plan are clear – everyone involved knows the part they have to play.
- Implementation of the plan is monitored and feeds into service development where appropriate.
- There is an identified date for review.
- The plan is backed by broader initiatives, which mean that it is more likely that individual Heath Action Plans will be successfully implemented.
• The plan reflects any relevant national or local initiatives aimed at improving health, including actions to reduce health inequalities and National Service Frameworks.

Other mechanisms for evaluating progress

Health Action plans are a new idea. It will be important to learn from early implementation, and to alter approaches if necessary, in the light of experience.

An audit cycle can be implemented, to:

• set clear shared objectives or standards
• measure practice against these standards
• identify areas for change
• implement the change
• re-audit to ensure change is effective.

(see Muir Grey 1997)

People with learning disabilities and their families and supporters can play a central part in the audit cycle, agreeing standards and assessing individual Health Action Plans, as well as identifying common concerns or blocks to implementing plans, and seeing if they are being acted upon.

The experiences of health facilitators could provide useful input into evaluation, including the identification of examples of good practice (in service provision and facilitation) to be shared, as well as indications of service deficiencies and blocks to progress.

‘Tracking’ the Health Action Plans of specific individuals may be useful, particularly in evaluating the service given to people who are not usually able to contribute to written and verbal consultations. The content, progress and outcomes of their Health Action Plans could be assessed jointly with them and people close to them.

Other approaches to evaluation might include:

• accessible surveys
• stakeholder meetings
• focus groups
• interviews with key stakeholders.
It might be helpful to create or join a network to share learning from existing initiatives and early moves to implement Health Action Planning. Members could co-operate to get the most from early experiences. Internal networks in your area could also be used to promote and assess the progress of Health Action Planning.
Section 13
Challenges and responses – reorienting local approaches to Health Action Planning

Health Action Plans will raise challenges (as well as opportunities) for everyone involved in their implementation. The reasons why it might be difficult to implement Health Action Plans, reflect the reasons that people with learning disabilities have traditionally experienced inequalities in health. The examples below show how some potential challenges could be addressed. You may want to carry out a similar exercise for particular challenges in your area.

Challenge 1

Learning disabilities staff in your area provide health checks for people with learning disabilities – many undetected and untreated health conditions have been found. Why do you need to change your practice?

Reasons for change:

- There is a danger of focusing energies on the health checks – leaving insufficient capacity for subsequent actions.
- The White Paper is clear in its commitment to including people with learning disabilities in mainstream provision of all sorts – including health.
- Health checks may not lead to a greater understanding of their own health for people with learning disabilities and their carers.

Response:

- Learning disabilities staff can support primary health care staff to provide health assessments that may be needed. The focus of learning disabilities staff can then be reoriented to facilitation, and helping to ensure that necessary actions arising from such assessments are carried through.

Valuing People says:

‘Because mainstream services have been slow in developing the capacity and skills to meet the needs of people with learning disabilities, some NHS specialist services have
sought to provide all encompassing services of their own. As a result the wider NHS has failed to consider the needs of people with learning disabilities. This is the most important issue which the NHS needs to address for people with learning disabilities.’

**Challenge 2**

Some mainstream health providers in your area are not keen on co-operating to maintain and improve the health of people with learning disabilities. They feel this is additional work for which they have insufficient time, skills or resources.

*Reason for change:*

- People with learning disabilities have an equal right to access mainstream health services. Primary Care Trusts are responsible for the health of everyone in their area, including people with learning disabilities.

*Response:*

- Build a close and effective relationship between the Learning Disability Partnership Board and the Primary Care Trust, and plan together how to overcome this barrier.
- Look for and create ‘champions’ among professional groups who can help to influence their peers to include people with learning disabilities in the service they provide.
- Offer training and support to staff in mainstream services, to help them meet the needs of people with learning disabilities. Include people with learning disabilities as trainers.
- Look for opportunities to include the needs of people with learning disabilities in initiatives that target vulnerable people in mainstream settings.

**Challenge 3**

Some members of your local community argue that it is not right for people with learning disabilities to have Health Action Plans when they are not offered to anyone else. They may believe this goes against the principles of normalisation, or that it privileges people with learning disabilities in comparison to other disadvantage groups.

*Reasons for change:*

- People with learning disabilities continue to experience inequalities in health that must be addressed. People’s health related needs have not been adequately considered and services and supports have not satisfactorily ensured good health.
Health Action Plans offer a structured and individual approach to tackling such deficiencies. Sometimes it is appropriate for disadvantaged groups to have a different approach to get them to the same place as others.

Response:

Health Actions Plans must be offered and implemented in a person centred way. They should be offered when appropriate, and, with support to ensure that the person understands why a Health Action Plan is being suggested.

- Confidentiality and privacy must be protected, to ensure that Health Action Plans become a way of tackling inequalities, and not an oppressive mechanism.
- The Caldicot Guardians in each NHS Trust will advice on any Data Protection issues.
- Primary Care Trusts could extend the use of Health Action Plans to other vulnerable groups if they find them a useful mechanism for improving the health of vulnerable people.
Appendix 1
Useful Resources for Health Action Planning

Consent


Mencap (June 2001) Considerations of Quality of Life; in Cases of Medical Decision-Making for Individuals with Severe Learning Disabilities – a Consultation Document. Mencap (available from campaigns@mencap.org.uk).


Examples of Health Assessments

The Comprehensive Health Assessement Programme. For copies or more information, e mail Dr Nick Lennox, at N.Lennox@sph.uq.edu.au

The Cardiff Health Check. See the website, www.uwcm.ac.uk/study/medicine/psychological_medicine/research/welsh_centre_learning_disabilities/research/primary_health_care.htm).

St George’s Hospital Medical School health check. See the website, www.sghms.ac.uk/depts/psychdis/ or www.intellectualdisability.info


Accessible information

Advisory Unit: Computers in Education (1997) Getting started with symbols. Published by the Advisory Unit, 126 Great North Road, Hatfield, Herts., AL9 5JZ. Tel: 01707 266714. A4 folder and two demonstration disks.

Your good health is a set of 10 booklets and tapes about things people can do to keep well. For more information, contact BILD Publications, Plymbridge Distributors, Plymbridge House, Plymouth, PL6 7PZ. Tel: 01752 202301.
Books Beyond Words are accessible picture books about a range of topics, with 20 titles relating to health, including epilepsy, depression, counselling, and about accessing NHS services, e.g. breast and cervical screening for women with learning disabilities. They are available from Gaskell Press, 17 Belgrave Square, London SW1. Tel 020 7235 2351. Website www.rcpsych.ac.uk/publications/bbw/index.htm

Change, Change Picture Bank CD Rom and Pack available from Change, Unit D, Hatcham Mews Business Centre, Hatcham Park Mews, London, SE14 5QA. Tel 0207 639 4312. PC and Apple Mac compatible. £60.00 to groups managed by disabled people and/or people with learning disabilities. £120 to all other groups and organisations. £4.00 postage and packing.

Department of Health. The healthy way is a pack and tape about how to stay healthy. It is free from the Department of Health, PO Box 410, Wetherby, LS23 7LN.

People First (1997) Access First. Published by People First, Instrument House, 207-215 Kings Cross Road, London, WC1X 9DB. Tel: 0207 713 6400. A4 loose-leaf folder, video, copyright free disk and pictures.


General resources

Cardiff Acuity Test for people who are not able to cooperate with a vision test
Keeler Limited
Clewer hill Road, Windsor, Berkshire, SL4 4AA

Down’s syndrome Association Health Alert website for medical and healthcare students, www.intellectualdisability.info

Appendix 2
References


Grieg, R (2001) Meeting the General Health Needs of People with Learning Disabilities: Developing a Framework for Supporting Primary Care Trusts to be Effective Partners. (London: Institute for Applied Health and Social Policy, King’s College). For information contact Alison Giraud-Saunders, alisongs@compuserve.com


St Albans Medical Centre PHCT (2001) ‘Support of vulnerable patients’ *Primary Health Care*. 11 (6) July/August 2001


Appendix 3

A leaflet for family carers and paid carers is reproduced here. It may be useful to distribute locally. You may want to personalise it with local details and contacts. There is also an electronic version available on the Department of Health website at www.doh.gov.uk/learningdisabilities where you can download all of the artwork used in the Health Action Plans publications for local materials.
What can you do to help?

- You might help the person carry out some of the actions in the plan. Things like extra exercise or a healthier diet, or to help to get a blood test or other appointment.
- You can help by making sure the person understands what is in their plan and what it means, this might mean adding pictures or putting it on tape.
- You can help the person learn more about health and how to stay healthy. You can get more information from local services, health promotion and NHS Direct.
- You can get involved with any work that the local Partnership Board is doing on health.

What if there are problems?

If there are problems with carrying out the Health Action Plan you should tell your GP. If things prove difficult you could ask at the surgery for the local contact for Health Facilitation.

You want to know more?

The Department of Health has sent more detailed information to Partnership Boards. You can get information locally from:

Do you support someone with a learning disability? Have you heard about Health Action Plans?
**Valuing People** is the Government plan to make life better for people with learning disabilities. It says that everyone with learning disability should get the chance to have a Health Action Plan.

There are **Partnership Boards** in every area. They have the job of putting ‘Valuing People’ into practice. They come from different organisations (like health and social services) and include people with learning disabilities and family carers.

Valuing People says **Every Partnership Board needs to have a plan of how they will make Health Action Plans work by Summer 2003**

**Health Action Plans**

A Health Action Plan lists the actions needed for the person to be healthy, and the help they need for this to happen

**Health Facilitation**

This is making sure that people get the services and support they need to be healthy and make their Health Action Plan work well.

**Why do we need these changes?**

It has often been difficult for people with learning disabilities to lead a healthy life. They tend to have worse health than other people. That is not fair, and we need to change it.

**A Good Health Action Plan** should be all of the following:

- Individual for that person
- Takes into account any individual lifestyle, culture and health care issues.
- Supports the White Paper values of rights, independence, choice and inclusion
  - Is not ‘done to’ the person - it is prepared with them and where appropriate, people close to them
  - Involves primary care, and other ordinary health service staff
  - The person concerned and/or those close to them know what is in the plan and are actively involved in making it happen
- Fits in with other assessment and planning in that person’s life; so that things are clear, not confused or duplicated
- Is ‘live’ with the focus on the action, not just the plan
- Everyone involved knows the part they have to play
- There is a date for review

**How will it be recorded?**

The person should get an easy-to-understand summary of their Health Action Plan. It should be geared to the way they communicate, for example using easy words, recording on tape or pictures or symbols that they find helpful.

A record of the plan should also be held at the GP surgery. The surgery record can also be used to record any more private matters

**How do you get a Health Action Plan started?**

A Health Action Plan can be started in different ways, including:

- The staff at the doctor’s surgery can help you start one
- Health can be included when other plans are made, like Person Centred Planning, Transition Planning or Care Management
- The person and their family might start the plan.
- Support staff might help start a plan.
Other books in the Health Action Plans series are

Health Action Plans and Health Facilitation, Good Practice Guidance for Learning Disabilities Partnership Boards (Easier to read version – reference no 28602)

Health Action Plans, What are they? How do you get one (booklet for People with Learning Disabilities – reference no 28599)

Tapes of the following versions will be available from end August 2002:

Health Action Plans and Health Facilitation, Good Practice Guidance for Learning Disability Partnership Boards (Easier to read version – reference no 28611)

Health Action Plans, What are they? How do you get one (booklet for People with Learning Disabilities – reference no 28612)

Copies of the books are on our website
www.doh.gov.uk/learningdisabilities

Free copies of this book are available from:
Department of Health Publications
PO Box 777
London SE1 6XH
Fax: 01623 724524
E-mail doh@prolog.uk.com

Please ask for the books by title and reference number when you order them

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