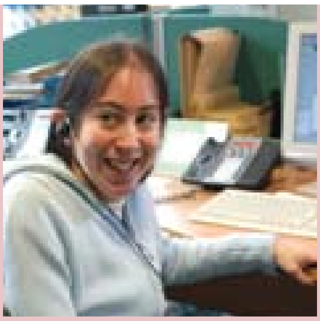
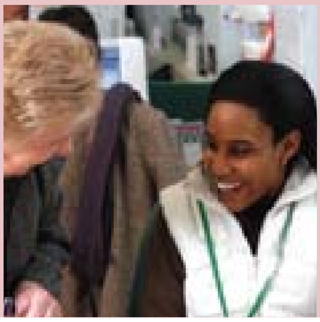
HM Government

Health Action Planning and Health Facilitation for people with learning disabilities: good practice guidance





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DH INFORMATION

Policy **HR/Workforce** **Management** **Planning/Clinical**	**Estates** **Commissioning** **IM & T** **Finance** **Social Care/ Partnership Working**

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Description	The purpose of this guidance is to describe and clarify good practice in health facilitation and health action planning and support localities to make progress on this and on reducing health inequalities experienced by people with learning disabilities. It builds on previous DH guidance and reflects the learning that has taken place since 2002 along with key recommendations of relevant recent reports and research.	
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Foreword

The NHS Next Stage Review, which concluded during the 60th anniversary year of the National Health Service, defined more personalised services as one of the hallmarks of high-quality care for all:

'Personalising services means making services fit for everyone's needs, not just those of the people who make the loudest demands. When they need it, all patients want care that is personal to them.'[1]

Providing personalised care and support for people with a learning disability can be seen as a litmus test for whether the service is fulfilling this vision. A succession of reports, including most recently that of Sir Jonathan Michael's independent inquiry, have highlighted some basic shortcomings in the way that services are provided for people with a learning disability, contributing to poorer health outcomes, avoidable suffering and, at worst, avoidable deaths. All NHS organisations, whether as providers or commissioners, have a basic duty to promote equality for disabled people and make reasonable adjustments to the way in which services are delivered to meet their individual needs. This should apply as much to promoting health as it does to treating illness.

One of the four overarching objectives of the Government's new three-year strategy for people with learning disabilities, *Valuing People Now,*[2] is to give people with learning disabilities and their families greater choice and control over their lives and the support to develop person-centred plans.

The concept of health action planning, as a way of maintaining and improving the health of the individual, was originally introduced in the 2001 White Paper, *Valuing People,*[3] followed shortly by practical guidance in *Action for Health* (2002).[4] The latter document emphasised that health action planning should go hand in hand with wider changes to help link the individual with the range of services and support that they need to stay healthy – part of what we now refer to as 'health facilitation'.

This updated guidance on health action planning and health facilitation is published at an important time. The recommendations of Sir Jonathan Michael's report, together with the publication of *Valuing People Now*, provide – I hope – a fresh stimulus for all NHS organisations, with local

[1] *High Quality Care For All: NHS Next Stage Review Final Report*, Department of Health (2008)

[2] *Valuing People Now: a new three-year strategy for people with learning disabilities*, Department of Health (2008)

[3] *Valuing People: A New Strategy for Learning Disability for the 21st Century*, Department of Health (2001)

[4] *Action for Health – Health Action Plans and Health Facilitation*, Department of Health (2002)

authorities and other partners, to review how they plan and provide services in ways that improve quality of care and health outcomes for people with learning disabilities.

More specifically, primary care trusts should now be working with GP practices to implement the system of annual health checks that we agreed last year with the British Medical Association. This is an important step forward, but health checks will only have their full impact if they encompass health action planning and if people with learning disabilities can then access the services they need to maintain and improve their health. This requires good communication and partnership working across a range of services, including primary care, local government, public health, mental health services, acute care and specialist services.

The guidance also provides practical support in putting people with learning disabilities at the centre of all action relating to their health, not just through person-to-person work on health outcomes, but also through wider engagement with people with learning disabilities and their families and carers in reviewing and planning services.

The Valuing People Now healthcare steering group, which I chair, is committed to working with the NHS, local government and service users to improve healthcare for people with learning disabilities. I very much hope that you will embrace and champion the good practice in this guidance, which we see as an integral part of promoting the NHS Next Stage Review vision of high-quality care for all.

Ben Dyson

Ben Dyson CBE
Director of Primary Care
Department of Health

Acknowledgements

We wish to thank all those who supported the development of this guidance and shared their practical experiences of health action planning and health facilitation.

This guidance was prepared for the Department of Health by Debra Moore.

Contents

1. Introduction

Scope and purpose of this guidance

In 2001, the Government published the White Paper for learning disabilities, *Valuing People,* which included specific targets relating to the health of people with learning disabilities, namely:

- health facilitators to be identified for people with learning disabilities by spring 2003;
- all people with learning disabilities to be registered with a GP by June 2004; and
- all people with learning disabilities to have a health action plan by June 2005.

To support this, the Department of Health issued detailed guidance for Learning Disability Partnership Boards: *Action for Health – Health Action Plans and Health Facilitation*. In this guidance, a **health action plan** is described as:

'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... the plan is primarily for the person with learning disabilities and is usually co-produced with them.'

Health facilitation is described as a process that has evolved from roles developed by family carers, practitioners and others and from the wishes of people and families for support in accessing, navigating and using the NHS. Health facilitation takes place on two levels.

- **Level 1 – Service development work and informing planning and commissioning**

  This includes responsibility for the outcomes described in *Valuing People* and the development, monitoring and auditing of initiatives designed to reduce health inequalities. This is a role that can be fulfilled by a range of health professionals, managers and commissioners.

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

  This involves a focus on individual health outcomes and is recognised as a key role that could be taken on by a range of people including support workers, family carers, friends and advocates as well as health professionals.

However, despite the best efforts of many people in local areas, the achievement of the health-related targets in *Valuing People* is one of the areas where least progress has been made in the last eight years.[5]

Moreover, since *Valuing People* was published, there have been a number of reports and inquiries concerned with the care and treatment of people with learning disabilities in both mainstream and specialist health services.

The findings of these reports present irrefutable evidence of the inequalities and poor health outcomes experienced by this group and the barriers that prevent them enjoying the same level of access and experience within the NHS as the general population.

In March 2007, the Department of Health published *Promoting Equality*.[6] This is the response document to the formal investigation undertaken by the former Disability Rights Commission into the health inequalities facing people with learning disabilities. *Promoting Equality* details a series of recommendations and actions, including a commitment to publishing further guidance on health action planning.

This guidance fulfils that commitment. It draws on research and best practice in health action planning and health facilitation across the country and on the direct experience of a range of people who attended a number of health-focused workshops and events held in 2007. Participants included people with learning disabilities, family carers and a range of health and social care professionals across mainstream and specialist provision, including those responsible for commissioning.

The purpose of this guidance is to describe and clarify good practice in health facilitation and health action planning and support localities to make progress on this and on reducing the health inequalities

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[5] *Valuing People: The story so far…*, Department of Health (2005); *Valuing People Now: From progress to transformation*, Department of Health (2007); *Valuing People Now: A new three-year strategy for people with learning disabilities*, Department of Health (2008)

[6] *Promoting Equality*, Department of Health (2007)

experienced by people with learning disabilities. It builds on the previous Department of Health guidance and reflects the learning that has taken place since 2002 along with the key recommendations of relevant recent reports and research.

There is a particular emphasis on the strategic rather than the one-to-one aspects of health facilitation and on the work that needs to happen across strategic health authority (SHA) and primary care trust (PCT) areas and within Learning Disability Partnership Boards (Partnership Boards).

Accordingly, this guidance does not repeat the detail relating to health action planning that is contained within the original documents that should be read alongside this publication (see www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005503).

Target audience

This good practice guidance is primarily written for

- health facilitators;
- Partnership Boards and health implementation subgroups;
- PCT commissioners;
- providers of mainstream and specialist health services and healthcare professionals;
- local authority commissioners;
- social care support providers;
- SHAs; and
- the Healthcare Commission, Commission for Social Care Inspection and Mental Health Commission to assist in their regulatory and inspection roles.

An easy read summary of this document is available to assist people with learning disabilities, family carers and self-advocacy organisations to participate in health action planning and health facilitation and/or the planning and commissioning of these activities locally.

Headlines for commissioning bodies

The following ‘headline’ sheets summarise the key issues (adapted from the World Class Commissioning competencies) for those primarily responsible for the commissioning of health and social care services, namely SHAs, PCTs, local authorities and Partnership Boards. These will be available as separate downloadable documents on the revised Valuing People website (see http://valuingpeople.gov.uk/).

Useful and related publications

Valuing People: A New Strategy for Learning Disability for the 21st Century, Department of Health (2001)
www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Learningdisabilities/DH_4032080

Valuing People Now: A new three-year strategy for people with learning disabilities, Department of Health (2009)
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377

Action for Health – Health Action Plans and Health Facilitation, Department of Health (2002)
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005503

Valuing People: The story so far..., Department of Health (2005)
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4107054

Promoting Equality, Department of Health (2007)
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_072955

Equal Treatment: Closing the Gap, Disability Rights Commission (2006)
http://83.137.212.42/sitearchive/DRC/library/health_investigation.html

Treat me right! Better healthcare for people with a learning disability, Mencap (2004)
www.mencap.org.uk/document.asp?id=316

Death by Indifference: Following up the Treat me right! *report,* Mencap (2007)
www.mencap.org.uk/document.asp?id=284

A life like no other, Healthcare Commision (2007)
http://2007ratings.healthcarecommission.org.uk/_db/_documents/LD_audit_report.pdf

Supporting health action planning and health facilitation: headlines for strategic health authorities

Leadership

- Provide strategic leadership to support better health for people with learning disabilities. In particular, ensure that measures are in place to check performance on disability equality and plans to improve health service delivery for people with learning disabilities in mainstream and specialist learning disability health services.

Data and knowledge management

- Work with the public health observatories and other regional and national bodies to provide information to support the commissioning, planning and development of services to improve the health of people with learning disabilities.
- Make use of tools such as the regional health self-assessment and performance framework (see page 129 of *Valuing People Now*) and any regional forums to monitor progress and promote the sharing of good practice across the region.

Commissioning to improve outcomes

- Ensure that local systems work effectively to improve the health of people with learning disabilities and their families and reduce the health inequalities they experience, including underlying determinants of health such as education, housing, employment and transport.
- Support organisational and workforce development of specialist learning disability professionals to support the mainstream NHS and deliver interventions to support reductions of out-of-area placements and promote community-based services.
- Ensure that regional plans in response to *High Quality Care For All,*[7] the NHS Next Stage Review final report, include targets and activities that are relevant to, and support, better health outcomes for people with learning disabilities.

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[7] *High Quality Care For All: NHS Next Stage Review Final Report*, Department of Health (2008)

Engaging with people with learning disabilities and family carers

- Ensure that opportunities and mechanisms to hear and act on the views of patients and the public include people with learning disabilities and family carers, and action is taken to ensure that everyone is included, e.g. people from black and minority ethnic communities and, specifically, NHS Centre for Involvement, Overview and Scrutiny Committee (OSC) and Local Involvement Networks (LINks).

Working with community partners and collaborating with clinicians

- Support the development of Local Area Agreements (LAAs).
- Support the development of evidence-based care pathways that engage relevant regional and local stakeholders.
- Support regional and national networking opportunities.

Useful and related publications

A Life Like Any Other? Human Rights of Adults with Learning Disabilities, Joint Committee on Human Rights (2008)

www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf

Commissioning Specialist Adult Learning Disability Services: Good Practice Guidance, Department of Health (2007)

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_079987

Good practice in learning disability nursing, Department of Health (2007)

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081328

The NHS in England: The operating framework for 2009/10, Department of Health (2007)

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091445

Supporting health action planning and health facilitation: headlines for primary care trusts

Leadership

- Lead and steer the local mainstream and specialist health agenda to ensure that it includes and meets the needs of people with learning disabilities as well as achieving specific *Valuing People Now* and related health targets
- Attend the local Learning Disability Partnership Board and provide senior leadership for the delivery of the local Action for Health framework and related strategies.
- Build local leadership capacity in both mainstream and specialist health services – invest in posts that assist the PCT to deliver the changes required, e.g. strategic health facilitation, and deliver provider support, e.g. acute liaison.

Data and knowledge management

- Ensure that robust local data is collected and made available about the health needs of children and adults with learning disabilities, and that this impacts on commissioning priorities and activities (this should include those placed out of area and/or in regional or national services, e.g. offenders).
- Data should be made available to compare uptake in key areas such as screening and between groups, e.g. uptake by people with learning disabilities from black and minority ethnic communities and according to age, gender etc.
- Employ coherent data systems to monitor GP registration and the uptake of health checks and health action plans.

Commissioning to improve outcomes

- Utilise mechanisms such as the Local Enhanced Service (LES) to offer annual comprehensive health checks for all people with learning disabilities, and make best use of the Primary Care Service Framework for the health of people with learning disabilities.[8]

[8] *Primary Care Service Framework: Management of Health for People with Learning Disabilities in Primary Care*, NHS Primary Care Contracting (2007)

- Implement the Directed Enhanced Service (DES) to provide annual health checks for all adults with learning disabilities who are known to the local authority (see guidance on clinical DES for the General Medical Services (GMS) contract 2008/09,[9] available at www.nhsemployers.org/publications).
- Monitor progress on the *Valuing People* and *Valuing People Now* health targets, set local standards and encourage the use of clinically relevant tools such as Better Metrics and the Essence of Care benchmark for health action planning.
- Make sure that local health policies and practices are assessed (through equality impact assessments) to ensure that they do not disadvantage people with learning disabilities, including those from black and minority ethnic communities.
- Undertake reasonable adjustments to promote fair and equal access to the NHS, including mental health and offender health services.

Engaging with people with learning disabilities and family carers

- Provide accessible health information and opportunities for people with learning disabilities and family carers to participate fully in health action planning and related initiatives such as Expert Patient and Expert Carer Programmes.
- Ensure that robust systems are in place to capture and act on issues relating to patient experience and complaints, and make best use of Patient Advice and Liaison Services as well as focusing specific activity around the quality and availability of health action plans and facilitation.

Working with community partners and collaborating with clinicians

- Make use of Partnership Boards to work in partnership with local government and other key stakeholders to promote the wider health and well-being agenda, improve outcomes and reduce health inequalities. This includes engaging with specialist learning disability health professionals, practitioners with special interest, public health and health promotion.

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[9] *Clinical directed enhanced services (DESs) for GMS contract 2008/09: Guidance and audit requirements*, British Medical Association and NHS Employers (2009)

Ensure that the needs of people with learning disabilities are reflected in relevant local mechanisms such as joint strategic needs assessment (JSNA), local strategic partnerships and workforce development plans.

Supporting health action planning and health facilitation: headlines for local authorities

Leadership

- Jointly appointed directors of public health should ensure that health intelligence systems are developed to inform and direct the commissioning of services for people with learning disabilities and to ensure their inclusion in health protection and health promotion initiatives.
- Directors of adult social services should ensure that initiatives contained within LAAs aimed at improving the health and well-being of all citizens include people with learning disabilities – this includes making good use of information from public health observatories.

Data and knowledge management

- Work in partnership with PCTs to identify those who would benefit from, and be eligible for, enhanced services.
- Ensure that databases and relevant issues such as demographic changes are highlighted and addressed within commissioning strategies, e.g. the number of people with learning disabilities from black and minority ethnic communities.

Commissioning to improve outcomes

- Ensure that contracts with housing and support providers pay due regard to their role in supporting and meeting the health needs of people with learning disabilities – specifically health action plans and health facilitation.
- As the Learning Disability Development Fund transfers into local authority area-based grant budgets, it will be important to ensure continuity and clarity of funding on health priorities.

- Workforce and training strategies should include opportunity for family carers and supporters to increase their skills and knowledge in supporting individual health needs and promoting healthy lifestyles.
- Commissioning strategies need to ensure the socio-economic and wider determinants of health are accounted for and addressed, for example, opportunities for people with learning disabilities to gain paid employment.

Engaging with people with learning disabilities and family carers

- Ensure that people with learning disabilities have knowledge of, and opportunity to participate in, relevant forums to promote the health and well-being agenda, for example LINks and OSCs. OSCs should make use of the 'Ten questions to ask'[10] when scrutinising mainstream health services.
- Ensure the provision of advocacy services, including an Independent Mental Capacity Advocacy (IMCA) service.

Working with community partners and collaborating with clinicians

- Lead on the development of the LAA and ensure the engagement of public, private, community and voluntary sectors in improving the health, well-being and quality of life of people with learning disabilities.
- Work with partners in the PCT and local provider organisations across sectors to ensure that the health needs of people with learning disabilities reflect the priority status in *Valuing People Now*.

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[10] *Ten questions to ask if you are scrutinising mainstream health services for people with learning disabilities*, The Centre for Public Scrutiny (2008)

Supporting health action planning and health facilitation: headlines for Learning Disability Partnership Boards

Leadership

- Provide strong chairmanship to the health implementation subgroup and clear reporting mechanisms to the main board on national *Valuing People Now* and related health targets and locally identified priorities.
- Ensure that health subgroups contain relevant representation and leadership from mainstream and specialist health services (including mental health) alongside people with learning disabilities, family carers, support providers, the voluntary sector etc.

Data and knowledge management

- Ensure that Action for Health frameworks are reviewed, based on, and contain, robust information about the health needs of the local population and make good use of, and share, good practice and lessons learned.
- Action for Health frameworks should contain clear agreed targets and progress for the implementation of health action planning and related activity that responds to key findings in national reports, for example the Disabilty Rights Commission's report into primary care and the Independent Inquiry report *Healthcare for All*.[11]

Commissioning to improve outcomes

- Provide information to members of the Partnership Board to support understanding of structures and processes for commissioning and providing health services and to ensure that there is a 'good fit' across other relevant strategies, e.g. workforce.
- Make sure that the Partnership Board has clear and agreed outcomes relating to the health agenda and makes use of appropriate tools to support performance management, e.g. the Regional Standards Framework.

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[11] *Healthcare for all: report of the Independent Inquiry into Acess to Healthcare for People with Learning Disabilities*, Department of Health (2008)

- Consider the opportunities to promote increased choice and control and increased health and well-being, such as personal budgets.
- Act as a ‘champion’ and hold to account those who have responsibility for commissioning and delivering services to meet the health needs of people with learning disabilities, especially those with more complex needs, and the health needs of family carers, particularly older family carers.

Engaging with people with learning disabilities and family carers

- Make sure that the Partnership Board and the health subgroup have good representation from people with learning disabilities and family carers, including people who may have more complex health needs and people from black and minority ethnic communities.
- Utilise opportunities to understand and respond to the needs of children and young people, e.g. information from year 9 reviews and transition planning.
- Ensure representation at local and regional networks for people with learning disabilities and family carers and relevant community groups.

Working with community partners and collaborating with clinicians

- Ensure that the Partnership Board subgroup has appropriate representation across agencies and sectors and, specifically, of people with learning disabilities and family carers and those who commission and work within mainstream and specialist health services.
- Create ‘project’ groups with expert membership which may be local or across boroughs, to take forward work on very specific issues such as meeting the needs of people who are medically dependent on technology or offender health.

2. Background

As previously described, there is increasing evidence about unmet health needs of people with learning disabilities, the failings of the NHS to address the inequalities experienced by them and growing concern about lack of progress against the health targets in *Valuing People*.

The recent report of the Joint Committee on Human Rights – *A Life Like Any Other?* – recommends that a 'human rights-based approach' be taken to reducing inequalities with due regard to the Human Rights Act 1998[12] and the Disability Discrimination Act 1995[13] (as amended), the European Convention on Human Rights[14] and other international legal standards.

As part of its commitment to redressing this situation, the Government has made 'Better Health' for people with learning disabilities one of its top five priorities within the policy 'refresh' document *Valuing People Now*.

In 2007 the Department of Health published its Primary Care Service Framework[15] for the health of people with learning disabilities. It also published good practice guidance on *Commissioning Specialist Adult Learning Disability Services* and *Good practice in learning disability nursing*. All of these documents stress the importance of, and give advice on, making progress with the *Valuing People Now* health targets.

Importantly, the NHS Operating Framework 2008/9 explicitly requests that PCTs work with local authorities to make service improvements to ensure both quality of care and equal access to the NHS for people with learning disabilities. It is also clear that health action plans support the wider personalisation agenda with the emphasis on helping people to keep well and independent.

When implemented effectively, health facilitation and health action plans have the potential to support a range of wider Government aspirations such as enablement and early intervention.

These activities are also complementary to, and should sit alongside, a number of other person-centred health initiatives such as information prescriptions*, Common Core Principles to Support Self Care*[16] and personalised care plans for people with long-term conditions.

[12] Human Rights Act 1998 Chapter 42

[13] Disability Discrimination Act 1995 Chapter 50

[14] Convention for protection of Human Rights and Fundamental Freedoms Rome 4.XI.1950

[15] www.primarycarecontracting.nhs.uk/uploads/primary_care_service_frameworks/primary_care_service_framework_ld_v3_final.pdf

[16] *Common core principles to support self care: a guide to support implementation*, Department of Health (2008)

Importantly, they are supportive to the agenda laid out in the NHS Next Stage Review final report *High Quality Care for All*.

'An NHS that gives patients and the public more information and choice, works in partnership and has quality of care at its heart.'

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825

Useful and related publications and websites

Information prescriptions

www.dh.gov.uk/en/Healthcare/PatientChoice/Choice/BetterInformationChoicesHealth/Informationprescriptions/index.htm

Common core principles to support self care: a guide to support implementation, Department of Health (2008)

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084505

Long-term conditions

www.dh.gov.uk/en/Healthcare/Longtermconditions/index.htm

Better Health, Better Metrics

As part of the Better Metrics project, the Foundation for People with Learning Disabilities published a Commissioning Note for PCTs to support better commissioning for health

www.learningdisabilities.org.uk/our-work/improving-service/better-health/#commissioning

3. Taking a whole-system approach

Making sure that people are able to receive health facilitation and get a health action plan if they want one requires all stakeholders to work together to develop a local model and implementation strategy. It requires commitment from mainstream health commissioners and providers, particularly those in primary care (including mental health).

Progress is also dependent on a fundamental shift in practice for specialist learning disability services to develop more inclusive, community-based support and make best use of skills and resources.

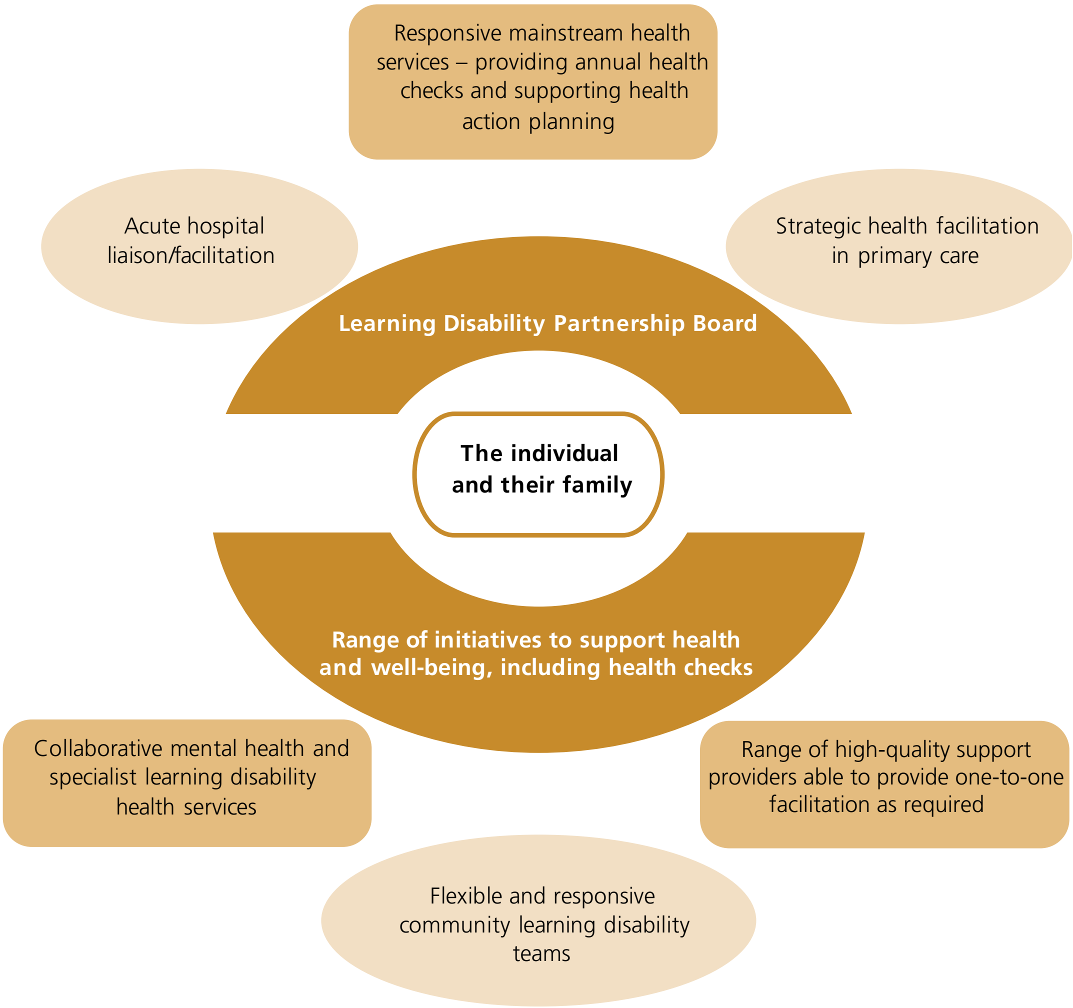
We should also be reminded that person-centred approaches and person-centred planning have to be at the heart of this strategy along with partnership working, not just between health and social care but also with wider services such as leisure, housing and employment and the voluntary sector. Local plans should clearly account for the needs and wishes of local people and their families and the work required to bridge sectors and manage change.

Similarly, health action planning and health facilitation cannot be seen as isolated processes and much of their effectiveness and success depends on good collaboration between individuals at all levels from commissioning through to one-to-one support.

Local Partnership Boards are the key mechanism for getting all stakeholders together and are charged with taking responsibility for the delivery of *Valuing People Now*, including its health objectives.

Setting the best local conditions for health action planning and health facilitation

The diagram below illustrates the best conditions to help local areas make progress on the health agenda.



Good practice example

In Leeds a template was developed to help identify patients with learning disabilities in general practice.

The tool was piloted in 30 GP practices in Leeds and validated against the city-wide database.

The findings raised significant issues relating to registration and the need for improved consistency in identification.

It clearly demonstrated the need for health and social care practitioners to work together on this issue.

4. Identifying health needs and monitoring progress

Despite the requirement on PCTs to manage knowledge and assess local health needs, some PCT commissioners still do not have access to an accurate 'baseline' of information including the number of people with learning disabilities in their locality.

This means that in many places local commissioners have an incomplete picture of population need and also cannot measure their progress in relation to the *Valuing People/Valuing People Now* targets for health;[17] specifically, those targets relating to registration with a GP and the availability and uptake of health action planning and health facilitation.

This situation is unacceptable and undermines progress not only on *Valuing People Now* objectives but also on those supporting **world class commissioning** as this quote illustrates.

'In order to do this [world class commissioning], commissioners will require outstanding knowledge management and analytical skills in order to develop a long-term view of community needs. They will also need to build on their position within the local community, developing closer relationships with key partners and playing a more pro-active role in shaping and defining local services. Key to success will be a PCT's ability to both listen and communicate back to its community partners.'

More information on world class commissioning can be found at www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/index.htm

Good practice example

In Norwich PCT the strategic health facilitator and the person who leads on ensuring patients are tracked on GP registers have worked together to develop new computer read codes for people with learning disabilities.

This enables the local area to monitor the uptake and provision of health assessments, health action plans and health facilitation.

Where good use has been made of available knowledge and information systems it has helped commissioners to check access and uptake of

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[17] Meeting 'Valuing People' health targets: recommendations from a research workshop.*British Journal of Learning Disabilities*: 35:2 pp75–83, Mir G (2007)

services such as screening or medication reviews, as well as progress on specific targets.

In identifying health needs and checking access and uptake of health initiatives by people with learning disabilities it is important to include access not only to GPs' services, but also to those provided by other primary care professionals such as dentists, opticians and chiropodists.

In 2007 the Department of Health published *Valuing People's Oral Health*[18] best practice guidance to improve oral health in disabled children and adults (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080918).

Similarly, having access to robust information supports local areas and the region to set standards and to meaningfully monitor and improve performance. To do this requires a range of methods to be employed to capture the views and experience of people with learning disabilities and their family carers and make sure it is reflected in commissioning and delivery.

Again this approach reinforces the vision set out in the NHS Next Stage Review final report *High Quality Care for All* that aims to ensure that the NHS delivers:

'High quality care for all users of services, in all aspects, not just some.'

Good practice example

In the Yorkshire and Humber region, work has recently taken place to find out about the experiences of people with learning disabilities and family carers when using local health services and to make sure these experiences are taken account of in future plans and developments.

The information forms part of a wider Standards Framework and annual data collection system that is reported on by Partnership Boards.

It will be used by the SHA and local statutory organisations to create a baseline and check their progress on the *Valuing People/Valuing People Now* and other related health targets such as campus closure.

This system, supported by the Valuing People Regional Leads, will be offered and rolled out to other regions.

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[18] *Valuing People's Oral Health: A good practice guide for improving the oral health of disabled children and adults*, Department of Health (2007)

Action

- PCTs should ensure that they have systems in place to collect information about the health needs of children and adults with learning disabilities. Care should be taken to ensure that it contains explicit reference to groups who might be described as 'seldom heard', for example people from black and minority ethnic communities, people in out-of-area treatment and offender services and those with more complex needs. This information should contribute to local arrangements that serve the whole population, e.g. JSNAs.
- Learning disability services can support PCTs to develop more robust information about the population and ensure initiatives such as annual health checks are appropriately targeted to identified adults with learning disabilities known to local authorities.
- PCTs and Partnership Boards should have a clear process in place to monitor performance and report on progress against *Valuing People Now* health targets; specifically, registration with a GP and the availability and uptake of health action plans and health facilitation.
- PCTs should employ knowledge management systems that support innovation and improvement in service delivery, for example communicating 'lessons learned' and sharing best practice.
- PCTs and local authorities need to ensure that they have mechanisms in place to hear and respond to the voice of people with learning disabilities and their family carers and include them in important related initiatives, e.g. LINks.

Good practice example

In South Birmingham PCT, the clinical lead for health facilitation has recently led a process of analysing the data that was gained by undertaking health checks for people with learning disabilities.

This has revealed valuable information about the unmet health needs and a wide range of previously undiagnosed conditions within the population.

5. Comprehensive health checks

The National Primary Care Research and Development Centre, among others, describes how registration with a GP and the provision of comprehensive health checks can support improved access and health outcomes (www.npcrdc.ac.uk/Publications/Health_checks.pdf).

Such research, including that undertaken by the Welsh Centre for Learning Disabilities and others, provides evidence that health checks can help detect a range of previously undiagnosed health problems in people with learning disabilities (www.cardiff.ac.uk/medic/subsites/learningdisabilities/currentresearch/primaryhealthcare/index.html).

However, despite these findings, and the fact that they are a useful tool in understanding local population need, we know that only a handful of PCTs have made health checks available to this population.

In 2006 the Department of Health affirmed its commitment to introducing comprehensive health checks in the White Paper *Our health*, *our care, our say*[19] (www.dh.gov.uk/en/Healthcare/Ourhealthourcareoursay/index.htm).

The significance of health checks can also be seen reflected in the current Department of Health proposals to enhance patient services by offering annual health checks to people with learning disabilities (who are known to local authorities) through a Directed Enhanced Scheme (DES). These proposals also include the requirement for primary care staff to undertake learning disability awareness training provided by strategic health facilitators and/or members of the local community learning disability team, in partnership with self-advocates.

Detailed information on the steps to delivery of health checks can be found in the suite of practical materials available on the Primary Care Contracting website (www.primarycarecontracting.nhs.uk/204.php).

Action

- PCTs should make available comprehensive annual health checks for people with learning disabilities using local or directly enhanced schemes.

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[19] *Our health, our care, our say: a new direction for community services*, Department of Health (2006)

- Local authorities should work in partnership with PCTs to identify those who would benefit from, and would be eligible for, enhanced services.
- PCTs should make sure that available tools and templates are utilised to support better identification and registration of people in primary care and increased consistency of coding within the locality.
- Undertaking comprehensive annual health checks will require considerable effort by primary care staff, therefore PCTs should ensure the availability of resources including support from specialist learning disability community teams as appropriate.
- PCTs should support learning disability awareness training for mainstream health professionals.

Good practice example

In Salford, the local acute hospital trust has worked closely with the PCT healthcare facilitator (learning difficulties) to employ a range of initiatives to improve access and safety for patients with learning disabilities.

This includes information, training for health professionals and tools to support the admission and discharge process.

The Royal College of Nursing has produced practice guidance for nurses in mainstream services to better support people with learning disabilities (www.rcn.org.uk/development/publications).

6. A human rights-based approach

'Quite simply, we cannot hope to improve people's health and well-being if we are not ensuring their human rights are respected.' (Rosie Winterton MP, 2007, Joint Committee on Human Rights: Eighteenth Report)

Despite their complex health needs, there is overwhelming evidence that many people with learning disabilities and their families are poorly served by the NHS and that those from black and minority ethnic communities often experience 'double disadvantage', facing barriers relating to both disability and race.

PCTs have a legal responsibility to ensure that local health policies and practices are assessed (Equality Impact Assessments) to make sure they do not disadvantage people with learning disabilities (www.equalityhumanrights.com/en/Pages/default.aspx).

However, we know that some places have not appropriately considered this requirement or the need to make 'reasonable adjustments' to facilitate fair and equal access to the NHS.

In some PCTs where careful consideration has been made, it can be evidenced in a number of initiatives ranging from changes to appointment systems to the employment of acute hospital liaison nurses.

The 2008 Department of Health publication *Human Rights in Healthcare*[20] offers a framework for local action and contains case studies illustrating the issues (including learning disabilities) (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_088970).

The Centre for Public Scrutiny has also produced useful information for OSCs, *Ten questions to ask if you are scrutinising mainstream health services for people with learning disabilities*[21] (www.cfps.org.uk/publications/item.php?itemid=77).

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[20] *Human Rights in Healthcare: A framework for local action*, Department of Health (2008)

[21] *Ten questions to ask if you are scrutinising mainstream health services for people with learning disabilities*, The Centre for Public Scrutiny (2008)

Good practice example

In Shropshire the local acute hospital has employed an acute hospital liaison nurse.

They have also seconded two additional general nurses to work alongside her and build up their knowledge and skills and, therefore, increase capacity to support people with learning disabilities in acute hospital settings.

Action

- PCTs and providers, including acute hospitals, need to fulfil their ‘public sector duty’ and ensure that there is consideration and evidence of ‘reasonable adjustment’ to support access to healthcare for people with learning disabilities. This includes consideration of workforce learning and development needs as well as environmental factors.
- PCTs should utilise available tools to support better commissioning and reduce inequalities, such as the Primary Care Service Framework for the management of people with learning disabilities (www.pcc.nhs.uk).
- Partnership Boards should ensure that local services account for their actions in relation to promoting equality.
- Mainstream and specialist health and social care commissioners and providers should work together with people with learning disabilities and their families to reduce barriers to healthcare.

Good practice example and link

Bristol and North East Somerset PCT have appointed a learning disability nurse (who has an MA in public health) within their public health department.

She works closely with self-advocates to make sure people with learning disabilities benefit from local and national public health initiatives.

Recent work includes local activities to increase awareness of the use and dangers of salt in food.

Information about the health profiles of the general population are also published by the Association of Public Health Observatories and are useful tools in assessing need and targeting action (www.communityhealthprofiles.info/).

7. Public health

In 2004 the Government published the Public Health White Paper *Choosing Health.*[22] The document contained three key principles to support health improvement (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4094550):

- informed choice for all;
- personalisation of support to make healthy choices; and
- working in partnership.

We know that many people with learning disabilities live in areas with high levels of social deprivation and experience material and social hardship.[23]

The need to promote health and improve health outcomes for all is also emphasised in the *Commissioning framework for health and well-being*[24] (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_072604).

Health action planning and health facilitation are useful tools in providing opportunity for people with learning disabilities to make healthier and more informed choices and thus complement the local public health agenda for all members of the population.

Good practice example

In Sheffield work has been undertaken to assess the local population's current and projected needs.

This initiative has helped clarify resources and activity that will be required to respond to these needs and has provided valuable data about changes in the level and complexity of need, such as information about the number of children and young adults who are medically dependent on technology.

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[22] *Choosing Health: Making healthy choices easier*, Department of Health (2004)

[23] *People with Learning Disabilities in England*, Emerson E and Hatton C, Centre for Disability Research (2008) (http://eprints.lancs.ac.uk/9515/1/CeDR_2008-1_People_with_Learning_Disabilities_in_England.pdf)

[24] *Commissioning framework for health and well-being*, Department of Health (2007)

Action

- Partnership Boards should make sure that their health frameworks make good use of, and alliances with, the public health agenda.
- Partnership Board health subgroups should ensure that Action for Health frameworks take account of public health issues and make relevant connections with this agenda by, for example, looking at access to, and use of, community leisure and sport facilities by people with learning disabilities.
- PCTs should consider how to make best use of local public health departments to collect and make available relevant data and information, for example obesity rates in the population of people with learning disabilities.
- Information about the local population of people with learning disabilities should feed into and form part of the local mechanisms such as JSNAs and LAAs.

Good practice example

Greenwich Learning Disability Partnership Board is co-chaired by a councillor and an elected person with learning disabilities. The health subgroup and the local acute liaison group are also co-chaired by a person with learning disabilities.

Health subgroup meetings are hosted by a Greenwich PCT commissioner and the acute liaison meetings are held in the local acute hospital.

Recent work includes the production and launch of an accessible DVD for people with learning disabilities who use the acute trust’s services.

8. Learning Disability Partnership Boards

The health implementation groups that are subgroups of Partnership Boards are the key mechanism for the delivery of the 'better health' objectives in *Valuing People Now* and in related policy and guidance. These subgroups are responsible for working on the development and delivery of the local Action for Health framework and related health strategies. However, at some Partnership Boards there has been slow progress in meeting the health objectives in *Valuing People Now*.

Problems engaging senior PCT representation at Partnership Boards has contributed to the failure in many areas to make sufficient progress on health action planning and health facilitation and related activities. In some places, this has also presented barriers to achieving other related health objectives such as improving access to mainstream mental health services.

Anecdotal evidence would suggest that where there is poor PCT representation at Partnership Boards it is due to a number of factors. These include: learning disabilities having been seen as a low priority within the NHS, small population sizes, and a lack of capacity and expertise in PCTs.

Some health implementation subgroups have worked well together over the last five years. Others, however, have also had difficulty not only with getting and keeping the right membership and expertise, but with developing and reviewing local strategies and achieving clear outcomes.

People with learning disabilities and family carers often describe the difficulties of moving forward with targets because the 'decision makers' are not present at meetings. Professionals can experience similar problems when other parts of the NHS, particularly primary care, are absent.

Some places have also experienced difficulties getting 'health' onto the main agenda of Partnership Boards alongside other priorities such as housing, employment and transition. This can be made worse when the boards meet infrequently or are conducted as 'information-giving' sessions rather than taking action and being accountable for change.

A good practice guide and toolkit for Partnership Boards is being produced to help them to review their strategic function and to set specific targets and review progress regularly. Once published this toolkit will be disseminated to all Partnership Boards and will be available on the *Valuing People* website.

Engaging with people with learning disabilities and family carers has been variable across the country. In some places, self-advocates and family carers joined groups and gave ideas, etc. but then stopped going when nothing seemed to happen. As one facilitator put it:

'Our local parents are so very sick and tired of 'focus' groups etc.... they just want action.'

To improve the situation, many places have successfully appointed a parent or self-advocate as co-chair to the health subgroups. However, some groups of people continue to be hard to reach and require targeted and sustained interventions, for example people with severe and complex disabilities and people from black and minority ethnic communities.

Some health subgroups are working well on the health targets but find that the way the Partnership Board is organised makes it difficult to connect well with other subgroups and ensure their plans fit together. For example, making sure that there is good joint working between those implementing person-centred planning, health action planning and those supporting the transition from children to adult services.

Meeting the health needs of family carers and people with learning disabilities who may be in a 'mutual caring' situation is an issue that has gained more prominence recently and is another area that would benefit from a joined-up approach. Information about the Foundation for People with Learning Disabilities' Mutual Caring Project can be found at www.learningdisabilities.org.uk/our-work/family-support/mutual-caring/.

Action

- Partnership Boards should ensure that they have an up-to-date Action for Health framework and a health implementation subgroup to specifically attend to the health action planning targets and related health objectives.
- Chairing the Partnership Board health subgroup is a key leadership role and one that the PCT representative is well placed to fill, with a co-chairing role undertaken by a self-advocate or family carer.

- Partnership Boards should regularly review the membership of the health subgroups to make sure that there is representation from mainstream and specialist health services alongside people with learning disabilities, family carers, support providers, etc.
- Partnership Boards need to act to make sure that 'harder-to-reach' groups have good representation. This would include people with complex needs and people from black and minority ethnic communities.
- Given the complexity of the health agenda, it would be prudent of Partnership Boards to make sure that members have basic information about the local structures and process for commissioning and providing healthcare.
- Subgroups should consider creating 'project' groups with expert membership, in order to take forward very specific issues, such as the health needs of people who are dependent on medical technology. It may also be advantageous for project groups across neighbouring boroughs to work together on specific issues, such as prison health. This would also allow for contributions from people whose work is across those areas – for example regional commissioners of forensic health services.
- Partnership Boards need to ensure that there is a 'good fit' between health action planning and transition planning for children in year 9, and, more particularly, for children and young people returning from residential schools and colleges.

Some useful networks and links

UK Health and Learning Disability Network
www.learningdisabilities.org.uk/ldhn

Mental Health in Learning Disabilities Network
www.estiacentre.org/mhildnetwork.html

National Health Facilitation Network
www.networks.nhs.uk/networks/page/845

National Learning Disability and Ethnicity Network
www.lden.org.uk

- Partnership Boards should make sure that plans for supporting family carers contain actions to support people with learning disabilities who may also be carers.
- Partnership Boards should also ensure that parents with learning disabilities are offered support with the health action planning process.
- The regional health networks supported by the Valuing People Regional Leads provide an invaluable opportunity for the sharing of good practice and for generating ideas and solutions to take forward this agenda. Partnership Boards should ensure that they have appropriate representation at regional networks and that mechanisms are in place to ensure that knowledge and information can be disseminated.

9. Action for Health frameworks

When the implementation guidance for health action planning and health facilitation was published it carried an expectation that by **June 2003** all Partnership Boards would **'have an agreed framework for the introduction of health action plans'**. Additionally, support and advice on the production of frameworks was commissioned and made available to Partnership Boards (Norah Fry Research Centre, 2002).

However, although many localities did produce these frameworks they often lacked detail in relation to implementation and accountability. Since that time it has not been uncommon to find that frameworks have not been updated or reviewed to reflect more recent guidance and findings of reports such as the Disability Rights Commission's formal investigation in 2004 – *Equal Treatment: Closing the Gap*.

The reasons for this include the absence of key stakeholders in the planning process, lack of senior leadership, poor monitoring of performance by the Partnership Board and inadequate resource allocation.

It is particularly noted that many frameworks have not fully accounted for the human resource implications across both health and social care providers – specifically, how capacity to deliver and support health action planning and facilitation would be created across all sectors. Evidence would suggest that there is a need for more detailed work about the skills and knowledge needed by various groups such as support workers, personal assistants and registered managers.

The involvement of people with learning disabilities and families in the development of frameworks has also been variable across the country, particularly people with more complex needs or people from black and minority ethnic communities. Similarly, some people's health needs are not included in the framework because they are 'out of sight', for example, those in the criminal justice system or in out-of-area treatment services.

Action

- Health frameworks should contain clear plans and targets for the implementation of health action planning **and** related activity that respond to the key findings in recent national reports.

- Partnership Boards should ensure that all groups are represented and involved in the development, implementation and evaluation of the Action for Health framework, e.g. people with more complex needs.
- Health implementation subgroups should also ensure that there is appropriate detail within the framework of the health needs of people with learning disabilities who may be 'out of sight' in out-of-area placements, residential colleges or the criminal justice system.
- Partnership Boards need to assure themselves that their Action for Health framework is up to date and regularly reviewed. It is advised that there should be a full written report from the chair of the health subgroup to the Partnership Board and PCT at least every six months. This report should identify progress against targets for health action planning and health facilitation as well as what is and is not working well to support 'better health' more broadly.
- Chairs of the Partnership Board and health subgroup should ensure that there is a 'good fit' between the Action for Health framework and the strategies and frameworks across the other subgroups.
- Partnership Boards need to ensure that the health needs of family carers are considered in local strategies and the work of health subgroups.

Good practice example

In Bexley and Greenwich, training materials and accessible information are uploaded on to the GP practice computer systems by the health facilitation co-ordinator.

Creating an electronic learning disability resource folder on the computer desktop supports the training delivered to practice nurses, managers, GPs and receptionists.

Information also includes accessible letters for appointments etc and helps to embed the practice of using and providing accessible information in primary care.

Some useful networks and links

National Library for Health – Learning Disabilities Specialist Library www.library.nhs.uk/learningdisabilities/

Learning about Intellectual Disabilities and Health – a web-based learning resource for medical and healthcare students and practitioners www.intellectualdisability.info/home/about.html

10. Workforce

In the original guidance it was envisaged that primary care professionals such as GPs and practice nurses would play a major role in health facilitation and the instigation and development of health action plans. Moreover, specialist learning disability health professionals would **support** mainstream health professionals in this role and in reducing health inequalities.

What we have learned since is that in many places specialist learning disability health services have, in the main, led the implementation of health facilitation and health action planning. However, in taking this pragmatic approach some places have not considered issues of capacity and contracting which has led to a tension and lack of clarity about resources and accountability.

There is also an inherent risk that an over-reliance on specialist services maintains a situation whereby the mainstream NHS fails to meet its obligations and build the confidence, capacity and capability to deliver.

We also know that the level of engagement and collaboration between specialist learning disability health professionals and mainstream health professionals varies across the country and between practices and hospitals.

Research indicates that there are some systemic difficulties including lack of capacity within primary care teams to deal with the requirements of health facilitation, confusion about the health facilitation role, problems with skilled specialist support and involvement of stakeholders.

Some areas have worked to clarify what ‘support’ to the mainstream NHS looks like and found that using specialist learning disability professionals (often community nurses) to provide a ‘link’ is a useful way forward. This principle can be extended to other health and social care settings and helps to ensure that specialist knowledge is used to best effect in building up skills and competence in the mainstream.

This should be enhanced by the development of practitioners with special interest roles (www.dh.gov.uk/en/publicationsandstatistics/publications/publicationslegislation/dh_074792).

Good practice example

A one-day learning disability awareness training package has been developed for prison staff (in both adult and juvenile establishments).

This was a joint commission by the Valuing People Team and Offender Health, with design and delivery by two learning disability charities (KeyRing and The Skillnet Group).

The course is delivered by a learning disability specialist and a co-trainer with learning disabilities.

We know that strategic health facilitators play a vital role in providing training for health facilitation and health action planning but that not all PCTs have such a post and, in some areas, the funding is not secure. A similar picture is evident for the provision of acute hospital liaison nurses despite the safety issues presented by people with learning disabilities.

In social care there have also been some problems in raising the profile of, and commitment to, health action plans and health facilitation. Some providers have made good use of the process to improve health, promote healthy lifestyles and ensure that healthcare needs are met; however, this is not consistent.

Problems include high turnover of staff, inadequate information, training and attention to health needs, and some support providers not recognising their contribution to planning and facilitation.

Clearly, there is scope for commissioners to make specific reference to activities that support an individual’s health needs within their contracts with support providers and to commission local learning and development opportunities for social care workers on key areas such as health action plans.

Similarly, there is growing concern regarding the needs of offenders with learning disabilities who may be ‘off the radar’ of local Partnership Boards and who may have significant unmet health needs.

Good practice example

In Sheffield, members of the community learning disability team are formally linked to local GP practices.

This means that they are able to work more easily in partnership and support the practice to improve access and reduce barriers to primary care for people with learning disabilities.

They are also able to help with identification of patients with learning disabilities and ensure that they are offered a health action plan and facilitation.

Action

- Partnership Boards need to ensure that local workforce development strategies consider and address capacity and training implications related to achieving the health objectives in *Valuing People Now*. Workforce subgroups should ensure that people with learning disabilities and family carers are fully included in all aspects of workforce planning and development.
- Given the current organisational changes, it would be prudent for PCTs to ensure that they have clarity with regards to the role of strategic facilitator and where it is best placed. Experience and views from the field would suggest that it could be most effective at leading changes and employing levers when based within the commissioning function of PCTs.
- Meeting the health needs of people with learning disabilities requires all parts of the NHS to work together. PCT commissioners need to be engaged in determining the implications and agreeing the resources to support mainstream health professionals to fulfil their role in health facilitation and reducing inequalities. This would include consideration of the development of posts such as GP with special interest.
- While specialist learning disability professionals are well placed to act as health facilitators, particularly to those with complex needs, commissioners must also ensure that capacity and support is developed within social care and particularly for families.

Good practice example

In the West Midlands good reporting on the Action for Health framework at the Partnership Board resulted in local PCTs investing in eight strategic health facilitator posts.

These posts, employed in 2005, for three PCTs across Stoke, North Staffordshire and South Staffordshire, provide an average of one postholder per 150,000 general population.

They work closely with the GP practices in their area.

They provide support and training, tailor-made resources and navigation to primary care professionals, people with learning disabilities and family carers, and social care providers.

- Partnership Board strategies need to make explicit reference to how they will achieve relevant workforce policy objectives specifically linked to health, including offender health – for example, meeting the workforce recommendations contained in 2007 Department of Health guidance (the Mansell Report[25]) relating to the support of people with learning disability and challenging behaviour or mental health needs.
- Local authority commissioners should ensure that training for support staff includes basic awareness of health issues for people with learning disabilities and how to 'navigate' the local NHS.

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[25] *Services for people with learning disabilities and challenging behaviour or mental health needs*, Department of Health (2007) Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129

11. Supporting people with learning disabilities and family carers to plan

We know that many adults with learning disabilities live with family carers and that a large percentage of people within this group have severe disabilities and chronic health needs. However, local strategies may not fully consider the investment, support and training needed for family carers in relation to health action planning and health facilitation.

Similarly, the health needs of family carers themselves may be overlooked, along with the specific issues faced by particular groups – for example, the needs of older family carers.

There are good examples of training for family carers in relation to health action planning and health facilitation but again this is not consistent across the country or even within regions. Where local areas have worked closely with family carers, much has been gained in relation to both health facilitation and health action planning, as one strategic facilitator explained:

'Family carers don't move, go on maternity leave, get promoted... family carers don't stop caring.'

Equally, there are lots of good examples of training in health issues for people with learning disabilities to support them with health action planning, and activities to promote increased choice, control and self-care.

Many strategic health facilitators stressed the importance of making tools (such as folders and templates for health action planning) available to people with learning disabilities and family carers who may not have the same access to resources as paid staff.

It is really positive to know that many places have harnessed the expertise of people with learning disabilities and family carers to train other people, including health professionals, to better understand how to meet their individual needs. Some of the most powerful training opportunities have been provided by the many self-advocacy organisations making use of a range of multi-media techniques, art and drama.

Good practice example

The 'H' team at Grapevine, a local self-advocacy group in Coventry, provide support and training by and for people with learning disabilities on a range of health issues, including:

- healthy lifestyles training;
- easy-to-understand information leaflets on health subjects;
- training for health services staff; and
- health buddies to support people with learning disabilities to speak up.

The original Department of Health guidance on health action planning stressed the need to offer health action plans at the time when people are undergoing major changes in their life. Health action planning and health facilitation can be really practical ways to minimise the difficulties described by people with learning disabilities and family carers going through transition but also when accessing a new or different service due to changing needs.

It will be important to make sure that the people who will be leaving NHS Campus provision, many of whom will have complex health needs, have good health action plans and facilitation. Additional NHS Campus revenue funding will be made available during the three years to 2010/11 to support this and other transitional supports.

Lastly, the problems facing parents with learning disabilities have gained more prominence in recent years. In 2007 the Department of Health and the Department for Education and Skills jointly issued good practice guidance for health and social care professionals on how adults and children's services should work together to improve support to parents with learning disabilities and their children.[26] Ensuring that parents with learning disabilities have good health action plans is also vital in supporting them in their roles as parents.

[26] www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075119

Action

- Partnership Boards need to review their local health frameworks and their strategies for ensuring that people with learning disabilities and family carers get appropriate training and support in health action planning and health facilitation.
- If they have not already done so, health subgroups should urgently review any progress in relation to training for people with learning disabilities and family carers in health facilitation and health action planning and their experiences of the process.
- PCTs and local authorities should ensure that they are appropriately investing in programmes that will support people with learning disabilities and family carers who wish to train as ‘trainers’. This would include training for health professionals but also for relevant specific health issues, e.g. in postural care skills, dysphagia, continence etc.
- Similarly, PCTs need to make sure that the local strategies for the delivery of complementary initiatives such as the Expert Patient and Expert Carer Programmes include people with learning disabilities and their family carers.
- PCTs should ensure that people with learning disabilities are included in any health initiatives to support prevention and early intervention in their locality, such as use of assistive technology.
- PCTs and local authorities should make sure that NHS Campus closure plans pay due regard to the need to ensure that those people affected have health action plans and facilitation.
- Partnership Board health implemetation subgroups should ensure that their plans include parents with learning disabilities and consider the support they may need to navigate and access health services – in particular, maternity and health visiting.

Good practice example

In Tamworth, work took place with a group of families to help them improve the health of their children who had severe disabilities and complex health needs.

It focused on improving the individuals' poor posture as this was seen as the predisposing factor for a range of serious health problems, including respiratory illness.

In doing this, it recognised that family carers were the most committed and spent most time with the individual.

Health information was provided and carers were trained in techniques to better support the individual and to 'navigate' the health and social care system.

Some of the family carers have gone on to gain qualifications as trainers in postural care skills.

Useful resources

The Profound and Multiple Learning Disabilities (PMLD) Network contains resources and useful information guides e.g. multi-media profiling:
www.pmldnetwork.org/resources/index.htm

The British Institute for Learning Disabilities has produced factsheets on intensive interaction and communication:
www.bild.org.uk/

The National Patient Safety Agency published best practice guidance in 2007. The guidance contains information about assessment, care plans and protocols:
www.npsa.nhs.uk/patientsafety/alerts-and-directives/directives-guidance/dysphagia/

12. Including everyone

Making sure that everyone gets the chance to have a health action plan is a key objective within policy guidance. However, experience tells us that many localities have had difficulty making sure that they are available to people with more complex needs. This includes people who have profound and multiple learning disabilities and people with learning disabilities whose behaviour presents a challenge, or who have mental health needs or an autistic spectrum condition.

Given the complexity of need, it is vital that health action planning and good health facilitation is available to help all people with learning disabilities and their family carers and supporters to navigate and make best use of the NHS. This is particularly so for people who are described as 'living with medical technology'.

Research by the National Primary Care Research and Development Centre[27] about the experience of families caring for a technology-dependent child in the community shows that appropriate community support is often not available and that health professionals such as nurses, GPs and health visitors need specialist information and advice as much as parents themselves.

Many people are aware that problems in accessing healthcare are often exacerbated in the transition between children's and adult services. However, less well recognised are the problems that may arise for older people with learning disabilities. This can be especially difficult for those individuals who experience health problems associated with ageing earlier than the general population as in the case of some people with Down's syndrome and dementia. They may find that they cannot get access to the right service or that their changing needs are not accommodated.

Skilful health facilitation and health action planning is an important tool in helping people to remain as independent as possible. Ensuring a person-centred approach is particularly important for those people who may be assessed as eligible for continuing NHS healthcare. A guide to help Partnership Boards think about continuing care is available on the Valuing People website (http://valuingpeople.gov.uk/).

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[27] *Supporting families caring for a technology-dependent child in the community*, National Primary Care Research and Development Centre (2000). Available at: www.npcrdc.ac.uk/Publications/Es16.pdf?CFID=30914&CFTOKEN=37521798

Useful resources

Information about the issues to consider and action to take to support people with mental health needs can be found in the service improvement guide and toolkit 'Green Light – How good are your mental health services for people with learning disabilities?'

www.valuingpeople.gov.uk/

Mental health care pathway for children and young people with learning disabilities and mental health needs

www.annafreudcentre.org/ebpu.htm

Foundation for People with Learning Disabilities – good practice for child and adolescent mental health services (CAMHS)

www.learningdisabilities.org.uk/our-work/children-and-young-people/children-and-mental-health-services/

As previously described, there has been some good work regarding health action plans and the Care Programme Approach to support individuals with learning disabilities and mental health needs, but it does remain patchy.

Strategic health facilitators and other health professionals have described the difficulties of accessing appropriate health services for people with learning disabilities and mental health needs, especially those who use substances such as alcohol and drugs whose needs may be overlooked.

For some groups, specifically people from black and minority ethnic communities, the health inequalities and problems accessing a range of health services are well documented. Research published by the Foundation for People with Learning Disabilities in 2005[28] examined the issues facing young people with learning disabilities and mental health needs from Pakistani and Bangladeshi communities in Bradford. The findings indicated that the individuals and their families faced significant problems accessing services for a number of reasons, including:

- lack of knowledge and awareness about what support is available;
- language barriers;

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[28] *Making us count: Identifying and improving mental health support for young people with learning disabilities,* Foundation for People with Learning Disabilities (2005). Available at: www.learningdisabilities.org.uk/publications/?EntryId5=22347

- inability or reluctance to get help; and
- perceptions and beliefs about caring and the role of the family.

However, the study also found that many of these problems could be improved by the appointment of a liaison worker whose role was to raise awareness of existing service provision and support people to get access to the services they wanted. Those families who had the use of a liaison worker had significantly more frequent contact with a wider range of services and more positive outcomes than those who had not.

Clearly, this work has similarities with the role of health facilitators and is useful in helping Partnership Boards' health subgroups to take practical steps to reduce inequalities for people from black and minority ethnic communities.

Good practice example

The 'Let's Plan Together' DVD has been developed in Leicestershire, Leicester City and Rutland to introduce parents and family carers to the concepts of person-centred plans, health action plans and communication passports.

The DVD was produced in response to concerns that family carers often find it difficult to access formal training and are not always aware of the tools and support that are available to them.

Over 1,200 family carers have been given a copy of the DVD with an invitation to an event to support planning and networking.

The DVD can be viewed in sections and has an option to view in Gujarati and Urdu.

Action

- Partnership Boards need to ensure that there is opportunity and support for people with more complex needs and their family carers to be fully involved in the health agenda and work of the health subgroup.

- Partnership Boards should ensure that they have systems in place to check who is getting a health action plan and make sure that certain groups are not missing out, e.g. people from black and minority ethnic communities, older people, offenders, people with autistic spectrum conditions and people with mental health needs.
- PCTs and local authorities should ensure that the process of assessing and providing for people eligible for continuing NHS healthcare is person centred.
- PCTs should ensure that people with learning disabilities and mental health needs, including children and young people, have access to appropriate local services.
- Health subgroups should ensure that there is sufficient representation from those concerned with the commissioning and delivery of mainstream mental health services and offender health.

13. What does good health facilitation look like?

'Health action planning needs to be person centred 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.'*[29]

We have already looked at how the original guidance described the process of health facilitation as taking place on two levels – strategic and individual. We know that across the country there are variations in the style and delivery of health facilitation.

Many localities have employed a strategic health facilitator and we know that this has been helpful in providing leadership and building capacity and expertise. Sometimes this strategic role has been taken on by those who may carry other responsibilities, such as nurse consultants. In some places they have also employed an acute liaison nurse and this has enabled good support to be provided across primary and secondary healthcare.

At the one-to-one level of health facilitation we can again see variation across localities in investment and across groups. We know different places have had differing degrees of success in engaging and training people, particularly family carers, to fulfil the role. Some areas have also found they have to provide a constant training programme to cope with the changes in personnel and support workers.

However, there has been a consistent message about the problems of engaging mainstream health professionals in the health action planning process. Anecdotal evidence would suggest there are several reasons for this, including lack of capacity, competing demands and a lack of incentives and targets around learning disability.

In some places the result of this is that, contrary to the original guidance, some people have not had their health action plan checked by a generic health professional or had access to a health assessment. This situation needs to be addressed as it compromises both the quality of the process and the development of skills and knowledge in understanding and meeting the health needs of people with learning disabilities in primary care.

[29] *Action for Health – health action plans and health facilitation*, Department of Health (2002)

In social care, providers do not always recognise their role in supporting and facilitating health and well-being. In some places people have experienced difficulties getting basic needs, such as personal hygiene and nail-clipping, attended to. Equally, many people rely on social care staff to help them shop for food and access leisure facilities, so good knowledge and awareness of health matters is critical. Similarly, many people rely on support staff to facilitate and navigate them through the health service as well as make and attend appointments with doctors, dentists, opticians, outpatients etc.

A common concern expressed by mainstream health professionals such as doctors is that often the person with a learning disability is not accompanied to an appointment by someone who knows them well. This highlights the importance in investing in all those who support an individual on a day-to-day basis, including social care staff as well as family carers, support staff etc.

Helping social care staff, family carers and others to gain and develop these skills should be a key shared objective of Partnership Board health and workforce subgroups and may involve providing a range of opportunities for people to learn. This might include coaching, mentoring and networking as well as more formal training and information sharing, and support to make the best use of IT and web-based materials.

A good one-to-one health facilitator:

- is known and trusted by the person;
- puts the person at the centre of the plan and is a good listener;
- works closely with the individual and those who love and support them;
- knows a lot about the individual's health needs, wishes and rights;
- knows how to access local health services, dentists, opticians etc;
- is a good communicator; and
- knows how to format a plan to make it useful for the individual.

Additionally, a good strategic health facilitator:

- is a good leader;
- knows about the health needs of people with learning disabilities;
- understands how health services are commissioned and delivered;
- can develop, monitor and audit initiatives to reduce inequalities;
- can work across a locality with different agencies and services; and
- understands mainstream and specialist health policy.

Action

- Partnership Boards need to check that they have capacity to drive the strategic health facilitation work across their locality and provide leadership. It will be crucial to engage with the PCT to ensure that strategic activity is resourced appropriately and that useful structures are in place for them to engage with wider agendas, e.g. public health.
- Health implementation subgroups must ensure that they have good measures in place to check progress and should consider using tools such as Better Metrics to help with this.
- Health implementation subgroups and workforce subgroups should ensure that their plans account for the resource and training implications for health facilitators.
- Training in health facilitation should be closely aligned to the local delivery of training for person-centred planning. Partnership Boards should be assured that there is a ‘good fit’ between their plans and delivery in these areas.
- Local investment in the training of family carers is paramount and PCTs and local authorities should ensure that they are able to access training both for health facilitation and for supporting relevant and specific health needs such as postural care.
- Local authority commissioners should ensure that contracting and standards frameworks for support providers pay due regard to supporting the health needs of people with learning disabilities and the competence of staff to support this area.

Good practice example

In Westminster, a four-day course has been developed and run for frontline social care staff on health facilitation and person-centred planning.

The course covers a range of issues including health inequalities, working with GPs, developing person-centred plans, finding local resources, facilitating and writing a plan.

So far, around 70 people have been trained and each service in the area has a trained health facilitator.

Health messages are cascaded to the health facilitators who disseminate them to their teams.

Workshops are held on a bi-monthly basis to cover specific topics and to explore any presenting barriers to the implementation of health action plans.

14. Health action plans

We have learned a lot since 2002 about health action plans and their design and implementation. These quotes are typical of the things many people said when we talked about what should be in a health action plan and what it should look like:

> Focus more on the process – not what the health action plans look like at the end.

> Don't prescribe one approach. Health action plans should not all look the same.

> Style and format less important than explaining the plan clearly and ensuring actions take place.

> Need to be flexible – can just be a way of life. Need to be person centred.

> Style should be flexible but having some 'similar' features helps primary care staff recognise what they are.

We have also learned a lot about accessible health information and there are now many examples available to download. The Department of Health recently sponsored two projects that provide information for people with learning disabilities, family carers and professionals – 'Easyinfo' (www.easyinfo.org.uk) and Clear Thoughts, the mental health and learning disability website (www.clearthoughts.info/).

Healthy Lives Project – Foundation for People with Learning Disabilities

This Department of Health funded project looked at supporting people with learning disabilities to think about their lives and how to stay healthy and well. It specifically looked at the relationship between health action plans and person-centred plans.

In their work across five sites they found that four important issues emerged:

Communication: how people let you know what is important to them.

Consent: helping people to understand a health check or treatment and whether they want to say yes or no to it.

Sharing information: helping people to think about the information that is OK to share and what they want to keep private.

Risk and duty of care: thinking about different sorts of risks in life and how to manage them.

www.learningdisabilities.org.uk/our-work/improving-service/healthy-lives/#outcomes

Many people felt that the implementation of health action plans in their area had been helped by using a uniform style that was then personalised to suit individual need. The reasons cited in support of this approach included the following:

- It helped mainstream healthcare professionals to recognise a health action plan and know where to look for information.
- It gave people a 'framework' to follow rather than having to start from a blank sheet of paper.
- It helped facilitators to check that they had covered all the main areas such as hearing, dentistry, medication and continence.
- People liked to have a 'folder' where information about their health and important things such as hospital appointment cards could be kept together.
- It helped social care providers to have a recognised tool that supported health facilitation.

Katie's vision

Katie has no sight in her left eye and blurred sight in her right eye.

She needs to be approached from her right side. She will 'jump' if approached from her 'blind side' and this can trigger a seizure.

She has problems with 'glare' – even when sighted people don't think it's particularly bright. She likes to wear sunglasses. She needs to be warned before they are put on to her face.

She likes people to call her name before they touch her.

Variations in vision

Katie sees better in the daytime, but has 'night blindness'. She may get upset when taken from the well-lit lounge into the hall – if the lights aren't on.

She doesn't see so well in the morning because of her medication.

Her vision is much worse after a seizure or when she is tired.

Helping Katie to use her vision

Katie needs even, consistent lighting. She finds it hard to go from well-lit to dark settings.

She is helped by colour contrast – such as a white cup on a red tablecloth. This helps her to use her eyesight to direct her hands.

She sees big things better than small things.

Things need to be placed so she can find them with her right eye.

She needs to sit with her back to the window at mealtimes – to avoid glare.

Katie may take time to make sense of what she is seeing and to decide how to respond.

Useful resources

The 'Do Once and Share' (DOAS) project for health action planning describes the components of a health action plan.

It also takes readers through an integrated care pathway to support people with learning disabilities and family carers to make decisions about their health.

www.informatics.nhs.uk/doas/actionteam2005/learningdisabilities

The Valuing People website contains information and resources to help people think about person-centred planning and approaches.

http://valuingpeople.gov.uk

Over the last five years many facilitators have put a lot of effort into working through these issues and capturing what is important to and for an individual to maintain good health.

Where standard templates are in use there is good evidence that they are valued 'tools' and have been developed and co-produced with self-advocacy groups and family carers.

In capturing what is important to the person, many health facilitators have made good use of person-centred planning tools and approaches, also making sure that the health action plan is part of the person-centred plan. However, there has also been a practical approach to make sure that where there are barriers to completing both together, neither process delays the other.

Similar considerations have been required to meet the standards of the Care Programme Approach (CPA). Good physical and mental health and well-being are paramount in supporting people to achieve their hopes and aspirations. The CPA may be used for some people with learning disabilities and mental health needs. It is important that we include physical health needs when completing this process and that the information from CPA care plans forms an integral part of the individual's health action plan. More information about the CPA is available on the CPA Association website (www.cpaa.co.uk).

Action

- A key task for Partnership Boards will be ensuring that there is a 'good fit' within the local strategies to support the implementation of person-centred plans and health action plans.
- Health subgroups need to make sure that local plans contain explicit actions to ensure that there is sufficient and available expertise to include everyone in the health action planning process – specifically, people from black and minority ethnic communities and people who may have more complex needs, for example people with significant sensory impairments or with communication difficulties.
- Partnership Boards need to have in place mechanisms (including use of primary care IT systems) to capture emergent themes from the local health action planning process – for example, barriers to accessing screening or services such as dentistry. They should ensure that good use is made of this information in plans for service development and delivery.

15. Quality

Making sure that the quality of health action planning is consistently good and that the goals and health outcomes they contain are achieved is an issue that some localities have found difficult.

Facilitators described to us some of the problems encountered in trying to ensure that people have plans that are person centred and meet their health needs.

There can also be a danger that the health action plan may be based on poor information or ill-informed views if the person has not had a recent health assessment or there has been no input from a health professional. This can mean that behaviours that could indicate an illness may be overlooked or that inappropriate actions or activities may be instigated, e.g. inappropriate dietary regimes.

However, some places have made progress in this area and strategic health facilitators and others have employed various methods such as:

- having a standard to review individual health action plans and their outcomes at least yearly;
- making sure that people have good health facilitation training; and
- providing opportunities for people with learning disabilities to discuss their plan properly and how they feel it is working or not.

Sometimes, outcomes are not achieved because of barriers presented by local health services rather than poor health action planning. We have described some of these issues and recommendations in previous sections, particularly those relating to PCTs and health providers.

Good practice example

Essence of Care is a benchmarking tool and takes a structured approach to sharing and comparing practice, identifying the best and developing action plans to remedy poor practice.

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005475

In Surrey, nurse consultants have developed an Essence of Care benchmark for health action planning.

The agreed outcome is that ‘Every health action plan is person centred’.

Action

- Partnership Boards should ensure that there is proper consideration of quality monitoring within their Action for Health framework.
- Health action plans need to be firmly outcome-focused with good monitoring of progress and achievement. People with learning disabilities and their family carers should be at the centre of determining priorities and evaluating progress and outcomes.
- PCTs and local authorities should ensure that there are monitoring systems in place to make sure that the quality of health action planning is good, and utilise tools to support this such as the Essence of Care benchmark of best practice for health action planning.
- People with learning disabilities and family carers should be at the centre of quality assurance systems and their skills and experience harnessed to best effect.
- Given the inequalities in health services, it would be prudent for SHAs to swiftly implement the regional health self-assessment and performance framework to support the monitoring of quality and progress against health action planning and related health targets.

Good practice example

East Lancashire organised a ‘bring and share’ event for people with learning disabilities.

The aim was to provide an opportunity for people to say how they felt about health facilitation and health action planning, and what was and was not working for them.

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